A Health Handbook for
Women with Disabilities

Jane Maxwell, Julia Watts Belser, and Darlena David

hesperian
Berkeley, California, USA

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This book provides basic information to help women with disabilities stay healthy, and will also help those who assist women with disabilities to provide good care. You can help us improve this health guide. So, if you are a woman with a disability, a caregiver, or anyone with ideas or suggestions about how to improve this book and the health of women with disabilities, please write to us. We would like to hear about your experiences and practices.

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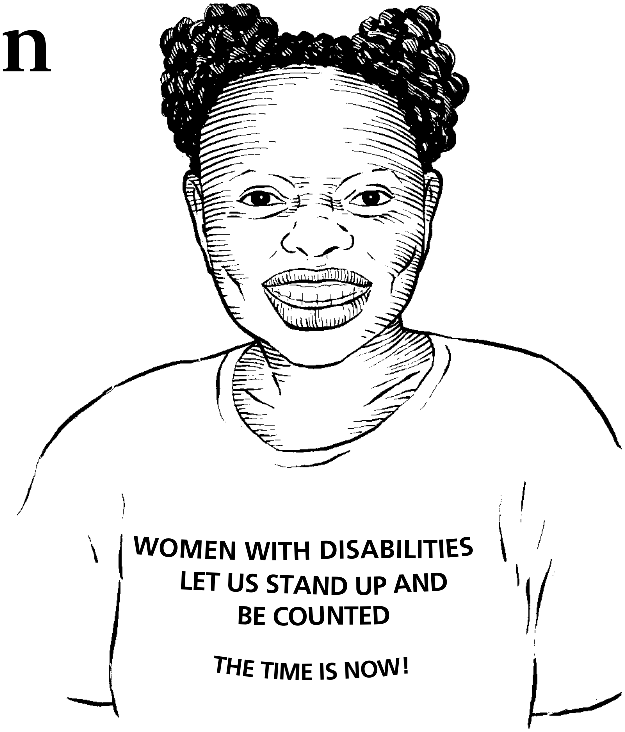


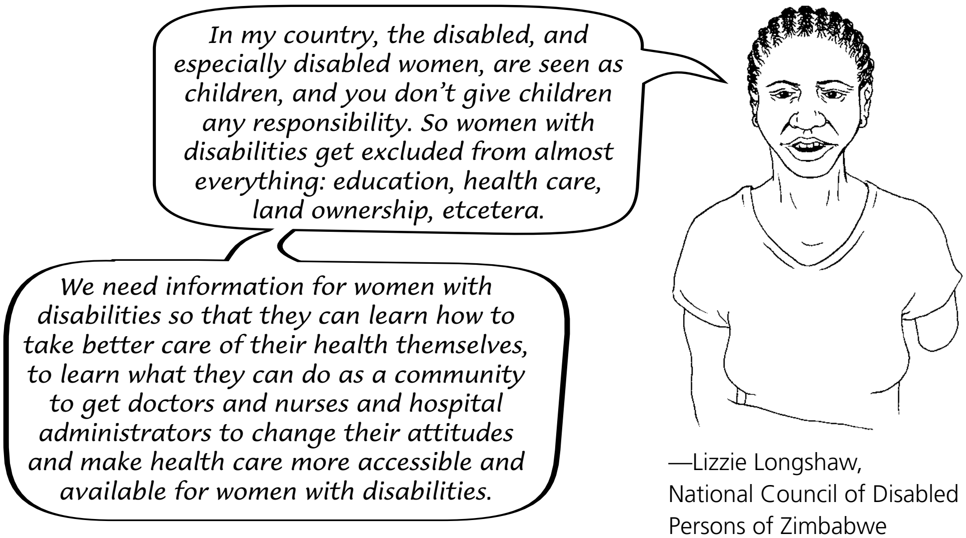
Why a book about health for women with disabilities?

Women with disabilities need good health. Good health is more than the absence of disease. When a disabled woman has good health it means she experiences well-being—of her body, mind, and spirit.

Women with disabilities can take charge of their own health when they have information that affirms their own experience of their bodies and health needs. They can also use this information to change the way people think about disability. As women with disabilities take charge of their lives, they will gain respect and support in their communities.

While disability itself may not be a health problem, many times the health problems of women with disabilities go untreated. This can mean that a simple health problem in a woman with disability, if left untreated, can become a life-threatening problem.

We must remove the barriers that keep disabled women from achieving good health.



—Lizzie Longshaw,
National Council of Disabled
Persons of Zimbabwe

BARRIERS TO GOOD HEALTH CARE

Like most women, women with disabilities often find it difficult to get the health care they need, when they need it.

Even if a woman lives near a health center and has enough money to pay for services, most clinics, health centers and hospitals have not been designed to make it easy for everyone to use them. Disabled women find barriers to care when health facilities do not have ramps for wheelchair users, do not have information in Braille or on audio cassettes for blind or vision-impaired people, do not have sign language interpreters for women who are deaf, and do not have people who can assist women who have trouble learning or understanding.

Another problem is that doctors and other health workers are not usually trained to understand the health needs disabled women may have. Because of this, health workers may have ideas about disability that make it uncomfortable and hard for disabled women to get good health care.

When women with disabilities do not have access to resources, education, and other opportunities, they are more vulnerable to poverty, exploitation, and abuse. Without confidence in and awareness of their rights, they are often socially marginalized. This creates even more barriers to their access to health care.

WHO THIS BOOK IS FOR

This book is written for the millions of women with disabilities around the world who suffer and die needlessly because they lack access to respectful and appropriate health care.

This book can help most women with disabilities better care for themselves, improve their general health, their capabilities and self-reliance, and their ability to participate more effectively in their communities.

This book is not a rehabilitation manual and does not have all the information needed to diagnose and treat different kinds of disease, sickness or disability. The book has other goals.

This book gives information about the ways a disability may make the health needs of a woman with a disability different from those of a woman who does not have a disability.

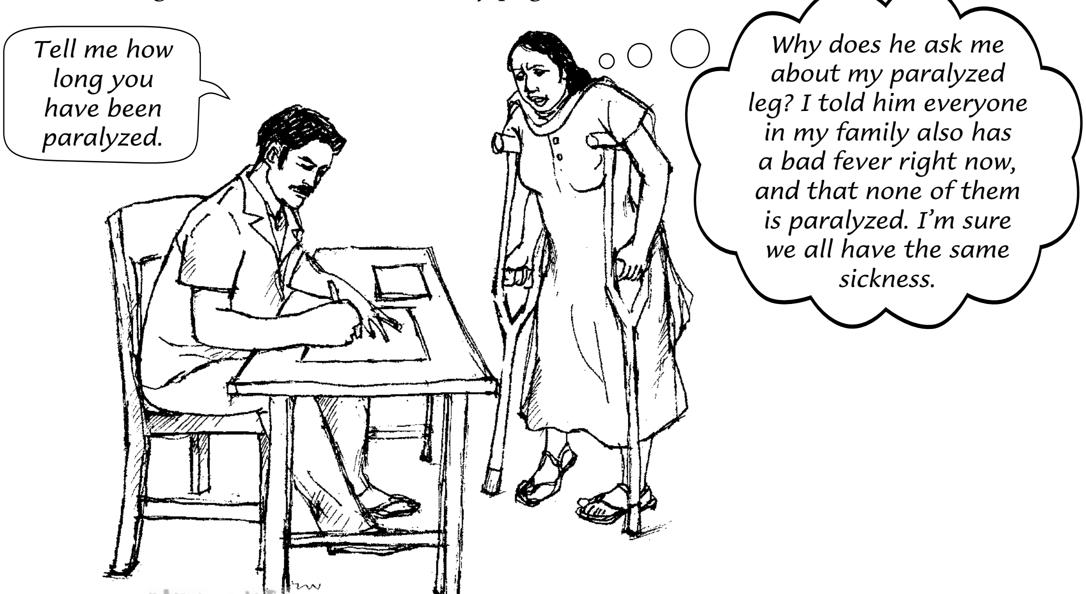
The information in the book will help women with disabilities get better care from others.

This book will help health workers, as well as family members and caregivers, learn that disability by itself does not mean sickness, but that a woman with a disability—a blind woman, or a woman who uses a wheelchair—may have illnesses such as HIV/AIDS or malaria, just like women who do not have disabilities.

This book will help families, friends, community health workers, and other people who assist women with disabilities to be partners in caring.

This book also has information about the social causes of disability, and suggests ways to help change feelings and beliefs that are harmful to the health of women with disabilities, their families, and their communities.

To make the book as useful as possible, women with disabilities around the world shared their health needs, beliefs, and practices, and told us what they would most like included in the book. Their voices, experiences, and stories helped shape the writing and are reflected on every page.



CHAPTER 1

Disability and the community

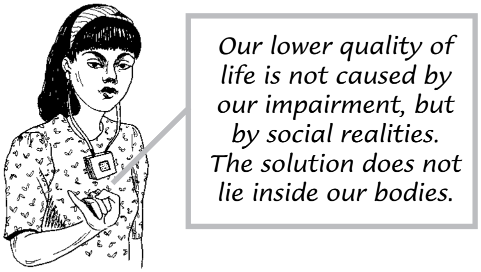
Women with disabilities have a right to good health. Good health depends on enough nutritious food to eat, regular physical activity, and access to information and services to prevent and treat health problems, especially problems of reproductive health. Also, to develop to their full potential, girls and women with disabilities need good education, jobs, and opportunities to be involved in their communities.

1 out of every 10 women has a disability that affects daily living.

What is disability?

Many women with disabilities use the term "impairment" to refer to their individual limitations. These limitations may include blindness, deafness, conditions that make it difficult or impossible to walk or to speak, conditions that make it harder to understand or learn, and conditions that can cause seizures.

A woman with a disability may move, see, hear, or learn and understand differently from a woman without a disability. She may take care of the activities of daily living differently when she communicates, eats, bathes, dresses, gets up from lying down, and carries or feeds her baby. Adapting to her limitations is an ordinary part of her life.

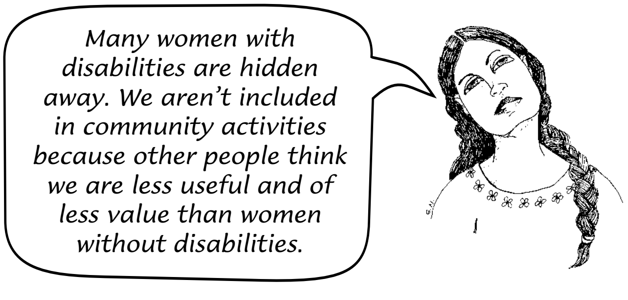


Despite each woman's ability to find solutions to problems caused by her disability, she also faces social, physical, cultural and economic barriers that can stop her from getting health care, education, vocational training and employment.

Attitudes create barriers

Attitudes and wrong ideas about what a disabled woman can or cannot do can prevent a disabled woman from living a full and healthy life, or taking part in the life of her community. They add to her disability by creating barriers that can prevent her from getting education or work, and from having a social life.

For example, a teacher may believe a girl cannot learn because she is blind or deaf. But a girl's ability to see or hear is not the problem. A girl who is blind can learn by listening and using other senses such as smell and touch. She can learn even more if she has books in Braille or information on audio cassettes. And a girl who is deaf can learn when people use sign language and visual methods of teaching.



A woman who cannot walk may be capable of having a very good career and be able to earn money to support her family. But if her family or community are ashamed of the way she moves and want her to stay hidden, then it is their feelings of shame that will make her disabled.

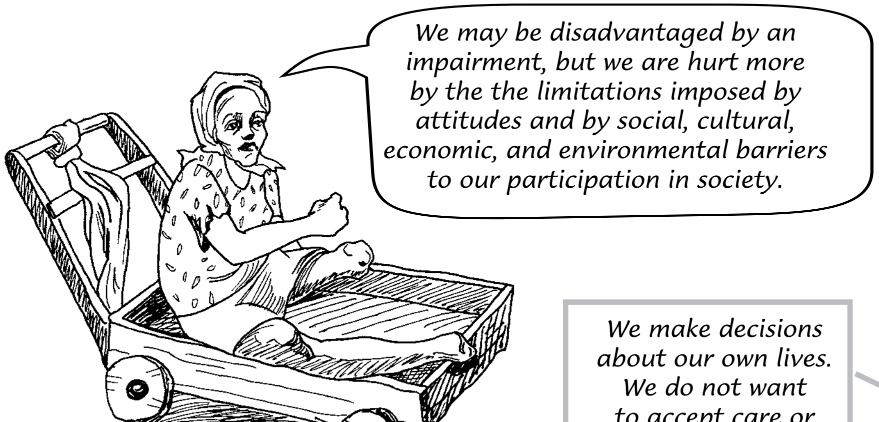
All communities include people with impairments. That is normal. But it is not normal for a person to be discriminated against and excluded because she has an impairment. That is disabling!

The medical understanding of disability

Many doctors and other health workers see only the disability someone may have. They do not see a person with a disability as a total person or woman. They think people with "impairments" have something "wrong" with them and must be cured, rehabilitated, or protected.

When stairs or bad attitudes make hospitals and other public health facilities not useable by everyone, then it is the medical system which has something "wrong" with it and must be cured or rehabilitated. In those cases, it is not a woman's disability but the medical understanding of disability that makes it impossible for her to live a healthy and fulfilling life.

We will deal with our disabilites, but only you can stop causing the social discrimination we face.



Disability is a natural part of life

There will always be some people born with impairments. And there will always be accidents and illnesses. But governments and communities can work to change the social causes of disability—the limitations imposed on people with disabilities by attitudes, and social, cultural, economic, and physical barriers to their participation in society. The physical and mental health of women with disabilities will improve when communities improve access, challenge prejudice, and create employment opportunities.

Women with disabilities show the way in Bangalore, India

In the southern Indian city of Bangalore, 4 young women with physical disabilities—Shahina, Noori, Devaki and Chandramma—make and fit other women with rehabilitation aids and appliances. They work at the Rehabilitation Aids Workshop by Women with Disabilities (RAWWD) which was started in 1997 by 8 women with disabilities who were trained by an NGO called Mobility India to make mobility aids.

Although there were other facilities, until RAWWD started, only male technicians were available to measure and make the aids, and women with disabilities were hesitant to go to them. They were embarrassed to let men measure and fit them with appliances. Because of this, many women did not use the appliances which would have made them mobile.

RAWWD now makes a wide variety of rehabilitation aids for the ankles, feet and knees. These include crutches, walkers, shoes, belts, and braces, as well as prosthetics (artificial legs and feet).

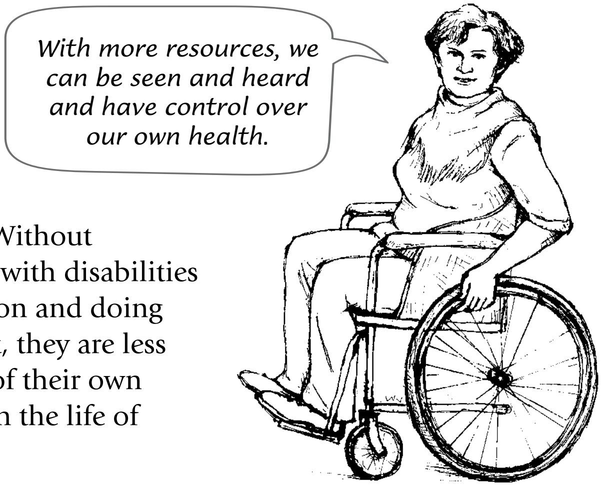
As the women at RAWWD increased their confidence and skills, they began providing services to other organizations working for people with disabilities, and now also provide services to several hospitals and private doctors in Bangalore.

The women get the materials to make the aids, keep records of the clients, conduct regular follow-up visits, and manage their business. RAWWD also encourages other women with disabilities to become technicians and trains them to make and repair rehabilitation aids and appliances. This promotes equality for women with disabilities, especially women who have been abandoned by their families, and also provides them with a livelihood.

Resources and opportunities

In many communities, women have fewer resources and opportunities than men. This inequality between men and women is also true among people with disabilities.

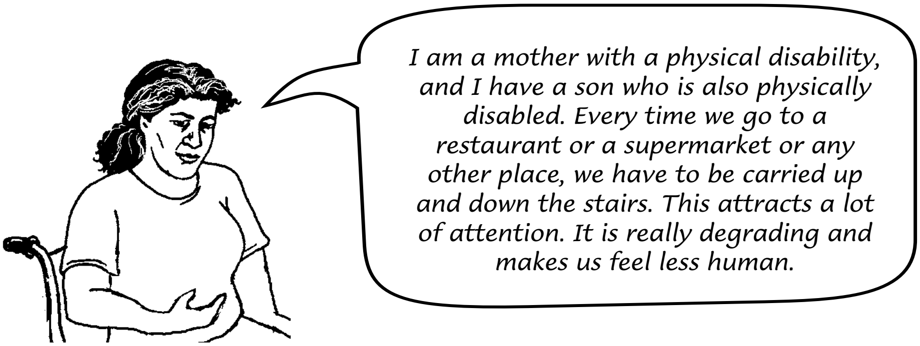
Wheelchairs, artificial limbs, sign language classes, Braille slates (which enable blind women to read) and other resources are often expensive and less available for disabled women than for disabled men. Without aids like these, girls and women with disabilities have a hard time getting education and doing things for themselves. As a result, they are less able to get jobs, to take control of their own lives, and to take an active part in the life of their communities.



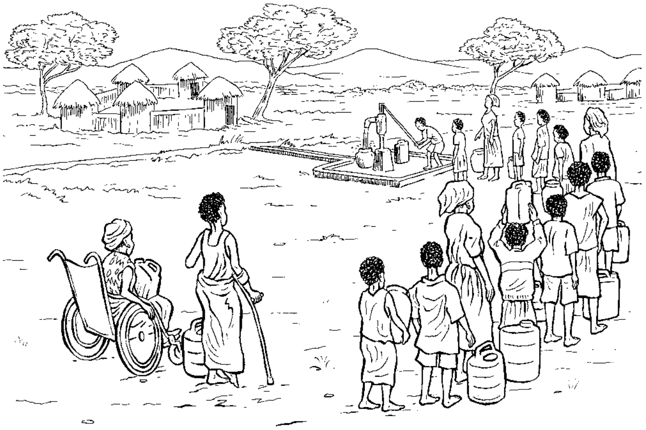
Physical barriers

Many women with disabilities cannot use community facilities, banks, or hospitals because most buildings have no ramps, handrails, elevators, or lifts. Physical barriers make it difficult for women with disabilities to move around by themselves. When women are stopped by these barriers, they are often unable to get good food, enough exercise, or the health care they need.

Many people, including health workers, may believe that if a woman who uses a wheelchair cannot get into a building because there are only stairs, then she must learn to wear leg braces, or use crutches, or have someone carry her. It is not her disability, but the physical barriers that make it impossible for her to get into the building. If there was a ramp so she could roll her wheelchair into the building, there would not be a problem.



> The development workers come to the villages, they come with their projects. And they work with the women there, all the women there. And the disabled woman… she will be raising a family, too. They will put in the water projects that are not accessible to the disabled woman. And she will also want to draw the water. And they do not think about it at all.
>
> — From a Zimbabwean woman attending the 3rd World Conference on Women, Nairobi, 1985



Disabled women have a right to the removal of social and physical barriers.

Causes of disability

Some women have been disabled since birth. Some women become more disabled over time. Some women become disabled suddenly, because of an accident or disease.

It is not possible to prevent all impairments. Some babies form differently inside the womb and no one knows why.

But many disabilities in babies are caused by harmful conditions of women's lives. If women can get enough nutritious food to eat, can protect themselves from work with toxic chemicals, and can get good health care, including care at the time of childbirth, then many disabilities could be prevented.

POVERTY AND MALNUTRITION

Poverty is one of the biggest causes of disability. Poor people are most vulnerable to disability because they are forced to live and work in unsafe environments with poor sanitation, crowded living conditions, and with little access to education, clean water, or enough good food. This makes diseases such as tuberculosis and polio—and the severe disabilities they cause—much more common because diseases get passed from one person to another more easily.

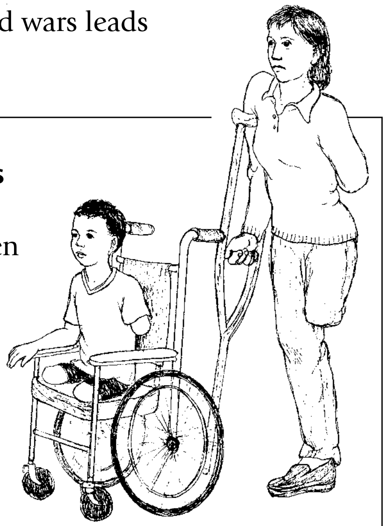
Many babies who are born in poor families may be born with disabilities or may die in infancy. This may be because the mother did not get enough to eat when she was pregnant. Or it may be because she did not get enough to eat when she was a girl. Starting in childhood, a girl is often given less food to eat than a boy. As a result, she may grow more slowly and her bones may not develop properly, which can later cause difficulty during childbirth—especially if she does not receive good health care.

If a baby or young child does not get enough good food to eat, she or he may become blind or have trouble learning or understanding.

While she was pregnant, the mother of this girl with cleft lip and palate did not get enough food to eat containing folic acid and calcium (such as dark green leafy vegetables, beans, and eggs).

WAR

In today's wars, more civilians than soldiers are killed or disabled, and most of them are women and children. Explosions cause people to become deaf, blind, and lose their limbs, as well as causing other injuries. Their mental health is also badly affected by the violence. The destruction of homes, schools, health centers, and means of livelihood that results from conflicts and wars leads to increased disability, poverty, and disease.



Land mines, cluster bombs, bullets, and chemicals used in wars cause more disabilities in the world today than anything else. They often injure women who are carrying out their daily activities, such as farming, or gathering water and wood.

Explosions and landmines cause many leg and arm injuries, and often a child's or a woman's leg has to be amputated. But only about 1 of every 4 amputees gets an artificial leg to replace a lost leg, because they are usually expensive or difficult to get. The Mukti and Satti limbs and the Jaipur Foot are good quality, low-cost, artificial legs made by groups in India. For more information about these, see page 377.

The international treaty to outlaw land mines could save many lives and prevent many disabilities, but some governments still refuse to sign it. If it has not, pressure your government to sign it.

NUCLEAR ACCIDENTS

Many people have suffered after being exposed to massive amounts of radiation. This happened after accidents in nuclear power plants at Three Mile Island in the USA in 1979, and at Chernobyl in the Ukraine in 1986. And it also happened when the USA dropped nuclear bombs on Japan in 1945. These incidents caused widespread destruction and death from exposure to radiation.

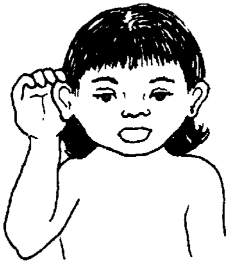
The people who survived these accidents and bombing attacks have suffered mainly from cancers—either tumors in various parts of the body, especially in the thyroid gland—or leukemia (cancer of the blood), all of which bring an early death. In communities where these nuclear incidents happened, there has also been an increase in the number of children born with learning difficulties, such as Down syndrome.

POOR ACCESS TO HEALTH CARE

Good health care can prevent many disabilities. Difficult labor and birth can cause a baby to be born with a disability such as cerebral palsy. Trained birth attendants who can identify risks and handle emergencies can prevent babies from being born with many disabilities. Immunization can also prevent many disabilities. But many times vaccines are not available, or people who are poor or live far from cities cannot afford them, or there are not enough for everyone.

ILLNESS

Some illnesses a pregnant woman may get can cause physical or learning problems when her baby is born. Illnesses that can cause birth defects include German measles (rubella), which is a common cause of deafness in newborn babies. There is a vaccine that gives protection against rubella, but a woman who gets an immunization of the rubella vaccine should not get pregnant for one month afterward.



If a woman gets German measles (rubella) during the first 3 months of pregnancy, her child may be born deaf.

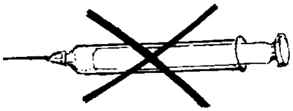
Syphilis (see page 163), herpes (see page 165), and HIV (see page 169) can also be passed from a mother to her baby and can cause birth defects. So women need to be tested and treated for sexually transmitted infections to protect the baby developing in the womb.

Some illnesses a baby or small child may get can also cause disability, such as meningitis, polio, and measles. It is important for newborn babies to get immunizations for protection (see page 276). Children who live in places where leprosy (Hansen's disease) is common need to be tested as early as possible.

MEDICINES AND INJECTIONS

When used correctly, certain injected medicines, like some vaccinations, are important to protect health and prevent disability. However, there is a worldwide epidemic of unnecessary injections. Each year these unnecessary injections sicken, kill, or disable millions of persons, especially children.

Giving injections with an unclean needle or syringe is a common cause of infection and can pass the germs that cause serious diseases such as HIV/AIDS or hepatitis. Unclean injections are also a common cause of infection that can lead to paralysis or spinal cord injury or death. Also, some injected medicines can cause dangerous allergic reactions, poisoning, and deafness to a baby in the mother's womb.



Avoid unnecessary injections.

A needle or syringe must never be used to inject more than one person without disinfecting it each time.

Some medicines and drugs taken during pregnancy can cause disability in the baby. The overuse of injectable medicines, such as oxytocin, to speed up childbirth and 'give force' to the mother's labor, deprives the baby of oxygen during birth. It is a major cause of brain damage. Alcohol and tobacco used during pregnancy can also damage a developing baby.

Everyone must consider the possible risks and benefits of using any medication. Doctors, nurses, other health workers, pharmacists, and everyone else must stop the misuse and overuse of medicines—especially of injections. For ideas on teaching about the danger of unnecessary injections, see ***Helping Health Workers Learn***, Chapters 18, 19, and 27.

DANGEROUS WORK CONDITIONS

Women who work long hours without enough rest are likely to have accidents. Women who work in factories, mines or on agricultural plantations can be exposed to dangerous machinery, tools, or chemicals. Accidents, overwork and exposure to chemicals can all cause disability.

A growing number of women have also been permanently injured due to violence at work. Supervisors sometimes use violence and threats to try and make women work harder and faster. Sometimes the authorities bring in the military or police to stop women from striking or protesting unsafe working conditions.

ACCIDENTS

Many women and children get disabling injuries at home by burns from cooking fires, falls, road accidents, and breathing or drinking toxic chemicals. Workplace accidents, especially in less regulated sectors such as construction, agriculture, mining, and smaller businesses, are a common source of disability.

POISONS AND PESTICIDES

Poisons such as lead found in paints, pesticides such as rat poison, and other chemicals can cause disabilities in people and cause birth defects in babies growing in the womb. Smoking or chewing tobacco, breathing smoke, and drinking alcohol during pregnancy can also harm a child before she is born.

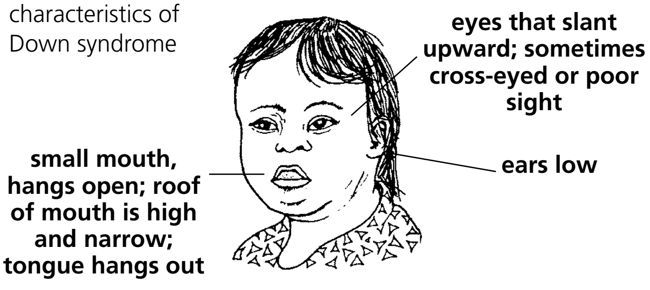
Workers often use chemicals on the job or in the fields without being taught how to use them safely, or without even knowing if they are dangerous. Accidents in factories can release poisons into the air, water, or ground, causing terrible health problems, including permanent disabilities.

This woman was a farm worker and was exposed to dangerous chemicals when she was pregnant. This affected her baby while he was in the womb, and he was born with a disability.

INHERITED DISABILITIES

Some disabilities are known to be inherited, such as spinal muscular atrophy and muscular dystrophy (diseases of the muscles and nerves). Women who already have one or more children with an inherited disability are more likely to give birth to another child with the same problem. Other disabilities can result when close blood relatives (such as brothers and sisters, first cousins, or parents and children) have children together. Children born to mothers 40 years of age or older are more likely to have Down syndrome. **However, most disabilities are not inherited.** In most cases, the parents of a baby born with a disability did nothing to cause the disability. They should never be blamed.

Physical characteristics of Down syndrome



Wrong ideas and myths about disability

Local customs and beliefs may include wrong and harmful ideas about disability. Some people think a woman gets a disability if she or her parents did something bad in a former life, or that they displeased their ancestors, or one of her parents had a sexual relationship outside their marriage. Usually people blame the mother. But **mothers are not to blame for a child's disability**. And blaming anyone for a disability does not help.

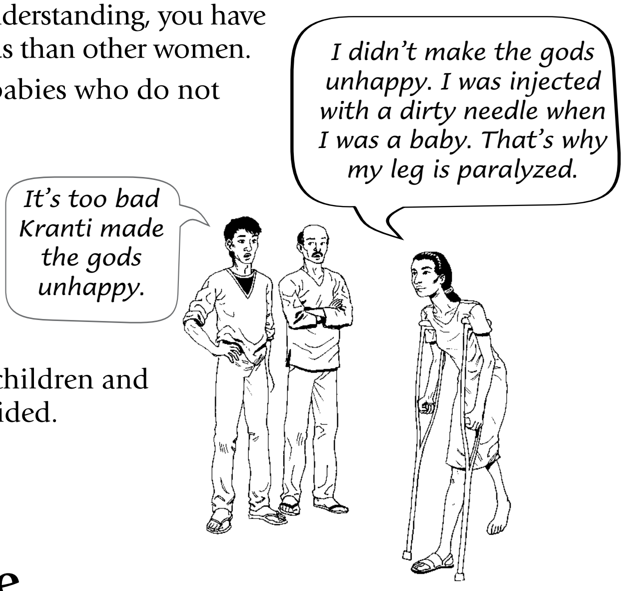
Another harmful idea about disability is the belief that anybody who is 'different' should be excluded, mocked and criticized. Some people think a person with a disability is a bad omen or will bring bad luck. Women with disabilities are often abused, or forced to become beggars or do sex work for a living. Sometimes women with disabilities are sexually abused because people believe they are free of HIV/AIDS or that having sex with a disabled woman can cure HIV/AIDS.

But the truth is: No woman with a disability should ever be abused. Disability is **never** a punishment. Disability is **not** caused by witchcraft or a curse. Disability is **not** infectious and cannot spread to other people.

People may also not understand what a disabled woman can or cannot do. They may not realize that:

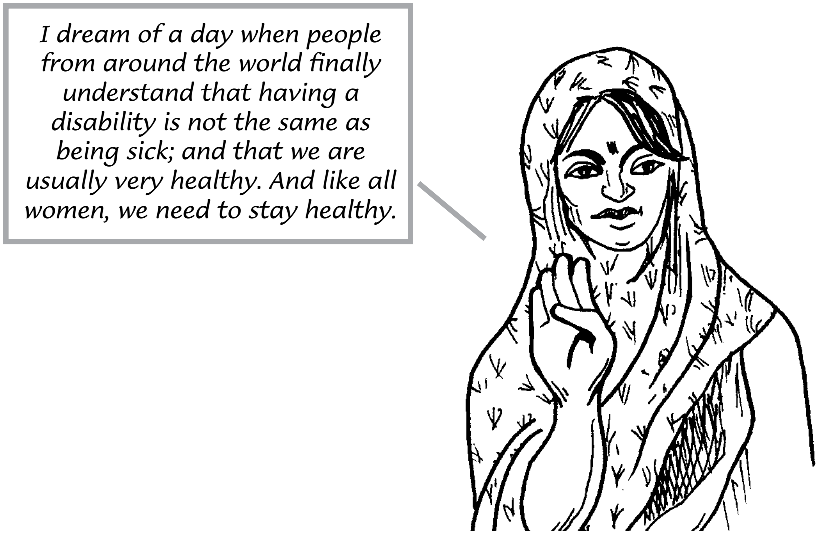
- you are an adult and can make decisions.
- you need an education.
- you need health care.
- you can also get diseases, such as cancer and HIV/AIDS.
- you need opportunities and respect, not pity and sympathy.
- you can work. You can be a professional and have a career.
- you can earn, own property and raise and support your family.
- you think, feel and have emotions.
- you can dance and exercise.
- you can take responsibilities, make decisions and take a leadership role and involve yourself in your community.
- you can have close relationships with anyone. You can love or be loved by a person without disabilities or a person with a disability.

- you have sexual desires, and you can be sexually active.
- you can marry and have children.
- you are capable of having sex, but may not want to have sex.
- if you have difficulty learning or understanding, you have neither more nor fewer sexual needs than other women.
- you will most often give birth to babies who do not have disabilities, just like other women.
- you are a good mother.
- if you have a physical impairment or a learning disability, you are not mentally sick or unstable.
- you do not curse people or curse children and you are not a bad omen to be avoided.



Working for change

A woman's disability affects not just herself. It affects many people: her family, friends, and most of all, her community. A woman with a disability can become more healthy when those around value and support her. Changing the way women with disabilities are treated is hard work. But it is not impossible.



WHAT WOMEN WITH DISABILITIES CAN DO

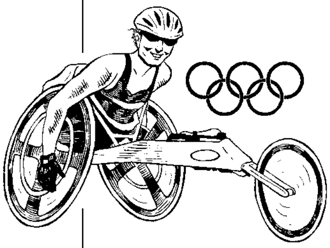
Make your voices heard by advocating for your rights and making sure disability issues become a priority.

- Refuse to be confined to one place. Be adventurous and welcome different experiences.
- Learn business skills, and empower yourself economically.

Finding security in the market

Oppah Ndlovu from Zimbabwe is a wheelchair user and is a respected member of her community. She started a successful project selling vegetables and tomatoes. Now, community groups purchase vegetables from her. With this steady income, Oppah has managed to buy a house.

- Insist on participating at all levels in the community.
- Become role models for other girls and women.
- Speak about your disabilities.
- Offer to accompany other disabled girls and women to where they need to go.
- Take part in sports.



Olympic-level athletes

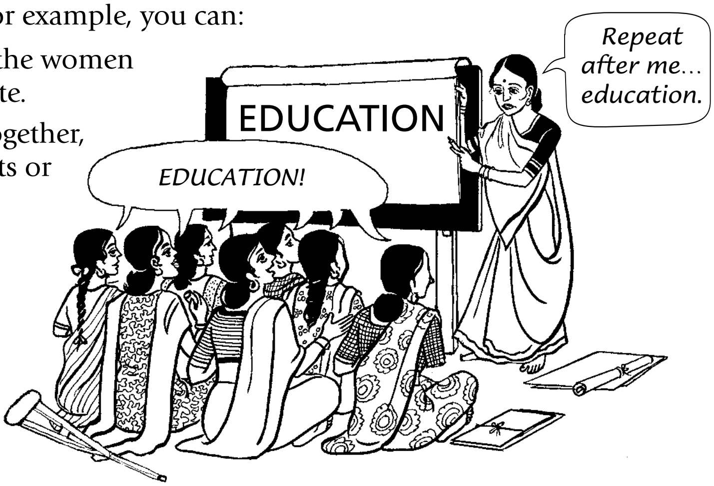
An increasing number of women are taking part in the Paralympic Games, an international sporting competition for athletes with disabilities including mobility disabilities, amputations, visual disabilities, and cerebral palsy. The Paralympic Games are held every 4 years, following the Olympic Games. It is an eye-opener for many people to see women with disabilities compete with confidence and skill.

Bowler dispels myths

Constance Sibanda, a blind bowler, was nominated the Sportsperson of the Year in Uganda, dispelling myths that as a woman with a disability she was “long dead and useless.” Constance won a double gold medal in a world competition. Since then she has amassed more medals in blind bowling and participated in competitions in South Africa, Scotland, and the United Kingdom. Constance challenges all women and girls to explore their hidden talents.

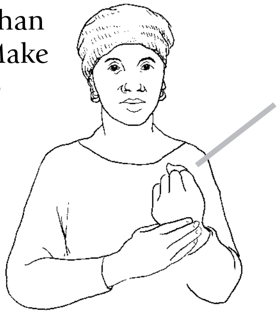
Together you can decide what things in your community can be changed in order to make life better for all. For example, you can:

- start a literacy class for the women who cannot read or write.
- start a small business together, making and selling crafts or tools.
- share information with each other about community services and work together to make them more accessible.
- try to get funds—either through a low-interest loan or through a donation—to begin an income-earning project or to make the community more accessible.
- raise awareness about disabilities and advocate for new ways of thinking about independence.
- work with local leaders or the government to get better treatment for women with disabilities.



You can also help community groups:

- Look at the different causes of health problems that you and other women with disabilities face, and decide which ones the community can change.
- Take action by advocating for activities and services that make life better for everyone, including better health care, education, and transport for people with disabilities. Insist on accessible facilities.
- Set up a small group. The voice of an organization is stronger than the voice of an individual. Make a plan about what the group will do and what steps the group will take to carry out each of these ideas.
- Raise your voice against policies and laws that discriminate against you.



At one time, deaf people in Uganda were not allowed to drive. But because we protested, we can now buy cars and are allowed to drive.

Educating people to get access

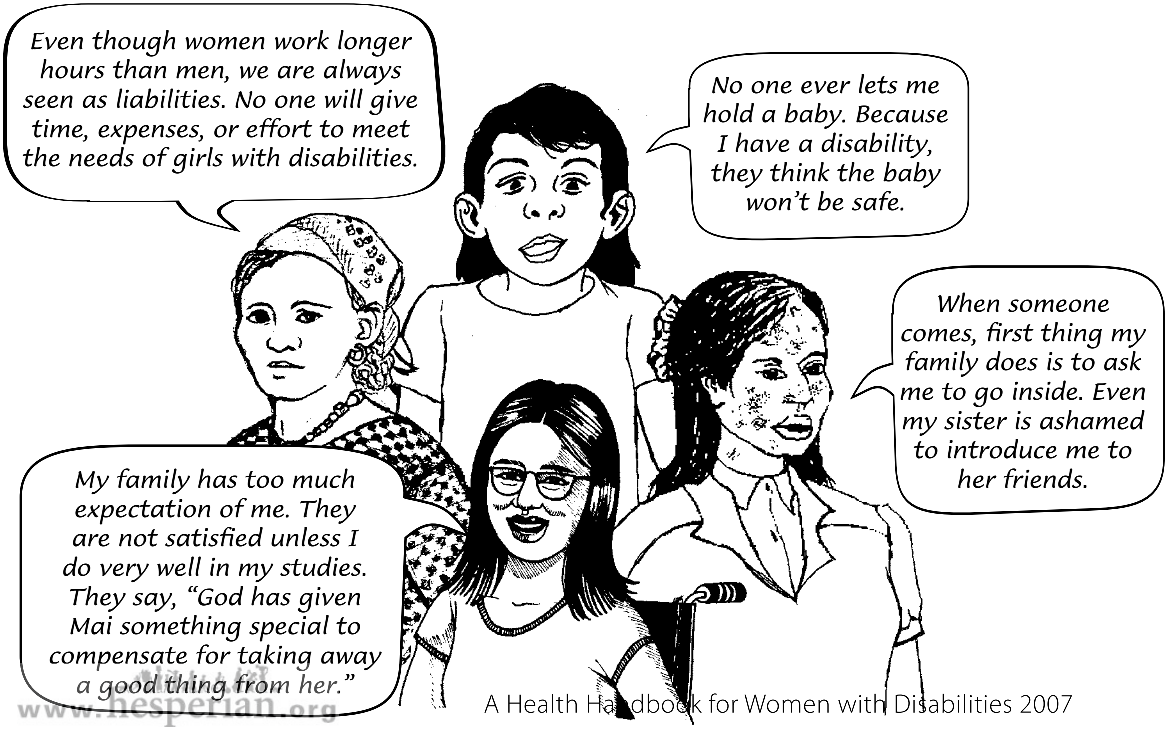
Dorothy, a wheelchair user in Bangalore, a state capital in India, found that the building which housed the chief minister's offices had no ramps. Also, the entrance to the building was too narrow for her to enter. She spoke about this to the guards and insisted they help her keep her appointment.

Afterwards, Dorothy sent hundreds of emails to tell people what had happened. This increased the pressure on the government to make changes.

At another time, Dorothy attended a cricket match, where the police asked her, "Why do you want to come here and watch the cricket match live? You might as well sit at home and watch the match on TV comfortably." She replied that, just like others, she too wanted to see the match live.

WHAT FAMILIES CAN DO

The way women with disabilities are treated by their families, friends, and other people who assist them makes a big difference. Many times a girl with a disability is seen as stupid, dependent, unable to help herself and others, and therefore does not deserve any resources. Sometimes families also see her as a shameful burden to be hidden away, and they deny her the right to be heard or to make her own decisions. If this happens in a family or community, the problem is not with a girl or woman with disability, but with the people around her.



Nurture confidence

When Christine was 13 years old, her leg was amputated because of an illness. At first, Christine thought it was the end of her dreams. But her parents treated her well and soon Christine's confidence was restored. At first Christine's parents overprotected her, but she insisted they treat her like her other siblings. Christine was able to finish her college and received awards for excellence. The change in Christine made the rest of her family and community realize that Christine's missing leg would not keep her from fulfilling her dreams.

The only thing that can change these attitudes is social awareness. Women and girls with disabilities need good food, education, health care, and opportunities to be involved in physical and social activities. See the chapters on 'Mental Health' and 'Support for Caregivers.'

You can develop many skills

Hong Ha from Laos had polio when she was 2 years old. With the support of her family, she was able to graduate from university with a degree in French. When Hong Ha could not find a job, she learned to sew and then opened a sewing shop at home. Together with sewing, she started to study English. With a friend, Hong Ha then opened a small English training center at her home. She is also a coordinator of a program on disability.

Early assistance

In their first years of life, all children will learn more physical, mental, communication, and social skills and learn them more quickly and easily than at any other time in their lives. Since a baby starts learning as soon as she is born, it is important that families begin giving extra attention to help children with disabilities as soon as possible.

This is important because each new skill a child learns builds on the skills she already has. Each new skill also makes it possible for her to learn other, more difficult skills. So when a child does not learn a skill, she cannot learn other skills that depend on it.

Start a support group for parents of disabled children

Women with disabled children are often deserted by their partners and have to bring up their children by themselves. Parent support groups can help. Adult women with disabilities can offer advice on the types of concerns that girls with disabilities will face as they are growing. This can help their mothers support them better.

You can also start a support group for teenage girls with disabilities so they can help and support each other.

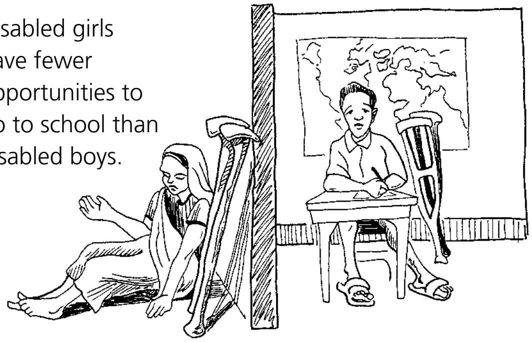
WHAT COMMUNITIES CAN DO

Community groups can help government, health workers, teachers, community-based rehabilitation workers, and community leaders learn about disability issues. They can also make the public aware through street plays, discussions, and in other ways that women with disabilities have the same rights to education, health care and transportation as non-disabled people. Communities can create employment opportunities and give information about services for women with disabilities.

Girls and women with disabilities become confident, believe in themselves, and grow to their full potential when parents and families love and accept them, and when they can get education, jobs, and health care. All community resources, such as schools, banks, religious places, hospitals, and clinics must also become accessible for everyone.

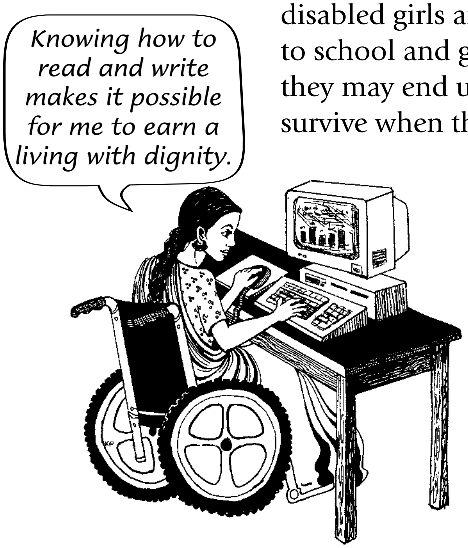
Education

Education is very important for girls with disabilities, including education in sign language and Braille or audio cassettes, for girls who are deaf, or blind.



Disabled girls have fewer opportunities to go to school than disabled boys.

In many poor countries, if disabled girls are not able to go to school and get an education, they may end up begging to survive when they are adults.



It can make a big difference when a whole community works for educational rights for people with disabilities.

Community-based groups can discuss problems and encourage everyone, including other children, to welcome and respect girls with disabilities. They can arrange opportunities for early childhood education, or access government grants, or help in other ways.

With education, girls with disabilities can support and enrich their communities.

Make communities accessible for everyone

All around the world, women with disabilities are organizing to help make clinics, schools, markets, city streets, buses, and communities more accessible for people with disabilities.

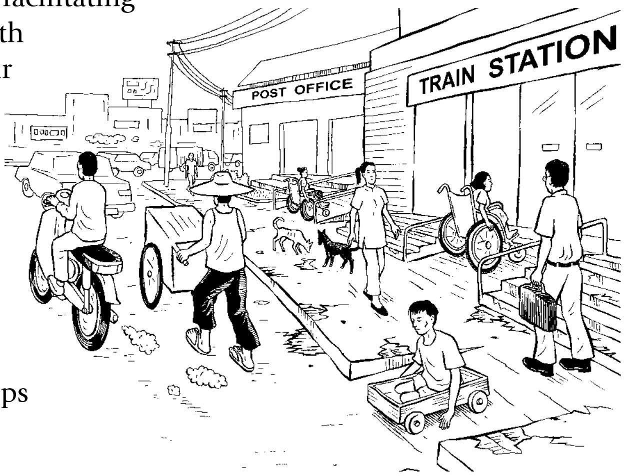
Communities can make sure buildings and roads are accessible when they are first built rather than changing them later. This way all public facilities are as usable as possible by as many people as possible regardless of age, ability, or situation. They will serve people who are young or old, with excellent or limited abilities, in ideal or difficult circumstances (see pages 38 to 40).

But access is about more than physical things such as ramps. Accessibility also means everyone can communicate and understand what is happening. Then a woman with a disability can do more things for herself and more people will see that disability is a natural part of life. When disabled women are valuable members of the community, the community will start thinking differently about disability.

Governments must provide the resources necessary to make transportation systems, buildings, public programs and facilities easy to use for everyone, including women with disabilities. Some governments penalize those who refuse to cooperate.

Getting the government to make changes

After taking part in a workshop on barrier-free access, the Lao Disabled Women's Development Center produced a videotape about barrier-free access for people with disabilities. They started talking to the different government sectors about facilitating participation of people with disabilities in society. Their ideas were approved by the Prime Minister's office, the ministries of communication, transportation, post and construction, labor and social welfare, and foreign affairs. They were able to get funds to construct ramps at 47 places in the capital city, Vientiane.



Making access possible

As a child, Alicia Contreras of Mexico became disabled from polio. A wise therapist counseled Alicia´s parents on the importance of motivating her to be independent. Her parents arranged for her to attend regular school from childcare through high school. Alicia was the first student with a disability in her school, and her success there opened the schoolhouse doors to more children with disabilities.

Eventually, Alicia went on to university. She had a class on the third floor, and it wasn't easy to climb the stairs using crutches. Alicia went to the university director and asked him to move the class from the third floor to the first. He agreed right away. "They had another room available," Alicia recalled. "But the director had never thought about how students with disabilities would not be able to get to classrooms on upper floors, and I never thought to ask." Other times, Alicia had to fight harder to make changes.

Alicia became a member of a disability association called "Free Access." The group believed people with disabilities had the same rights as everybody else and worked to make the community more accessible. For example, they discussed with city transportation officials how difficult it was for people with disabilities to move around the city. As a result, the city adapted some buses to make them accessible to people with physical disabilities.

Free Access is still active today. Since 1993, it has worked with government officials and non-governmental organizations to promote changes to better the lives of people with disabilities. And there is still so much more to be done!

Changing policies is not easy. It can be long and complicated. It can take many years and a lot of effort by many people. You must understand the costs, the people affected, and the politics that affect the conditions you want to change. It is easy to feel discouraged if you are organizing for change. When you feel overwhelmed or discouraged, try to seek advice from other women with disabilities elsewhere in your country, and even outside your country. And remember you have a right to use all public facilities. You can create an accessible community.

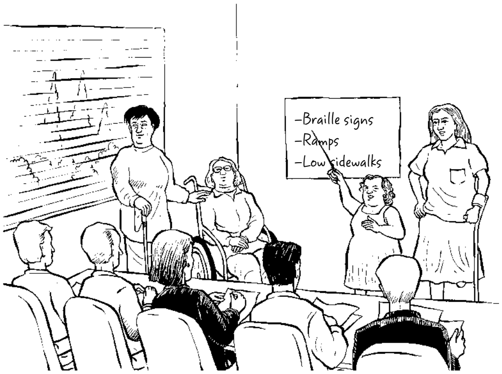
Here is a story about people with disabilities who formed a group that made great change in their city.

Making a city accessible

In Ekaterinburg, Russia, the Freedom of Movement Society has been working together with the city government to make their city more accessible. Russian law requires that people with disabilities should be able to use public buildings and buses, but many places are still not accessible. The city government in Ekaterinburg developed a disability program to make buildings accessible.

But a group of people with disabilities who use wheelchairs or crutches realized that, even though the government had been trying to help, many of the places they had changed were still hard for disabled people to use. They realized the government could not do it without the help of people with disabilities.

So the people with disabilities formed the Freedom of Movement Society. They started by making a list of the most important places in the city to make accessible. They met with city officials, and showed them the list. The city realized they needed the advice of people with disabilities. The Freedom of Movement Society made sure their members were included in the city committee that became responsible for improving access. The people with disabilities had to approve any project the committee decided to do.



The Freedom of Movement Society created guidelines that architects could use to make buildings accessible. They were able to take photographs of buildings they wanted to fix, and then draw clear pictures of how to make changes.

Now, the old buildings are slowly being changed. And the new guidelines are used all over the city. Because of the work of the Freedom of Movement Society, all new office buildings and many other buildings are accessible to people with disabilities. New sidewalks are lowered in places for people who use wheelchairs. The new city mall is easy for people with disabilities to use. The Freedom of Movement Society also got the city to make several schools as well as the city's movie theater accessible.

—*Disability World*

Taking action

- Organize social activities that help disabled girls come out of their homes and meet other people with disabilities and other young girls.
- Share information about finding or creating work.
- Support women who are treated badly at home or in public or in the workplace.
- Offer training in leadership and social skills.

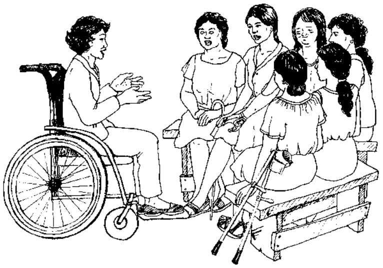
Providing resources for change in Uganda

The Uganda Disabled Women's Association maintains a revolving loan program for disabled women to start their own businesses, provides education and mobility aids, and runs a drama group to raise public awareness about disabled women. They strive to increase disabled women's rights and well-being, to advocate for better education for disabled children, to teach independent living skills, to share reproductive health information, and "to fight poverty, ignorance, social differences, and disease."

Women make change happen in El Salvador

In El Salvador, the disability rights group ACOGIPRI has organized women's programs since 1987, bringing together disabled women from diverse backgrounds to hold discussions about sexuality and other issues. They also:

- provide literacy and leadership training.
- make aids and services available to girls and women with any form of disability.
- prevent discrimination and violence.



Communities are stronger when everyone is included

Despite barriers of prejudice, ignorance and discrimination, women with disabilities around the world are improving their skills for self-sufficiency.

Women with disabilities must be heard when decisions are made at every level and about every issue—not just disability issues. No one has all the answers. Everyone, women and men, both with and without disabilities, people who struggle for human rights, and for the rights of workers and for the dignity of women in all parts of the world must join together to support women with disabilities to live healthy, independent, and productive lives. By making sure we nurture life in each of us, and learn from each other, we can build a more just world for all of us.

CHAPTER 2

Organizing for disability-friendly health care

Women with disabilities have a right to be healthy and to have access to good care. But few health centers, clinics, and hospitals are designed to be used by women with disabilities. Also, they may be too expensive, or too far away, and you may not have a way to get there, pay for the medicines or for treatment, or be able to communicate with the health workers.

In this chapter we tell the story of one woman, Delphine, and how she worked with other women in her community to solve a health problem she had. Delphine and her friends discovered that a lasting solution to her problem involved looking beyond Delphine's situation. The health problems of a woman with a disability, like most health problems of all women, are almost never her problems alone—her health problems are a community issue.

Like Delphine and her friends, you and other disabled women you know can work together to have access to good health care, to identify the root causes of the problems in your community, and work to change them.

Delphine's story

Delphine has cerebral palsy. She uses a wheelchair to get around. She has a boyfriend who does not want anyone in the community to know he is having a sexual relationship with a woman with a disability. He is a "midnight husband," who comes to see her only when it is dark at night, and leaves before it gets light in the morning.

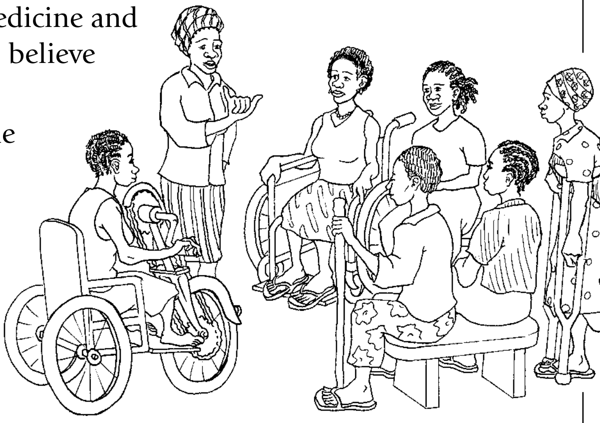
One day Delphine realizes she has an unusual discharge from her vagina. She tries local remedies to cure it, but nothing helps. The discharge starts to get worse, and she also gets a pain in her belly. Finally, Delphine goes to a clinic. They do not want to believe her when she says she has sexual intercourse, and she does not want to give them the name of her boyfriend because she fears he will not see her any more.

At the clinic they insist her disability must have caused her problem and try stretching her arms and legs, which makes her muscle spasms worse, and they try giving her medicines to relax her muscles. The medicines do nothing to help the pain in her belly, which gets worse and worse. She also starts sweating and gets a high fever, and has pain when she passes urine.

Delphine remembers a friend telling her about a group of disabled women who meet together and she goes to them to tell them her problem. They have recently been studying a book someone gave them called *Where Women Have No Doctor* and they read about how infections can be passed from one person to another during sex.

Two of the women in the group volunteer to go with Delphine to the clinic again. Together they are able to convince the doctor that she has had sex. So the doctor does the proper tests and discovers Delphine has a serious sexually transmitted infection in her womb caused by gonorrhea and chlamydia (see Chapter 8). He gives her the proper medicine. He also tells her that her boyfriend will also need to take the medicine, and that he should use condoms when they have sex so he does not pass an infection to her again.

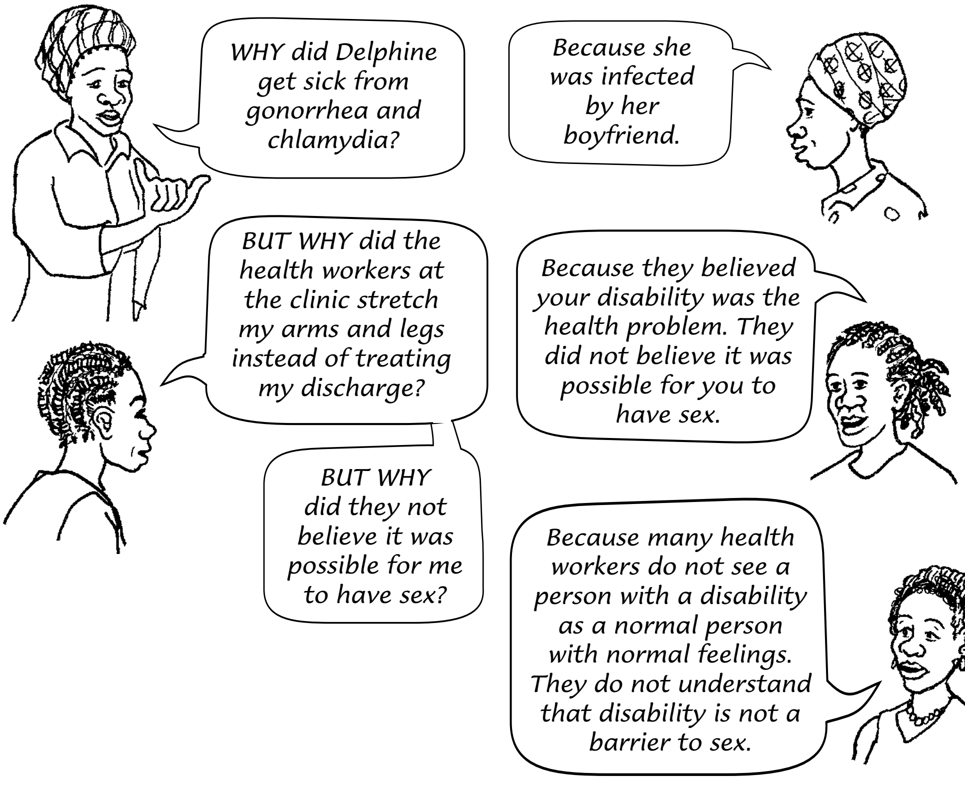
LOOKING FOR THE ROOT CAUSES OF PROBLEMS

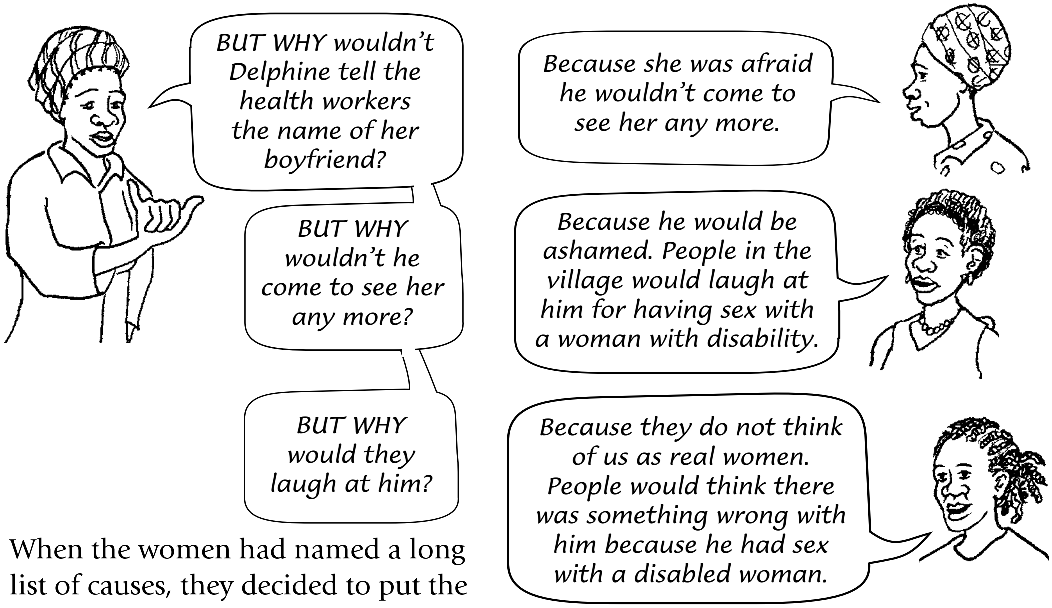


After Delphine had taken the medicine and was feeling better, she wanted to believe her health problem was over.

But after reading the book, she knew this was not true. The next time her boyfriend came to see her, she would get infected again if he did not also take the medicine and use condoms.

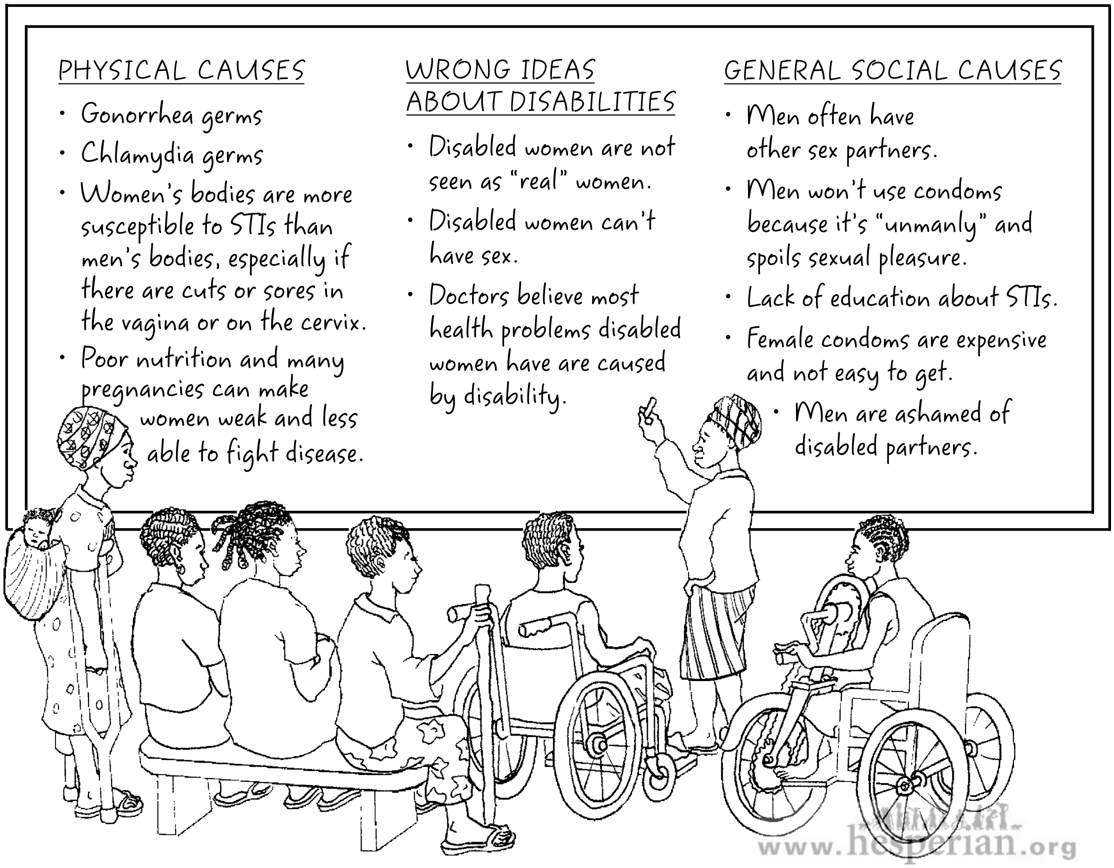
Delphine discussed the problem with the other disabled women in the group, and together they decided to play a game called "But why…" to help everyone identify all the conditions that created the problem.





When the women had named a long list of causes, they decided to put the causes in groups.

This way it was easier to see the different kinds of conditions that cause health problems and the different areas in which solutions had to be found.



PHYSICAL CAUSES

- Gonorrhea germs
- Chlamydia germs
- Women's bodies are more susceptible to STIs than men's bodies, especially if there are cuts or sores in the vagina or on the cervix.
- Poor nutrition and many pregnancies can make women weak and less able to fight disease.

WRONG IDEAS ABOUT DISABILITIES

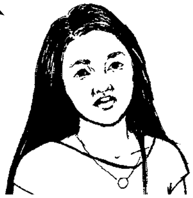
- Disabled women are not seen as "real" women.
- Disabled women can't have sex.
- Doctors believe most health problems disabled women have are caused by disability.

GENERAL SOCIAL CAUSES

- Men often have other sex partners.
- Men won't use condoms because it's "unmanly" and spoils sexual pleasure.
- Lack of education about STIs.
- Female condoms are expensive and not easy to get.
- Men are ashamed of disabled partners.

Health care is a human right for all

Good health care prevents problems that make disabilities worse. Good health care also prevents health problems caused by disabilities. Treating a modest problem, at the right time—such as treating a pressure sore caused by sitting or lying in one position too long—stops it from turning into a life-threatening crisis.



Health care must be made available to all disabled women, regardless of social status. Good health care includes free or low-cost health services, insurance or access to funds to pay for health care, and public transportation that is easy to use. This is especially important for women who are isolated or poor.

Poverty and health

Economic and trade policies worldwide have created more poverty, fewer resources for health care, and greater social differences between people. These inequities have made it harder for women to get health care for themselves and their families. User fees for health care are another barrier to health services. Other financial barriers, such as the cost of medicines and transportation, can make health care unaffordable.

It is very hard for women with disabilities to get health care. In most countries in Africa, for example, only 1 out of every 100 people with disabilities has access to the health services he or she needs. Added to the lack of services and facilities is the cost, distance, physical barriers, and harmful attitudes. Even when a woman has some money, the health services available are rarely appropriate for the health needs of women with disabilities, especially their reproductive health needs.

Breaking barriers in Nigeria

Ekaete Judith Umoh is from the oil-rich Niger Delta region of Nigeria and is a polio survivor. Today, she is sometimes called "Mama Mainstream," because of her insistence that all health care programs include girls and women with disabilities at every step of program planning and services. "She who wears the shoe knows where it hurts the most," Ekaete says. "We are women and entitled to whatever services are provided for other women in the society."

In 2000, Ekaete founded the Family-Centered Initiative for Challenged Persons (FACICP), a non-governmental organization that works to ensure that the rights and needs of disabled people, especially women and girls, are respected in all health care and development programs. Ekaete describes FACICP's Health Care Without Barriers Project: "The aim of the project is to make reproductive health care services, including information on HIV/AIDS, accessible to women with disabilities. We are in the process of translating simple reproductive health information into Braille for blind women, and we now hold monthly meetings to discuss sexuality education, especially as it relates to pregnancy, parenting, and disability."

FACICP also works in partnership with the Society for Family Health (SFH), an organization that provides health education about a wide range of women's health issues. "SFH agreed to invite us to any training program or workshop they conduct to further raise awareness of the health needs of women with disabilities," Ekaete told us. FACICP works with SFH to make sure workshops are held in places with access for wheelchairs and that sign language interpretation is provided, so deaf women can fully participate. With SFH training, disabled women can become family health educators in their communities.

Ekaete and her colleagues are also challenging governments, multilateral organizations, and civil society to begin using a "disability lens" in all their development work. They have proposed, for example, that World Bank-funded projects include people with disabilities in training, technical assistance, consultations, project funding, and distribution of material resources. This will ensure that the health rights and needs of people with disabilities are always in focus and not forgotten. As Ekaete reminds us, "People with disabilities are everywhere, entitled to the same rights and privileges enjoyed by the citizens of any community."

Making health services easier to use

Together disabled women and health workers can make health services better serve women with disabilities. They can find ways to make it easier for women with disabilities to get into a health center, to use the equipment, to increase knowledge about disabilities, and to improve the attitudes of health workers towards disabled women. Most of these changes are not difficult or expensive to do.

These changes will also help many others, such as older people who do not move as easily as when they were young, or anyone who has had an accident and is temporarily disabled with a broken leg or arm.

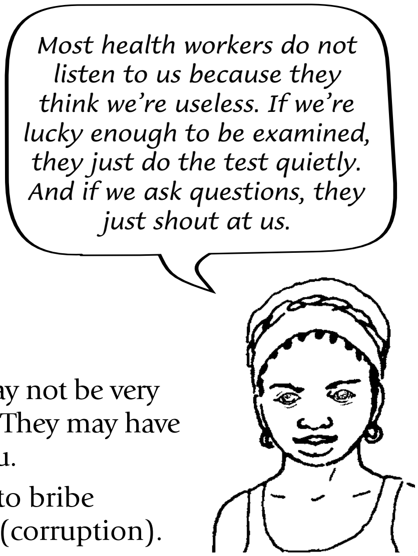
Ideas to make health services more disability-friendly

- Offer weekly or monthly home visits to people who live far from health centers.
- Offer free health services for women with disabilities.
- Make equipment easy to use.
- Provide public or private transportation to the health center. Transport must be easy to use for people who use wheelchairs, crutches, or have difficulty walking.

For more information about access, see To learn more, beginning on page 376.

BARRIERS TO HEALTH CARE

- For a woman using a wheelchair or crutches, most health centers and hospitals are difficult to get to. They are often far away and there is no transport a woman with a disability can easily use to get there.
- Equipment and supplies such as lower beds or good quality catheters, are often not available.
- The hours the health center is open may not be convenient.
- There may be few women doctors even though many women feel embarrassed to go to a male doctor.
- Health workers do not know how to communicate with someone who is deaf, and there are no health information materials for women who are blind.
- Health care workers, including nurses and doctors, may not be very well trained, or may not know much about disability. They may have wrong ideas about disability and may not listen to you.
- Health services can be expensive and you may have to bribe someone before you can meet with a health worker (corruption).



SUGGESTIONS TO MAKE CLINICS AND HOSPITALS EASIER TO USE

Clinics or hospitals must:

- be nearby and there must be transport available to reach them.
- be easy to use for people who use wheelchairs or crutches, or have difficulty walking.
- have ramps or lifts as well as stairs.
- have toilets that disabled women can use.

Clinics and hospitals must also have trained staff members who can communicate effectively with people who are deaf or blind, or who have cerebral palsy, and who can make sure that women who have learning difficulties understand what is happening in the clinic.

Clinics and hospitals can:

- train everyone about disability.
- include women with disabilities as health workers and staff members in clinics and hospitals.
- put handrails or ropes around the building so that people who are blind or do not see well can find their way inside safely.
- organize activities about health and women with disabilities.
- provide monthly or regular counseling sessions for women with disabilities.
- make it easy for women with disabilities to combine as many appointments in different departments as necessary during the same day they go to the clinic or hospital. Some health centers allow village health workers to make these appointments for women with disabilities.
- make information on how to use health services easy to obtain and understand.
- provide health information in different languages.
- provide blind women with health information in Braille or on audio cassettes.
- encourage health workers to use simple, clear language and pictures to illustrate what they are saying to women who have trouble learning or understanding.
- train health workers to communicate with women who have problems with speaking clearly.
- train staff members in sign language so they can give health information to deaf women.

A clinic will be easier for deaf women to use if even one health worker knows the sign language used among deaf people who live in that community. If there are no formal sign language classes close to the clinic, perhaps a clinic worker can learn sign language from the national deaf association, or learn sign language from a deaf person who lives nearby. They can also use a local sign language dictionary if one is available. Even without using formal sign language, health workers can use gestures to communicate. Deaf women themselves will be the best people to tell health workers the type of communication that works best for them.

See pages 369 to 371 for some health-related sign-language suggestions.

Community health workers can provide care

In many countries, the skills needed to care for disabled women are considered special and provided only by doctors. Yet many of these services could be provided at lower cost by trained community health workers, teachers, and rehabilitation workers.

Bringing services to disabled children

Field workers from the Hospital and Rehabilitation Centre for Disabled Children in Kavre, Nepal support disabled children throughout Nepal. These trained field workers provide disabled children with treatment for their pressure sores, and provide physical therapy and exercises to strengthen affected muscles and prevent contractures. Field workers also provide aids so the children can move about in their communities more easily.

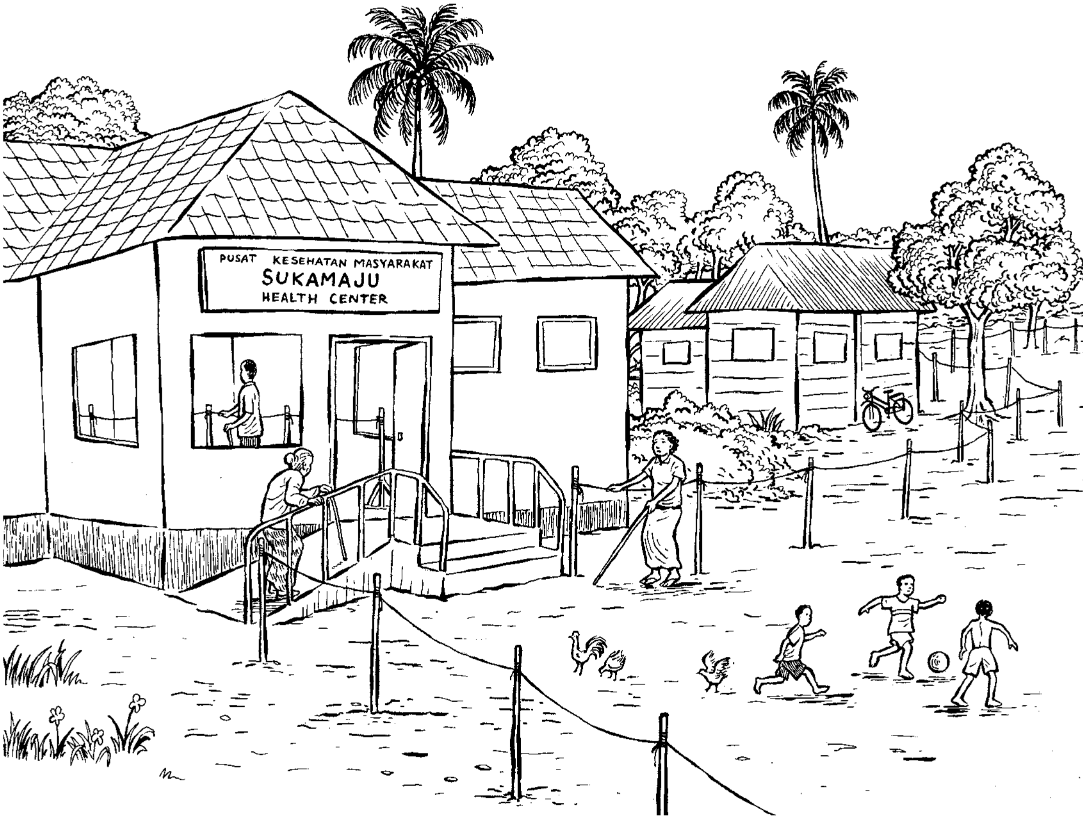
For more information about community-based support for people with disabilities, see *Disabled Village Children*.

Low-cost ideas to make health center and hospital buildings easier to use

Buildings can be designed to welcome all people or to keep some people out. It is amazing what a few good pathways, ramps, handrails, staircases with shorter steps, lifts (elevators), larger toilets, or floors that are not slippery can do to make it easier for people to get in and use any building.

Handrails (or ropes)

Handrails or ropes along pathways leading to a building and along the walls inside will help people who are blind, or who have balance problems or difficulty walking, to get in and find their way around.



Roped pathways and smooth road surfaces with textured edges make areas around health centers easy to use. Textured edges can help women who are blind or do not see well.

Doors

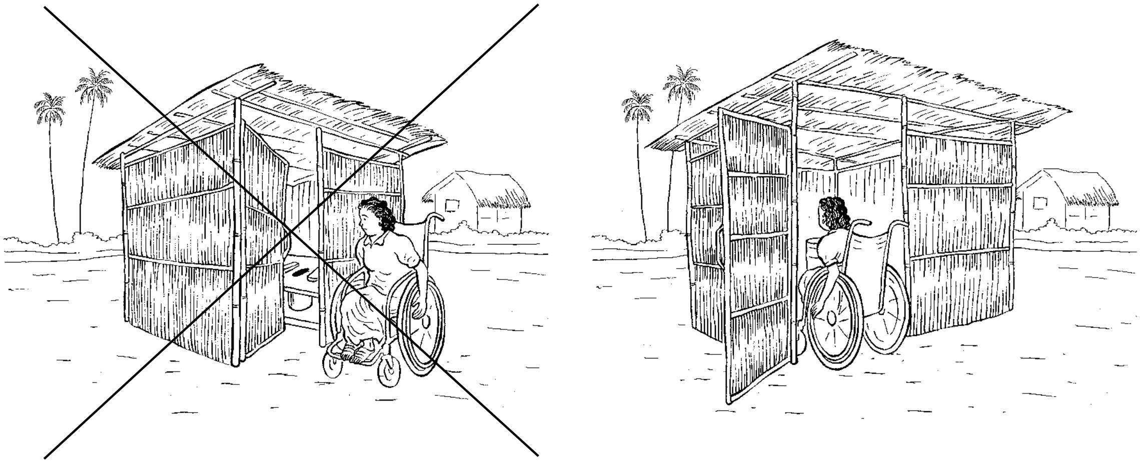
A door handle is easier to use than a round door knob. People who cannot easily move their hands can often press down on a handle. Most people who use wheelchairs also find handles easier. And anyone who is carrying something will always find a door handle easier to open.

You can change a door knob into an easy-to-turn door handle by welding a metal plate onto the door knob. Put the handle low enough for easy reach by someone of small stature or someone who uses a wheelchair.

If a door is hard to open, you can use oil, grease, or candle wax on the hinges. Then the door will swing more easily.

Also, doors sometimes do not leave space to move a wheelchair into a room. If the space is small, such as in a toilet, try to make sure the door opens out into the bigger space or room. When a door swings into the smaller room, it can make it hard for someone to move in and out of the room or space. Sometimes, doors can be made to slide if space is limited.

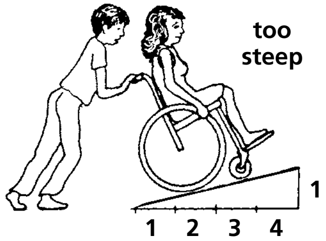
The doorway itself should be wide enough for a person in a wheelchair to pass through. It should leave enough space for her wheelchair and her hands on the wheels.



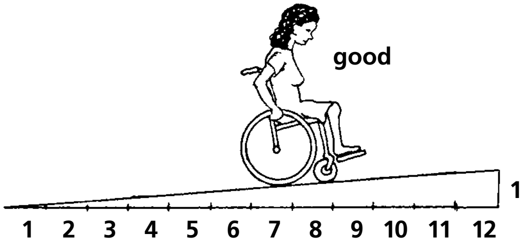
Often you can change the hinges on a door so it opens the other way.

Build ramps

Ramps make it easier for many people to get in and out of buildings and public places such as health centers, schools, and libraries. Ramps not only help wheelchair users, they also help people who have a hard time walking and people with temporary injuries.

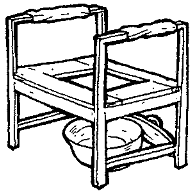


This ramp is 4 times as long as it is high. It is too steep for most people to use, except for short distances.



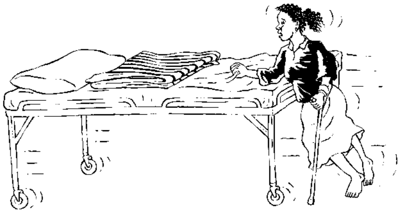
Ramps can be between 8 to 12 times as long as they are high. This ramp is 12 times as long as it is high. This slope is easier for people who use wheelchairs.

Toilets



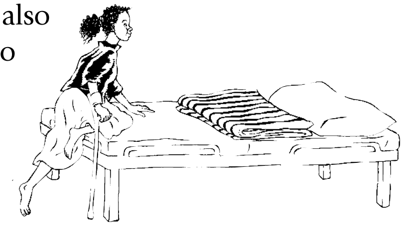
If you use a wheelchair, toilets should have enough space for you to move around and transfer from your chair onto the toilet seat. It is easiest for you to get onto the seat if the toilet is at the same height or a little lower than your wheelchair seat. If there is not a seat (in a squatting toilet or latrine), or if the seat is too low, you can make a simple box seat with hand-holds and an opening. You can also put a bar or a hand-hold on the wall so you do not fall (see page 123.)

Hospital beds



Many people, not just people with disabilities, complain that hospital beds are difficult to get onto. These beds are usually higher off the ground or floor than the beds people sleep in at home. It is easier for health workers to take care of sick people if they do not have to bend down to reach them in a lower bed.

But when people are sick or disabled, getting onto a high bed can be very difficult. And because the beds usually also have wheels, it can be dangerous, because the bed can start to roll away from the person who is trying to get onto it.



If some beds in a health center have no wheels and are low to the ground, everyone could choose the bed that works best for them.

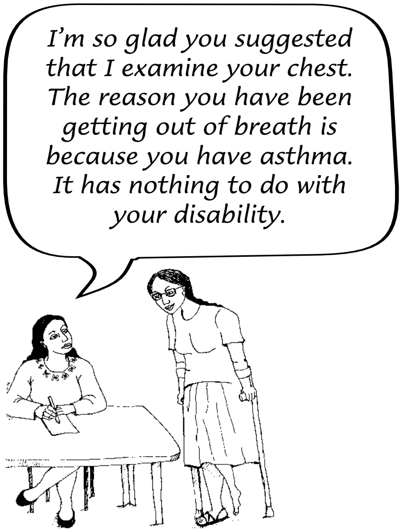
To the health worker:

LEARNING ABOUT DISABILITY

Doctors and other health workers are usually trained to treat only people without disabilities. They often learn very little about disability in their education. Their only contact with disabled people may be in trying to 'cure' their disability.

Health workers need to learn more about disabilities. They have to learn how a specific disability may affect aspects of a woman's life, such as getting pregnant or growing older.

One good way for health workers to learn more about disability is to include women with disabilities in training programs. Health workers will gain confidence by learning from the experiences of women with disabilities, and they will learn how to best teach health workers to make their care disability-friendly.

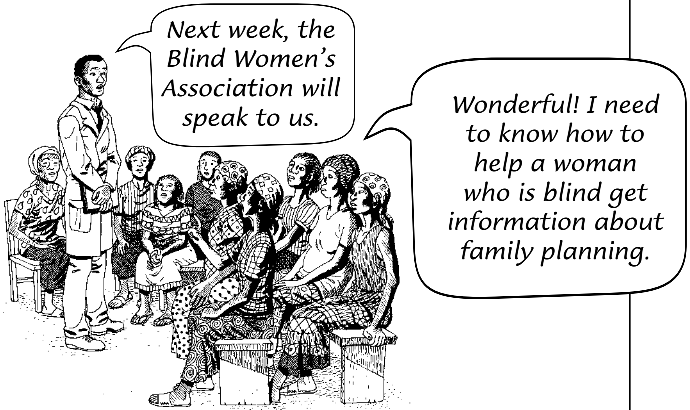


Listen to what a woman with disability tells you about her health. Later you can ask her whether or not she feels her disability affects her health problem.

Health workers learn from women with disabilities

The health ministry in Uganda surveyed and talked with midwives and traditional birth attendants across the country to find out what information they needed to do their jobs better. Several of them said they needed more information about how to help women with disabilities.

Now, the health ministry in Uganda is beginning to organize training sessions to share more information about disabled women's health. Women with disabilities help lead the training sessions. By sharing their experiences with health workers, women with disabilities can answer questions about good ways to treat disabled women. And, health workers and disabled women are able to learn from each other.

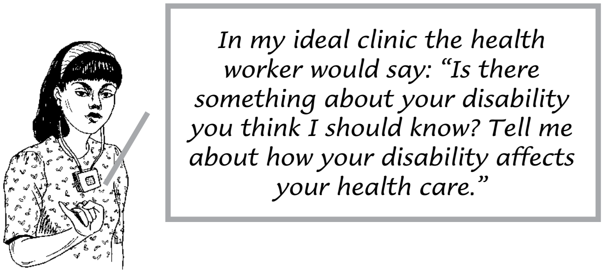


When a woman with a disability comes to see you for a health problem, remember she is a woman, just like any other woman. First, ask her why she has come to see you and how you can help her. Do not assume it is because of her disability.

Encourage her to ask questions. That way, she can explain her problems. Respect her opinions. After all, she understands her health problems better than anyone else and can make good decisions about her treatment.

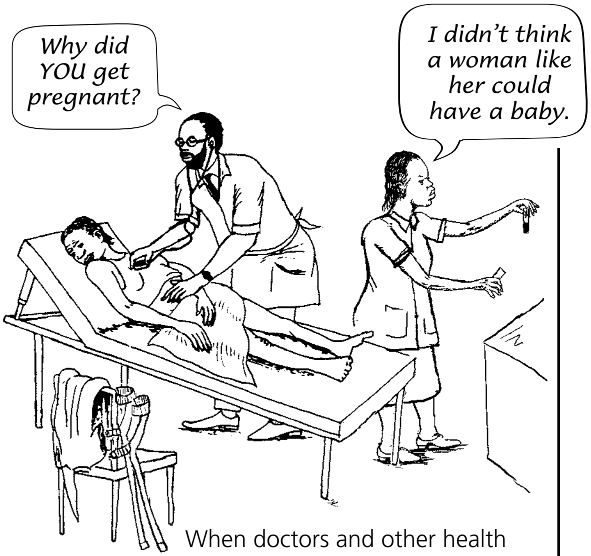
Help her relax and give her time to express her unspoken questions. This will help her not to be afraid. Sometimes a woman with a disability may not have the confidence to ask questions about what is really worrying her. Or she may not have enough privacy. But you can help reduce the fears of women with disabilities, help them become more confident, and get the information and care they need.

Ask people with disabilities how they would like you to do things. And when they ask questions, you do not have to have all of the answers. It is fine to admit you do not know something, and then offer to find the information they need.



Respect

Anyone who is concerned about the health of a woman with a disability should know how to care for her in a sensitive way. Anyone who provides her health care must always treat her with dignity and respect. Unfortunately, people sometimes need to be reminded of this. The woman should be encouraged to talk about what she thinks is causing the problem and how she would like to solve it. This way a health worker will learn to understand different disabilities. Working together reduces conflicts and confrontations, and brings the best results!

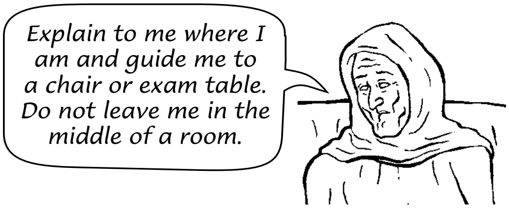


When doctors and other health workers know little about disability, their attitudes can humiliate a woman with a disability.

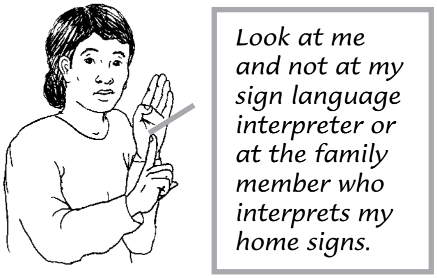
HELPING WOMEN WITH PARTICULAR DISABILITIES

A woman who is blind or has difficulty seeing

- Unless it is an emergency, do not touch the woman before telling her who you are.
- Do not think she cannot see you at all.
- Speak in your normal voice.
- If she has a stick, do not take it away from her at any time.
- Say good-bye before walking away or leaving.



A woman who is deaf or has difficulty hearing



- Make sure you have her attention before speaking. If she is not facing you, touch her gently on the shoulder.
- Do not shout or exaggerate your speech.
- Look directly at her, and do not cover your mouth with anything.
- Ask her what is the best way of communicating.

A woman who has difficulty moving

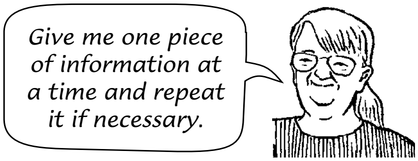
- Do not assume she is mentally slow.
- If possible, sit so that you are at eye level with her.
- Do not move any crutches, sticks, walkers, or wheelchairs without the woman's permission or without arranging for their return.
- If she is a wheelchair user, do not lean on or touch her wheelchair without her permission.

A woman who does not speak clearly

- Even though her speech may be slow or difficult to understand, this does not mean she has any difficulties learning or understanding.
- Ask her to repeat anything you do not understand.
- Ask questions she can answer by "yes" or "no."
- Let her take as much time as she needs to explain her problem. Be patient.

A woman who has trouble learning or understanding

- Use simple words and short sentences.
- Be polite and patient, and do not treat her like a child.



Working for change

Here are some suggestions you can use to work together with health workers to improve health care services. These activities can be used to:

- raise awareness about accessibility, availability, and the attitudes that make it hard for disabled women to find and get good health care.
- identify actions that can improve health care for disabled women.

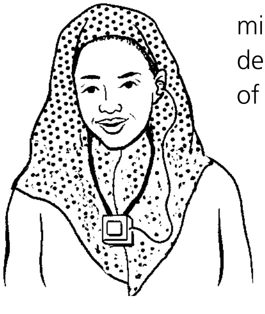
Meeting in a group to share personal experiences of health care barriers can build each woman's confidence.

Step 1. Everyone has something to offer

To help everyone feel comfortable, and to show how each person has a contribution to make, you can ask each woman to tell about something she does well or that she is proud of. (No one has to talk about herself if she does not want to.)
For instance:

Kranti is a good cook.

Maria keeps the peace between her sisters.

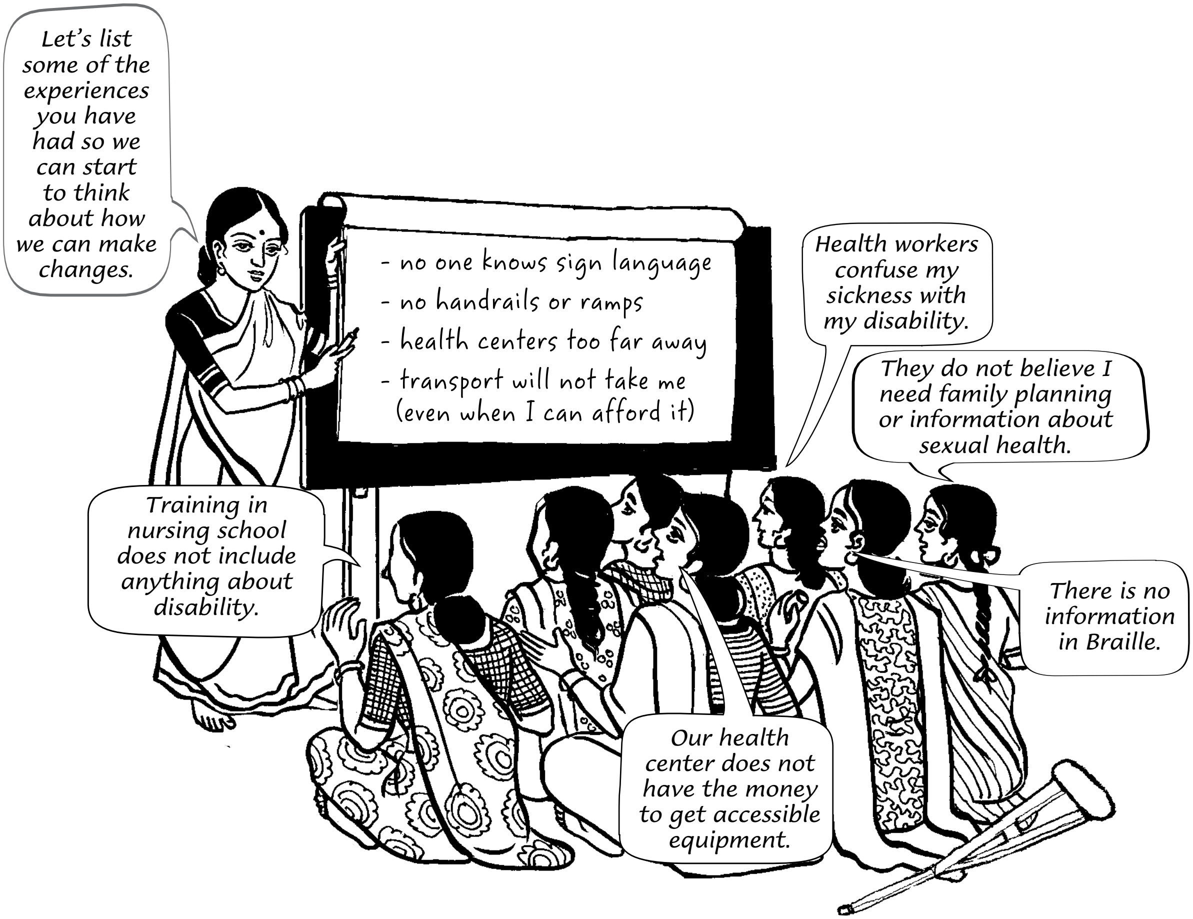


Rania is a skilled midwife and has delivered hundreds of babies.

Adetoun is a good storyteller. The children in her family and neighborhood love to listen to her.

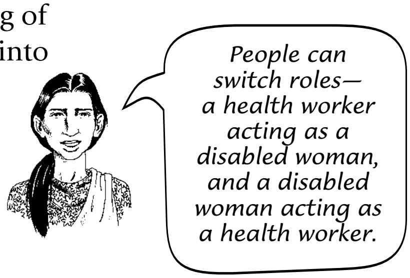
STEP 2. Share experiences about health care access

Ask each person to tell about something she has seen or experienced that has prevented a woman with a disability from getting good health care. Make a list, in no particular order, of the difficulties the women describe.



STEP 3. Role plays to learn about barriers to good health care

Use role plays to deepen everyone's understanding of the difficulties they have listed. Divide the group into several teams that include both health workers and women with disabilities. Ask each team to spend a few minutes preparing a role play about a disabled woman who has trouble getting good health care. Encourage everyone to participate.



Role plays

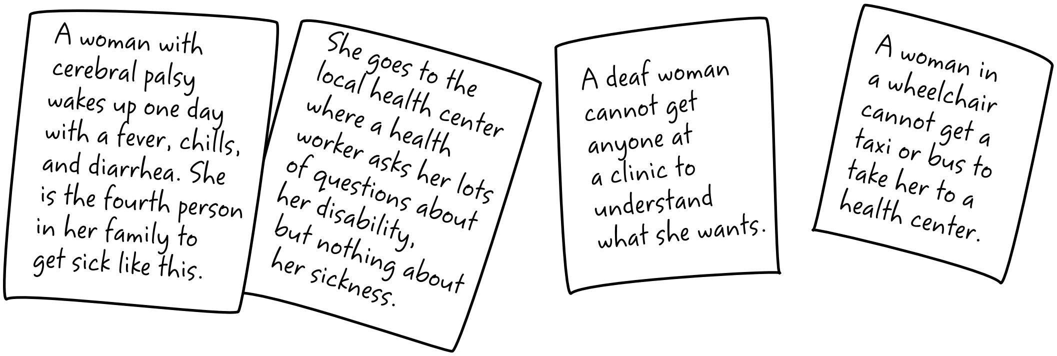
One of the best ways to help people understand real-life problems or situations is by acting them out. When followed by an organized group discussion, a role play can help a group look at attitudes, customs, and patterns of behavior, and how they affect women's health. Role playing is useful for developing awareness and exploring alternative solutions to social problems.

Role playing should be fun—but it should be taken seriously. Actions and characters may be exaggerated at times, but they should basically be true to the way things and people really are. Role playing can be done with little or no practice ahead of time, and no memorizing of parts.

(For more information about role plays and other educational theater, see *Helping Health Workers Learn*, Chapters 14 and 27.)

Role play possibilities

Here are some role plays you can suggest if the group has trouble coming up with ideas of its own:



A woman with cerebral palsy wakes up one day with a fever, chills, and diarrhea. She is the fourth person in her family to get sick like this.

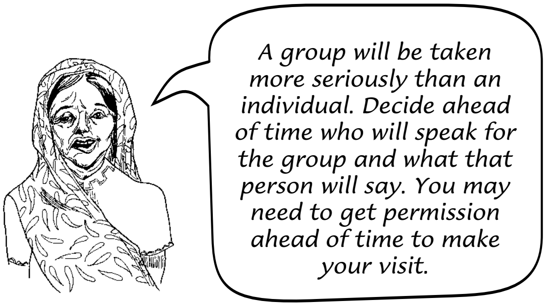
She goes to the local health center where a health worker asks her lots of questions about her disability, but nothing about her sickness.

A deaf woman cannot get anyone at a clinic to understand what she wants.

A woman in a wheelchair cannot get a taxi or bus to take her to a health center.

After each role play, ask the "actors" to return to the group. Invite the group to ask each other questions about the role plays that will help deepen their understanding of the problems disabled women have in getting good health care.

Step 4. Visit a health center



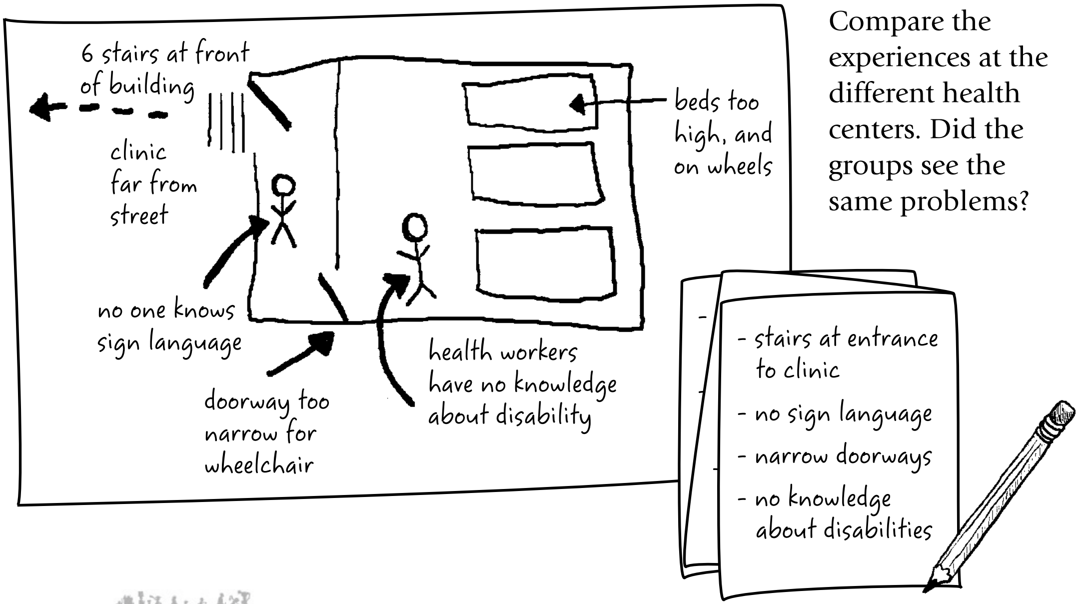
After the group has identified some general barriers to good health care access, they can visit local health centers to take a closer look at things that can cause problems for a woman with a disability. Divide the group into 2, if there are enough people, with at least one health worker in each group, and visit one or more health centers. (If possible, do not send a group to visit a health center where the health workers in that group work.) Ask 1 or 2 women in the group to write down or make note of any problems and obstacles they find. Also ask them to note anything they find that is helpful for women with disabilities.

The trip to the health center can also be used as an example of how women can help each other and work together to use each other's strengths to overcome problems. For example, wheelchair riders can guide blind women, and blind women can support women who need help with walking.

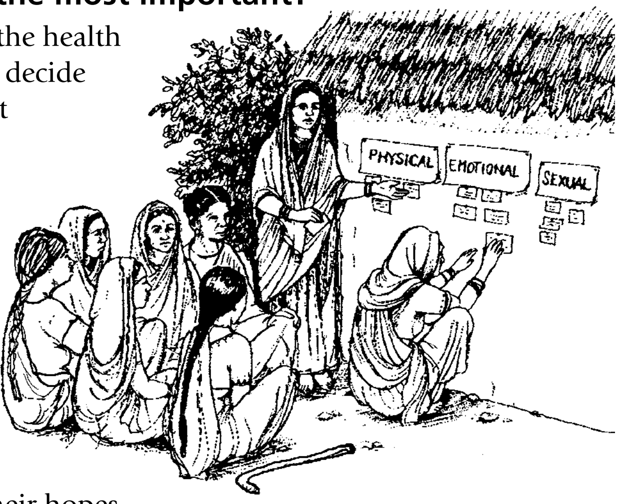
Step 5. What did you find at the health center?

When you return from the visits, have each group describe the problems they found and things that were helpful to women with disabilities. Also ask each group to describe how they were treated by the director of the health center and the staff. You can make a list or draw a map of the problems they found.

Compare the experiences at the different health centers. Did the groups see the same problems?



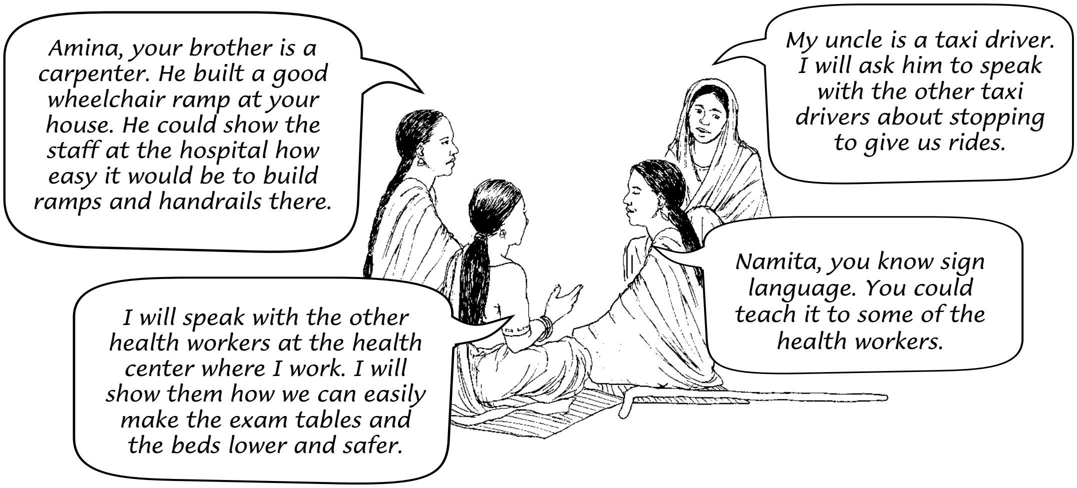
Step 6. Which problems are the most important?



Discuss the problems seen during the health center visits and ask the women to decide which ones they think are the most important to change, or that they would like to change first. Making improvements to health care services can take planning and time. Your group may want to study the list to see which things you can change quickly, and which may take longer to change. Ask them to talk about why the problems they have chosen are important to work on, and what their hopes and wishes are for the change they may bring if these problems are improved.

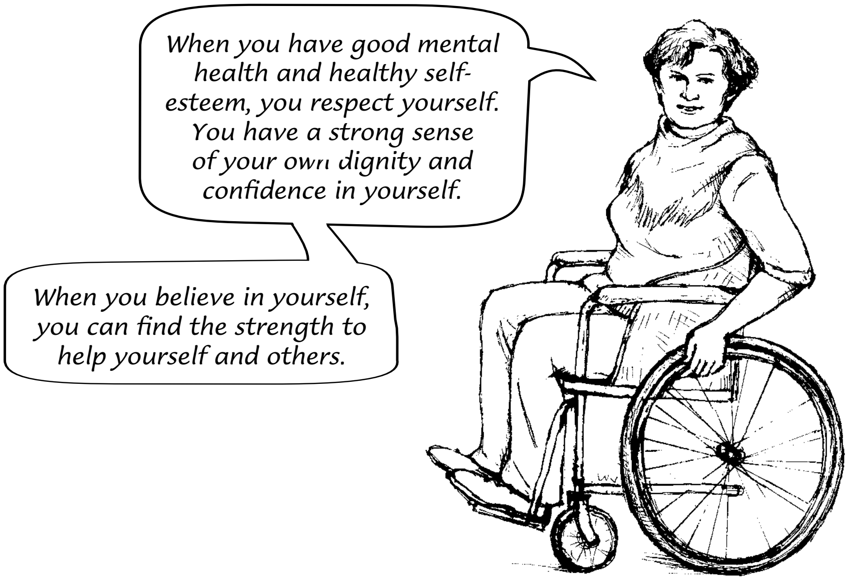
Step 7. An action plan for improvements

Once the group has chosen 1 or 2 problems that make it difficult for women with disabilities to get good health care, they can work on a plan to solve these problems. Ask the group to discuss different ways they can solve each problem, and ask them to think about other people who can help them make these improvements. Work out the steps that will be needed to make these improvements and decide who will be responsible for which step. Then, take action!



CHAPTER 3

Mental health



Having a healthy mind and spirit is just as important as having a healthy body. When your mind and spirit are healthy, you have the emotional strength to take care of yourself and your family, to see problems and do your best to solve them, to plan for your future, and to form satisfying relationships with others. When you are mentally healthy, you can accept help from other people and still value yourself.

Many disabled women develop mental health problems that make it hard for them to face challenges, feel satisfied with their lives, or contribute to the community. Sometimes, these mental health problems are caused by a woman's disability. But usually, they are caused by the way a community treats women with disabilities.

This chapter describes the challenges to mental health that many women with disabilities face. It also describes common mental health problems and gives suggestions about how to work toward feeling better. It also shows how families and communities can promote mental health.

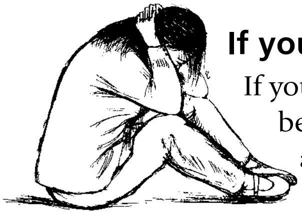
Remember **there are no quick solutions to mental heath problems.** Beware of anyone who promises this.

Challenges to mental health

Stress, discrimination, isolation, and traumatic events are some of the challenges to mental health that women with disabilities face. Of course, not everyone who has to cope with these problems will develop mental health problems. Stress, for example, is not a mental health problem, although when you can no longer cope with the challenges you face, too much stress has become a problem. Traumatic events in your life do not always cause mental health problems, but if you have no support in trying to understand them and work through them emotionally, they often do.

When thinking about mental health problems, remember:

- There is no clear line between normal responses to life's events and mental health problems.
- Most people have some of the signs described in this chapter at different times in their lives, because everyone faces problems at one time or another.
- Signs of mental health problems can vary from community to community. Behavior that looks strange to an outsider may be a normal part of a community's traditions or values.



If you think someone has a mental health problem

If you suspect someone has a mental health problem, get to know her better. Listen to what other people are saying about her behavior and the ways she has changed. Since mental health problems often have roots in the family or community, think about how these may contribute to the problem. But not all mental health problems have causes that can be identified. Sometimes we just do not know why someone develops a mental health problem.

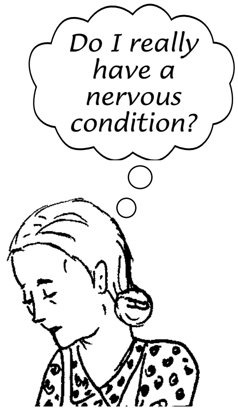
STRESS

When you face a lot of stress every day and for a long time, you may begin to feel overwhelmed and unable to cope. The problem may be made worse if you have been taught not to value yourself and to neglect your own needs.

Physical changes and disease caused by stress

When you experience stress, your body gets ready to react quickly and fight off the stress. Some of the changes that occur are:

- The heart starts beating faster.
- The blood pressure goes up.
- A person breathes faster.
- Digestion slows down.



You may be made to feel you are weak or ill. But the real problem may be something that is not fair or not right in life.

If the stress is sudden and severe, you may feel these changes in your body. Then, once the stress is gone, your body returns to normal. But if the stress is less severe or happens slowly, you may not notice how the stress is affecting your body, even though the signs are still there.

Stress that goes on for a long time can lead to the physical signs common in anxiety and depression, such as headache, intestinal problems, and lack of energy. Over time, stress can also cause illness, such as high blood pressure.

Social barriers create stress

Many of the same barriers that prevent women with disabilities from getting health care also cause stress in their daily lives. Since they face so many sources of stress, it is especially important for women with disabilities to find the support they need to feel strong and confident in their abilities, and maintain their self-esteem.

Gender

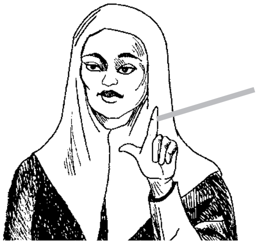
Gender is the way a community defines what it means to be a man or a woman. In communities that do not value girls as much as boys, girls experience more stress. Your brothers may be given more education or more food. You may be criticized a lot. Your hard work may go unnoticed. A girl with a disability is much more likely to be treated this way than a girl without a disability or a boy with a disability. As you grow up, you may not believe you deserve to be treated well by your partner and family, to have health care when you are sick, or to develop your skills. When you feel this way, you may even think your lack of importance in the family and community is natural and right—when, in fact, it is unfair and unjust.

Poverty

When a family is poor, it is harder for a disabled girl or woman to get the skills she needs to work. She may not get the hearing aids or crutches she needs in order to go to school. If a disabled girl or woman does not have a chance to help support the family, they may treat her like a burden. If the family has only a little food, they may decide more food should go to the family members who go out to work and help support them.

Attitudes about disability

Communities may also have lower expectations for what girls and women with disabilities can accomplish in life. Having learned they have little to hope for, women with disabilities tend to value themselves less. They often lack the self-confidence to advocate for change in the community.



When you grow up surrounded by people who love you but who do not believe you are capable of much, you start to believe that yourself. Low expectations from people you love and trust hurt your feelings about yourself.

Discrimination, stress, and self-esteem

Our Association was formed in 1989 by women with disabilities to help promote the welfare of the woman with a disability. We have 21 members with various disabilities (sight, hearing, speech, and movement). We hold a meeting once a month to talk about our problems and to try to find solutions.

We all agree that women with disabilities are often discriminated against because:

- we are women.
- we have disabilities.
- we are mostly poor.

We are rejected as suitable marriage partners or regarded as the 'wrong' image in the workplace. Girls and women with disabilities are often not able to get an education, even when education is available. For example, even in special schools for children with disabilities, boys usually receive priority.

We are unlikely to receive training for any kind of work. We experience abuse—physically, emotionally, and sexually. Unlike all men and women without disabilities, we are seldom allowed to make decisions at home or in the community.

But for each of us in the Association, the biggest problem is lack of self-esteem. We are taught by society not to value ourselves. We are generally considered to be incapable of keeping a man and bearing children, and unable to do meaningful work. Therefore we are considered worthless. Even our extended families only want us if we prove valuable to them.

—Dormaa Ahenkro, Ghana

Body image

The community may judge disabled women as less worthy than other women because they do not fit that community's image of a beautiful woman. But women with disabilities see a wide variety of bodies and behaviors around them and can appreciate these differences. They can come to see themselves as being beautiful, well-dressed, capable, and strong, even with their scars, deformities, amputations, hearing aids, unusual expressions and gestures, wheelchairs, crutches, sticks, canes, or the possibility of seizures ('fits') or bowel and bladder accidents in public.

How I changed my image

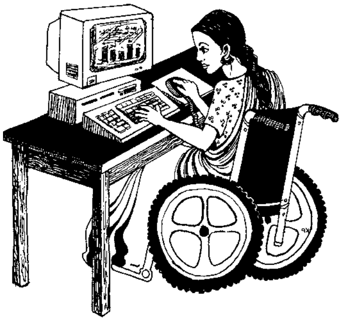
My name is Rose, and I come from Kenya. I am blind, and I have many family members and friends who help me with my daily care. I appreciate their help very much. But I was also frustrated because I did not have much control over how I was dressed or how things were done. I felt I was being treated like a child all the time because no one seemed to treat me with any respect.

I wanted to feel more independent. So I started asking questions. When someone helped me get dressed, I asked what the clothes looked like and how my hair was done. I also asked how other women my age were dressed and how they styled their hair.

I soon realized that when my helpers dressed me and did my hair, I ended up looking like a child. No wonder people didn't treat me with respect. But I am a grown woman of 25, and don't want to be treated as a child. So I asked my helpers if they would help me learn to fix my hair myself the way other women in the community did theirs. They were glad to. They had never thought about it before. Because they were used to fixing their own young daughters' hair, they helped me in the same way. Now, my friends help me to dress like other women in the community. And other people in the community treat me with respect.

Isolation

Disabled girls may grow up separate from other children and not have the chance to develop friendships. They may not learn the social skills they need to build strong relationships as adults. Being alone and isolated creates stress. Having friends and being part of a community is important for good self-esteem. A teenage girl who has a disability also needs support to develop confidence about her sexuality so she can form close personal and sexual relationships (see page 142).



Job skills

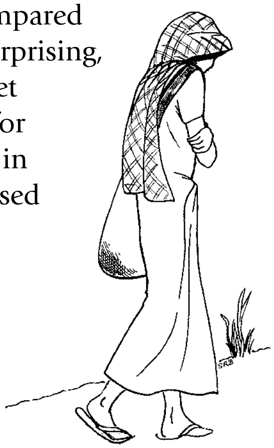
Women with disabilities are less likely to receive training for work so they can earn money. If they have not had a chance to gain job skills, it is harder for them to support their families and themselves.

Common mental health problems

Although there are many kinds of mental health problems, the most common ones are anxiety, depression, reactions to trauma, and misuse of alcohol or drugs.

DEPRESSION (EXTREME SADNESS OR FEELING NOTHING AT ALL)

Depression affects almost 5 in 10 women with disabilities, compared with around 2 in 10 people without disabilities. This is not surprising, because many girls with disabilities do not get the chance to get an education, develop confidence, or learn how to do things for themselves. As you grow older, the social barriers and changes in your health that make it more difficult to do as much as you used to, make you more likely to feel unhappy and depressed.



Signs:

- feeling sad most of the time
- difficulty sleeping or sleeping too much
- difficulty thinking clearly
- loss of interest in pleasurable activities, eating, or sex
- physical problems, such as headaches or intestinal problems, that are not caused by illness
- lack of energy for daily activities
- thinking about death or suicide

Although it is hard to believe when you are suffering from it, depression does not last forever. See pages 60 to 69 for ways to overcome depression.

As you grow older

Your body will continue to change as you grow and age. Your daily tasks will take longer, some disabilities will get worse, and you may get 'secondary' disabilities from overuse of certain parts of your body. As you grow older, more things may go 'wrong' with your body and you will have to adapt the way you do things frequently. These constant changes can make you feel as though you will never be really independent and that you must constantly rely on others to help you. Feelings that your dependence is increasing can affect your self-esteem. See Chapter 13, Growing older.

If you are feeling sad a lot of the time, or you are unable to sleep, or if you see changes in your mood, talk to someone in your family you trust, or talk with a health worker.

Suicide

Serious depression can lead to suicide (killing oneself). Many people have thoughts of suicide at least once in their life. But when these thoughts come more and more often or get very strong, you need help from a trained counselor or mental health worker right away.

- Are you feeling lonely and isolated from family or friends?
- Have you lost the desire to live?
- Do you regularly use alcohol or drugs?
- Do you have a serious health problem?
- Have you thought of killing yourself?
- Have you ever tried to kill yourself?

If the answer to any of these questions is 'yes,' you may feel better simply by talking about your problems with someone you trust. Some counselors or doctors also may use medicines to treat depression.

If someone you know talks about killing herself, encourage someone to watch her closely and to be with her at all times. Ask them to remove dangerous objects from her surroundings. If there are mental health services in your community, find out if someone can talk with her regularly.

ANXIETY (FEELING NERVOUS OR WORRIED)

If feelings of nervousness or worry (other common names for anxiety are 'nerves,' 'nervous attacks,' and 'heart distress') continue for a long time or become more severe, then you may have a mental health problem.

Signs:

- feeling tense and nervous without reason
- sweating
- feeling the heart pound (when there is no heart disease)
- frequent physical complaints that are not caused by physical illness and that increase when you are upset

Panic attacks are a severe kind of anxiety. They happen suddenly and can last from several minutes to several hours. In addition to the signs above, you may feel terror or dread, and fear you may lose consciousness (faint) or die. You may also have chest pain, difficulty breathing, and feel that something terrible is about to happen.

TRAUMA

When something horrible has happened to a woman, she has suffered a trauma. Some of the most common kinds of trauma are violence in the home, rape, war, torture, and natural disasters. Trauma threatens a woman's physical and mental well-being. As a result, she feels unsafe, insecure, helpless, and unable to trust the world or the people around her. It can take a long time for a woman to recover from trauma, especially if it was caused by another person.

Disability caused by trauma

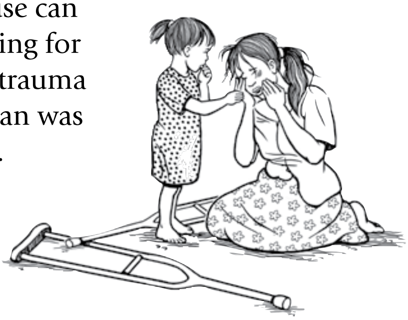
When a woman becomes disabled later in life, because of war, an accident, or an illness, the sudden change can be very difficult for her. Some women who are newly disabled may feel they have lost all worth to themselves, their families, and communities. They may also be afraid or disturbed because of trauma.

Often, a woman who becomes disabled later in life has grown up with confidence, good education, and many skills. She may have always had strong relationships with others and expects to be treated with respect. When she becomes disabled, it can take time to adjust to the changes in her body. It can be even harder to adapt to the changes in how other people see her, or how she sees herself.

Many women who become disabled later in life say they had to make a decision not to give up. Even though they felt sad and shocked, they realized they had choices about how to live their lives. (See Annie's story on page 63.)

Abuse is one kind of trauma

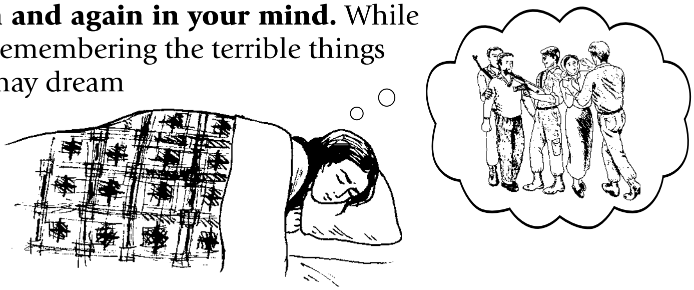
Girls with disabilities are especially at risk for abuse or violence from someone in their family. Abuse happens if anyone touches a girl in a sexual way, or if a father, brother, cousin, or caretaker forces a girl to have sex. Abuse can also involve hitting or hurting a girl, humiliating her, caring for her cruelly, or refusing to care for her. Abuse is a kind of trauma that causes great harm to a girl's mental health. If a woman was abused or hurt as a child, it can affect her for many years.



Many women with disabilities who continue being abused as adults don't complain because they believe they do not deserve to be treated well. For more information about abuse, see Chapter 14.

REACTIONS TO TRAUMA

If you have experienced trauma, you may have many different reactions, such as:



- **going over the trauma again and again in your mind.** While you are awake, you may keep remembering the terrible things that happened. At night, you may dream about them or be unable to fall asleep because you are thinking about them.
- **feeling numb or feeling emotions less strongly than before.** You may avoid people or places that remind you of the trauma.
- **becoming very watchful.** If you are constantly looking out for danger, you may have difficulty relaxing and sleeping. You may overreact when startled.
- **feeling very angry or full of shame about what happened.** If you have survived a trauma where others died or were seriously injured, you may feel guilty that others suffered more than you did.
- **feeling separate and distant from other people.**
- **having outbursts of strange or violent behavior,** in which you are confused about where you are.

People suffering from reactions to trauma may also feel anxious or depressed, or misuse alcohol or drugs.

Many of these signs are normal responses to a difficult situation. For example, it is normal to feel angry that a trauma has happened, or to be watchful if the situation is still dangerous. But you need help if the signs are so severe that you cannot carry out daily activities, or if the signs start months after the trauma has happened.

Helping overcome reactions to trauma

If you have suffered a trauma, you may need help to:

- **learn to trust others again.**
- **talk about your life before the trauma as well as your current experiences.** This way you can realize that although life has changed a lot, in many ways you are the same person as before.
- **express painful things that are too difficult to talk about or that are 'buried' where they cannot be remembered.** Drawing or painting, or a healing activity like massage, can help you express or relieve these painful feelings.
- **understand your reactions.** Once you understand your reactions, the feelings usually have less control over you.
- **make a plan for those reminders that you cannot avoid.** If reminders of the trauma make you react in fearful ways, it will help to make a plan for those reminders that cannot be avoided. For example, you might tell yourself: "His face is like the face of the man who attacked me, but he is a different person and does not wish to hurt me."

- **remember that you are not responsible for what you said or did if you were raped or hurt in any way.** All responsibility lies with those who hurt you. People who hurt you can make you feel as if you can never feel whole again. While bad experiences can change you, with support from those who care about you, even the most terrible experiences can be overcome.

Try to keep an object from your new life nearby as you sleep. This way if you dream of the trauma, when you wake the object will help you remember that you are safe now.

If someone you know has experienced trauma

At first it may be best for friends, families, or caregivers of a woman who has experienced a trauma to do everyday activities together with her or to do some of them for her if that is what she wants. You can let her know you are willing to listen and wait till she feels ready to talk. Later, encourage her to take up some of the same activities she enjoyed before or that were part of her daily routine.

Serious mental illness (psychosis)

Women with disabilities are at risk for mental illness if they have:

- had mental health problems in the past.
- lost family members or are separated from their families.
- witnessed violence or have violent partners.
- little social support.

A woman with a disability may be mentally ill if she has any of these signs:

- She hears voices or sees things that others do not hear or see (hallucinations).
- She has strange beliefs that interfere with daily life (delusions)—for example, she thinks her neighbors are trying to kill her.
- She no longer cares for herself—for example, she does not get dressed, clean herself, or eat.
- She behaves in a strange way, like saying things that make no sense.

Similar signs can be caused by some diseases, poisoning, medicines, drug abuse, or damage to the brain. People who are not mentally ill sometimes act in ways that make others question their mental health, particularly if these behaviors are related to beliefs or traditions that are not shared by the entire community. For example, if a woman says she received guidance in a "vision," she may be drawing upon traditional sources of knowledge and guidance—not suffering from hallucinations or mental illness. These signs are more likely to be signs of mental illness if they come so often and are so strong that a person has difficulty carrying out daily activities.

GETTING CARE FOR MENTAL ILLNESS

Although in most places family members care for those who are mentally ill, it is best if the person can also be treated by a trained mental health worker. In some situations medicines are necessary, but they should never be the only treatment.

Traditional healers often play an important role in treating mental illness. A healer who comes from the same community as the person with the problem may know her and her family, understand her, and have a clear idea of the stresses she has experienced. Some healers use treatments or rituals that can help a woman overcome her problem.

No matter what treatment is given, a person with a mental illness should always be treated with kindness, respect, and dignity.

Ask these questions before deciding on a treatment for mental illness:

- What is the purpose of each step in the treatment?
- What is expected to happen?
- If the person is not a danger to herself or others, can she get mental health care while living at home or living together with others in her community?
- Will the family be involved in the treatment?
- Is the person providing treatment respected in the community?
- Do any of the treatments cause side effects, physical harm or shame?

The most important part of any treatment is the support and care of family and friends.

If someone must be treated in a hospital, always ask for a tour of the facility before leaving her there. Make sure the hospital is clean, that patients are safe and can have visitors, and that they will get regular treatment with trained mental health workers. Patients should be free to move about, unless they are a danger to themselves or others. Also, make sure you find out what must be done to release the person from the hospital later.

Mental health facilities can have the same barriers as other buildings and services that make it difficult for people with disabilities to move around and communicate. See pages 36 to 40 for ideas about improving access to all health services.

Working toward mental health

To build a better life, women with disabilities need health, education, and the ability to move around independently and earn a living. But the difficulty in achieving these goals can create challenges to your mental health. You usually do not need treatment from a trained mental health worker to overcome most feelings of depression, anxiety, or low self-esteem. There are ways you can help yourself and ways you can begin to feel better with the support of another person or a group.

Things you can do with few resources

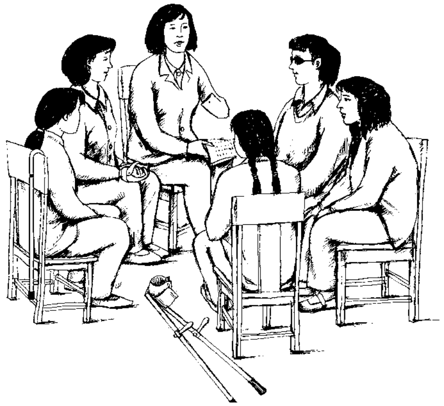
- Spend time with friends, gardening, cooking, or sharing other daily activities.
- Let your feelings out. Making up poems, songs, and stories can be helpful when you have trouble saying things to others. Or you can express your feelings without using words, through dancing, drawing, painting, or music. You do not have to be a trained artist to express yourself in these ways.
- Create pleasing surroundings. Try to arrange your living space in ways you like. Try to have as much light and fresh air as possible.
- Try to have some beauty around you. This could mean putting some flowers in the room, playing music, or going where there is a nice view.
- Practice traditions that build inner strength and help calm the body and mind.

Learn to relax

- Close your eyes and imagine a safe, peaceful place where you would like to be. This might be anywhere: on a mountain, by a lake or ocean, or in a field.
- Keep thinking about this place as you breathe deeply in through your nose and then out through your mouth.
- If it helps, think of a positive thought, such as "I am at peace," or "I am safe."
- Keep breathing, focusing either on the safe place or the thought. Do this for about 20 minutes (as long as it takes to boil rice).
- If you start to feel uncomfortable or frightened at any time during this relaxation exercise, open your eyes and breathe deeply.

You can practice this exercise in your group or at home whenever you have difficulty sleeping or feel tense and afraid. Breathing deeply helps calm nervous feelings.

Helping relationships

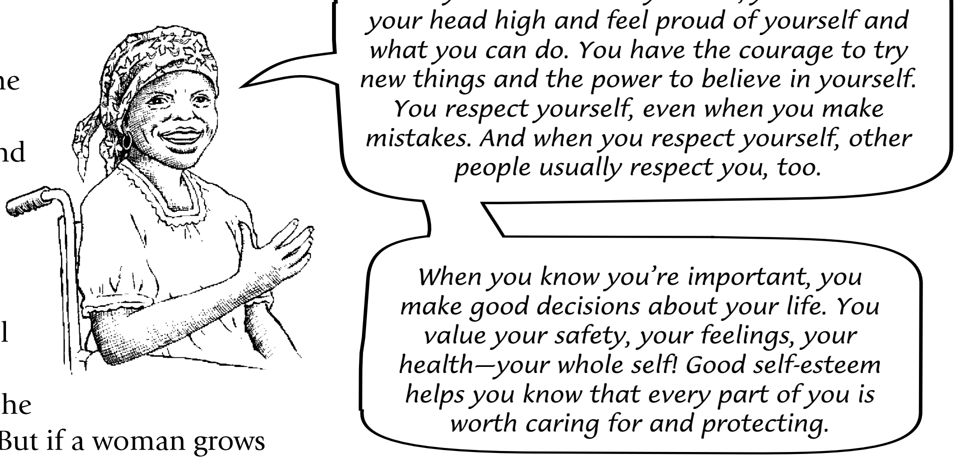


In a helping relationship, 2 or more people make a commitment to get to know, understand, and help each other.

Helping relationships can help you get support, recognize feelings, and control impulsive reactions. A helping relationship can be formed among friends, family members, a group of women with disabilities, a group of women who work together, or a group that already meets for another purpose.

Be careful when choosing helping relationships. Form relationships only with people who will respect your feelings and your privacy. For information about forming support groups, see pages 65 and 66.

LEARN TO VALUE YOURSELF



When a woman grows up with the support of her family, school and community to live the best life she can, her feelings of self-worth will be very high, whether or not she has a disability. But if a woman grows up feeling she is worth less than others because she has a disability, she has to learn to value herself.

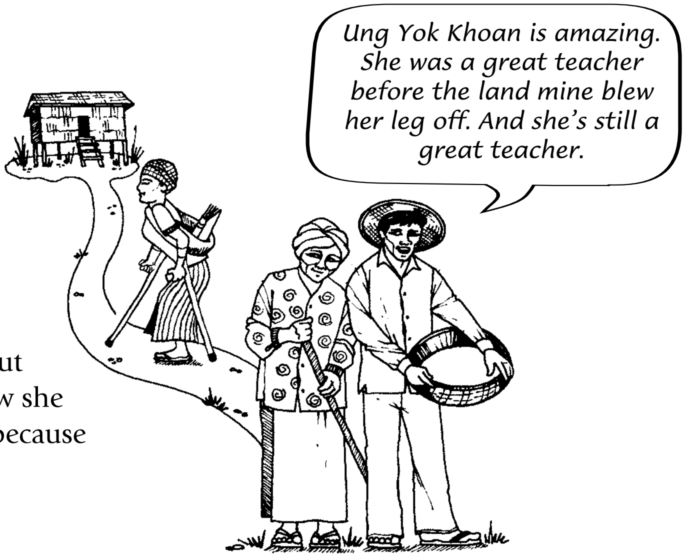
One of the most important parts of mental health is self-esteem. You have good self-esteem when you know you are worthy of being treated with respect. You know people listen to you and value your opinions. You feel capable of facing difficulties and challenges.

Girls and women who are treated with respect by their families, schools, and communities develop good self-esteem. The more support families and communities can give you to live the best life you can, the more self-worth you will feel. Other things that help you have good self-esteem are meaningful work, economic security, loving relationships, and safety from physical or sexual abuse.

Building self-esteem

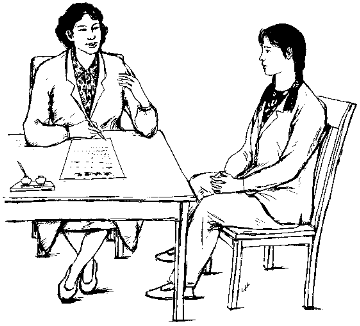
Learning to value yourself and develop self-esteem is a process that starts when you are growing up and continues the rest of your life. But even if you were not valued as a child, or were overprotected, or did not get a chance to develop confidence or learn how to do things yourself, you do not have to live that way as an adult. You can value and respect yourself, and be seen for who you are—after all, your experience has taught you to adapt and work with your disability.

With help and support from her friends and family, a woman who suddenly becomes disabled can learn to cope with her disability. She can learn to do things differently, in a way that works with her disability. But she does not have to change how she values and respects herself just because her body or mind has changed.



Annie's story

Dr. Annie is a medical doctor as well as a wife and mother. She became deaf due to an illness and suddenly found herself disabled because of her loss of hearing. As she entered the world of the disabled, she experienced the loneliness that many disabled women feel. Dr. Annie knew she could either give up her old way of life or make choices that would enable her to live as normal a life as possible. She learned to read lips and to communicate by writing when others could not understand her. Dr. Annie's dignity and courage in the face of much personal loss and suffering have been a positive example to many.



Neelima's choice

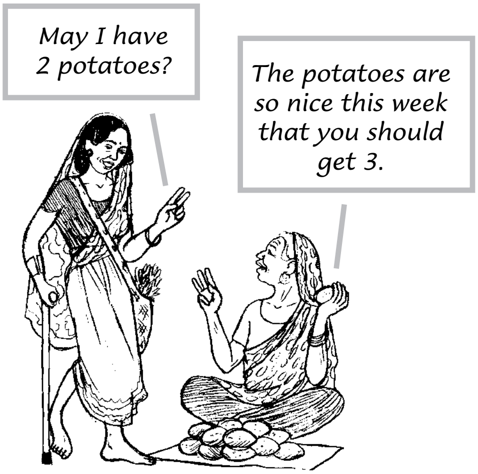
When Neelima was an adolescent, she tried to commit suicide by drinking acid. The acid completely burned out her gut and stomach. The skilled Indian doctors who saved her life told her she had a choice: after her operation she would either be able to speak or to swallow small portions of food, but she could not do both. Neelima chose to be able to swallow. Neelima remained mentally strong after her voice box was removed and she could no longer speak. In spite of this handicap, Neelima finished her school exams and took up a career in catering.

Always a good cook, Neelima made a name for herself by preparing food at home and selling it.

Learning to value yourself is not always easy, but it can be done by taking small steps.

The first step is to meet other people. If you are not used to going out, you might try sitting at the door of your home and greeting your neighbors. Then, if you are able, go to the market and talk with people there. As they get to know you, they will find out that women with and without disabilities are not really very different from each other. Each time you go out it will become easier to meet and talk with others.

Sometimes a woman's disability makes it hard for her to talk with others. Women who are deaf or women who cannot speak clearly can try using gestures or pictures to communicate. A deaf woman could also teach some sign language to her neighbors. Start by picking out 2 or 3 people you want to talk with. Try to find people who are patient and willing to work with you. Together, you can find ways to communicate about more and more things. Then, over time, you can work on reaching out to more people.



The second step is to start or join a group for women with disabilities. A group can provide a safe place for women to speak freely. Talking with other women can help you begin to:

- appreciate your own self-worth and assert your right to make decisions to improve your lives.
- learn about your strengths and weaknesses.
- share thoughts and experiences about the challenges that come from having a disability.
- talk about accepting and treating your bodies well.
- support each other during both happy and difficult times.
- learn how to become independent.
- feel good about yourselves, and not allow negative images about disability to change that feeling.

It was hardest to convince myself

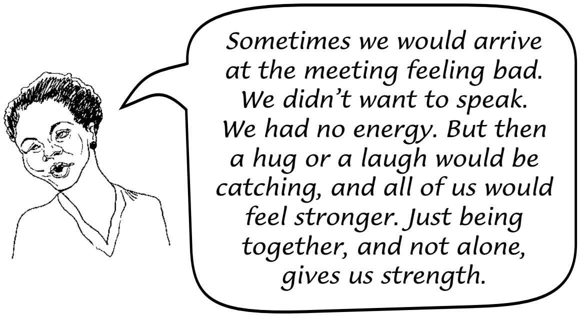
Tina, a woman from Georgia who became disabled after she was the victim of a crime, shares her experience:

When I realized I was disabled and in a wheelchair, I was shocked. I thought I was to blame. But day after day, I told myself, "Your sons love you, and your husband needs you. You are a cosmetologist, and women are waiting for you to make their faces beautiful. You have to live." I realized I was useful to the members of my family and to my society.

I decided to live—and work for them and with them. Now I can see that my life has changed for the best.

FORM SUPPORT GROUPS

Meeting together with other disabled women can give a woman more strength and hope, which then helps her cope with daily challenges.

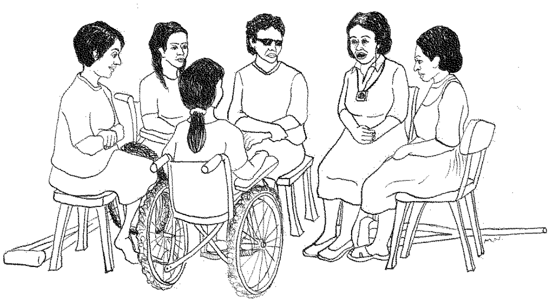


Just being able to talk about a problem can be helpful. After one woman tells her story, the leader can ask for similar experiences. After everyone has listened to these, the group can discuss what the stories have in common, whether the problems are partly caused by social conditions, and if so, what we might do to change these conditions.

Then the women can decide whether to work to solve problems separately or together. Women acting together are more powerful than one woman acting alone.

How to start a support group

1. Find 2 or more women who want to start a group.
2. Plan when and where to meet. It helps to find a quiet place, such as a school, health post, cooperative, or place of worship.
3. Discuss what you hope to do. Choose the most important topics you want to talk about together. Usually, support groups work best when they are run by women with disabilities, for women with disabilities.
4. Give support instead of advice. Remember—every woman has to choose how to face her challenges for herself. No one should tell her what she has to do.
5. Ask everyone to keep the group discussion private.
6. Let everyone have a chance to talk but make sure the discussion stays focused on the main point. After the first few meetings, members may want to take turns leading the group. Having more than one leader can also help shy women lead.



Recognize feelings. Sometimes women hide their feelings (or do not even realize they have them), because they think they are bad, dangerous, or shameful.

Create a story, drama, or painting. You can make up a story about a situation similar to those experienced by members of the group. Hearing others talk about feelings can help a woman deal with her own feelings. The leader starts the story, and then another member continues to tell another part, and so on, until everyone has contributed something and the story is complete. The group can also act out the story as it is told or paint a picture of the story.

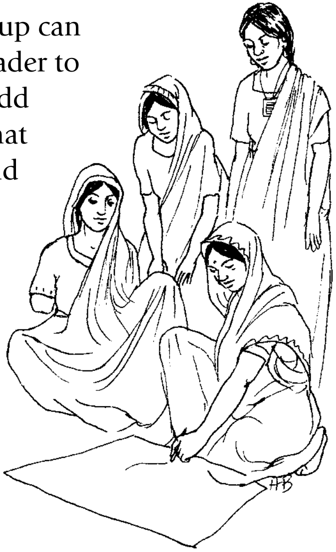
These questions may help the group talk about their feelings:

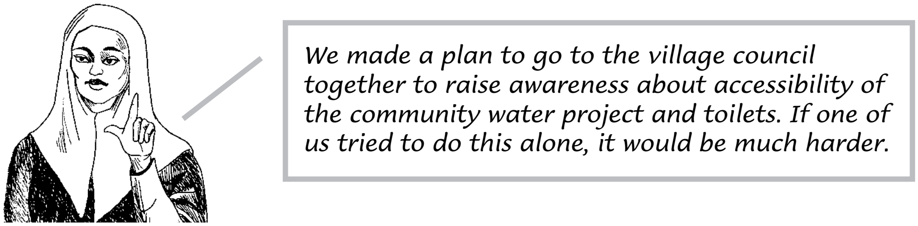
- What feelings or experiences are most important in this story?
- Why did these feelings occur? How is the woman coping with these feelings?
- What can the group do to help?

Understand the causes of a problem. By talking together, women with different kinds of disabilities begin to realize that many of them suffer from the same kinds of problems. This can help identify root causes of problems.

Create a picture of your community. This exercise works best after the group has been meeting together for a while. Your group can draw a picture of your community. (It may help for the leader to draw a simple picture to get things started.) Then others add to the picture, drawing in those parts of the community that contribute to mental health of women with disabilities and those that cause mental health problems. These questions can help your group create a plan of action.

- How can we strengthen those parts of the community that now contribute to good mental health for women with disabilities?
- What new things need to be done?
- How can we help bring about these changes?





Families and communities can promote mental health

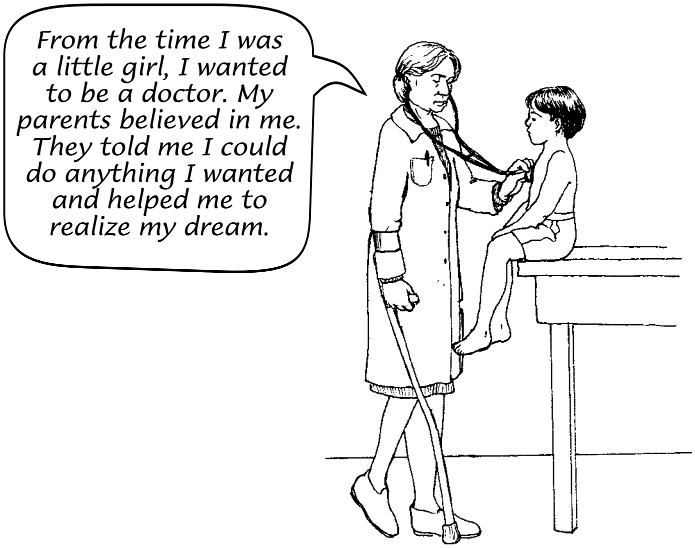
Families that encourage and build on the strengths of girls and women with disabilities promote their mental health. The way your family and community treats you shapes how you value yourself. When family and community expect you to do well at things and want you to do your best, you will likely grow up with a strong sense of self-esteem, be strong in your inner self, and learn that you are capable.

Families and communities need to:

- recognize disabled women and girls as fully contributing members.
- show by example that they value and accept girls as much as boys, and disabled girls and women as equally as others.
- support girls with disabilities during the teenage years when they change from girls to women. They need the same knowledge and treatment as other girls in their community. It is important they be encouraged to dress according to their age and recognize their sexuality as young women.
- support girls and women with disabilities who have mental health problems.

Families, teachers, health workers and others can all help by **focusing on what you can do rather than what you cannot do**, such as:

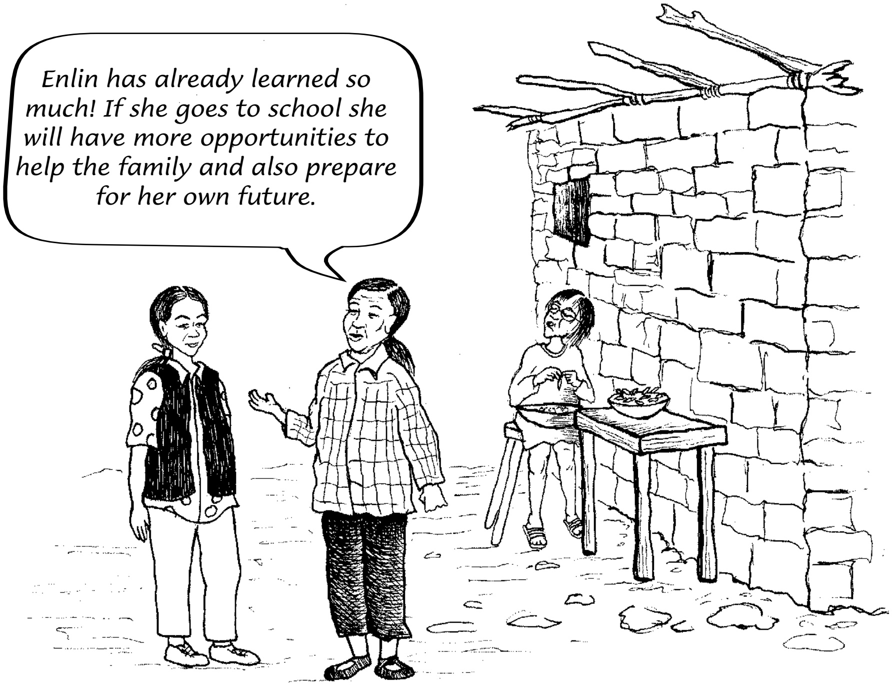
- believe you can live a happy and fulfilling life, and contribute to your community.
- encourage you to try new things and do things for yourself, instead of over-protecting and doing everything for you.
- make sure you help at home and contribute to the family business.



Educate girls with disabilities

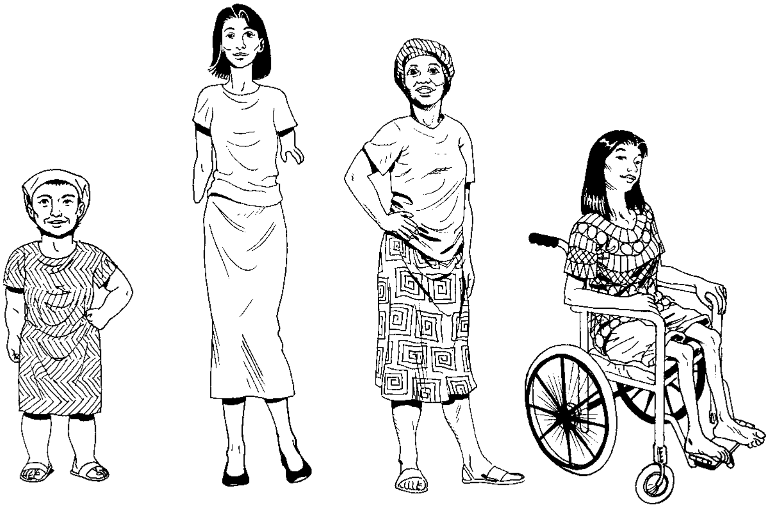
Girls with disabilities need to go to school and learn with other children. A disabled girl is more likely to have strong self-esteem if her family finds a way for her to go to school and the school makes a place for her. Work with other families to make schools accept children with all kinds of disabilities. Talk with teachers to help them understand your daughter's strengths and to raise their awareness about disabilities. Help the school understand how to include her in different activities.

Girls with disabilities need an education and need to learn skills that enable them to get jobs. They will then be able to support themselves and contribute to their families and communities.



CHAPTER 4

Understanding your body



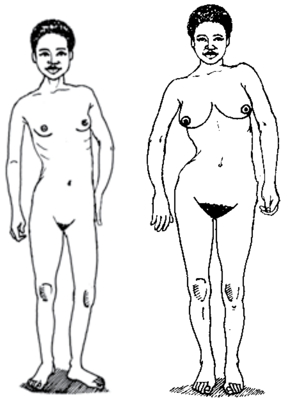
These 4 women's bodies may look different from each other, but they all go through the same changes.

It is important to understand how your body works. The more you know about your body, the better able you will be to take care of yourself. When you understand your body and your normal changes, you will be able to recognize if something happens because of your disability or if it is a normal change that happens to all women. This will also help you decide for yourself if the advice others give you is helpful or harmful.

When a girl's body starts to change (puberty)

However different they seem on the outside, most women's bodies go through the same changes during their lifetime.

Sometime between the ages of 9 and 15, a girl's body begins to grow and change into a woman's body. This is called puberty. Your disability will not prevent this from also happening to you. All these changes are normal and can happen to any girl, whether or not she has a disability.



Here are the main changes you will notice during puberty:

- You grow taller and rounder.
- Hair grows under your arms and between your legs, on your genitals.
- Your breasts grow as they become able to make milk for babies after pregnancy.
- Inside your body, the womb (uterus), tubes, ovaries, and vagina grow and change position.
- Wetness (discharge) starts to come out of your vagina.
- Your monthly bleeding starts (period, menstruation).
- You begin to have more sexual thoughts and urges.
- Your face may get oily, and pimples or spots may grow.
- You may sweat more, and your sweat may smell different than it did before puberty.

These changes are natural and normal. Changes in your body and in your feelings help you be aware that you are changing into a woman who is ready to have a sexual relationship and who can get pregnant.

Still, puberty can be difficult. You may not feel like a girl or like a woman—your body is somewhere in between.

Whether or not you have a disability, during these years it is important for you to look after yourself, to eat healthy food (see page 86), and to stay clean during your monthly bleeding (see page 109). It is equally important for you to protect yourself from sexual abuse (see Chapter 14).

Sometimes, because of the way people treat her, a disabled girl may pity herself and feel ashamed of her body. She may become submissive, withdraw from meeting other people, and be more dependent on family members. For information on self-esteem and mental health, see pages 62 to 63.

Hormones

Many of the changes a girl experiences while her body is changing are caused by hormones. These are chemicals your body makes that control how and when your body grows. A little while before your first monthly bleeding starts, your body starts to produce more of the hormones called estrogen and progesterone—the 2 main hormones that regulate the menstrual cycle (see page 75).

Hormones also control when a woman can get pregnant—by controlling when her ovaries will release an egg (one egg every month)—and allowing her breasts to make milk to feed her baby after she gives birth. Many family planning methods work to prevent pregnancy by controlling the hormones in a woman's body (see page 196).

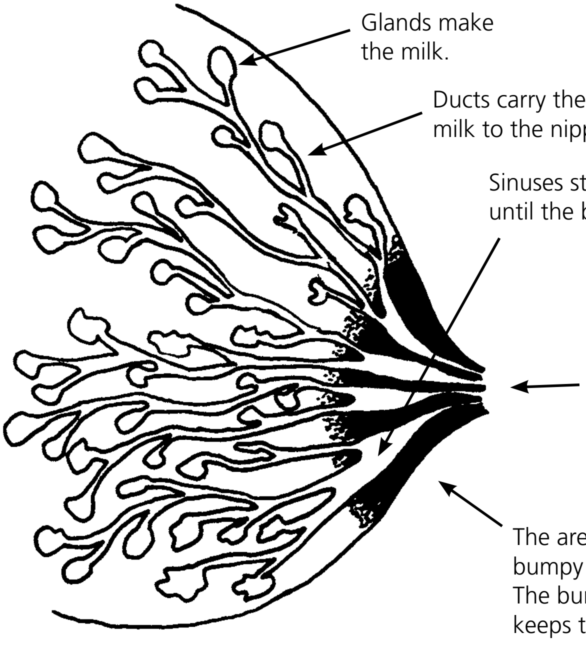
THE BREASTS

A young girl's breasts start to grow when she is between 9 and 15 years old. You do not have to be shy or self-conscious of your breasts. They are a sign your body is changing into a woman's body. One of your breasts may start to grow before the other, but the smaller breast almost always catches up. Do not be alarmed if your breasts do not look exactly alike. Many women have breasts that are slightly different in size or shape from the other. And if your breasts look different from another girl's breasts, that's just the way breasts are. They come in all shapes and sizes!

As your breasts grow larger, they become able to make milk for babies after pregnancy. Breasts can be very sensitive. When they are touched during sexual relations, they can excite your entire body, making your nipples hard, and your vagina wet and ready for sex.

Your breasts can also get swollen and sore just before monthly bleeding starts, or your nipples may sometimes hurt.

Once your breasts have grown, you should start to examine them once a month to make sure they stay healthy and do not develop any unusual lumps. Usually a woman can find unusual breast lumps herself if she learns how to examine her breasts. Sometimes a breast lump that does not go away can be a sign of breast cancer. Regular health exams will help you find health problems early. See page 128 for information on how to examine your breasts.



Glands make the milk.

Ducts carry the milk to the nipple.

Sinuses store the milk until the baby drinks it.

The nipple is where milk comes out of the breast. Sometimes nipples stick out. Sometimes they are flat.

The areola is the dark and bumpy skin around the nipple. The bumps make an oil that keeps the nipples clean and soft.

Monthly bleeding (period, menstruation)

Almost all girls and women with disabilities will have the same monthly bleeding cycle as women who are not disabled. Monthly bleeding is a sign that you can become pregnant. No girl can know exactly when she will get her first monthly bleeding. It usually happens after your breasts and the hair on your body start to grow. Also, several months before your first monthly bleeding, you may notice some wetness coming from your vagina. It may stain your underclothes. This is normal.

You may feel stomach cramps, get a headache, pain in your lower back or breasts, or feel mood changes just before your monthly bleeding starts. For example, you may feel overly sensitive or easily lose your temper.

If you are blind or have difficulty seeing, or if you have difficulty moving your arms or legs, ask your family or friends you trust to help you manage your monthly bleeding. To help a girl or woman who has difficulty understanding or learning about monthly bleeding, see page 110. For information on how to care for yourself during monthly bleeding, see page 109, and for information on sexual health and monthly bleeding, see page 182.

As a woman grows older, her monthly bleeding will end. For most women, this change happens when they are between 45 and 55 years old. For information, see page 282.

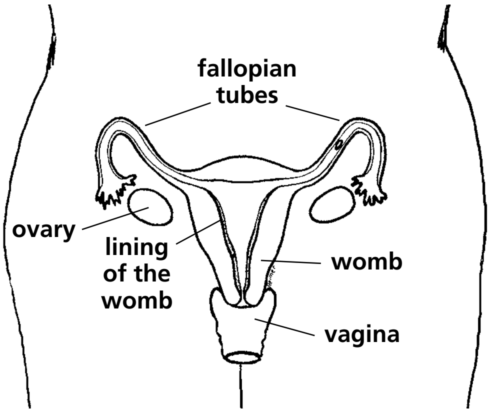
Around the world, women have many different names for their monthly bleeding.

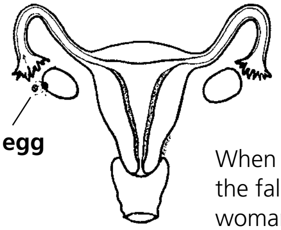
The monthly cycle (menstrual cycle)

The monthly bleeding cycle is different for each woman. For most women, the whole menstrual cycle takes about 28 days—just like the cycle of the moon. But some women bleed as often as every 20 days, or as little as every 45 days. During the first year you get your monthly bleeding, it will probably come at a different time each month. This is normal. It will take several months for you to start having a regular cycle.

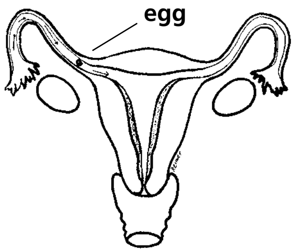
The monthly cycle

About 14 days before the end of your monthly cycle, an egg is released by one of the ovaries. This is called ovulation. At this time, the hormone progesterone causes the lining of the womb to become thicker and to get ready for the possibility of pregnancy.

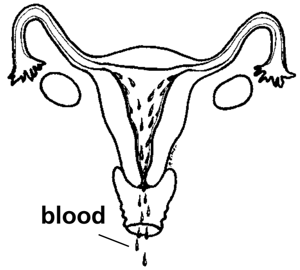




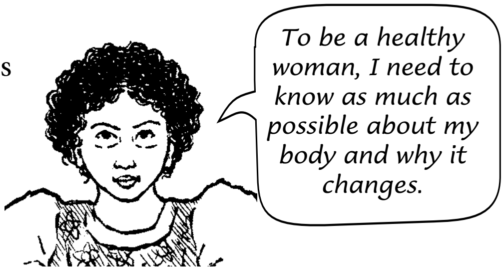
When an ovary releases an egg, the egg travels through the fallopian tube into the womb. During this time a woman is fertile, and if she has sex with a man, his sperm may join with her egg to fertilize it and start a pregnancy.



Most of the time, the egg is not fertilized so the thick lining of the womb is not needed. The lining breaks down into a bloody fluid that flows out of the body through the vagina during the monthly bleeding. Then the cycle starts over again.



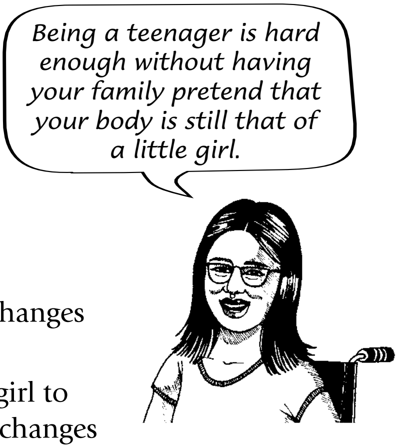
When your body changes



It is important to be able to ask questions and express your feelings, especially your confusions and fears, about your changing body and emotions. This is true throughout your entire life, when puberty, sexuality, fertility and childbearing, and menopause can signal great changes for your body and your health. When you accept your physical development, emotions, and sexual feelings, you can care for and respect yourself as a woman. Take the time to examine your own feelings and share them with others:

- Be comfortable with your body and accept your disability as part of your body.
- Learn about sexuality and the responsibilities that accompany sexuality. Older family members, health workers, counselors, and other adults with disabilities can be good sources of information.
- Develop and nurture loving, caring relationships with family, friends, and loved ones. Positive relationships are essential for well-being. These interactions will provide you with an important support network.
- Interact with other girls and women with disabilities, especially women who have jobs and are raising families.
- Avoid spending time with people who make you feel bad.
- Be involved in events outside your home. Treat them as opportunities to explore and develop friendships, and to develop and share the things that you do well.
- Protect yourself from sexual abuse (see Chapter 14).

HELPING A GIRL BECOME A WOMAN



It is important to prepare a girl for the changes her body will go through as she becomes a woman.

Make sure she learns about monthly bleeding before she has her first period, and help her prepare to manage monthly bleeding when it begins.

Help her understand that her physical and emotional changes are normal.

Older family members and caregivers can encourage a girl to talk and ask questions openly by asking about her body's changes in a light-hearted way. This lets a girl with disability know, even before she begins puberty, that the people closest to her are available for questions.

What families and caregivers can do

Parents and other family members can:

- Accept that she is becoming a woman changing just like any other girl.
- Help her meet other girls and women with disabilities.
- Encourage her to develop friendships and activities outside the home. This will help give her confidence and a sense of herself.
- Give her good food and timely health care.
- Talk to her about sexuality. Encourage her to ask questions and express her feelings about her sexuality.
- Protect her from sexual abuse.

Coming-of–age ceremonies

In some communities, the ceremony to mark a girl reaching puberty is a big event to let people know the girl is "grown up" and ready for marriage.

If you live in a community that has ceremonies to mark the change when a girl becomes a woman, make sure your daughter has a coming-of-age ceremony.

In some communities in India the girl is given a ceremonial bath and dressed like a bride. A grand feast follows and the participants present gifts to the girl.

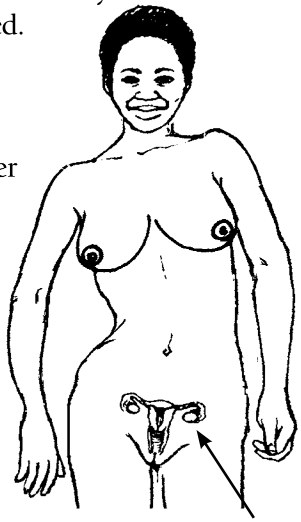
What health workers can do

Make sure to include girls with disabilities in any health education projects you organize for girls to learn about their bodies. Teach families and schoolteachers of girls and women with disabilities that the body of a girl or a woman with a disability is almost always the same as that of a girl or woman who is not disabled.

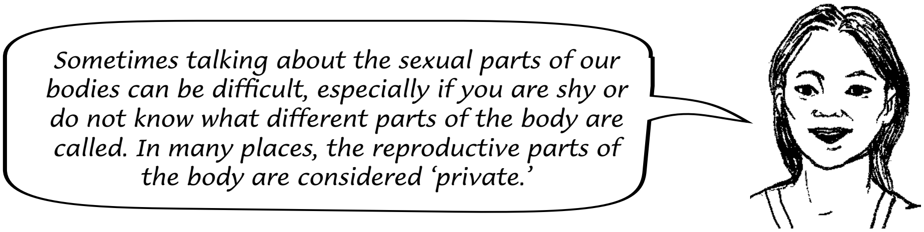
A woman's reproductive system

In many ways, a woman's body is no different from a man's, whether or not one of them has a disability. Women and men both have hearts, kidneys, lungs, and other body parts that are the same. But their sexual or reproductive parts are very different. Many women's health problems affect these parts of her body.

The sexual and reproductive parts of women with disabilities and women who do not have disabilities usually look and work in similar ways. The sexual parts outside the body are called the genitals. Inside, they are called the reproductive organs.



A woman's reproductive organs



Sexual parts on the outside

The sexual parts outside the body and between a woman's legs are together called the vulva. The drawing shows what the vulva looks like and what each part is called. But every woman's body is different. There are differences in the size, shape, and color of the parts, especially of the outer and inner folds of skin.

Understanding how your sexual and reproductive parts work will help you know how to get pregnant and also how to prevent pregnancy.

Sometimes people may use the word vagina for the whole area. But the vagina is the part that begins as an opening in the vulva and leads inside to the womb. The vagina is sometimes called the 'birth canal.'

The outer and inner folds of skin protect the vagina. These folds are sometimes called 'lips.' The inner folds of skin are soft, without hair, and are sensitive to touch. During sex, the inner folds swell and turn darker.

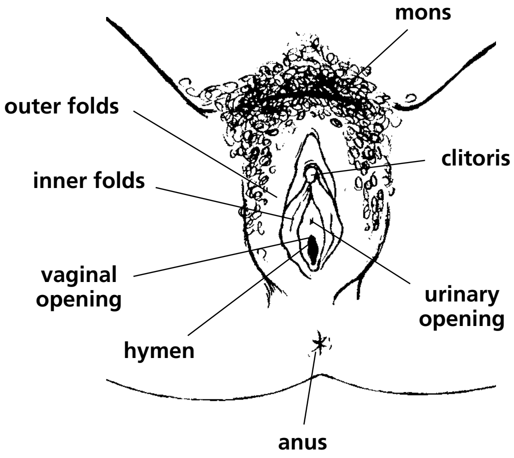
The hymen is a thin piece of skin just inside the opening to the vagina. A hymen may stretch or tear and bleed a little because of hard work, sports, or other activities. This can also happen when a woman has sex for the first time. All hymens are different. Some women do not have a hymen at all, and not all women bleed during their first sexual intercourse.

The clitoris is small and shaped like a flower bud. It is the part of the vulva that is most sensitive to touch. Rubbing it, and the area around it, can make a woman sexually excited and cause climax (orgasm).

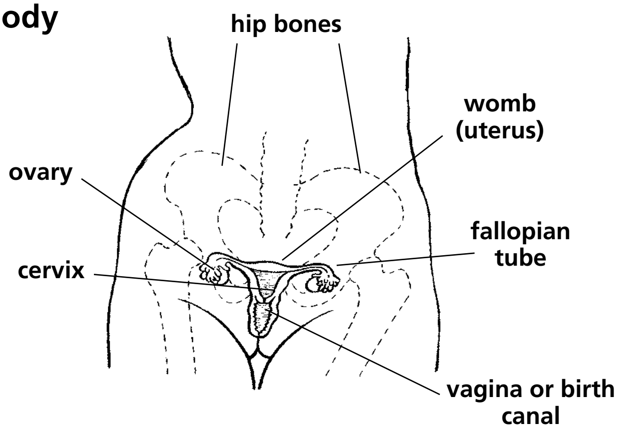
The urinary opening is a small hole between the vaginal opening and the clitoris. It leads into the urethra, which is a short tube that carries urine from the bladder to the outside of the body.

The anus is the opening of the intestine, where waste (stool) leaves the body.

The sexual parts on the outside (the vulva)

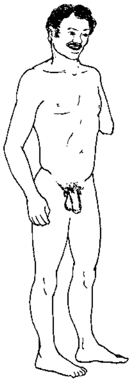


Sexual parts inside a woman's body



The reproductive parts inside a woman's body are in the pelvic area—the area between the hips. You can feel your hip bones just below your waist. If your hip bones are not shaped evenly, your reproductive parts will not be affected.

A woman has 2 ovaries, one on each side of her womb. Each ovary is about the size of an almond or grape. One of the ovaries releases an egg into one of the fallopian tubes each month. The egg moves through the fallopian tube to the womb (uterus), a small, hollow muscle that stretches and grows larger when a woman is pregnant.

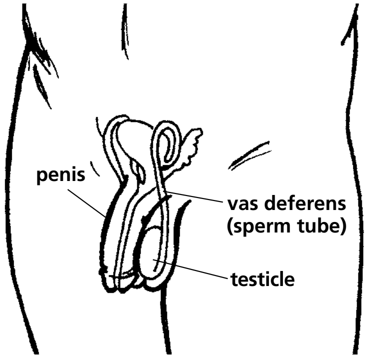


A man's sexual parts

A man's sexual parts are easier to see than a woman's because they are mostly on the outside of his body. The testicles (balls) make the main male hormone called testosterone. When a boy's body begins to change, it makes more testosterone. This causes the changes that make a boy look like a man. These are like the changes that happen when a girl's body makes more female hormones.

The testicles also make a man's sperm. Sperm travel from the testicles through a tube into the penis where they mix with a liquid produced by glands. This mixture of liquid and sperm is called semen.

What happens during sex?



During sex, the man's semen comes out of his penis when he ejaculates (comes). Each drop of semen has thousands of sperm, which are too small to see. When the man ejaculates in the woman's vagina or near her genitals, the sperm can enter the through the 'mouth' of the womb (the cervix) into the womb.

The vagina is made of a special kind of skin that stretches easily during sex (and also when giving birth). The vagina makes a fluid or wetness (discharge) that helps it keep clean and prevent infection. The vagina makes more fluid than usual during sex to make it easier for the penis to enter, to help prevent tears in the vagina, and to help sperm reach the womb.

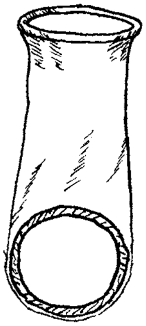
Becoming pregnant

9 months later...

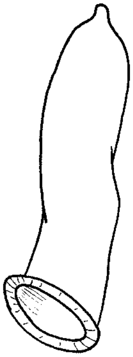
About 14 days after the beginning of each monthly bleeding, when the lining in the womb is ready, an egg is released from one of the ovaries. This is called ovulation. The egg then travels down a tube into the womb. At this time a woman is fertile and can become pregnant. If she has recently had sex with a man, his sperm may enter the womb through the cervix and join with her egg. This is called fertilization and is the beginning of pregnancy. If the egg does not join with a man's sperm, there is no pregnancy, and the lining of the womb is shed during the monthly bleeding.

WHAT EVERY WOMAN SHOULD KNOW ABOUT HAVING SEX

- You can get pregnant the first time you have sex with a man.
- You can get pregnant any time you have sex without using a family planning method (even if you have sex only once).
- You can get pregnant even if the man thinks he did not let his sperm (seed) come out.
- You can get a sexually transmitted infection (STI) or HIV if you do not use a condom when you have sex with an infected person. (You cannot tell by looking at a person if he is infected or not—see page 172.)
- It is easier for a girl or a woman to get an STI or HIV from man during sex than it is for her to give these diseases to him. This is because the man's semen stays in her vagina for a long time.
- It is harder to know if a girl or woman has an STI because the signs of infection are often inside her body.



condom for women (female condom)



condom for men

Always use either a male condom or a female condom for protection against STIs and HIV/ AIDS. Even though sperm, and the germs that cause infection, are very small, they cannot get through the plastic or latex of a condom if it is put on properly (see pages 190 and 191).

For more information about protecting yourself from infection, see Chapter 8. To prevent unwanted pregnancy, see Chapter 9.

When you are not able to get pregnant (infertility)

Disability does not cause infertility. Some women with disabilities will be infertile, but no more so than women who are not disabled. If a woman with a disability is infertile, it is usually not because of her disability.

WHAT IS INFERTILITY?

We say a couple—a man and a woman—is infertile if they cannot get pregnant after having sex together a few times a month for a year, without using a family planning method. A couple may also have a fertility problem if they have had 3 or more miscarriages (lost pregnancies).

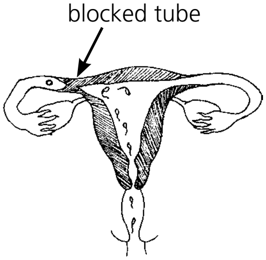
A man or woman who has already had a child can also become infertile. A problem can develop after the last child was born. Sometimes the problem is not the man's or the woman's alone but a combination of the two. And sometimes both partners seem to be healthy and no doctor or test can find out what is causing the problem.

WHAT CAUSES INFERTILITY?

Infertility in a woman

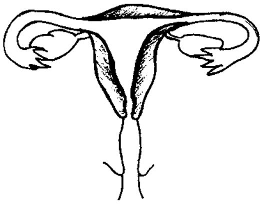
The main causes of infertility in a woman are:

1. Scarring in the tubes or inside the womb. Scarring, or thickened rough skin, in the tube can prevent the egg from moving through the tube, or the sperm from reaching the egg. Scarring in the womb can prevent the fertilized egg from attaching to the wall of the womb. Sometimes a woman gets scarring but does not know it because she does not feel ill. But years later she learns she is infertile.



Scarring can be caused by:

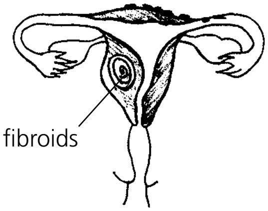
- an infection from an untreated STI that travels up into the womb or tubes (pelvic inflammatory disease or PID), or from tuberculosis (TB) in the pelvis.
- unsafe abortion or problems in childbirth that caused damage or infection in the womb.
- unclean conditions when an intrauterine device (IUD)—a small device implanted inside the womb to prevent pregnancy—was put in, which caused an infection.
- problems from an operation on the vagina, womb, tubes, or ovaries.



Ovary does not produce an egg.

2. Problems with ovulation. If an infertile woman's monthly bleedings are less than 21 days apart, or more than 35 days apart, she may not produce eggs. This can be caused by her body not making enough hormones, or not making them at the right time. Sometimes this happens as a woman gets older and is close to the end of her cycle of monthly bleeding (menopause). Some women do not produce eggs if they gain or lose weight very quickly, or if they are too fat or too thin, or if they become ill.

3. She has growths (fibroids) in her womb. Fibroids are tumors that do not cause cancer, but they can cause a miscarriage.



Infertility in a man

The main causes of infertility in a man are:

1. He does not produce enough sperm.

2. His testicles do not make healthy sperm. This can happen if he wears tight clothing that press his testicles close to his body, or if he works in a hot area, such as near boilers, furnaces, or engines—especially if he drives for many hours without a break. This can also happen if he sits all day, or sits for a long time in a hot bath before having sex.

3. He cannot ejaculate because he has scars in his tubes from a sexually transmitted infection (STI), or he has a spinal cord injury.

Infertility in both men and women

In both men or women, infertility can be caused by:

1. Illnesses such as mumps, diabetes, tuberculosis, and malaria.

2. Drinking alcohol, smoking or chewing tobacco, or using drugs.

3. Malnutrition, too much stress, overwork, or exposure to some chemicals.

CREATING A FAMILY THROUGH ADOPTION

Some women with disabilities choose to create families through adoption. A woman may do this because she or her partner are infertile, or she has a health problem that prevents her from giving birth. Or she may decide to adopt a child simply because she believes it is a good way to become a mother and to make a family.

How I became a mother

When I was growing up, like most young girls in the US, I had a dream of finding a partner and having a family. But unlike most other young girls, I didn't believe it would come true. I use a wheelchair to get around, and I had no role models of women who used wheelchairs as parents. I had never been encouraged to think it would be possible for me to have my own family.

When I first met my husband, I was sure he was the right partner for me. He shared my secret dream of making a family through adoption. I knew there were many children who had lost their first family and were waiting for a "forever family." I knew in my heart we could be that family for the right child.

At first, my parents felt it would be unfair to my husband to "burden him with all the child care." They didn't think I could care for a child. Although I was nervous, I knew I had figured out how to do many things that others had said I would never do. I took care of our house, had my own job, and had cared for friends' children in the past. I knew my husband and I could do this!

We had to try several adoption agencies until we found one that supported our plan to become parents. We realized we couldn't change people's prejudices, so if an adoption agency felt our plan would not work, we just went to another agency. After we found a supportive agency, we showed them how well I could parent, rather than what I couldn't do.

Finally we were matched with a child who met our hopes and dreams. She was a wheelchair user, just like me. We were worried that the judge who had to legally approve the adoption might say no because of my disability. But he saw we were a great match and approved our adoption.

I feel honored to guide my daughter through her growing years, and to help her become the lovely and competent person she is now.

—Karen Braitmayer

CHAPTER 5

Taking care of your body

Some people think having a disability means you are sick. This is not true. But having a disability may mean you need to take more care in your daily routines to stay healthy.

As a disabled woman, you know and understand your body better than anyone else. For example, you know you may not rely on pain to tell you something is wrong—you need to check your body carefully and regularly every day, especially the parts you cannot feel or see. Or if you have an unusual feeling, or body reaction, or a pain somewhere, or any sores or illnesses, you try to find out as soon as possible what might be causing it. When it is necessary, you ask a family member, friend, or someone you trust to help you.

This chapter has information to help you stay healthy and prevent many health problems. If you need assistance with daily care, this chapter has information to help your family and caregivers to provide that assistance.

Eat well for good health

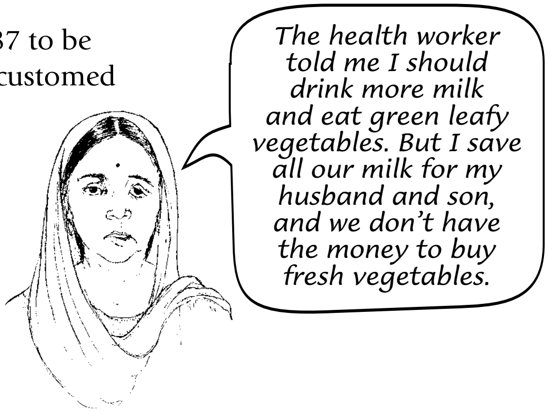
All women need good food to do their daily work, to prevent illness, and to have safe and healthy births. But not eating well (poor nutrition) is the most common and disabling health problem among women in poor countries. When food is not shared equally within a family or a community, it is usually women, especially disabled women, who do not get enough.

Starting in childhood, a girl is often given less food to eat than a boy. As a result, she may grow more slowly, her bones may not develop properly, and this can cause a disability later in life. For a girl who was born with a disability, it can make her disability worse. Also, when a woman who does not get enough to eat (is malnourished) becomes sick, she is more likely to have serious complications.

For better health, everyone in the family, including girls and women with disabilities, needs enough good food.

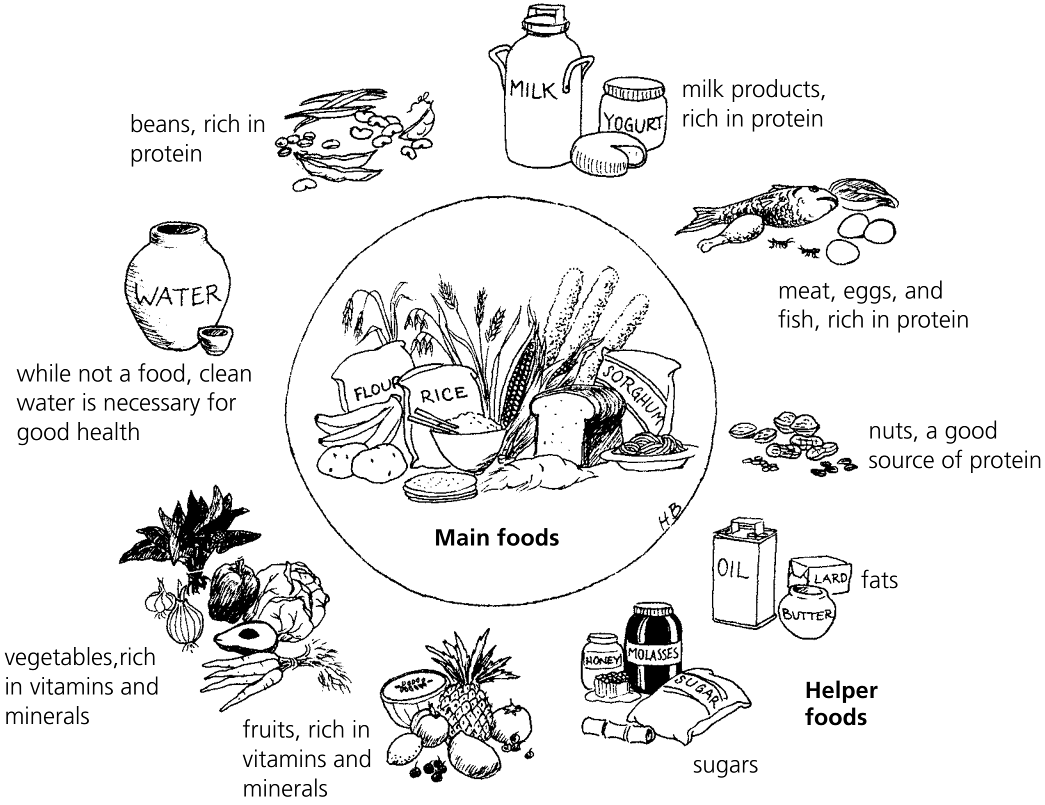
A healthy diet

You do not need to eat all the foods on page 87 to be healthy. You can eat the main food you are accustomed to, and if possible, add as many of the other foods as are available in your community. Foods with protein are especially good for keeping skin and muscles strong, and foods with calcium (milk and milk products, green leafy vegetables, soy beans, and shellfish) are especially good for keeping bones strong.



Here are some suggestions:

- a main low-cost food, such as rice, maize millet, wheat, cassava, potato and others.
- some foods with protein from an animal, such as milk, yogurt, cheese, eggs, fish or meats (which help build the body).
- other sources of protein, such as beans, lentils, seeds, nuts, seaweed, soy.
- fruits and vegetables rich in vitamins and minerals (which help protect and repair the body).
- and a small amount of fats and sugar (which give energy).



Prevent anemia (weak blood)

Without enough good food, any girl or woman can suffer from general poor health, and she may also suffer from anemia. This happens when you do not eat enough foods rich in iron. Anemia is very common among women, especially pregnant and breastfeeding women. It causes extreme tiredness, and lowers a woman's resistance to infection and disease. Heavy bleeding during childbirth can also cause anemia, as can malaria and hookworm. (Talk to a health worker about how to prevent or treat malaria. Hookworm can be easily treated with mebendazole, see page 346).

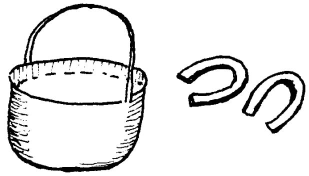
Signs of anemia include:

- pale inner eyelids, nails and inside of lip
- weakness and feeling very tired
- dizziness, especially when getting up from a sitting or lying position
- fainting (loss of consciousness)
- shortness of breath
- fast heartbeat

To both prevent and treat anemia, try to eat foods rich in iron every day, such as dark green leafy vegetables (edible hibiscus leaves, spinach, drumstick leaves, taro leaves, cassava leaves) and also eggs and milk, raisins, molasses, and meat.

It is possible to get even more iron if you:

- eat iron-rich foods together with tomatoes or fruits such as mangoes, papayas, oranges, lemons, and limes. These all contain vitamin C, which helps your body use more of the iron in the food.
- cook food in iron pots. If you add tomatoes, lime juice, or lemon juice to the food while it is cooking, more iron from the pots will go into the food.
- add a clean piece of iron—such as an iron nail or a horseshoe—to the cooking pot. **Make sure that these are made of pure iron**, not a mixture of iron and other metals. Some metals, like lead, are harmful and cause birth defects.
- put a clean piece of pure iron, such as an iron nail, in a little lemon juice for a few hours. Then make lemonade with the juice and drink it.



In many places, health centers will give iron pills (ferrous sulfate) to pregnant women to prevent anemia.

Keep your body moving

All women need exercise to keep their bodies strong, flexible, and healthy. Exercise helps your muscles, your heart, and your lungs stay strong, and it helps prevent you from getting high blood pressure, weak bones, and constipation. Exercise will also help prevent you from becoming too fat. To be very fat is not healthy and will make all of your daily activities more difficult.

Sometimes a woman's disability does not let her use or move her body, or parts of it, well enough to get the exercise she needs. Muscles that are not used regularly become weak or can develop spasms. Joints that are not moved through their full range of motion get stiff and can no longer be completely straightened or bent. If you have a disability that affects your body, make sure to move all the parts of your body through their full range of motion. Sometimes you may need help with this.

Exercise can also help women who feel depressed. Some kinds of exercise can actually help you feel less pain. Many people sleep better if they exercise regularly. When your body is strong and healthy, you have more energy, feel better, and hurt less.

Most women get all the exercise they need through ordinary daily activities, such as preparing and cooking family meals, cleaning, working in the fields, collecting wood and water, and carrying children. As much as possible, women with disabilities can get their exercise in these same ways.

If it is very difficult for you to move your body, try to change your position often. If you usually sit all day, change your position by lying down for a while.

If you are often bent forward...

...try to stretch the muscles in your chest.

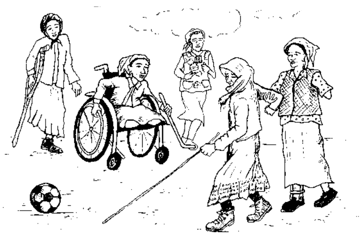
Exercise does not have to be hard work in order to be good for you. It is best to start slowly, especially if you do not move much now, or if you cannot move a part of your body, if it is weak or painful, or if you spend a lot of time in the same position. Not moving much can make joints and muscles stiff and painful, or can make the body freeze in a certain position. As your body gets more used to moving, you will be able to do more.

EXERCISE CAN BE FUN

Try to find exercise that is fun. Some women like to ride a donkey or burro. Controlling the animal, moving your body to respond to its movements, and keeping your balance are all forms of exercise.

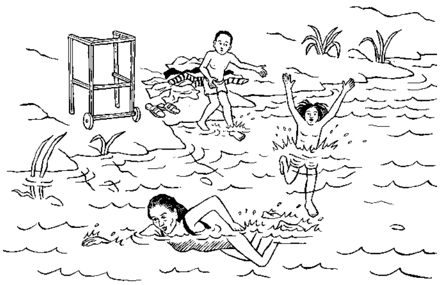
Try to exercise with another person. You are more likely to keep exercising when you are also spending time with a friend. It is also good to have another person who can give help if you need it.

Some women enjoy dancing...



...or playing a sport.

For many women with disabilities, swimming and moving in the water is a very good way to exercise. Because your body weighs less in the water, women who have a hard time moving or walking can often move better in the water. Or they have less pain in the water. Swimming is the best exercise for someone with arthritis.



Make sure the water is not too cold. Cold muscles can get hurt more easily.

Lifting heavy objects over and over again can help make your muscles and bones strong.

If you use a wheelchair, try to push it around your community by yourself.

If this is not possible, try lifting objects (such as rocks, cans of food, or a bottle filled with water) over and over again. This will help keep the muscles and bones in your shoulders and arms strong.

How to lift: Before you lift, sit up as straight and tall as you can. Take a deep breath in, and then out. As you blow out, pull your shoulder blades back toward your spine as you lift the object. Take another deep breath in as you hold the object, and then blow out as you lower the object back down slowly.

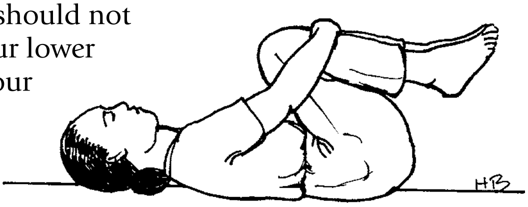
STRETCH YOUR MUSCLES

Stretching your muscles makes them more flexible, so you can bend and move more easily. For many women with disabilities, stretching regularly means they feel less pain. Stretching also helps prevent injuries.

Always stretch before you begin hard work or exercise. Stretching and starting gently will help keep you from hurting yourself and hurting your muscles. It is also a good idea to stretch after doing exercise or hard work. Stretching can also help keep your body flexible, and prevent pain and weakness as you grow older.

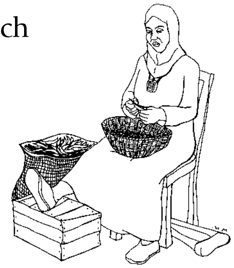
To stretch a muscle:

1. Find a position where you feel secure and are not likely to fall. The stretch should be gentle. It should not hurt. For example, to stretch your lower back, lie down on a mat with your face up. Bend your knees and pull both legs toward your chest as far as you can without causing pain.



2. Hold your body in this position, while you count slowly to 30 (or count to 10 three times). Do not bounce or move your body back and forth.
3. Remember to breathe while you are stretching. If the stretch starts to hurt, try moving the part you are stretching so that the stretch is more gentle. If this does not stop the pain, try a different position.

Women with limited movement may have to experiment to stretch certain muscles. Sometimes, you may need another person to help you. If someone else helps you stretch, make sure they move the muscle slowly. Then, you can tell them to stop when you feel a stretch.



Sana's leg is paralyzed from polio. While she prepares food, she stretches her leg to prevent it from getting locked into one position (a contracture).

Some people like to put ice, or a warm cloth or towel, or a heat pack (if available) on their muscles before stretching. You can try this yourself to see if it makes your body feel better.

Many women with tight muscles stretch every morning before they start the day's work, so they do not hurt as much during the day. At night, they stretch again to help sleep better and to have less pain after a long day.

Other women find they can stretch a muscle while doing some other task. If you can, find ways to include stretching in your everyday activities.

Maria has cerebral palsy. She is stretching her muscles at the same time as she is doing her daily work. The rock keeps her legs apart, allowing her to stretch the muscles inside her legs while she works. This helps to prevent muscle spasms. She keeps her back as straight as she can while she stretches her arms, legs and neck.

If you have tight muscles, paralysis from cerebral palsy or a spinal cord injury, or joint pain

Women who have painful joints or tight (spastic) muscles should be careful with exercises such as running or lifting heavy things. These kinds of exercises can put too much stress on the muscles and joints. They can hurt your muscles instead of making them stronger.

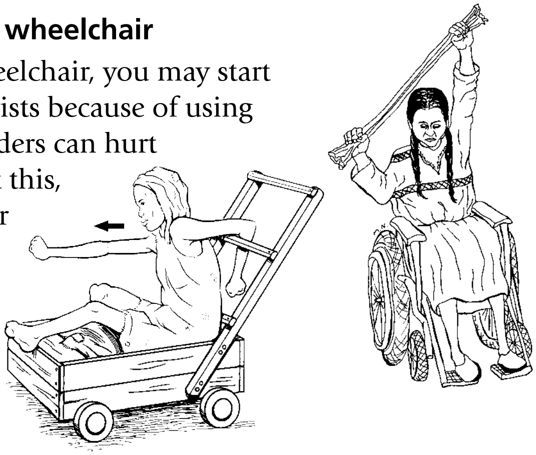
Relaxing tight (spastic) muscles

Women with cerebral palsy, multiple sclerosis, or spinal cord injuries often have muscles that are very tight and stiff (spastic muscles). A muscle may get very stiff or shake, and the woman may not be able to control how it moves. To help with tight spastic muscles:

- Do not pull or push directly against the spastic muscle. That makes it tighten more.
- Do not massage spastic muscles. Rubbing or massaging spastic muscles usually makes them tighter.
- To manage spastic muscles, find a position that helps the body relax. Rolling or twisting gently from side to side can help. Sometimes, moving a different part of the body will help ease the spastic muscles. You can also use warm cloths (wet or dry) to help relax spastic muscles.

If you use a wheeled cart, crutches, or wheelchair

If you use a wheeled cart, crutches, or wheelchair, you may start to have trouble with your shoulders or wrists because of using your arms so much. Your arms and shoulders can hurt and wear out more easily. To help prevent this, stretch your arms and shoulders often. For example:



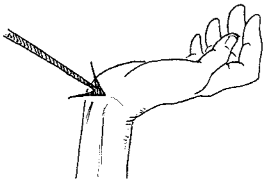
Women who use wheelchairs often have strong arms. But it is important to keep all the muscles in the arms and shoulder strong, not just the muscles you use to push your chair. To prevent overusing your arms and shoulders, try not to do the same thing for a long period of time. For example, change or alternate how you pick things up. First use your left hand, then the right.

A good way to strengthen the other muscles in your shoulders is to push your wheelchair backward.

Injuries from overuse

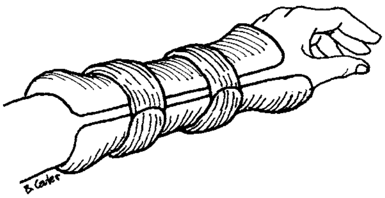
Joints are places in the body where bones come together. At these joints, tendons connect the muscle to bones. If you repeat the same movement over and over again, such as pushing your wheelchair or cart, or walking with crutches, the tendons in your wrists can be damaged.

You will feel pain in your hand, or here, when your wrist is gently tapped.

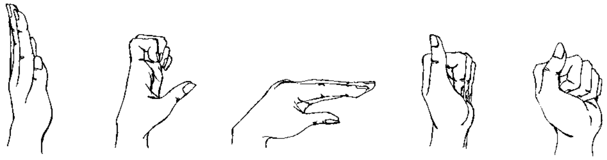


Treatment:

- **Rest:** Rest your wrists and hands in a comfortable position as much as possible. If you must continue to move or push yourself around, wear a splint to keep your hands and wrists as still as possible.
- **Splint:** To make a soft splint, wrap your wrist and lower arm with cloths so the joint does not move. Wrapping the cloth around a thin piece of wood first can help keep the joint straight. The cloths should be wrapped tightly enough to keep your wrist from moving, but not so tightly that the blood flow is blocked or the area gets numb. If you can, wear the splint while you are moving around, and also while you rest or sleep.



- **Water:** Fill one bowl with warm water, and one bowl with cold water. Place your hands and wrists in the cold water for one minute, and then in the warm water for 4 minutes. Do this 5 times, ending with the warm water, at least 2 times a day (more often if you can). The warm water bowl should always be the last one your hands go into.
- **Exercise:** After each water treatment, exercise your hands and wrists. This will help prevent more damage to the tendons. Count to 5 as you hold your hands in each of these positions. If you feel pain in any of these positions, try to change the position a little to make it more comfortable. Repeat these movements 10 times.



- **Medicine:** If your hands or wrists are painful or swollen, take aspirin or another pain medicine that reduces inflammation (see page 335).
- **Operation:** After 6 months, if the pain is constant, if you feel weaker, or if you lose feeling or notice tingling in your hands, get medical help. You may need to have medicine carefully injected into the wrist, or you may need an operation.

Prevention:

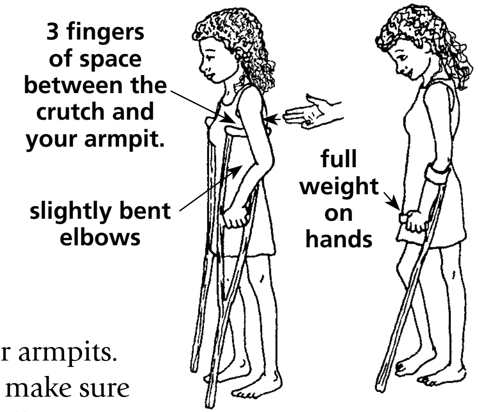
- If you can, try to push or move yourself in a way that bends your hands and wrists less and puts less pressure on them.
- If possible, ask someone else to push your wheelchair or cart from time to time, to give your hands and wrists a rest.
- Try to exercise your hands and wrists every hour, by moving them through all of the motions they can make. This will stretch and strengthen the tendons and muscles. If exercise causes pain, move slowly and gently.

If your hands and wrists are red or hot, they might be infected. See a health worker right away.

Using crutches

If you want to use crutches, make sure they fit properly. When you use crutches, most of your body weight will be felt in your hands. So follow the advice on page 93 to prevent damage to your hands.

If possible, always use elbow crutches to prevent possible damage to the nerves in your armpits. But if you prefer or can get only tall crutches, make sure they do not press up into your armpits. Your elbows should be slightly bent, and there should be 3 fingers of space between the crutch and your armpit. If tall crutches press up under your armpit, in time the pressure on the nerves there can cause paralysis of the hands.



Crutch

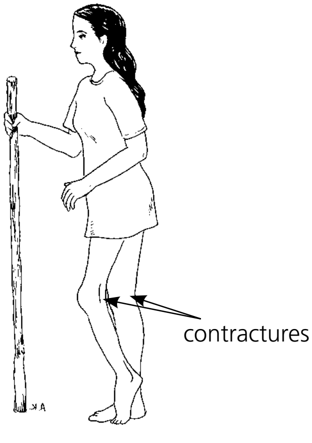
Elbow crutch

CONTRACTURES

An arm or a leg that has been bent for a long time can get locked into one position (a contracture). Some of the muscles become shorter and the arm or leg cannot fully straighten. Or short muscles may hold a joint straight so that it cannot bend. Sometimes contractures cause pain.

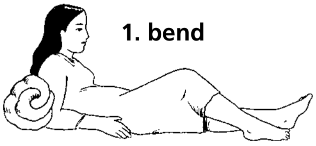
If you have had contractures for many years, gentle movement and stretching can prevent the joint from getting worse. It will be difficult to straighten the joints and muscles all the way. But gentle exercises can make your joints a little less stiff and keep your muscles strong.

To prevent contractures and keep your muscles strong, try to exercise your arms and legs every day. If necessary, find someone who can help you move different parts of your body.

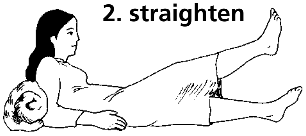


Examples of exercises that prevent some contractures and help keep muscles strong

To exercise the front of the upper leg

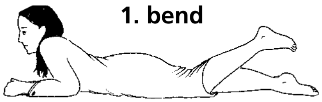


1. bend

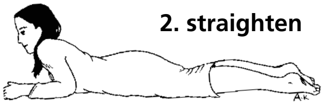


2. straighten

To exercise the back of the upper leg

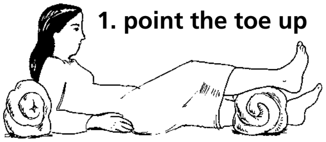


1. bend

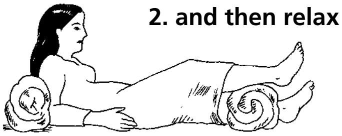


2. straighten

To exercise the lower leg



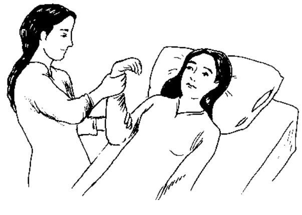
1. point the toe up



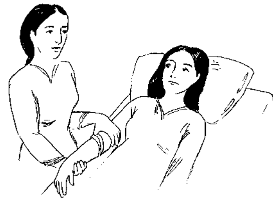
2. and then relax

To exercise the arms

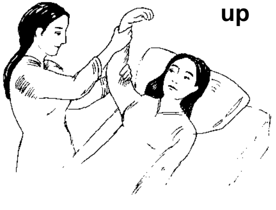
bend



straighten



lift straight up



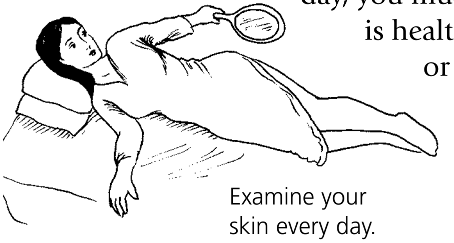
IMPORTANT If a joint has been bent for a long time, be gentle. Do not try to force it straight.

Preventing common health problems

Because you know and understand your body better than anyone else does, you can teach your family members, friends, and caregivers how they can best help you. Do not be afraid or ashamed to ask them for assistance if you have a problem. Although it is not always possible to prevent illness, most health problems will not become serious if they are treated early. If possible, try to get regular health exams (see Chapter 6).

DAILY CARE

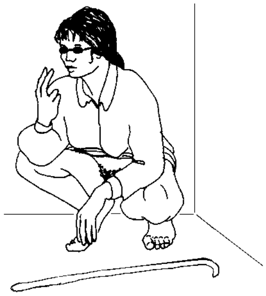
You can stay healthy and prevent infections by washing your body every day and checking your skin regularly. If you sit or do not move very much for most of the day, you must be extra careful to check your skin to make sure it is healthy (see pages 114 to 117). Look for swelling, redness, or other signs of infection. If you find scratches, cuts, or sores, wash and cover or bandage them so they do not get worse. You can use a mirror to help you look at hard-to-see places. Many blind women learn to check for sores or other warning signs by smell or by touch.



Examine your skin every day.

Wash your hair regularly, and check it often for lice. Also check the skin on your head for wounds or scabs. And try to wear clean clothes every day, especially your underclothes and socks.

Some women with disabilities have to pay attention to "minor" signs to tell when they have a health problem. For example, a woman who has an infection in her womb may not be able to feel pain from it. But she may notice an unusual discharge or smell from her vagina. A blind woman may not see that a cut is becoming a serious infection. But she may be able to feel some pain and swelling.



A change in the smell of the discharge from your vagina can mean you have an infection.

CARE OF THE FEET AND HANDS

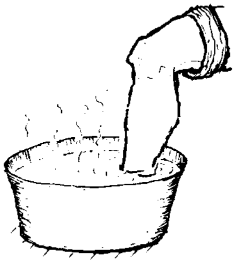
If you do not have much feeling in your feet and hands, be careful to protect them. Look for cuts and sores every day. It is easy to burn your feet or hands if you cannot feel them. Or you may get a sore or cut without feeling it. If you find a sore or a cut, keep it clean and covered until the injury has healed.

Protect the parts of your body that cannot feel heat or cold. Protect your hands with thick gloves or a folded cloth while picking up anything hot. And if you live where the weather gets very cold, cover your hands and feet to protect them.

Use a small mirror to see the bottoms of your feet. Or ask someone else to help you. Look for:

- redness, swelling, hot skin, or other signs of infection.
- cracks, sores, or broken skin.
- pus, bleeding, or bad smells.
- ingrown toenails (the edge of the nail is stuck inside the skin).

If you feel pain, tingling, burning, or have no feeling (numbness) in your feet, talk with a health worker. You may have an infection and need medicines to make it heal.



To help prevent infection, wash your feet every day with soap and warm water. First, check the water temperature with your elbow where you have more feeling, or ask someone with good feeling to check that it is not too hot for you. Dry your feet well especially between the toes.

If the skin on your feet gets dry or begins to crack, soak your feet in water for 20 minutes every day. Then rub vegetable oil, petroleum jelly (*Vaseline*), or lotion into them.

Other ways to protect your feet:

- Do not go barefoot.
- Cut your toenails straight across, not rounded, so they will not grow into your skin (ingrown toenail). And do not let them get so long that they catch and tear. Ask someone to help you if necessary.
- Make sure your shoes fit well and do not rub the skin and cause blisters or red areas.
- Check inside your shoes before you put them on for things that could irritate your feet, such as small rocks, thorns, dirt, or insects.
- Do not sit with your legs crossed. This makes it harder for the blood to flow to your feet.
- Do not cut corns, calluses, or hard skin from your feet. This can lead to an infection.
- Wear socks. Make sure socks are smooth and do not rub against your feet. If you need to mend holes in your socks, try to make the stitches very smooth.
- In hot climates, try to sit with your feet uncovered as often as possible during the day. This helps your blood circulation and helps prevent skin infection between your toes.

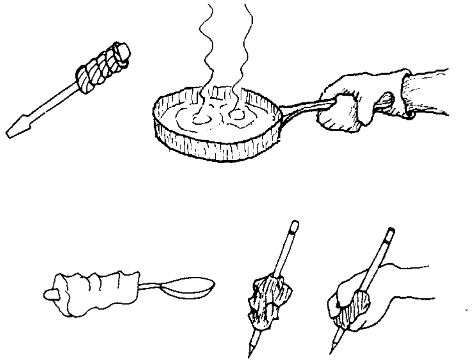
Women with leprosy (Hansen´s disease) must take special care to protect their feet from injury and infection. Because leprosy causes a loss of feeling in legs and feet, women who have leprosy are less likely to feel pain, itching, or other signs of a problem when it is still small and easy to treat.

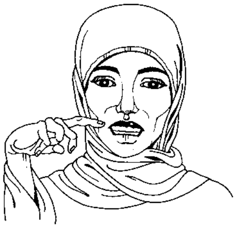
Women with leprosy often have a hard time holding things. To make it easier to hold onto things and prevent injuries, use or make tools with wide, smooth handles, or wrap thick cloth around the handles.

To make a handle:
You can mold a handle to the shape of the person's closed hand.

Use epoxy putty, or plaster of paris mixed with a strong glue. Have the person grip the handle while it is still soft. Then let it harden.

You can also make a handle with clay, or wrap several layers of thick leaves, such as banana leaves, or corn husks around the handle.





Sometimes dentists refuse to care for people with cerebral palsy. But it is very important that all people get good care for their teeth.

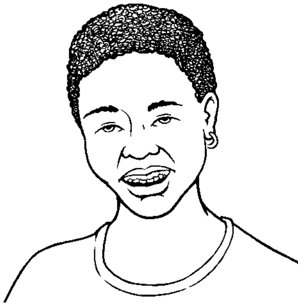
CARE OF THE MOUTH AND TEETH

Women who have a hard time controlling or moving the muscles in their mouth and tongue, or their hands and arms, such as women with cerebral palsy, may find it difficult to clean their teeth and gums. But if teeth are not cleaned regularly, any food that sticks to them or the gums can cause decay. If necessary, ask someone you trust to help you.

Women with epilepsy (seizures, "fits")

If you use the medicine phenytoin (diphenylhydantoin, *Dilantin*) to prevent seizures, it can cause your gums to swell and grow large. Taking good care of your mouth can prevent much of the swelling.

Try to clean your teeth carefully after each meal and rinse your mouth with clean water. Take special care to clean between your teeth. It also helps to massage your gums with a clean finger.



Medicine for epilepsy can make gums swollen and sore, almost covering the teeth. Keeping your teeth clean can help prevent this.

Toothpaste is not necessary to clean your teeth. Some people use baking soda or salt instead. If you have a toothbrush, it is the brush hairs that do the cleaning, so water on the brush is enough. Use a brush with soft hairs. A brush that is stiff and hard will hurt the gums, not help them. Be careful if you use a chewing stick. Some wood is very hard and can hurt and damage the gums. The soft wood from the neem tree (which grows in many hot countries) works well. You can also wrap clean cloth around the pointed end of a small stick or toothpick and use it to carefully clean the teeth one at a time.

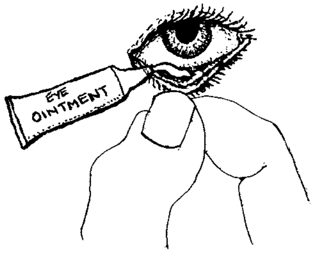
CARE OF THE EYES

Wash your face every day with mild soap and clean water. This will help prevent eye infections such as pinkeye (conjunctivitis). This infection causes redness, pus, and mild 'burning' in one or both eyes. The eyelids often stick together after sleep. Most conjunctivitis is very contagious. The infection is easily spread from one eye to the other, and from one person to another.

Do not use the same towel or cloth as someone who has an eye infection. And always wash your hands before and after touching your eyes. Keep flies away from the eyes. Flies can spread infection from one person to another.

Treatment:

First clean pus from the eyes with a clean cloth moistened with water that has been boiled and cooled. Then put in erythromycin eye ointment (see page 343). Pull down the lower lid and put a little bit of ointment inside, like this. Putting ointment outside the eye does no good.



CAUTION: Do not touch the tube against the eye.

If you have leprosy

Some disabilities, such as leprosy, make it more likely a person will develop vision problems or get an eye infection.

If you have leprosy, the muscles around the eyes may be weak, or may not have much feeling. This means that your eyes may not blink enough on their own. Not blinking can cause dryness and eye infection.

If you do not blink often, or if your eyes are red, you can:

- wear sunglasses, especially sunglasses that wrap around the sides of the face.
- wear a hat with a wide brim to shade your eyes.
- close your eyes tightly many times during the day.
- close your eyes tightly and roll your eyes upward frequently.
- wash the skin around your eyes often.

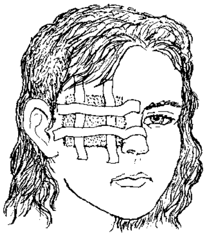
If pus forms, follow the treatment information for pinkeye (see page 99). Keep the eye closed as much as you can. If necessary, cover it with an eye patch.

You can make a patch with any clean soft cloth or gauze and tie it around the head (not too tightly) to keep it in place,

or

tape the cloth or gauze to the eye like this.

Do not press on the eye. →



If you cannot close your eyelids ('lid lag'), tape your eye closed with clean cloth or gauze to prevent dryness and infection.

To keep your eyes moist and help prevent infection, each day put a few drops of clean salty water (a pinch of salt to one cup or glass of clean water) into each eye.

Passing urine and stool

Some women with disabilities do not have complete control over when they pass urine or stool. This is especially common for women whose disability affects their muscles in the lower body, such as paralysis from polio or a spinal cord injury.

If you cannot wash your genitals by yourself, ask a family member or helper to help you keep your genital area clean and dry. If you need to wear cloth or nappies (diapers) to catch urine or stool, change them often to prevent rashes, infections and sores (see page 114).

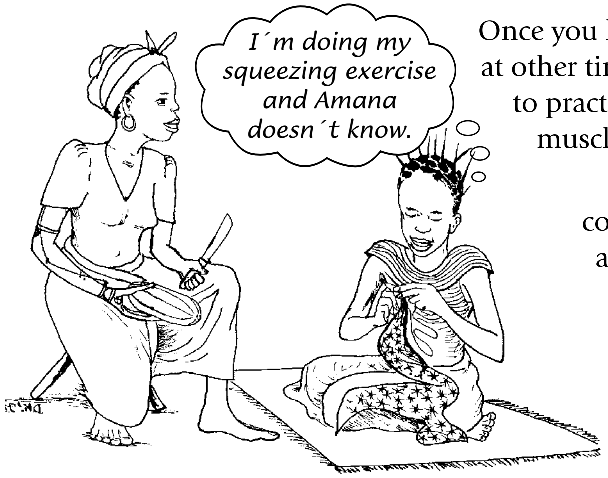
When you go outside, if possible take an extra change of clothing with you. Then, if you lose control of your bladder or bowel and soil your clothes, you will be able to change and avoid being embarrassed, and also avoid getting an infection.

BLADDER CONTROL

If you pass urine often or leak urine, try **the squeezing exercise** to help strengthen weak muscles. This exercise can also help keep your muscles strong so you will be less likely to leak urine when you are older.

The squeezing exercise

First practice while you are passing urine. As the urine comes out, stop it by tightly squeezing the muscles in your vagina. Count to 10, then relax the muscles to let the urine come out. Repeat this several times whenever you pass urine.



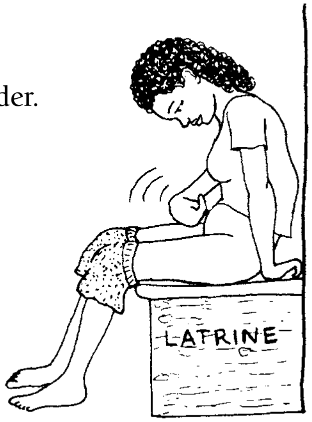
Once you know how, practice the squeezing exercise at other times during the day. No one will know. Try to practice at least 4 times a day, squeezing your muscles 5 to 10 times each time.

Some women may need surgery to help control leaking urine. If your urine leaks a lot and this exercise does not help, get advice from a health worker trained in women's health. The squeezing exercise is good for all women to do every day. It helps keep muscles strong and can prevent problems later in life.

Emptying the bladder

If your disability makes you unable to pass urine without assistance, you will need another way to empty your bladder. Some women can urinate and empty the bladder if they:

- tap their belly over the bladder, right below the belly button (navel, umbilicus) and above the pubic bone.
- push down with their hands on the lower belly, over the bladder.
- put a fist over the lower belly and gently press it by bending the upper body forward.
- strain to push urine out by making the stomach muscles tight.



You should use these methods only if the urine comes out easily with gentle pressure. If your muscles do not relax and let the urine out, pushing on your bladder can force the urine back into the kidneys and damage them.

If none of these methods work, you will need to use a rubber or plastic tube called a catheter. Do not use a catheter unless it is the only way you can pass urine. Even careful use of a catheter can cause infection of the bladder and kidneys.

Using a standard catheter

A catheter is a flexible rubber tube used for draining urine out of the bladder. Many women who need to use one put a clean or sterile catheter into the bladder every 4 to 6 hours to empty it. The more liquid a woman drinks during the day, the more often she needs to use the catheter.

Some women do not drink much water because they do not want to use the catheter very often. But this can cause other problems. If you do not drink enough liquid, you can get an infection in your bladder or kidneys, or have difficulty passing stool (constipation).

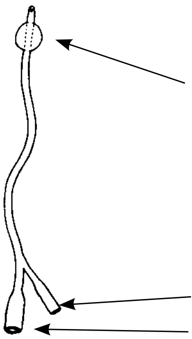
It is important not to let your bladder get too full. This can cause dysreflexia (see page 117), and can also cause the urine to go back up into the kidneys and damage them.

Many women learn to use a catheter while they are sitting on a toilet or pot. Women can also use a catheter in a wheelchair, emptying the urine into a toilet or a bottle. Experiment with what works for you. It takes practice to learn how to use a catheter when you are sitting, but many women find using a catheter makes it easier for them to do their daily activities. For most women, the best catheter size to use is a 16. A very small woman may find a size 14 fits better.

A person using a catheter is more likely to get a urinary infection than someone who does not. This usually happens because the catheter is not clean enough and germs get into the bladder. Cleaning your catheter carefully is the best way to prevent a urinary infection. Always wash your hands with mild soap and clean or boiled water before you touch the catheter, and wash it before and after using it. Keep the catheter in a clean place when you are not using it.

Standard catheter

Foley catheter

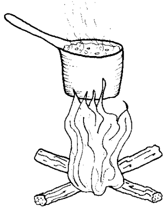


A 'Foley' (indwelling) catheter has a small balloon near the tip. The catheter is made this way so it will stay inside the bladder for long periods of time. The balloon is filled with water when it is inside the bladder, so it will not slip out. 5cc of water is usually enough to hold the Foley catheter inside. If it comes out, increase the amount of water to 12cc or 15cc.

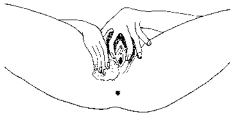
Water is injected into the balloon here.

Urine drains out here.

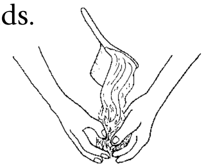
How to put in a catheter



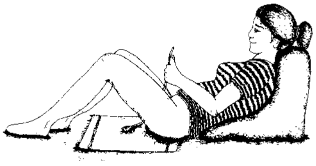
1. Boil the catheter (and any syringe or tool you may be using) for 20 minutes. Or at least wash them well in water that has been boiled and cooled, and keep them clean.



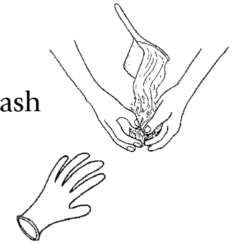
2. Carefully wash the skin around the genitals with mild soap and clean water. Take care to clean the area where urine comes out and the folds of skin around it (the vulva). If you do not have mild soap, use only clean water. Strong soap can harm your skin.



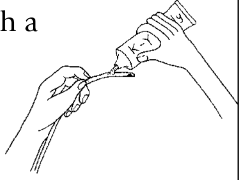
3. Wash your hands. After washing, touch only things that are very clean.



4. If you can, sit where your genitals are not touching anything, like the front of a chair, or on a clean toilet seat. If you have to sit on the ground or another solid surface, put clean cloths under and around the genitals.



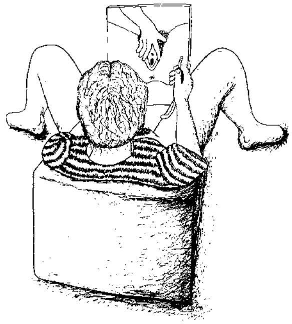
5. If you have to touch anything, wash your hands again with mild soap and water.

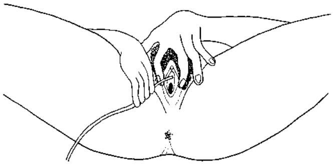


6. Cover the catheter with a sterile, water-based lubricant (not oil or petroleum jelly). This helps protect the soft skin of the genitals and urine tube (urethra). If you do not have any lubricant, make sure the catheter is still wet from the water you boiled it in or cleaned it with, and be extra gentle when you put it in.

(continued on next page)

7. If you put the catheter in by yourself, use a mirror to help you see where the urinary opening is, and use your pointing (index) finger and third finger to hold the skin around the vagina open. The urinary opening is below the clitoris almost at the opening to the vagina (see page 78). After you have done this a few times, you will know where the opening is and you will not need to use a mirror.





Make sure the catheter is in a downward position so that the urine can come out.

8. Then, with your middle finger, touch below your clitoris. You will feel a sort of small dent or dimple, and right below that is the urinary opening. Keep your middle finger just above that spot, and with your other hand, hold the clean catheter 4 to 5 inches from the end, touch the tip to just below the end of your middle finger, and gently guide the catheter into the opening until urine starts to come out. Be very careful not to touch the tip of the catheter with your fingers or hands.

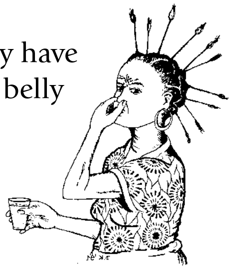
You will know if the catheter goes into the vagina instead of the urinary opening because it will go in easily, but no urine will come out. Also, when you remove it, the catheter will have discharge (mucus from the vagina) in it. Rinse the catheter in clean water, and try again. If you do get a bladder or kidney infection, talk with a health worker. You may have an infection in your vagina.

IMPORTANT To avoid infection when using a catheter, it is important for you to be very clean, and to use only a catheter that is sterile. If it is not possible to use a sterile catheter each time, make sure it is very clean.

Treating and preventing urinary infections

Bladder infection

Most women can tell when they have a bladder infection because they have pain or burning when they pass urine, or they have pain in the lower belly just after passing urine.



Smelly urine is a sign of infection.

If you have no feeling in the belly, you will have to look for some of these other signs:

- need to pass urine very often
- cloudy-looking urine
- urine that smells bad
- urine that has blood or pus in it
- sweating or feeling hot (signs of dysreflexia, see page 117)

Often bladder infections can be treated with teas or other plant remedies. Ask the older women in the community which plants will help.

Treatment for a bladder infection

Start treatment as soon as you notice the signs.

- **Drink a lot of water.** Try to drink at least 1 cup of clean water every 30 minutes. This will make you pass urine often and can help wash out germs before the infection gets worse.
- **Stop having sex for a few days** or until the signs have gone away.

If you do not feel better in 1 to 2 days, start taking medicines as well as drinking alot of water. If you do not feel better in 2 more days, see a health worker. You may have a sexually transmitted infection (see page 158).

Medicines for bladder infection

Medicine	How much to take	When to take
cotrimoxazole (160 mg trimethoprim and 800 mg sulfamethoxazole)	2 tablets of 480 mg	by mouth, 2 times a day for 3 days
or nitrofurantoin	100 mg	by mouth, 2 times a day for 3 days

Kidney infection

Sometimes a bladder infection can spread through the urine tubes into the kidneys. Kidney infections are more serious than bladder infections.

Signs of kidney infection:

- middle or lower back pain, often severe, that can go from the front, around the sides, and into the back
- nausea and vomiting
- feeling very ill and weak
- fever and chills
- any bladder infection signs

If you have signs of both bladder and kidney infection, you probably have a kidney infection. When a woman has a kidney infection, she is usually in great pain and can become very ill. She needs help right away and home remedies are not enough. Start taking one of these medicines right away. If you do not start to feel better after 2 days, see a health worker.

Medicines for kidney infection

Medicine	How much to take	When to take
ciprofloxacin (Do not use if you are breastfeeding)	500 mg	by mouth, 2 times a day for 10 days
or cefixime	500 mg	by mouth, 2 times a day for 10 days
or cotrimoxazole (160 mg trimethoprim and 800 mg sulfamethoxazole)	2 tablets of 480 mg	by mouth, 2 times a day for 10 days
If you cannot swallow medicines because you are vomiting, see a health worker. You will need medicines by injection.		

How to help prevent urinary infections

Keep your genitals clean. Germs from the genitals—and especially the anus—can get into the urinary opening and cause infection. Try to wash the genitals every day, and always wipe from front to back after passing stool. Wiping forward can spread germs from the anus into the urinary opening. Also, try to wash your genitals before and after having sex. Keep the cloths and pads used for your monthly bleeding very clean and dry.

- Make sure your catheter is not bent or twisted so that urine can come out easily.
- Pass urine after having sex. This helps wash out the urine tube.
- Drink plenty of liquids and empty your bladder regularly.
- Do not lie down all day. Stay as active as you can.

Most women take medicine only when they have signs of an infection. But some women get infections frequently, often when they begin their monthly bleeding, so they start to take medicine then.

Bowel control

Try to pass stool at the same time every day or every other day. Do it even if you have had an accidental bowel movement at another time. Eventually, your body will adjust to the schedule and the stool will come out more easily at a regular time. This is called a bowel program.

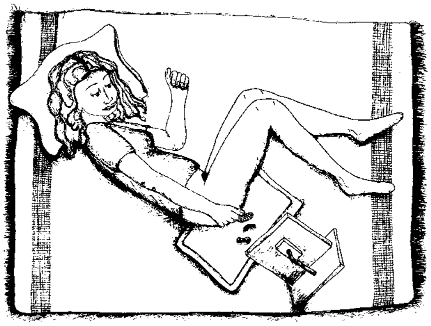
Suppositories such as bisacodyl or glycerin can be used. These bullet-shaped pills put into the anus will stimulate the bowel and cause it to push out stool.

If you cannot use the muscles in your lower body to pass stool, you can help the stool come out with a finger. You can also use this method if you have difficulty passing stool (constipation) or have hard stools.

Stool usually comes out easier when you are sitting, so try to remove the stool when you are sitting on a toilet or pot. If you cannot sit, try to do it lying on your left side. Ask someone to help you if necessary. Be careful not to get any stool in your vagina or urine hole. Harmful germs in the stool can cause an infection.

HOW TO REMOVE STOOL:

1. Cover your hand with a clean plastic or rubber glove, or a plastic bag. Put vegetable or mineral oil on your pointing finger or on whatever finger works best.
2. Put your oiled finger into the anus about 2 cm (1 inch).
3. Gently move the finger in circles for about 1 minute, until the muscle relaxes and the stool pushes out.
4. If the stool does not come out by itself, remove as much as you can with your finger. **Be gentle,** so you do not scratch or cut the skin inside the anus.
5. Clean the anus and the skin around it well, and wash your hands.



To keep your finger clean, use a thin rubber glove or 'finger cot.'

Some women can remove stool while sitting in a wheelchair. To do this, make a hole in the ground or have a container to put the stool into. Then move forward on the seat, and turn sideways as far as you can. Use a looped strap or a belt to pull one leg over and up, so that you can reach your anus with your hand. You can loop the other end of the strap around your chair, to keep your leg in place.

Constipation (difficulty passing stool)

Women with cerebral palsy and spinal cord injury often have constipation or hard stools that can take several days to come out. This can cause serious problems, such as when the stool forms a hard ball in the rectum (impaction), or dysreflexia (see pages 117 to 119).

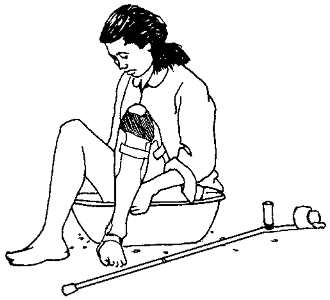
To prevent constipation:

- drink at least 8 glasses of liquid every day. Water is best, if you have it.
- try to eat plenty of fruits, vegetables, and foods with fiber—such as whole grains and cassava (manioc), beans, or other root foods that are high in fiber.
- keep your body moving and exercise as much as possible.
- keep a regular bowel program.
- add a little vegetable oil to your food each day.
- massage your belly.
- eat ripe papaya or mango, or green bananas.
- mix one spoonful of psyllium husks (isabgol, the crushed seeds of the *Plantago ovata* plant) with a glass of water, 2 times a day.

If you have not passed stool for 4 days or more, you can take a mild laxative, such as milk of magnesia. But do not do this if you have any pain in your stomach. And do not take laxatives often. Inserts that contain glycerin (*Dulcolax* is one brand) can also be used to relieve constipation.

Painful swellings around the anus (hemorrhoids)

Hemorrhoids are swollen veins around the anus. They often itch, burn, or bleed. Constipation makes them worse. Women who use wheelchairs, women who sit often, and women with cerebral palsy are more likely to have problems with hemorrhoids as they grow older. If you remove stool with your hand, watch for bleeding. This is a common sign of hemorrhoids.

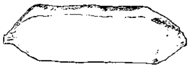

Sitting in cool water can make hemorrhoids less painful.

What to do if you have hemorrhoids:

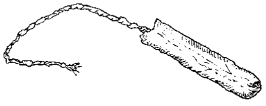
- Sit in a basin or pan of cool water to relieve the pain.
- Follow the advice on this page for preventing constipation.
- Soak some clean cloth in witch hazel (a liquid plant medicine) and put it on the painful area.
- Kneel with your buttocks in the air. This can help relieve the pain.

Monthly bleeding

During monthly bleeding, most women and girls use pads of folded cloth or wads of cotton to catch the blood coming from the vagina. They are held in place with a belt, pin, or underwear. The pads should be changed several times each day, and washed well with soap and water if they are to be used again.

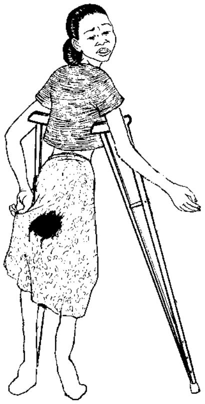


pad



tampon

If possible, after washing the cloths, dry them in the sun, or iron them with a very hot iron. The heat will dry them and will also kill germs and prevent infection when they are used again. Between bleedings, keep the cloths in a clean, dry place away from dust, dirt and insects.



Some women put something inside the vagina that they buy or make from cotton, cloth or a sponge. These are called tampons. If you use tampons, be sure to change them at least 3 times each day. Leaving one in for more than a day may cause a serious infection.

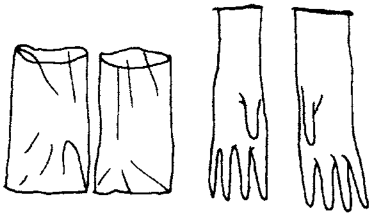
Wash your genitals with water each day to remove any blood that is left. Use mild soap if you can. If you pass urine with a catheter, pay special attention to cleaning the area around your urine hole when you are bleeding. If you get blood in the tube of the catheter, rinse it out right away. The blood can block the tube and prevent the urine from coming out.

Some women with disabilities may need extra help when they have their monthly bleeding. **Do not feel bad if you sometimes get blood on your clothing or bedding.** This happens to ALL women sometimes. If you need assistance to pass urine and stool, then your pads can be changed at that time. If it is difficult for you to change pads during the night, sleep with a towel or cloth underneath you that you can wash easily if blood gets on to it.

If you are blind

When you first start to get your monthly bleeding, because you cannot see the blood, it may be difficult to tell when you have it. But after a few months, it will become a regular part of your life, and you will probably have feelings in your body that will tell you. During the time you are bleeding, make sure to change your pads or tampons as often as possible. Wash your hands after each time you change your pads or check to see if you are bleeding. Ask family members or someone you trust to check that you do not have any blood on your clothing. And if you do, ask them to help you make sure you have been able to remove the blood stains from your clothing when you wash them.

If you help a woman with her monthly bleeding, it is best to wear plastic gloves or plastic bags on your hands to prevent the blood getting on your skin. Although the chance of diseases passing from one woman to another during monthly bleeding is very small, it is a good idea to prevent possible infection from hepatitis and HIV.



Helping girls who have trouble learning or understanding

If a girl who has trouble understanding needs help with her daily care, an older sister, aunt, or mother can show her how she takes care of her monthly bleeding:

- Be sure you use the same kind of pads or cloth to catch the blood that the girl will use.
- Show her where the supply of pads or cloth is kept.
- Show her where the pads or cloth are thrown out, or how they are washed if they are to be used again.
- Put a pad or cloth inside her underwear so she can "practice" and get used to wearing it.
- Explain that she may want to wear dark clothing when she does start bleeding so there will be less chance of blood stains showing.

Discomfort with monthly bleeding

During monthly bleeding, the womb contracts (squeezes) in order to push out the lining. These contractions can cause pain in the lower belly or lower back, sometimes called cramps. The pain may begin before or just after bleeding starts.

Heat on the belly can help reduce cramps. Fill a bottle or some other container with hot water and place it on your lower belly or lower back. Or use a thick cloth soaked in hot water. If heat does not help, you can take a mild pain medicine such as ibuprofen (see page 345).

Monthly bleeding can also make your muscles sore, or make you feel more tired than usual. The usual signs of your disability may become worse during monthly bleeding. Some women find that their breasts get swollen and sore during monthly bleeding. And some women have emotional feelings that are especially strong or harder to control.

For more information about monthly bleeding, see page 74.

Heavy monthly bleeding

Some women have heavy bleeding each month. This may be normal for many of them, but for others, it can cause anemia (see page 87). Monthly bleeding is heavy if your pad or cloth is soaked through in less than 3 hours. If this happens to you, take ibuprofen (see page 345). This can slow down the bleeding and prevent anemia. If this does not help, or if your monthly bleeding comes more often than once every 3 to 4 weeks, talk with a health worker.

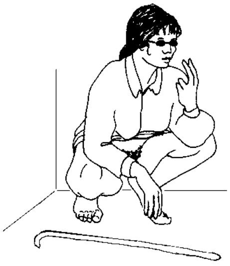
Discharge from the vagina

It is normal to have a small amount of wetness or discharge in the vagina. This is the natural way the vagina cleans and protects itself. A change in the amount, color, or smell of the discharge from your vagina sometimes means you have an infection, but it can be difficult to tell from your discharge what kind of infection you have.

VAGINAL YEAST INFECTIONS (YEAST, WHITE DISCHARGE, WHITE PERIOD, CANDIDA)

Yeast is a common infection caused by a fungus. It usually happens in the genitals or on the skin where it stays hot and damp (from leaking urine or sweat) for a long time. Yeast is not usually sexually transmitted.

Any woman can get a yeast infection in the vagina, especially if she sits for long periods of time as do women who ride wheelchairs. Yeast infections also happen more to women who have diabetes or are taking antibiotics. It is best for a pregnant woman to be treated before the birth, or the baby can get a yeast infection called thrush.



A change in the smell or color of your discharge can mean you have an infection.

Skin infection

Yeast infections are not always in the vagina. Women can also get yeast infections of the skin, especially between skin folds around the groin, down the insides of the thighs, or where skin touches on skin around a roll of fat or under the breasts.

A yeast infection of the skin can become an open sore. If it gets dirty with stool or urine, it can start other serious infections and pass to other areas of the body. For women with limited movement who sit for many hours at a time, this can be especially dangerous if it passes to the bones at the very bottom of the spine.

Signs of yeast infection:

- you feel very itchy inside or outside your vagina
- bright red skin outside and inside your vagina, in skin folds, or down the inside of your thighs, that sometimes bleeds
- a burning feeling when you pass urine
- white, lumpy discharge, like milk curd or yogurt
- a smell like mold or baking bread

Yeast can often be cured using natural remedies. One natural treatment is to mix 3 tablespoons of vinegar with 1 liter (1quart) of boiled and cooled water. Soak a piece of clean cotton in the mixture and insert it into the vagina every night for 3 nights. Remove the cotton each morning.

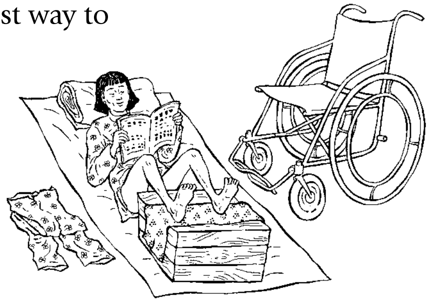
Medicines for yeast infection

Soak a clean piece of cotton in gentian violet 1%. Insert the cotton into the vagina, every night for 3 nights. Remove the cotton each morning. Or use any of the following medicines. Creams made of the medicines below can also be used on any red skin outside the vagina or on the buttocks or legs. Rub the cream in gently to the affected areas.

Medicine	How much to take	When to take
miconazole	put one 200 mg insert	high in the vagina, each night for 3 nights
or nystatin	put one 100,000 Units insert	high in the vagina, each night for 14 nights
or clotrimazole	put two 100 mg inserts	in the vagina, each night for 3 nights

If it is available, you can also use an antifungal powder such as nystatin. Apply the powders lightly to the affected areas.

Prevention of yeast infection



Yeast grows best in areas that are warm and moist. The best way to prevent yeast infections is to keep your vagina, the skin around it, your buttocks, and the skin under your breasts, clean and dry. Here are some suggestions:

- If you leak urine, change your underclothes as often as you can. You can use clean cloths or pads (like those used for monthly bleeding) and change them often during the day.
- If you sit most of the time, try to change your position at least once every hour—more often if you can. Also, try to get out of your chair and lie down with your legs open for 15 minutes at least 2 times a day. This will also help prevent pressure sores (see page 114).
- If you have no feeling in your lower body, use a mirror to look and see if there is any unusual redness in or around your vagina. If you cannot do this yourself, ask someone you trust to do it for you, especially if you notice an unusual smell from your genitals.

- Wear clean, dry underclothes made of cotton (because it absorbs wetness) and which fit loosely to let air in around your genitals and keep them dry.
- When you lie down to sleep, do not wear any underwear. This will help your genitals to stay dry.
- During your monthly bleeding, change the cloth or pad you use to catch the blood several times a day. If they are to be used again, wash them well with soap and water and let them dry completely in the sun.
- Use a tampon (made from cotton, cloth or a sponge) inside your vagina, and be sure to change it at least 3 times a day. Leaving one in for more than a day may cause a serious infection (for more information about monthly bleeding, see page 109).

Bacterial vaginosis

Bacterial vaginosis is another infection that causes a discharge from the vagina. It is not sexually transmitted. If you are pregnant, it can cause your baby to be born too soon.

Signs:

- more discharge than usual
- a fishy smell, especially after sexual intercourse
- mild itching

Treatment:

Medicines for discharge: to treat bacterial vaginosis

Medicine	How much to take	When to take
metronidazole	400 to 500 mg	by mouth, 2 times a day for 7 days
or metronidazole (avoid metronidazole in the first 3 months of pregnancy)	2 grams (2000 mg)	by mouth, in a single dose
or clindamycin	300 mg	by mouth, 2 times a day for 7 days
or clindamycin	5 grams of 2% cream	inside the vagina at bedtime for 7 days
Your partner should also be treated with 2 grams of metronidazole by mouth, one time only.		
IMPORTANT Do not drink alcohol during the time you are taking metronidazole.		

IMPORTANT Discharge in the vagina can be caused by sexually transmitted infections (STIs). For more information, see page 158.

Pressure sores

Pressure sores are especially common for women who use wheelchairs or lie in bed and do not move their bodies regularly. Pressure sores start when the skin over the bony parts of the body is pressed against a chair or bed. The blood vessels get squeezed shut, so that not enough blood can get to the skin. Eventually, a dark or red patch will appear on the skin. If the pressure continues, an open sore can develop and work its way deeper into the body. Or the sore can start inside the body, near the bone, and gradually grow toward the surface. If a pressure sore is not treated, the infection can spread through the body and kill the person.

Because her bones are less cushioned, a very thin woman is more likely to get pressure sores. You are also more likely to get a pressure sore if:

- you use a wheelchair, or sit or lie in bed most of the time.
- you have urine leaking (incontinence).
- you get muscle spasms that cause your body to rub against sheets or clothes.

Signs:

- hot, red, or dark skin that does not get lighter in color when you press it
- a swelling or an open wound on the skin

When you notice the first signs of a pressure sore:

- change your position at least once an hour.
- use extra padding to protect the area from pressure.
- keep watching the area to see if it gets better or worse.

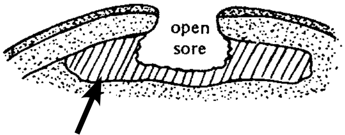
Examine your skin every day.

If you have a pressure sore:

- Keep all pressure off the sore area. Do not sit or lie on the sore at any time.
- Gently wash the sore and the surrounding skin twice a day, with clean or boiled and cooled water. Wash around the edge of the sore first. Then use a new piece of clean cloth or gauze to wash from the center out to the edges.
- After cleaning, spread some ointment on a clean cloth or piece of gauze, and cover the sore lightly. You can use any mild ointment, such as antibiotic cream or petroleum jelly *(Vaseline)*. This will prevent the skin from becoming dry and will also protect the sore from dust, dirt, flies and other insects.
- Be careful not to rub or massage the skin around the pressure sore. This can weaken the skin or tear it and make the sore worse.

If the sore is deep and has a lot of dead flesh:

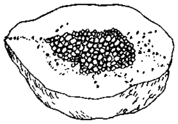
- The sore needs to be cleaned 3 times a day.
- The sore is often bigger than it looks. It can go deep under the edges of the skin. When the sore is cleaned, be careful to take out more of the dead flesh. Little by little, the dead flesh must be removed until the healthy red flesh or bone is visible.
- Wash the sore with soap and water every time dead flesh is cleaned away. Use liquid surgical soap if it is available. Afterward, rinse the sore with clean or boiled and cooled water.



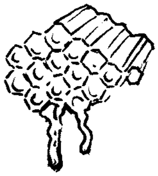
Dead flesh may be gray, black, greenish, or yellowish and may have a bad smell if infected.

Home treatments for pressure sores

Papaya (paw paw): This fruit contains chemicals that help make the old flesh in a pressure sore soft and easy to remove. Soak a sterile cloth or piece of gauze in the 'milk' that comes from the trunk or green fruit of a papaya plant. Pack this into the sore. Repeat this 3 times a day.



Honey and sugar: These will kill germs, help prevent infection, and speed healing. Mix honey and sugar together into a thick paste. Press this deep into the sore, and cover with a thick, clean cloth or gauze bandage. (Molasses or thin pieces of raw sugar can also be used.) Clean out and refill the sore at least 2 times a day. If the honey and sugar becomes too filled with liquid from the sore, it will feed germs rather than kill them.



If a pressure sore gets infected

If the pressure sore has a bad smell and is swollen, red, and hot, or if you have fevers and chills, the sore has become infected. It is best to go to a health worker who can find out what germs are causing the infection and what medicine will work best. If that is not possible, you can use an antibiotic, such as doxycycline, erythromycin, or dicloxacillin (see the Green Pages for information about using these medicines).

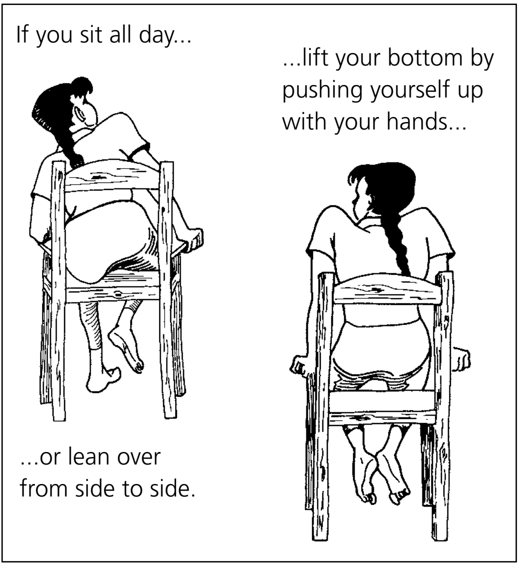
- Pressure sores heal from the inside out, so you will notice the sore gradually start to fill in. This will not happen quickly, so try to be patient.
- If necessary, take paracetamol for pain (see page 350).

If you have lost feeling in part of your body, it is important for you, and your family and caregivers, to learn as much as possible about pressure sores and how to treat and prevent them. Pressure sores are very common in persons with spinal cord injury. Often the sores start in hospitals shortly after the injury, because the injured person does not get moved enough from one position to another to relieve pressure. With proper attention, no one should get pressure sores.

Preventing pressure sores

Even if you cannot make big movements, try to move or shift your weight at least every 2 hours. If you lie down all the time, have someone help you change position if you cannot easily move yourself.

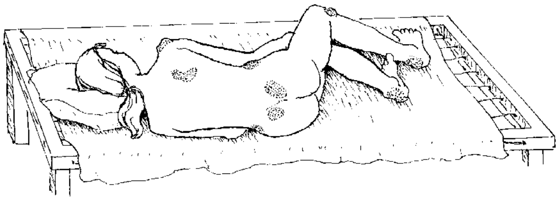
Try putting a pillow or soft blanket roll where your skin rubs together, such as between your knees or between your head and your arms. You can also lie or sit on something soft that reduces pressure on bony areas. A cushion or sleeping pad that has hollowed-out areas around the bony parts will help. You can make a simple cushion or sleeping pad from a plastic bag filled with uncooked beans or rice. It must be refilled with new rice or beans once a month. If you use a wheelchair, try to make sure you always sit on a good cushion.



If you sit all day...

...lift your bottom by pushing yourself up with your hands...

...or lean over from side to side.



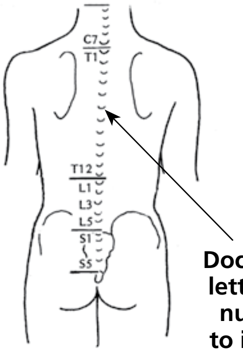
Examine your whole body carefully every day. You can use a mirror to look at your back. If you notice a dark or red place, try to avoid any pressure on this area until your skin returns to normal.

Try to wash every day with mild soap and clean water. Pat your skin dry, but do not rub it. To prevent dry skin, which can crack and tear more easily, gently apply a little lotion once a day. **Never use alcohol on your skin.** Alcohol can dry out the skin and make it weak.

Eat plenty of fruits, vegetables, and foods rich in protein and iron—such as lentils, beans, peas (especially when they are sprouted), meat (especially liver, heart, and kidney), fish, or chicken. This will make your skin and muscles healthy and strong, which will help to prevent pressure sores.

Sudden high blood pressure with pounding headache (dysreflexia)

People with a spinal cord injury above the T6 bone of the spine can get sudden high blood pressure with pounding headaches (dysreflexia). It is the body's reaction to something that would normally cause pain or discomfort, but which the person does not feel because of the injury. Dysreflexia can be caused when something touches or stimulates an internal organ such as the bowel, genitals, bladder, or intestine, or the skin on the lower body or the breasts.



Doctors use letters and numbers to identify bones in the spine. T6 is about here.

Common causes of dysreflexia:

- a very full bladder. This can be caused by a catheter that has become bent or twisted.
- a bladder infection, or stones in the bladder or kidneys (see page 105)
- too much stool in the body (constipation, see page 108)
- pressure sores, burns, or irritated skin which you may not be able to feel (for information about pressure sores, see page 114)
- hot or cold temperatures against your skin, such as from lying on a cold examination table
- womb contractions during monthly bleeding or during childbirth.
- sexual activity

Signs of dysreflexia:

1. sweating, especially from your face, arms, or chest
2. reddish or dark blotchy skin above the level of the spinal cord injury
3. goose bumps or pimples on arms or chest
4. blurry vision or seeing spots
5. stuffy nose
6. severe, pounding headache
7. feeling sick (nausea)
8. sudden high blood pressure (up to 240/150)

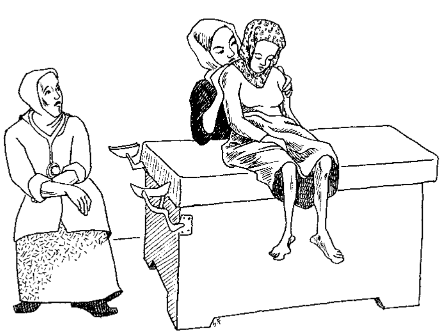
Any of these problems alone or in combination can be a sign of dysreflexia. If you think you have dysreflexia, you need help right away. Try to have a family member or another caregiver practice how to care for you if you have sudden high blood pressure. You and they must act quickly to remove the cause and lower the blood pressure. You can use this information to let a helper or a health worker know how they can also help if you have dysreflexia.

IMPORTANT Dysreflexia is a medical emergency. The high blood pressure can cause seizures or deadly bleeding inside the brain. Caregivers must never leave a person with dysreflexia alone.

Always pay attention to the signs of dysreflexia. Some signs do not indicate an emergency, but are the way some women with a spinal cord injury can know something is happening with their body. For example, if you start to feel a little hot and sweaty, or if you have a tingling feeling in your skin, it may be because your shoes or clothing are too tight, or you are sitting on something hard, or your urine catheter is twisted or bent, or your toenail is growing into your skin. Usually, if you can take care of the problem, your dysreflexia signs will go away.

Treatment for dysreflexia:

- If you are lying down, sit up and stay sitting until the signs have gone away.
- Loosen any tight clothing, including tight socks or stockings.
- If it is caused by pressure or temperature, change your position to remove the pressure or get away from the hot or cold surface.
- Remove anything that is rubbing against the skin.
- Feel the lower belly to see if the bladder is full.



If you cannot pass urine:

- Insert a catheter and empty the bladder (see pages 103 to 104).

If you are already using a catheter:

- Are there bends or twists in the catheter? Straighten them so urine can flow.
- Is the catheter blocked? Replace the catheter. Or inject 30 cc of boiled and cooled water (or sterile saline solution) into the catheter to clear the tube.

If you have signs of a urinary infection:

- See pages 105 to 106. If this seems to be the cause, inject an anesthetic solution into the bladder through a catheter. Use 10 cc of 1% lidocaine in 20 cc of boiled water. Clamp the catheter for 20 minutes and then release it. The infection also needs to be treated with antibiotics.

If your bowel is full:

- If it has been a long time since passing stool, put some lidocaine jelly on a gloved finger and gently put it in the anus to check if the bowel is full. If it is packed hard with stool, put more lidocaine jelly in the anus. Wait 15 minutes or until the headache becomes less. Then remove the stool with a finger (see page 107).

If the signs do not go away in 10 minutes, use medicine. Nifedipine will make the blood pressure go down in 5 to 10 minutes.

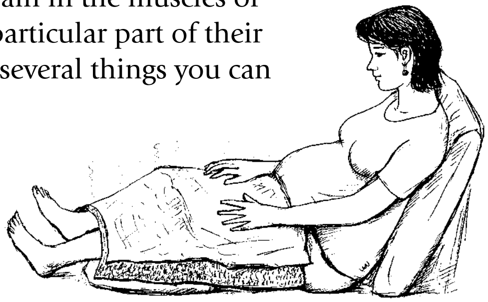
Medicines for dysreflexia

Medicine	How much to take
nifedipine	Bite into and swallow a 10 mg capsule.
or nifedipine	Crush a 10 mg tablet in a little clean water to make a soft paste and put the paste under the tongue.

Too much stool or urine in your body can cause dysreflexia. Take care to do your bowel program regularly. Drink a lot of water and eat foods that will help you have easy bowel movements. In addition, make sure to pass urine often. If you use a catheter, make sure it does not become twisted or bent.

Managing pain

Some disabilities, such as arthritis, cause pain in the muscles or joints. Sometimes women have pain in a particular part of their body. Or they may hurt all over. There are several things you can try to help ease pain.



Heat is usually best for sore, stiff joints and muscles. Soak cloths in hot water and place them on the painful areas. The water should be hot enough for you to be able to hold your hand in it comfortably. Otherwise, you may burn your skin.

Cold is usually best for inflamed joints or injuries. You can often tell when an area is inflamed because it will feel hot and may be red and swollen. Wrap ice in a cloth or a towel and place it on the painful areas. Do not put the ice directly on your skin. After 10 or 15 minutes, take the ice pack off and let your skin warm up. When your skin is warm, you can use the ice again.

Try to rest the area that hurts. Do not stress the muscles or joints, and try to avoid heavy work or overuse that strains the hurting place.

Gentle movement often helps the pain. Here are some ideas to keep your joints and muscles moving in ways that soothe the pain:

- Rub the painful areas gently.
- Stretch your muscles gently.
- Have someone massage your muscles.
- Swim or move around in clean, warm water.

A pain medicine such as paracetamol (acetaminophen) can help with the pain but will not reduce swelling. Aspirin and ibuprofen help control pain and reduce swelling in the joints. Look up these medicines in the Green Pages for more information on pain relief.

IMPORTANT If your ears start to ring, or you start to bruise easily, take less aspirin.

If you are taking aspirin or ibuprofen because your joints are swollen, keep taking the medicine even after the pain starts to go away, until the joints are less swollen. Do not take both aspirin and ibuprofen within 4 hours of each other.

Working for change

While many people believe it is important to take care of disabled women, in reality many women with disabilities do not get enough of the care and information they need to lead healthy and active lives.

What families and caregivers can do

Care from our families and helpers makes our lives easier in many ways. They can also help us to be more independent by encouraging us to do as much as we can to take care of our own bodies. Even so, as women with disabilities, we may need extra help to:

- get enough good healthy food and clean water.
- exercise and stretch to keep our bodies strong and flexible.
- bathe, and clean our teeth.
- remove stool or urine and change the cloths or pads used to absorb monthly bleeding.
- check, clean and treat pressure sores. (See pages 114 to 117.)
- keep some medicines and supplies at home or nearby, especially if medical care is far away. Try to include pain relievers, an antibiotic for urine or skin infections, clean gauze, and any medicines used regularly to treat her disability.

Most of us who are blind or deaf can take care of our own physical needs. But we may still need help getting information to keep ourselves healthy. For example, a blind person may need you to read health education information out loud to her—even if the information is about things you usually would not speak about. And a deaf person may need you to tell her about important health messages you hear on the radio or from a health worker.

What communities can do

Communities can do a lot to improve the conditions that will allow us to take care of our bodies so we can remain healthy. Many women with disabilities are poor and some live isolated lives. Like everyone else, we need access to care, nutritious food, clean water and sanitation, and a safe place to live. We also need the companionship and respect of our neighbors. Talk to us and to our families about things the community can do to help us look after our health.

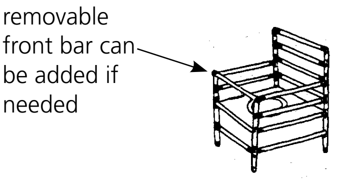
- Some of us may need daily care from our families and helpers. Community leaders and neighborhood groups can arrange other help so our needs can be met and our family and regular helpers get a break.
- Many older women with disabilities are very poor, live alone, or have a hard time finding someone to help us. By arranging for helpers or companions—or giving practical support in other ways—the community can greatly improve our lives.
- Help us farm our fields or go to market so we can have enough good food.
- Work to make sure that women with disabilities have access to clean water.
- Organize your community to build or remodel latrines and toilets so they can be safely used by people with disabilities (see page 123).

For more information on how communities and families can stay healthy, see Chapter 10 in *Where Women Have No Doctor,* and the booklets *Sanitation and Cleanliness* and *Water for Life.*

Making toilets and latrines easier to use

There are many ways to make toilets easier to use for children and adults with disabilities. Be creative in finding and showing the community solutions that fit your needs.

If a person has **difficulty squatting**, make a simple hand support or a raised seat. Or, if the toilet is set in the ground, make a hole in the seat of the stool or chair and place it over the toilet.



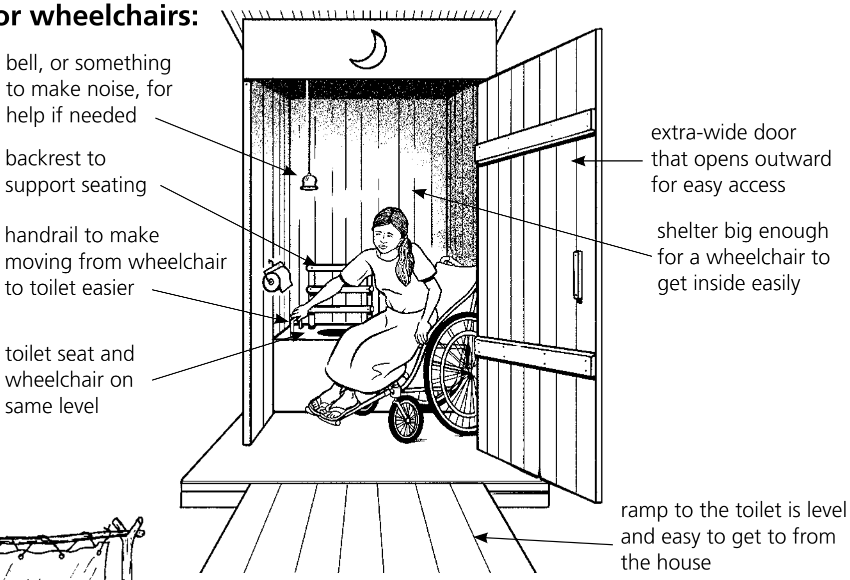
If a person has **difficulty controlling her body**, make supports for her back, sides, and legs, and a seat belt or bar.

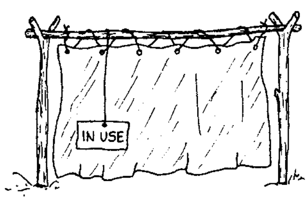
Use a rope or fence to guide **blind** people from the house to the toilet.

If a person has **difficulty adjusting or removing her clothes**, adapt her clothing to make it loose or elastic. Make a clean, dry place to sit or lie down and dress.

If a person has **difficulty sitting** you can make moveable handrails and steps.

Toilets for wheelchairs:





Remind people in the community that anyone with a disability has the same need for privacy as anyone else and should get the privacy they need.

CHAPTER 6

Health exams

Women with disabilities need health exams

Many people think a disabled woman's only health concern is her disability and that she needs no other health examinations. But this is not true. Checkups with a health worker every 2 to 3 years, even if you feel fine, are an important way for a woman to find health problems early, when they can best be treated.

Women with disabilities often have a hard time getting exams. You may not want to get exams because you have grown up feeling ashamed of your body. Or you may not want anyone to touch your body. Or you may already have had so many exams and operations that you do not want to see another health worker.

But because regular exams are just as important for women with disabilities as they are for all women, learn as much as possible about them from this book and other resources. Then you can ask local health workers—and demand of hospital directors and ministers of health—to make these services available to you and other women with disabilities.

This chapter has information about breast exams (see page 128) and pelvic exams (see page 130). Getting these 2 exams is important for any woman to stay healthy. For more information about other health tests, see page 135.

WHAT REGULAR HEALTH EXAMS CAN TELL YOU

Sometimes a person can be sick and not realize it until the problem has become very serious and difficult to treat or cure. But many health problems can be found by having regular health checkups. Some of the health problems that can be helped if they are found early are: anemia (weak blood), tuberculosis (TB), HIV/AIDS and other sexually transmitted infections, malaria, some cancers, high blood pressure, worms and other intestinal parasites, and diabetes. Any woman, whether or not she has a disability, can have these problems.

Bringing health exams to the community

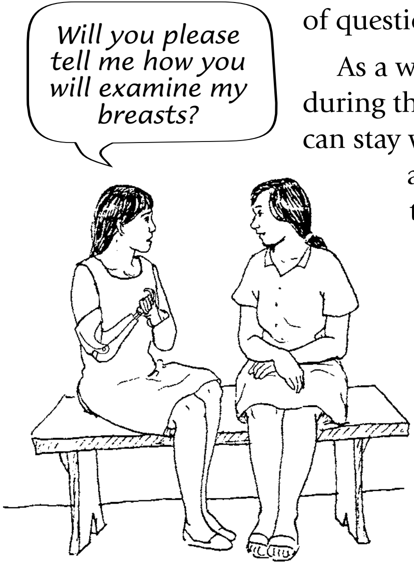
Lizzie Longshaw knew that most disabled women in her community in Zimbabwe never got pelvic or breast exams. Clinics that were accessible were too far away and too expensive for disabled women. But she knew how important these exams were for women with disabilities. Because exams were not easy to get, many women did not learn about their health problems until it was too late and many died from cancer.

Lizzie, who is herself disabled, called together a group of women with disabilities. Together, they learned as much as they could about cancer and other health problems, and about how exams can help all women by finding problems early. The group then persuaded a representative from the Ministry of Health to meet with them about the health problems disabled women face. They explained how disabled women had trouble traveling to clinics and paying for health services. The representative was so impressed with how much the women had learned, he arranged for the government to provide a free, mobile clinic once a month to provide cancer screening and family planning services for disabled women in that community.

Two of the most important regular exams a woman should get are breast exams and pelvic exams. Two common cancers women develop are in their breasts and cervix, and these tests can help identify and treat them early.

HOW TO PREPARE FOR BREAST AND PELVIC EXAMS

You can prepare for a breast or pelvic exam by knowing ahead of time what is going to happen. Ask the health worker to talk about each step of the exam and to explain anything you do not understand. It may help to think in advance of questions to ask her.



As a woman with a disability, you may have different needs during the exams. If possible, take a friend or family member who can stay with you the whole time. Talk with the health worker about your specific needs before the exam so she can do them in a way that is safer and easier for you.

If you are deaf or cannot hear well, bring a friend with you who can use sign language to help you communicate with the health worker.

If you are blind or cannot see well, bring a friend to explain and describe the exams. Ask the health worker to carefully explain what she is doing and what you cannot see.

If you have a mobility-related disability or cannot walk well, bring a friend, or plan ahead how to enter the clinic or health center.

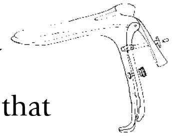
If you have trouble understanding or learning, and the breast or pelvic exam makes you frightened, nervous, or uncomfortable, ask for someone you trust to stay with you during the exam.

Family members and caregivers can help women who have disabilities that affect learning or understanding:

- **Talk about the exams in advance.** A family member or friend can explain the exams to a woman who has trouble learning. Help her understand that these exams are important for her to be healthy. Describe what will happen during the exams and answer her questions. If you can, tell her who will do the exams.
- **Visit the clinic before the exams, if possible.** The day before the exams, try to go with her to the place where the exams will be done.
- **Have someone she trusts go with her.** If she wants, a friend or family member can stay with her during the exams. If the health worker who does the exams is a man, make sure a woman she trusts stays with her the whole time.

Health workers can help:

- **Explain the exams again right before.** Explain what will happen before starting the exams and ask if she has any questions. She will probably be less afraid if she can ask questions before the exams start.
- **Show her any instruments you will use, such as the speculum.** Make sure she knows what the speculum is before the pelvic exam so that it does not surprise her, and let her touch it if she wants to.
- **Talk to her during the exams.** Explain what is happening at each step. Tell her what you need to do next. Ask her if she is ready and wait for her to agree. That way she has some control over what happens.



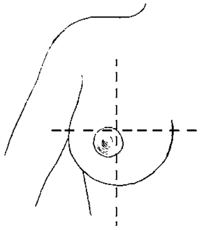
The breast exam

A sister or friend can do a breast exam for you if you cannot.

A regular breast exam is a good way to make sure you do not have any signs of breast cancer. Most women have some small lumps in their breasts. These lumps often change in size and shape during her monthly cycle. They can become very tender just before monthly bleeding. Sometimes—but not very often—a breast lump that does not go away can be a sign of breast cancer. Many women get breast cancer which, if not treated, can kill you. Regular breast exams ensure that cancer can be found and treated early, when it can still be cured.

A trained health worker should examine your breasts every time you have a regular check-up or pelvic exam. She will use the exam method described in this chapter.

Even though a health worker may examine your breasts every year or two, you can examine your own breasts more often.



If your breasts are large, divide them into 4 parts and examine them one part at a time. You can draw a picture like this and make a mark if you find a lump anywhere.

If you cannot do it yourself, someone you trust can do it for you. It is best to get the same person to help each time. That way, the person who helps will know if something changes.

Try to examine your breasts once a month on the same day during your menstrual cycle (see page 75). If possible, always do it 7 days after your monthly bleeding starts each month. If you can do it regularly, you will learn how your breasts usually feel, and you will be more likely to know when something is wrong. Also, try to examine your breasts when you have enough time to relax and do the exam well.

To help you remember how your breasts feel each month, make a simple drawing. Draw a large circle for the breast, and a smaller circle for the nipple. When you examine your breasts, if you feel any lumps, mark the place on the drawing. When you check again the next month, it will be easier to remember where any lumps were and if they are getting larger.

What to do if you find a lump

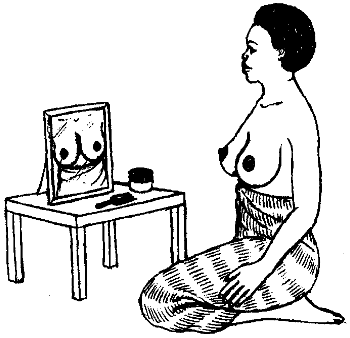
If the lump is smooth or rubbery, and moves under the skin when you push it, do not worry about it, but keep checking it each month. But if it is hard, has an uneven shape, and is painless or grows in size, keep watching it—especially if the lump is in only one breast and does not move even when you push it. See a health worker if the lump is still there after your next monthly bleeding. This may be a sign of cancer. You should also get medical help if there is a discharge from the nipple that looks like blood or pus.

Ask an experienced health worker to check **any** lump you find, whether it is smooth or uneven. **Continue having regular breast exams even after your monthly bleeding stops (menopause)**.

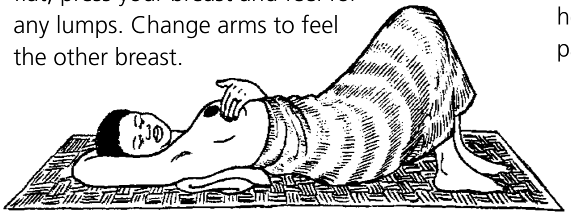
ONE WAY YOU CAN EXAMINE YOUR BREASTS

How to examine your breasts

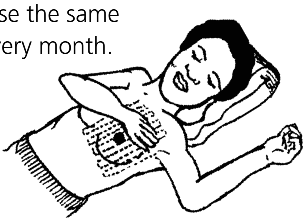
Look at your breasts in a mirror, if you have one. Raise your arms over your head. Look for any change in the shape of your breasts, or any swelling or changes in the skin or nipple. Then put your arms at your sides and look at your breasts again.



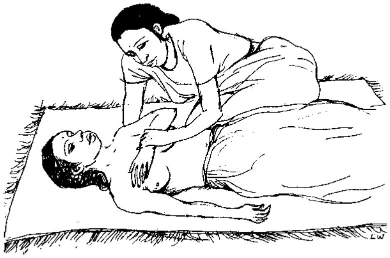
Lie down and, if possible, put one arm behind your head. Keeping your fingers flat, press your breast and feel for any lumps. Change arms to feel the other breast.



Be sure to touch every part of your breast. It helps to use the same pattern every month.

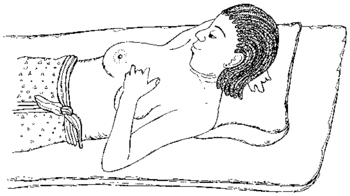


OTHER WAYS YOU CAN EXAMINE YOUR BREASTS

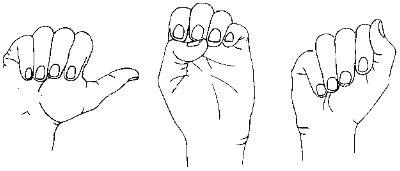


If you have weak muscles or your hands shake, you can use your other hand to guide your fingers. Or someone else can guide your hand. A helper can hold your hand up to your breast and keep your fingers in the right place.

Remember: If you get tired, take a break. You do not have to do the exam all at once.



If you cannot reach across your chest, you can use the hand that is closest to the breast.



If you cannot feel well with your fingers, you can use another part of the hand. You can use your thumb, your palm, or the back of your fingers. Be sure to feel all parts of your breast.

The pelvic exam

A pelvic exam can help you know if:

- you have any lumps, swelling, or sores, around your genitals. Some of these could be dangerous and may need treatment.
- you are pregnant.
- you have an infection in your womb, tubes, ovaries or vagina. Untreated infections are dangerous.
- you have cancer of the cervix, ovaries, or womb.
- you have other problems in the womb or the ovaries, such as fibroid tumors, endometriosis, or cysts that are not caused by cancer (see pages 81 to 82).

If you limp when you walk, or use a cane, crutch, or a wheelchair

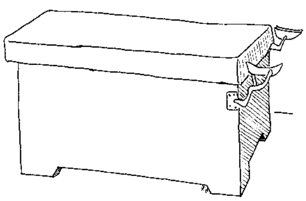
If you have difficulty moving your body, you will know best how to move from one position to another. Ask your friend or the health worker to help. Before the pelvic exam begins, make sure you are well-balanced and feel safe and comfortable. (See pages 133 and 134 for some ideas.)

Before the exam, try to pass as much urine and stool as you can. The pelvic exam can easily make the muscles relax and cause urine and stool to come out. If you wear a catheter all the time, you do not need to remove it. It will not affect the exam. If you have a urine bag tied to your leg, remove it and place it either beside you or across your belly. Make sure the tube does not bend, and that it continues to drain properly.

Steps of the pelvic exam:

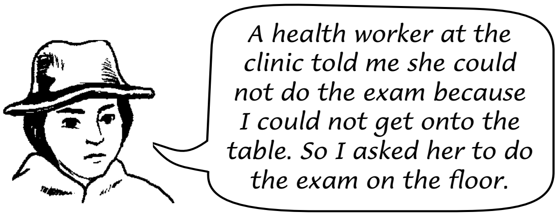
1. The health worker will look at your outer genitals for any swelling, bumps, sores, or changes in color.
2. Usually, the health worker will put a speculum into your vagina. A speculum is a small metal or plastic tool that holds the inside of the vagina open. She can then examine the walls of the vagina and the cervix for swelling, bumps, sores, or discharge. You may feel slight pressure or discomfort with the speculum inside, but it should not hurt. The exam is more comfortable if your muscles are relaxed and your bladder is empty.
3. If the clinic has laboratory services, the health worker should do a Pap test for cancer and, if needed, tests for STIs. To do a Pap test, the health worker uses a small, rounded stick to scrape a bit of tissue off the cervix. This is not painful. You should feel only a little pressure. The sample of tissue is sent to a laboratory where it is checked for signs of cancer. If cancer of the cervix is found and treated early, it can almost always be cured.
4. After the health worker removes the speculum, she will put on a clean plastic glove and put two fingers of one hand into your vagina. She will press her other hand on your lower belly. In this way she can feel the size, shape, and location of your womb, tubes, and ovaries. This part of the exam should not be painful. If it is, tell her. It may mean something is wrong.
5. For some problems, the health worker may need to do a rectal exam. She will put one finger into your anus and one finger into your vagina. This exam can give the health worker more information about possible problems of the vagina, and of the womb, tubes, and ovaries. The rectal exam will be easier if you push against the health worker's finger when it first touches your anus—as if you are passing stool. This will relax the muscles around your rectum so the exam is less uncomfortable.

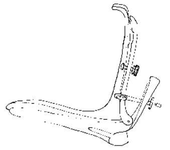
To the health worker:



In many clinics and hospitals, exam tables are high and hard to use for women who have difficulty moving their legs or holding them in place.

Tables closer to the ground are best for most women with disabilities. But you do not need to use a special table to do a pelvic exam. A health worker can do this exam on any clean, firm surface—even on a clean cloth on a clean floor.





A speculum can be used upside down to examine someone on the floor.

To examine someone on the floor, turn the handle of the speculum so it faces up when you put it into the woman's vagina. Otherwise the speculum will be hard to open. To make sure the speculum does not touch the floor, put some folded cloth under the woman's hips to lift them a little.

Many women are frightened when they first see a speculum. They imagine that it must hurt them when it is put inside their vagina. When you examine a woman who has never had a pelvic exam before, show her a very small speculum, even if you plan to use a larger one. Make sure she is relaxed, touch her gently, and always explain what you are about to do. When the exam is finished, thank her for making it so easy for you to do the exam.

For more suggestions about making exams easier for women with different disabilities, see pages 133 and 134.

Take precautions to prevent dysreflexia (sudden high blood pressure with pounding headache)

Dysreflexia is common in people with spinal cord injuries. It is the body's reaction to something that would normally cause pain or discomfort, but which the person does not feel because of the injury.

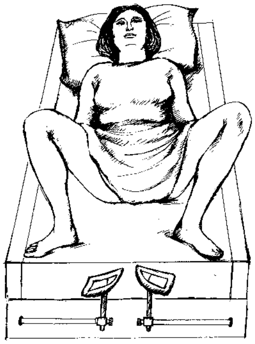
During a woman's pelvic exam, dysreflexia can be caused by:

- a woman's body touching a hard exam table or surface (even if she cannot feel it).
- pressure in the vagina or rectum from the hands of the person doing the exam or from an instrument (such as a speculum), especially if it is cold.
- cold temperature in the clinic where the exam is being done.
- a urine tube (catheter) that has become bent or twisted.

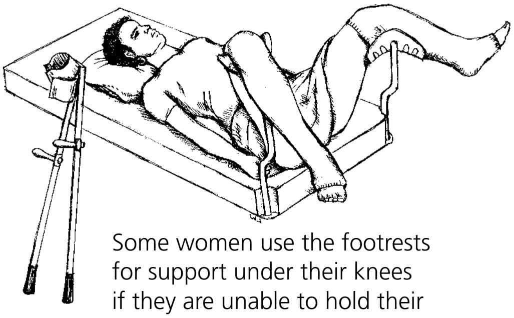
IMPORTANT If you examine a woman with a spinal cord injury, watch for signs of dysrelexia and be prepared to stop the exam. **Dysreflexia is a medical emergency.** The high blood pressure can cause seizures or bleeding inside the brain. Do not leave a person with dysreflexia alone. For signs and treatment of dysreflexia, see pages 117 to 119.

POSITIONS FOR A PELVIC EXAM

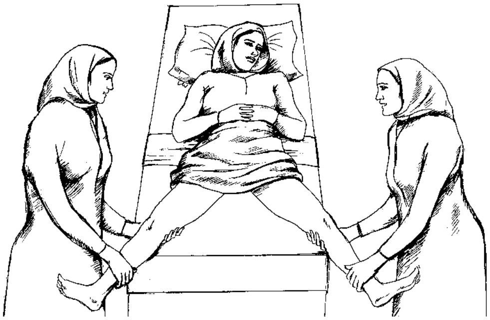
If you cannot separate your legs easily, this does not mean you cannot have the exam. Talk to the health worker about different positions that will work for your body. Here are some positions many women with physical disabilities use:



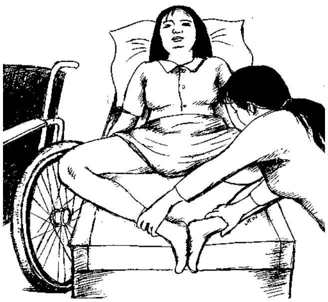
Women who have trouble with their hips may find this position easier. This position is good if there is no one to hold your feet, because many women can keep their legs in this position without tightening their muscles.



Some women use the footrests for support under their knees if they are unable to hold their knees up themselves.



Some exam tables have places for a woman's feet to rest. Many women with disabilities do not use these footrests.



This position works well for women who cannot move their legs on their own. It can also be good for women who have trouble bending their knees.

This position is more comfortable for women who have trouble separating their legs.

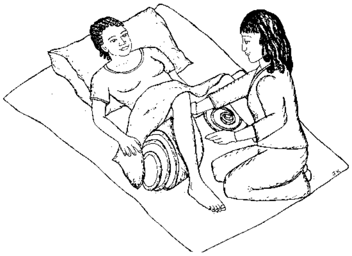
If you have stiff or tight muscles

A friend or family member can support your legs during the exam. Then you can relax your muscles, which makes the exam easier.

Muscles can suddenly get tight and stiff during an exam. This happens mainly to women with a spinal cord injury or cerebral palsy. Sudden muscle spasms can happen when:

- you move onto an exam table.
- you are in an uncomfortable position.
- an instrument such as a speculum is put into the vagina.
- a health worker puts her fingers in the vagina or anus, as with a 'bimanual' or rectal exam.

If you have tight muscles, ask the health worker to go slowly so you have more time to relax. If a spasm happens during the exam, ask the health worker to stop and wait until your muscles are relaxed or soft again. Do not pull or push directly against the tight muscles. This will make the spasm worse. A friend can gently hold or support the affected place until the muscle is soft again.



You can also roll up a blanket or use pillows to support your legs.

The exam will be easier if you can find a comfortable position where you can relax and do not have to make your muscles tight to hold yourself in place. Or ask a friend or family member to help hold your body during the exam. If this is not possible, you can roll up blankets and put them underneath your knees.

IMPORTANT Do not massage or rub spastic muscles. Massage will make the muscles tighter.

The pushing exercise

Women with cerebral palsy or spastic muscles often have a hard time relaxing their muscles. To help relax the pelvic muscles, you can practice a pushing exercise. First, practice pushing down as if you were trying to pass stool. Some women imagine they are laying an egg that comes out through the vagina. After a while, try taking a deep breath just when you start to push.

Practice this exercise before you have the exam. You can also do it again during the exam, especially before the health worker puts a finger or an instrument in your vagina. Once the health worker starts to examine you, it will help if you stop pushing and relax the muscles in your belly. If your muscles are tight, the health worker will not be able to feel inside you.

Other exams to stay healthy

All women can take better care of their own health when they know how to look for signs of illness. For example, you or a person you trust can use the information on pages 128 to 130 to check for signs of breast cancer.

There are other tests that can also be done at home by you, family members, or caregivers. But some tests are best done by a health worker in a clinic or hospital.

You can use a general health guide to learn to examine yourself, to learn the signs of different illnesses, or to learn more about the tests usually done in clinics. You can look at information in the books listed below: WWHND = *Where Women Have No Doctor;* MW = *A Book for Midwives;* and WTND = *Where There Is No Doctor.* All these books are available from Hesperian.

Exams that can be done at home:

- abdominal (belly) exam, to check for pain and unusual lumps (WWHND page 534)
- check for problems during pregnancy (MW pages 109 to 114)
- pulse check, to make sure the rhythm feels steady (WTND page 32 to 33)
- blood pressure (WWHND page 532) and temperature (WTND page 30)
- signs of anemia (WTND page 124)
- signs of hepatitis (WTND page 172)
- vision test (WTND page 33)

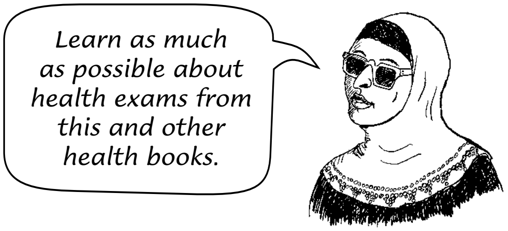
Exams that are done in a clinic or hospital:

- Pap test of the opening of the womb (cervix) to check for cancer
- tests for gonorrhea and chlamydia
- blood test for anemia
- blood test for syphilis
- blood test for HIV
- blood test for hepatitis A, B, or C
- blood test for malaria (especially important for pregnant women)
- urine tests for diabetes
- stool test for worms and parasites
- mucus (sputum) test for TB
- urine or blood test for pregnancy
- urine test for infection of the bladder or kidneys

Working for change

What women with disabilities can do

We can always ask to have breast and pelvic exams when we see a health worker. Also, we can get together as a group and study this and other health books to gather as much information as we can about the exams women should have. Then we can ask local health workers, and also hospital and clinic directors, to make these services available to us. As a group we can tell the Ministry of Health how important these exams are to women with disabilities.



People First makes easy-to-understand health booklets

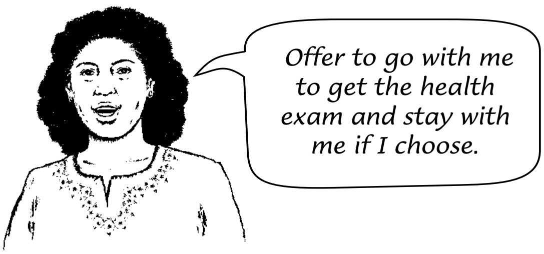
In 1997, several women with learning difficulties started a women's group, called People First Liverpool, so they could learn more about women's health care. They worked with a women's health clinic to produce several booklets that would make health exams easier to understand. To find out more about these booklets, see page 381.

Learning about sexuality and fertility

Kranti and Sabala are health workers in one of the poorest communities in India, where most women, with and without disabilities, are unable to get any health care.

They have taught women how to examine and understand their own bodies. They have looked at problems, such as unusual vaginal discharge, and discussed fertility awareness and sexuality. They have focused on finding remedies to problems that the women can do themselves and that do not require lots of resources.

What families and caregivers can do



Friends and families of women with disabilities can help by talking with disabled women about how important it is for all women to get regular exams. Learn to describe what will happen during the exam and why the results are important to know. Encourage women with disabilities to share what they know about exams and the ways health workers can adapt the exams to their needs.

Also, talk about the barriers in clinics and hospitals that keep women with disabilities from getting exams, and what can be done to make getting exams easier.

As your disabled daughter grows from a girl into a woman, help her to not be afraid of exams. Together, you and your daughter can work to make sure clinics are accessible, health workers are trained, and transportation is available.

Many women are anxious or afraid the first time they have an exam, especially a pelvic exam.

What health workers can do

Health workers can begin by talking with a woman before any exam. Explain what is going to happen, answer her questions, and tell her she can ask questions during the exam too.

Help women with disabilities understand why it is important for them to have health exams, including both pelvic and breast exams. You can explain why these exams are important for all women. Explain that a disabled woman can have these exams, even if it is hard for her to move her arms and legs. Explain that disabled women and their health workers have found many different positions women can use for these exams. Remember that the disabled woman understands her body better than anyone. So ask her to let you know how much she can move and if she will need another person to help.

Women are often taught not to touch their own bodies, and not to complain. Because of this, many women are uncomfortable doing the breast exam, or telling someone they have an unusual pain in the belly. Women are sometimes embarrassed to talk about sex or the sexual parts of the body. So it may be difficult for them to talk about a discharge from the vagina. Health workers can help by encouraging women in their communities to feel comfortable touching their bodies and talking about any problems they may have.

Always speak directly to the disabled woman and ask her about her health problem, even if there is someone else in the room assisting her. Talk with her as you do with other people, even if she has difficulty speaking with you.

When you examine a woman who is blind or cannot see well

For a blind woman, going to an unfamiliar place like a clinic can be confusing. She does not know where things are or where to go. Sometimes people treat blind women roughly or move them around. This is not very respectful.

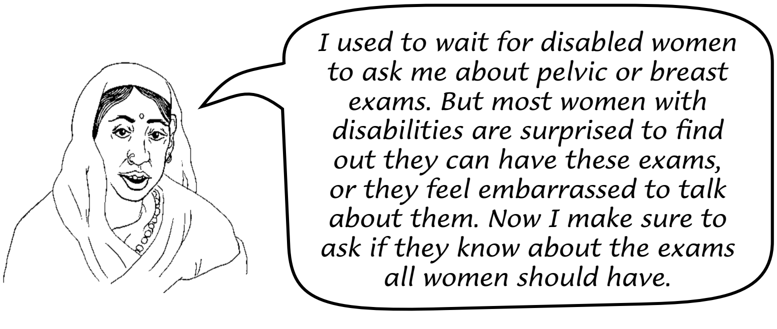
When you guide a blind woman, do not take hold of her arm or hand. Many blind women rely on their hands to "see," by touching. Instead, offer her your arm and let her hold your arm or rest her hand on yours. Tell her where things are and where you are going. Then she will learn how to get around the space better on her own and will feel more comfortable during the exam.

When you examine a woman who is deaf or cannot hear well

For deaf women, going to a clinic can be very frustrating when no one there can use sign language. Sometimes, a deaf woman will bring with her someone who can hear, and who knows her sign language and can interpret for her. If she does, make sure you look at the deaf woman and not at her interpreter when you speak to her and when she speaks to you. This includes when you listen to the interpreter. Look only at the deaf woman. The interpreter is there to help, but the deaf woman is the person who has come to you to receive health care.

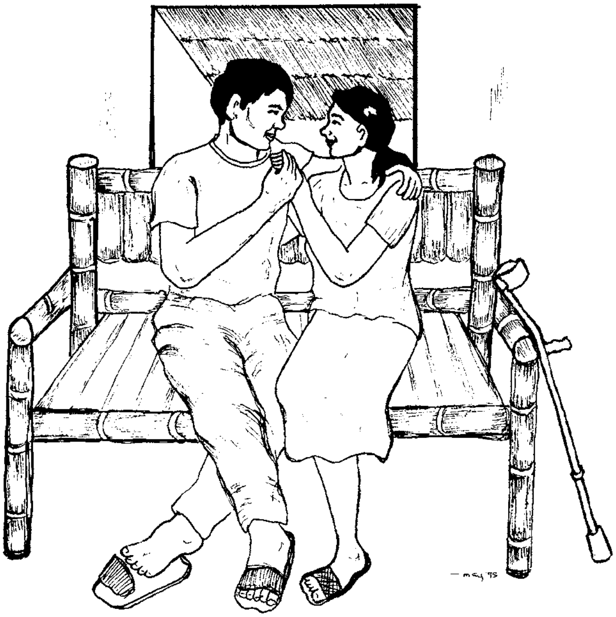
When you examine a woman who has trouble learning or understanding

Women who have trouble learning or understanding should still get information about their health and should help make decisions about their bodies. You may need to take more time to explain things to a woman who has trouble learning. Instead of just asking her if she understands, ask her to tell you in her own words what she has learned.



CHAPTER 7

Sexuality



Sexuality is a natural part of life. For many women, sex is a way to feel pleasure, to express love and desire for their partners, or to become pregnant with the children they hope for. But sexuality is more than having a sexual relation with someone. The way a woman is intimate with her partner, the way she relates to her own body and the way she thinks about herself as a woman are all part of her sexuality.

Women with disabilities can have, want to have, and have the right to have and enjoy close, loving, sexual relationships. Sometimes community attitudes influence or limit how women with disabilities experience their sexuality. If people in a community understand and agree that women with disabilities have the same needs for love, sex, and family as everyone else, then a disabled woman is able to:

- express sexuality in a way that gives her pleasure.
- choose her sexual partner.
- negotiate when and how to have sex.
- choose if and when she becomes pregnant.
- prevent sexually transmitted infections.
- be free from sexual violence, including forced sex.

Harmful beliefs about disabled women's sexuality

Some harmful beliefs about the sexuality of women with disabilities are described below. Many women with disabilities say these negative attitudes and beliefs disable them from enjoying close, loving, sexual relationships. Sometimes these wrong attitudes prevent women from finding faithful spouses and partners who respect and value them.

Harmful belief: *Disabled women's bodies are shameful*

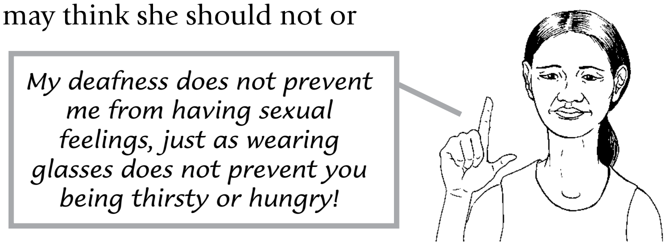
In most communities, women are valued by a standard of physical attractiveness. If a woman looks very different from that standard, people may not think she is 'worthy' to be married or to be a sexual partner.

Gita tells us about "perfect" marriage partners

In India, the problem is that we look for perfect people with perfect bodies. So much importance is given to physical appearance that there's no place for a person who is 'imperfect.' Just take a look at the matrimonial advertisements today—all the men want women who are slim, beautiful, fair-skinned, educated, of good breeding, etcetera. There is also a belief that if a boy marries into a family where one of the family members has a disability, his children will be born with that disability. It happened to me, so I know. There is a very strong gender aspect to this. It is the women who are expected to be perfect in every way. On the other hand, the groom could be disabled, ugly, epileptic, alcoholic, and he's still the perfect groom!

Harmful belief: *Disabled women cannot have sexual feelings*

Like other women, women with disabilities have sexual feelings. But members of her family or community may think she should not or cannot have sexual feelings.



Sometimes, a woman with a disability comes to believe she does not have sexual feelings and no one will be sexually attracted to her or want to have babies with her. If a woman is born with a disability, or if she became disabled as a young child, she may have a hard time believing she is sexually attractive as she grows and develops. If a young woman becomes disabled when she is starting to explore her sexuality, her self-image may be hurt and she may not believe she will ever have a sexual relationship.

Even an older woman who has developed and experienced her sexuality may change how she feels about her body after becoming disabled. She may think she is not sexually attractive anymore or feel sad that sex would be different now. She may not realize she can continue to enjoy sex.

Harmful belief: *Disabled women always want sex*

Some people think women with disabilities—especially women who have difficulty learning or understanding—always want sex. But this is not true.

Just like any group of women, disabled women have a variety of preferences. Some like to have sex often, and some do not like to have much sex at all.

Like any woman, a woman with a disability should be able to choose when she wants to have sex. And every woman must be able to say no to sex she does not want.

Prevent sexual abuse of girls and women who have trouble learning or understanding

Many girls and women with disabilities do not get enough attention or chances to develop the close relations they need.

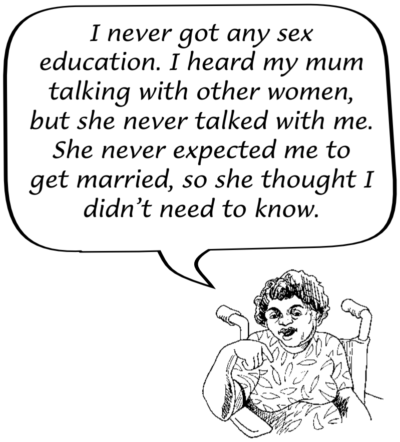
If you are left at home or ignored by your family, you may be lonely and look for a friend or someone else who will pay attention to you. Other people can mistake this need for attention with a desire for sex. Or they may try to take advantage of you, because you are alone or because they believe no one will care if they hurt you.

It can also be hard to express what you really want, especially if you have not been taught about sex. It is very important to learn about your body and about sexuality. Someone you trust can help you protect yourself and make good decisions about sex.

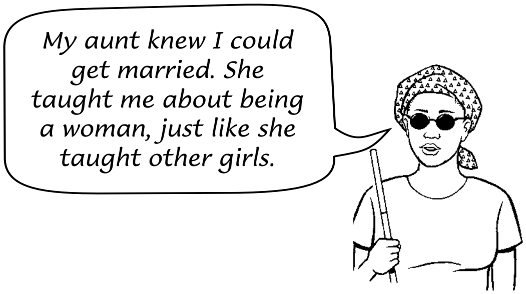
Learning about sexuality

Too many girls with disabilities first learn about sex when someone abuses them or lures them into having sex. Health workers, family, friends, and helpers can include girls and women with disabilities in talks about sexuality and womanhood. Include disabled girls in sex education programs and teach them about sexuality. This can help protect girls from men who want to take advantage of them. For information on sexual abuse, see Chapter 14.

In some communities, girls learn about becoming a woman from a respected elder in their community. In other communities, girls have special ceremonies when they become women. In still other communities, groups of girls get together to share experiences. They learn from each other as they talk about the latest hairstyles and clothes, boyfriends, and their favorite pop stars. Girls with disabilities need to be included in these gatherings.



Girls and women with disabilities need to learn about becoming a woman, about sexuality, and about relationships.



FINDING A LOVING PARTNER

Like other women, you deserve a partner who respects you and cares for you. You deserve a partner who will listen to you and who treats you well. You deserve to find someone who loves you for who you are—a partner who values your strengths and who will help you with your limitations. You deserve a partner who wants your help, your trust, and your love.

Many women who find loving partners say they refused to believe wrong ideas about disability. They gained skills and found ways to contribute to their families. And they learned to respect themselves. When you respect and value yourself, you are more likely to find a partner who respects you too. For information on self-esteem, see pages 62 to 65.

When a girl with a disability learns job skills and gets an education, she is more likely to find a loving partner. A job usually gives her more opportunities and stronger self-esteem. And it is easier for other people to believe that a woman with a disability who has a job is someone who could contribute to the family.

ABUSIVE PARTNERS

Sometimes a woman feels she must settle for any partner, even one who abuses her, or one who may not care for her or provide support for her or her family. Sometimes a woman accepts a person who will help bring money and support her family. Or a woman may trade sex for food or for the help she needs to survive. At other times, it is the woman who works and the man who takes her money. He tells her she should be grateful to have him.

When a woman is valued by her family, community, and herself, she has sexual relationships with people who treat her well. She will not accept partners who hit or abuse her.

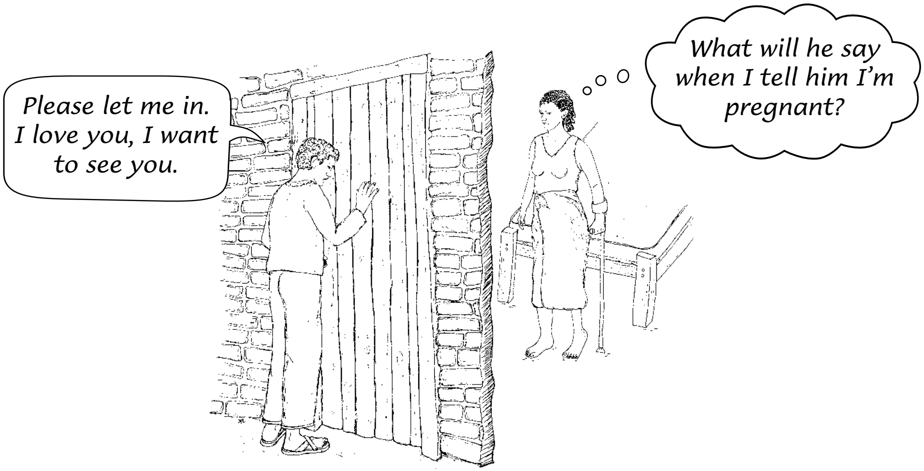
Arranged marriages

In some communities families arrange marriages for their daughters. When this happens, a disabled woman is often treated as less valuable than any other woman. Her family may arrange her marriage with anyone who will accept her, even if her future husband will not treat her well. The woman herself may agree to the marriage because she does not value herself or she thinks no one else will want to marry her.

Sometimes the husband demands a bigger dowry or other payments from the family because the woman has a disability. Or the disabled woman becomes a second wife and is not treated as well as a non-disabled wife. If a man asks for more money or gifts to make up for a woman's disability, it is a sign that he does not respect her as a woman. Often, he will abuse her in other ways as well (see Chapter 14).

Midnight husbands

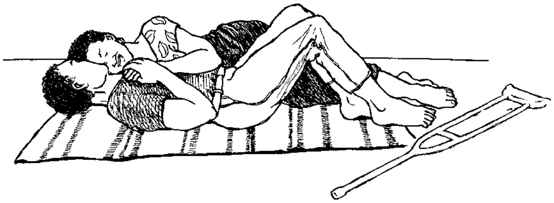
In some countries, a man will visit a disabled woman only at night, to have sex with her. Then, he will leave before morning, while it is still dark. These men are sometimes called midnight husbands. They usually stop visiting the woman if she becomes pregnant, and they almost never give any financial support for the child.



FEELING PLEASURE FROM SEX

It is natural for a woman to want to share sexual pleasure with her partner. But sometimes a woman may not feel pleasure from sex. There can be many reasons for this. If her partner is a man, he may not realize that a woman's body responds differently to sexual touch than a man's body does. The woman may have been taught that women should enjoy sex less than men, or that she should not tell her partner what she likes, whether her partner is a man or a woman.

A woman's disability may make it harder for her to feel pleasure. She may need to find different ways to have sex that feel good—especially if she has only recently become disabled. Just as she takes care of her daily personal hygiene in ways that work for her disability, she can also be sexual in ways that work for her disability to bring her pleasure.



A woman can have sex with a man, a woman, or with herself.

HOW THE BODY RESPONDS TO SEXUAL PLEASURE

Both women and men feel sexual desire, but their bodies respond differently to sexual thoughts and touch. When men and women have sexual thoughts or are touched in a sexual way, they feel excited. More thought and touch make the body more excited. It is easy to see sexual excitement in a man, because his penis gets hard.

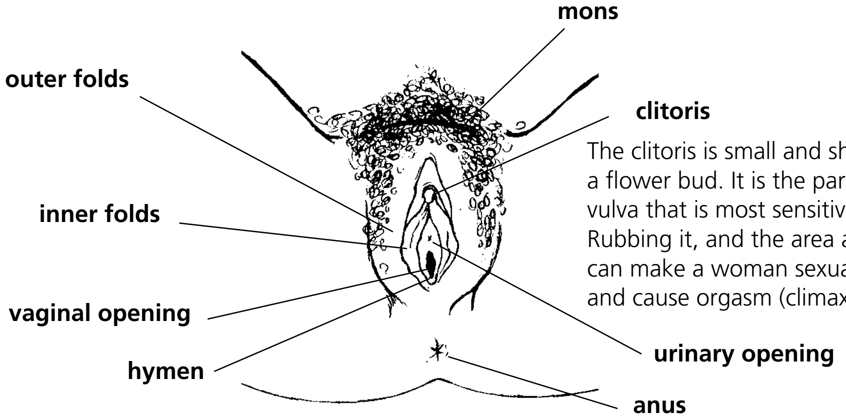
The woman's body also gets excited, but it is harder to see. The clitoris gets hard and may swell, and the labia and walls of the vagina become sensitive to touch. The vagina becomes wet with a clear, slippery fluid. Her nipples too may swell and become sensitive.

If sexual touch and thought continue, sexual tension builds up until she reaches her peak of pleasure and has an orgasm (climax). When orgasm happens, the energy and tension is released throughout the body, especially in the vagina. Generally, after orgasm a woman feels relaxed and full of pleasure.

When a man reaches his peak of pleasure, his penis releases semen, a fluid containing sperm (ejaculation). After orgasm, his body relaxes and his penis becomes soft again.

Touching the clitoris is the most common way a woman reaches orgasm. It may also happen from rubbing inside her vagina, with a penis or with fingers. Her breasts and anus may also be sensitive to touch. It often takes longer for a woman to reach orgasm than a man.

A woman's reproductive parts on the outside



The clitoris is small and shaped like a flower bud. It is the part of the vulva that is most sensitive to touch. Rubbing it, and the area around it, can make a woman sexually excited and cause orgasm (climax).

It is possible for most women to have orgasms, but each woman's body and experience is different. Women who have less feeling in their lower body may need more pressure and firm touching on their clitoris, sometimes at the same time as pressure in their vagina, in order to have orgasm. Even women with spinal cord injury and women who have no feeling in their bodies do have orgasms, though they may feel them differently.

Different women have different places on their bodies where they feel pleasure and like to be touched. Most people think of a woman's genitals or breasts as the "sexual" parts of her body. But a woman's hands, neck, face, and belly can also be sensitive areas that give her pleasure when they are touched. For women who are paralyzed or have a spinal cord injury, these other areas can become so sensitive that they can feel pleasure like orgasms because of being touched.

All the senses—touch, smell, hearing, taste, and sight—can be important and satisfying ways to feel sexual pleasure. Each person, man or woman, with or without a disability, experiences these senses in his or her own way. For a blind woman, touch, smell, and hearing might be most important. For a deaf woman, touch and sight may be the most satisfying parts of sex.

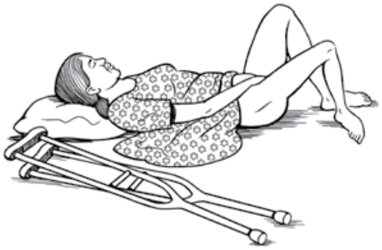
A woman can learn about the sensitive parts of her body and about how to have an orgasm by touching herself, or by letting her partner know what feels good. This will be especially helpful for a woman who has recently become disabled. It may make her partner feel good to know how to please her.

Different ways of having sex

There are many different ways people have sex and share pleasure together. People often think of sex as only between a man and a woman, and only with a penis in a vagina. But there are many other ways people have good sex and express their love with another person. Sex is not just about a person's genitals. Kissing, hugging, and talking are part of having sex. Touching a person's face, hands, back, and neck are also good ways of being sexual. Having oral sex (when one partner—or both—puts his or her mouth on the other's genitals and licks or sucks) may be pleasurable. Touching and rubbing each other's genitals (mutual masturbation) may be another way to give and get sexual enjoyment.

Touching oneself for pleasure (masturbation)

You can touch yourself in a way that gives you sexual pleasure. This is a good way to learn about your body and what kinds of sexual touch feel best. It can also help you feel more confident and good about your own sexuality. Many communities have beliefs that touching oneself is wrong or harmful, so sometimes people feel shame about doing it. But touching yourself does not cause harm or use up sexual desire. It can be a good way to feel pleasure and satisfy desire whether or not you have a partner.



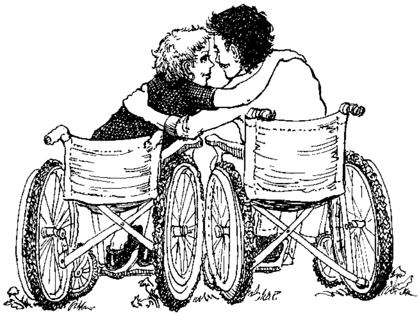
SEX IN A RELATIONSHIP

Most women want to have a close and loving relationship with someone who cares for them. These relationships may be with other disabled persons, or with non-disabled persons. Some disabled women are married, and others are not. Many disabled women have relationships with men, and some have relationships with other women. Some are mothers, others are not.

For women with disabilities and their partners, sex is often more enjoyable for both people if they are willing to experiment and find new ways of doing things. Instead of focusing on things you cannot do (or things that are hard to do), build on things you can do that bring pleasure to both you and your partner.

Talking with your partner

Many women are ashamed to talk about—or feel—their desires. But it is natural to feel desire and to want a relationship that makes you feel good. If you plan to have sex with someone, it will help to talk with that person ahead of time about things like safer sex (see pages 180 to 182) and family planning (see Chapter 9).



Talk with your partner about any limitations in your movement and about ways in which your body may respond to sexual stimulation. Sometimes a partner worries that sex will hurt a woman or be dangerous because of her disability. This can lead to lack of desire. When each partner knows the kind of sexual talk and touch the other likes, they can both enjoy sex more. Each person's desires are different, so the best way to learn what another person likes is to talk with one another and experiment.

Good things to talk about are:

- where it is easier to have sex. For example, on the bed, in your wheelchair, in a chair, or on the floor.
- what position hurts or could be more comfortable.
- how your disability affects how your body works.
- how you can give each other pleasure, and what does not feel good.
- if you tire easily, what times of the day or week you may have the most energy for sex.

If your partner is also your caregiver, it can be helpful to talk about the difference between the time you spend together for care and the time you spend together as sexual partners.

IMPORTANT Whether a woman has a sexual relationship with a man or another woman, it is important to practice safer sex to prevent sexually transmitted infections, including HIV. If you or your partner have had sexual relations with someone else, it is also important to go for an HIV test before having sex with your partner. For more information, see page 172. Also, if you want to have sex but do not want to get pregnant, see Chapter 9 for information about family planning, and page 205 about emergency contraception.

Sexuality for women who become disabled

A woman who becomes disabled due to an accident or illness may find that her sexual feelings change. Some women have fewer sexual feelings or are not interested in sex for a while. Sometimes women think they are no longer able to experience pleasure or enjoy sex. Every woman needs information about how her disability affects her sexuality. And if she has a partner, they both need information about how sexuality can be affected by disability.

If you were in a sexual relationship before you became disabled, you may be afraid to try having sex again. You may be concerned that your partner will not find you sexually attractive anymore. Or both you and your partner may be concerned that you will not be able to satisfy each other any more. It is helpful for you both to talk about your feelings and the changes you may need to make. The way you have sex may be different, but like most other couples, you will find ways to have sex and please each other. This is especially true if you had a trusting relationship and good communication before the disability.

PRIVACY

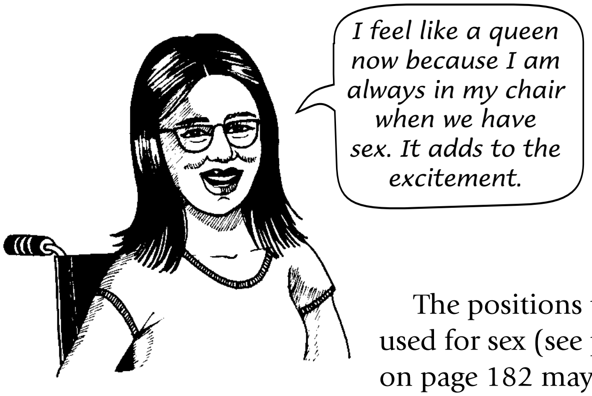
Finding a good time and place to have sex can be hard for women with disabilities, especially if they need someone else's help to get ready for sex. It can also be hard for women who live with their parents or other relatives.

There is no easy answer to this problem, especially if your family or caregivers do not think you should have sex. Sometimes, it can help to talk with the people who are helping you. Or you can try talking with another person you trust, who can then talk to your family or helpers. It is also helpful to talk with other women with disabilities, and to share experiences.

Some people find ways to manage on their own. For example, a woman can have sex with her partner while she is in her wheelchair. Then she does not need another person to help move her to a bed. And some people find that their helpers are sensitive to their needs and want to support their relationships.

FINDING A COMFORTABLE POSITION

If you have limited movement you may have to experiment to find a comfortable position to have sex. Women with cerebral palsy, weak muscles, tight or spastic muscles, or arthritis, and women whose disability causes pain or weakness, may need help from a partner to find a comfortable position. It may help to use pillows or rolled-up cloth to support your legs or hips. Also, if a partner's weight causes pain, try a position where you both lie on your sides, or sit in a chair together. Kissing and touching may be easy to do, but having sex with a penis in the vagina or anus may be difficult. Oral sex is easier if both people can get their bodies into the right position.

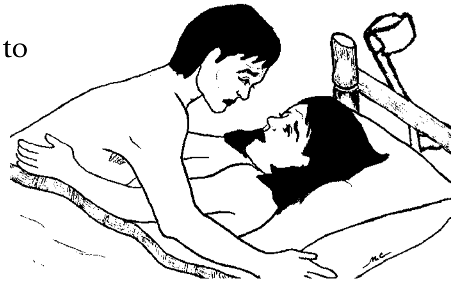


If you are paralyzed, you probably know how much you can move and what body positions are possible for you. Depending on how much of your body is paralyzed, it may be necessary to ask a partner or trusted caregiver for assistance.

The positions used for having a pelvic exam can also be used for sex (see page 133). And the "safer sex" positions listed on page 182 may also be helpful.

Possible problems during sex

Pain during sex



Sex should not hurt. Sometimes the pain is due to a woman's disability, but often there are other causes. Sometimes a woman feels pain when a man's penis, or a partner's fingers or hand, enters her vagina. This can happen when:

- her partner enters her too soon, before she is relaxed and her vagina is wet enough.
- she feels guilt or shame, or does not want to have sex.
- she has an infection or growth in her vagina or lower belly.
- she has had her genitals cut or stitched together (female genital cutting or infibulation).

Some women with tight, spastic muscles, and some women with spinal cord injury, may find it painful for anything to enter the vagina. If so, try to find another way to have sex that brings pleasure for both partners.

Dry vagina

Sex can be painful if the vagina is too dry. When a woman is sexually excited, her vagina usually becomes wet. This is natural. But sometimes a woman's disability makes it less likely for her vagina to become wet. This can happen to many women, but especially to some women with rheumatoid arthritis and spinal cord injury.

A common way to make the vagina wetter is to take more time with sex, so that the body makes more of its own wetness. You can also use a lubricant to make the vagina slippery so the skin will not tear.

IMPORTANT If a latex condom is used during sex, do not use oil, petroleum jelly *(Vaseline)*, butter, mineral oil, or lotion to make the vagina wetter. These can make the condom break. Use a water-based lubricant, such as *KY Jelly*, with a condom.

In some places, people prefer to have sex when the vagina is very dry. So some women put herbs or powders in their vaginas, or wash out (douche) their vaginas before sex. But when the vagina is dry, it can become irritated during sex, making it more likely to become infected with HIV and other STIs.

Painful muscles and joints

Sometimes a disability, such as arthritis, will cause a woman to have pain when she moves around more than usual. If this happens to you, heat can help ease pain. Use cloths soaked in warm water on painful or swollen joints, or take a warm bath before you have sex. This can help your body relax so you enjoy sex more. If you use medicines to help your pain, try taking them at a time of day that will help you feel good when you are getting ready to have sex.

Muscle spasms

When a woman with a disability such as cerebral palsy or a paralysis becomes sexually excited, her muscles may suddenly get tight (muscle spasms). A muscle spasm is not dangerous or harmful, unless it goes on for a long time. You do not need to stop having sex. Sometimes, pressing gently on the tight muscle can help ease the spasm. Sometimes, gently stretching the muscle can also ease the spasm. But do not pull on the muscle or try to break the spasm. If you take medicine to prevent muscle spasms, it may help to take the medicine before having sex.

Bladder and bowel care

It is best to pass stool and urine before having sex. Also, if a leg bag is used to collect urine from a catheter, make sure it is empty. To avoid bladder and bowel accidents during sex, it may help to not drink or eat for a short while before sex.

If a urine catheter stays in all the time, it can be taped or tied out of the way during sex. Make sure the tube does not get bent or twisted. It is also possible to take out a fixed (Foley) catheter for up to 4 hours. But before you do this, great care must be taken to prevent infection (see pages 102 to 104). Usually, it is best to leave the catheter in during sex.

If a woman removes her catheter during sex, she will likely pass urine during sex. Because of the catheter, her bladder is not used to holding urine inside and urine will leak out. There is also a chance she will pass stool during sex. Keep a cloth or towel close by to catch the urine or stool if this does happen.

It can help to discuss the possibility that this may happen ahead of time with your partner. This is a difficult subject, and every woman will talk about it differently. Some women treat it like any other part of life. Other women use humor and find a way to laugh about it.

IMPORTANT A condom can tear or break when it rubs against a catheter. To help prevent this, use a water-based lubrication jelly on the outside of the condom or inside the vagina.

IMPORTANT During sex, some women with a spinal cord injury can get sudden high blood pressure with pounding headaches, flushed or red skin, or a fast heartbeat. This is called dysreflexia and can be a serious health problem. To help prevent this, make sure you pass urine and stool before having sex. For more information about dysreflexia, see pages 117 to 119.

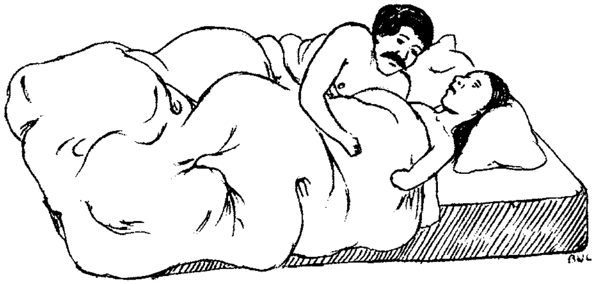
Feeling too tired

Your disability may sometimes make you feel tired for much of the day. Or you may take medications that make you feel tired. This can make you less interested in having sex. Try to have sex at the time of day when you feel the least tired. If that is not practical, ask a health worker if it is safe to take your medicine at a different time of day.

If you get tired easily, or your muscles are not very strong, you may also find it easier to have sex more slowly or gently, because it will take less energy.

If you are feeling too tired for passionate sex, you can still find ways to give your partner pleasure, and you can ask your partner to caress you. Often, a loving touch can reduce a woman's pain and help her sleep better. It can also bring great joy to her and to her partner as well.

Lack of desire



Many things can cause a woman to feel less desire or pleasure from sex. Some of these things may come from a woman's disability, and some may come from other reasons. You may feel less desire if:

- you are tired from hard work, from not eating enough, from a new baby, or from your disability.
- you have a partner you do not like or who treats you badly.
- your disability causes you pain and it hurts to move.
- you feel badly about your body or ashamed about your disability.
- you are depressed or feel very sad most of the time.
- you have been hurt or forced by someone in the past to have sex.
- you are afraid of becoming pregnant or of getting a sexual infection.

When a woman lacks desire, her body makes less of its natural wetness, and she may need to use lubrication so that sex is not painful (see page 151).

Sex after sexual abuse and rape

If a woman has been sexually abused or raped, it usually takes a long time for her to feel good again about her body and about sex. Long after the physical signs of the violence are gone, the woman carries emotional hurts and bad memories. For more information about sex after sexual abuse and rape, see page 305.

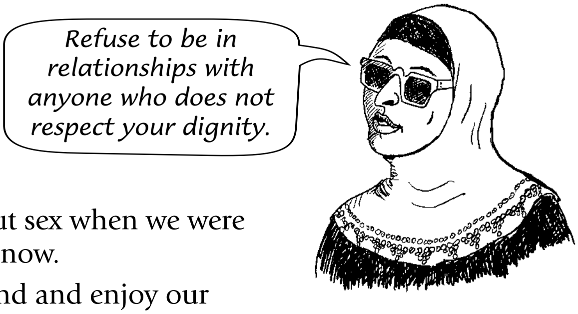
If you lack desire for sex, try imagining the things that give you sexual pleasure. Sexual thoughts and fantasies can help you see yourself as a woman who has desires. They can also help you build excitement, which can make your vagina wet and help you enjoy sex more. Fantasy can be something you think about alone or something you share with your partner.

Working for change

Changing community beliefs and attitudes about sexuality and the right to sex for women with disabilities can take a long time. But over time, they can change.

It is important for a woman with a disability to feel good about herself. A woman who values herself will be more likely to expect a partner to respect her.

What disabled women can do



- Educate ourselves about sexuality and our own feelings.
- Talk with other disabled women or other women we trust to learn more about sexuality. Even if we did not learn about sex when we were growing up, we can always learn more now.
- Advise each other on ways to understand and enjoy our sexuality.
- Form or join a group with other disabled women to support and value each other's sexual and family life.
- Advocate to include disabled women in all education about sexuality.
- Advocate for respect for the sexual needs of all women.
- Find ways to express our sexuality and celebrate who we are as women.

Disabled women in our community have been coming together to empower ourselves as women. Together, we are finding ways to express our femininity and sexuality. Some of us wear flowers in our hair or a bindi on our forehead. Sometimes we decorate our hands and feet with intricate henna patterns, wear anklets and jewelry, or have a ritual oil bath. All these things have helped us explore our sexuality and feel good about our bodies. We are learning to see ourselves as the kind of women we want to become.

—A group of women with disabilities from Tamil Nadu, India

What families and caregivers can do

- Treat a girl with a disability the same way other children are treated. This will help her grow up feeling good about herself, her body, and her feelings. When she grows up, it will be easier for her to have a loving, respectful relationship with her partner.
- Support a girl during her teenage years when she is changing from a girl to a woman. If a girl with a disability gets good information about sexuality, is allowed to make herself look attractive, and does not face discrimination about the way she looks, she will feel good about her body and her sexuality, and her self-esteem will grow strong.
- Make sure girls and women with disabilities are included in talks and ceremonies about sexuality and womanhood.
- Support women with disabilities in their decisions about potential spouses and loving partners.
- Do not arrange marriages for a disabled woman if the husband or the family expects extra money or presents to “make up for” the woman’s disability.
- Encourage people in the community to see women with disabilities as women first, with the same sexual needs as all women, and to treat them with respect.

It is normal for all people to want loving relationships. A woman with a disability is no different.

What the community can do

Train women with disabilities as health workers to provide sex education for other girls and women.

- Make sure women with disabilities are included and have important roles in community ceremonies about sexuality and womanhood.
- Advocate for respect for the sexuality of all women and girls.
- Adapt sex education programs to include girls and women with disabilities. For example, let blind women feel a condom and learn how to use one by touch. Use pictures and models to make learning easier for deaf women and women who have difficulty reading or understanding.
- Watch out for disabled girls and women, especially those whose disabilities affect their learning and understanding. They are often more vulnerable to sexual abuse. Women's safety is the whole community's responsibility. For more information about helping women who have been abused, see Chapter 14.

To the health worker:

Many women with disabilities have questions about sexuality. But they are often afraid or ashamed to ask. As a health worker, you can help by learning more about ways disabled women can be sexual and by talking with them about their concerns and hopes.

You can work together with disabled women to organize events or programs that reach out to women and girls who have disabilities. In one community, a group of young disabled women invites a health worker and woman's health doctor to participate in a yearly group conversation about sexual health. The women talk with one another and ask questions about sexuality and women's health.

You can also help girls and young women with disabilities get good information about how their bodies are changing. You can explain what it means to be a woman, and answer their questions about relationships and sexuality. As a health worker, you can work to change the beliefs and attitudes that make it harder for girls and women with disabilities to feel good about their bodies and sexuality.

CHAPTER 8

Sexual health:

Preventing sexually transmitted infections including HIV/AIDS

Sexual health is a physical and emotional state of well-being that allows us to enjoy and act on our sexual feelings. We can keep ourselves sexually healthy by learning about our bodies and what gives us pleasure, and by reducing the risk of unwanted pregnancy and infections passed through sex.

In many communities, harmful beliefs about what it means to be a woman can make it hard for women to have healthy sex. Because women often have little control over decisions about sex, and often cannot refuse sex, millions of women around the world become infected every year with HIV and other sexually transmitted infections (STIs).

People sometimes think a woman who has a disability cannot get an infection. This is not true. Women with disabilities can get the same infections non-disabled women get.

In fact girls and women with disabilities are more at risk for getting STIs than women who are not disabled. Not only do they find it difficult to get information about sexual health, they may have less control over how and who they have sex with. This makes them more vulnerable to being taken advantage of sexually, and more likely to get a sexually transmitted infection, including HIV. For more information about sexual abuse of women with disabilities, see Chapter 14.

This chapter has information about HIV/AIDS and other sexually transmitted infections, and how to prevent them. With good information, women can take steps to protect themselves and enjoy healthy sex.

What are sexually transmitted infections?

Sexually Transmitted Infections, or STIs, are infections passed from one person to another during sex. STIs can be passed from one person to another through any type of sex. It can be penis to vagina sex, or penis to anus sex, or oral sex (mouth to penis or mouth to vagina). Sometimes, STIs can be spread just by rubbing an infected penis or vagina against another person's genitals.

UNTREATED INFECTIONS ARE DANGEROUS

Many STIs can be treated with medicine. If they are not treated early, STIs can cause: infertility in both men and women; babies born too early, too small, or blind; pregnancy in the tubes; lasting pain in the belly (lower abdomen); cancer of the opening of the cervix; death from severe infection.

SIGNS OF AN STI

You may have an STI if you have one or more of the following signs:

- unusual discharge from the vagina
- unusual smell from the vagina
- pain or an unusual feeling in your belly (lower abdomen), especially when having sex with the penis in the vagina
- itchiness, a rash, a bump, or a sore on your genitals

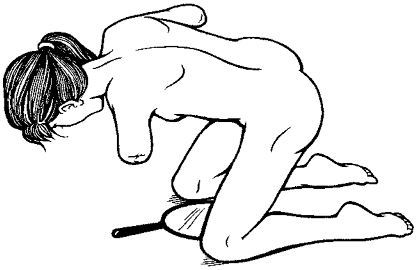
Depending on your disability, it may be difficult for you to tell if you have these signs. You may need to ask someone you trust to help you check for signs of an STI.

Changes in discharge

It is normal to have a small amount of wetness or discharge in the vagina. This is the natural way the vagina cleans and protects itself. The discharge changes during your monthly cycle. It becomes thicker, very clear, and slippery about 14 days before your bleeding starts. Other changes in the amount, color, or smell of the discharge from your vagina sometimes are signs of an infection, but it can be difficult to tell from your discharge what kind of infection you have. For information about discharge from infections that are not sexually transmitted (yeast and bacterial vaginosis), see pages 111 to 113.

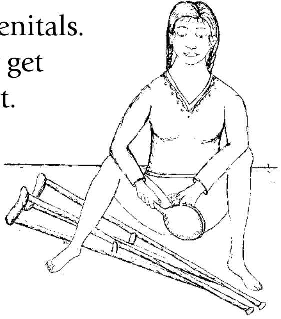
How to check for signs of STIs

If you are blind: When you wash your genitals, use your fingers to feel for any unusual discharge, lumps or soreness. Do this once a week. If you do it every day, it will be difficult for you to notice any changes.



If you have little or no hand control: If you are unable to use your fingers to feel your genitals for any changes, try to use a mirror to look for them instead. If you cannot hold the mirror, put it on the floor and crouch over it.

If you have a spinal cord injury: If you can feel and look at your genitals, do this once a week while you bathe. If you are unable to do this yourself, ask someone you trust to help you. You will probably not be able to feel if there is any pain in your belly or itching in your genitals. But if you have an STI and it does not get treated early, you may get dysreflexia. This is dangerous. See pages 117 to 119 for treatment.



If you have limited or no movement in your legs: If possible, find a position in which you can either feel your genitals with your fingers while you wash, or use a mirror to look at them. If necessary, ask someone you trust to hold your legs steady.

TRICHOMONAS

Trichomonas is a very uncomfortable and itchy STI. Men usually do not have any signs, but they can carry it in the penis and pass it to a woman during sex.

Signs:

- gray or yellow, bubbly discharge
- bad-smelling discharge
- red and itchy genital area and vagina
- pain or burning when you pass urine

If you are able to get tested and know for certain you have trichomonas, take one of the following medicines. If you cannot get tested, it is best to take the medicines listed on page 162 because the infection may be caused by other STIs.

Medicines for trichomonas

Medicine	How much to take	When to take
metronidazole	400 to 500 mg	by mouth, 2 times a day for 7 days
or metronidazole (avoid metronidazole in the first 3 months of pregnancy)	2 grams (2000 mg)	by mouth in a single dose
or clindamycin	300 mg	by mouth, 2 times a day for 7 days

IMPORTANT Do not drink alcohol during the time you are taking metronidazole. For more information about metronidazole, see page 347. Your partner should also be treated with the same medicine.

GONORRHEA (CLAP, GONO, VD) AND CHLAMYDIA

Gonorrhea and chlamydia are both serious infections. They are easy to cure if they are treated early. If not, they can cause severe infection and infertility in both women and men. The signs in a man usually begin 2 to 5 days after sex with an infected person. In a woman, the signs may not begin for weeks or even months. But both men and women can be infected and have no signs. Even a person with no signs can still give both gonorrhea and chlamydia to another person.

The most common signs in a woman are:

- yellow or green discharge from the vagina or anus.
- pain or burning when passing urine.
- fever.
- pain in the lower belly.
- pain or bleeding during sex.
- no signs at all.

The most common signs in a man are:

- discharge from the penis.
- pain or burning when passing urine.
- pain or swelling of the balls (testicles).
- no signs at all.

Treatment:

If you have any of the signs for gonorrhea or chlamydia, and you have had unsafe sex with someone you think may have an infection, try to get tested to see which infection you have so you will know which medicine to take.

Medicines for gonorrhea

Medicine	How much to take	When to take
cefixime	400 mg	by mouth, all at once

Medicines for chlamydia

Medicine	How much to take	When to take
azithromycin	1 g	by mouth, all at once
or doxycycline	100 mg	2 times a day for 7 days
or tetracycline	500 mg	by mouth, 4 times a day for 7 days
or erythromycin	500 mg	by mouth, 4 times a day for 7 days

Unfortunately, tests are not always available, so it is often best to take medicines for more than one infection. A person can have several infections at the same time, caused not only by gonorrhea and chlamydia, but also by trichomonas (see page 159), and bacterial vaginosis (see page 113). The medicines listed in the chart on page 162 will treat all these infections.

PELVIC INFLAMMATORY DISEASE

Pelvic inflammatory disease (PID) is the name for an infection of any of the reproductive parts in a woman's lower abdomen. It is often called a 'pelvic infection.' A pelvic infection can develop from an STI that was not cured, especially gonorrhea or chlamydia.

You may have one or more of these signs:

- pain in the lower belly
- high fever
- you feel very ill and weak
- green or yellow bad-smelling discharge from the vagina
- pain or bleeding during vaginal sex

Treatment:

Because this infection is usually caused by a mix of germs, more than one medicine must be used to cure it. Take the medicines listed in the chart on page 162.

Medicines for gonorrhea, chlamydia, trichomonas, bacterial vaginosis, and PID

If you have signs of these infections, and you cannot get tested to know which infection or infections you have, take a combination of these medicines.

Medicine	How much to take	When and how to take
cefixime	400 mg	by mouth in a single dose
AND		
azithromycin	1 gram (1000 mg)	by mouth as a single dose
or erythromycin	500 mg	by mouth, 4 times a day for 7 days
or amoxycillin	500 mg	by mouth, 3 times a day for 7 days
or doxycycline	100 mg	by mouth, 2 times a day for 7 days
(do not use doxycycline if you are pregnant or breastfeeding)		
or tetracycline	500 mg	by mouth, 4 times a day for 7 days
(do not use tetracycline if you are pregnant or breastfeeding)		
AND		
metronidazole	400 to 500 mg	by mouth, 2 times a day for 7 days
	or 2 grams (2000 mg)	by mouth, in a single dose
(avoid metronidazole in the first 3 months of pregnancy; instead use both clindamycin and tinidazole)		
OR		
clindamycin	300 mg	by mouth, 2 times a day for 7 days
	or 5 grams of 2% cream (one full applicator)	in the vagina at bedtime for 7 days
and tinidazole	2 grams (2000 mg)	by mouth in a single dose
	or 500 mg	by mouth, 2 times a day for 5 days

IMPORTANT *Do not drink alcohol during the time you are taking metronidazole or tinidazole. Your partner should be treated with the same medicines.*

SORES ON THE GENITALS (GENITAL ULCERS)

Most sores or ulcers on the genitals are sexually transmitted, but pressure sores, boils or injuries can also cause sores on the genitals. Any genital sores should be kept clean by washing with soap and clean water. Dry them carefully. Wash any cloth you dry them with before you or anyone else uses it again.

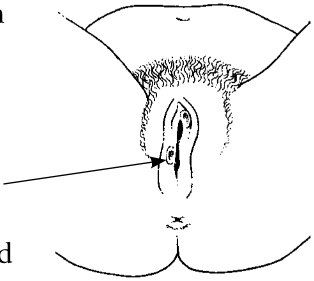
WARNING! When a person has a sore on the genitals, it is easy to get other infections through the sores—especially HIV and hepatitis B. To prevent infection, avoid sex until the sores heal.

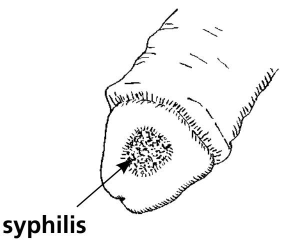
Syphilis

Syphilis is a serious STI that affects the whole body. It can last for many years, getting worse and worse. Syphilis can be cured if it is treated early.

Signs:

1. The first sign is a small, **painless** sore that can look like a pimple, blister, a flat wet wart, or an open sore. The sore lasts for only a few days or weeks and then goes away by itself. But the disease continues to spread throughout the body.





2. Weeks or months later, the infected person may get a sore throat, mild fever, mouth sores, swollen joints, or a rash—especially on the palms of the hands and soles of the feet. During this time the infected person can infect others.
3. All of these signs usually go away by themselves, but the disease continues. Without treatment, syphilis can cause heart disease, paralysis, mental illness, and death.

Treatment:

For a complete cure of syphilis, the full treatment is essential.

- **If signs have been present less than 1 year,** inject 2.4 million Units of benzathine penicillin all at once—put half the dose into each buttock. Persons allergic to penicillin can take tetracycline, 500 mg, 4 times each day for 15 days.
- **If signs have been present more than 1 year,** inject 2.4 million Units of benzathine penicillin—half in each buttock—once a week for 3 weeks (a total of 7.2 million Units). If allergic to penicillin, take tetracycline, 500 mg, 4 times each day for 30 days.

NOTE Pregnant or breastfeeding women who are allergic to penicillin can take erythromycin (see page 343). Your partner should also be treated.

Pregnancy and syphilis

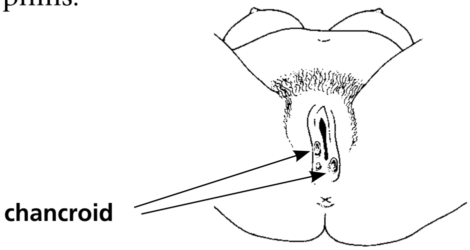
A pregnant woman can pass syphilis to her unborn baby, which can cause it to be born too early, deformed, or dead. You can prevent this by getting a blood test and treatment during pregnancy. If you and your partner have blood tests that show you have syphilis, you should both be treated with benzathine penicillin, 2.4 million Units, by injection (IM), once a week for 3 weeks.

Chancroid

Chancroid is an STI that causes sores on the genitals. It can be cured with medicine if it is treated early. It is easily confused with syphilis.

Signs:

- one or more soft, **painful** sores on the genitals or anus that bleed easily
- enlarged, painful glands (bubos) may develop in the groin
- slight fever



Medicines for Chancroid

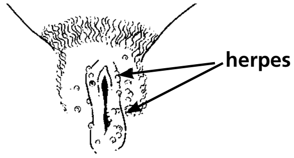
Medicine	How much to take	When to take
azithromycin	1g	by mouth, all at once
or erythromycin	500 mg	by mouth, 4 times a day for 7 days
or ciprofloxacin (If you are pregnant, do not take ciprofloxacin.)	500 mg	by mouth, 2 times a day for 3 days

NOTE If you cannot tell for certain that your sores are caused by chancroid, or if you cannot get tested, it is probably best to also take the medicine for syphilis (see page 163).

GENITAL HERPES

Genital herpes is an STI caused by a virus. Small blisters appear on the genitals. Genital herpes is spread from person to person during sex. Occasionally genital herpes appears on the mouth from oral sex. (This is different from the kind of herpes that commonly occurs on the mouth, which is not spread by sex.)

The herpes virus produces sores that can come and go for months or years. There is no cure for herpes, but there is treatment that can make you feel better.



Signs:

- a tingling, itching, or hurting feeling of the skin in the genital area or thighs
- small painful blisters that can look like drops of water on the skin. They burst and form painful, open sores.

The first time you get herpes sores, they can last for 3 weeks or more. You can have fever, headaches, body aches, chills, and swollen lymph nodes in the groin. Though the sores go away, the infection does not. But the next outbreak will be milder.

Treatment: Use acyclovir, see page 333.

Pregnancy and herpes

A pregnant woman who is infected with herpes and has sores at the time of the birth can pass the virus to her baby. This can cause dangerous problems for the baby, especially if it is the mother's first outbreak. The risk to the baby is less if the mother has had herpes before.

If you have herpes sores, try to give birth in a hospital. Doctors may do an operation to get the baby out (a c-section, see page 244) so the baby does not get infected from the sores, or may give the baby medicines when it is born.

GENITAL WARTS (HPV)

Genital warts are caused by a virus called human papilloma virus (HPV). They look like warts on other parts of the body. It is possible to have HPV and not know it, especially when the warts are inside the vagina or inside the tip of the penis. And some people with HPV never get warts. Warts may go away without treatment, but this can take a long time. Usually they continue to get worse and should be treated. HPV is passed very easily from one person to another during sex.

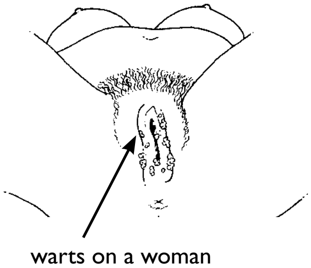
IMPORTANT If warts on the genitals are not treated, some can cause cancer of the cervix. If you have genital warts, try to have a Pap test (see page 131) to see if your cervix has any signs of HPV or cancer.

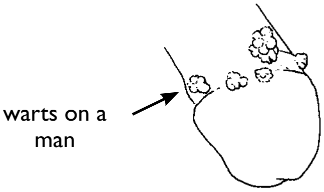
Signs of HPV:

- itching
- painless, whitish or brownish bumps that have a rough surface

In women, these bumps usually grow on the folds of skin around the opening to the vagina, inside the vagina, and around the anus.

In men, they usually grow on the penis or just inside it, and on the balls (scrotum), or the anus.





Treatment:

These products to treat warts can usually be found in a pharmacy or chemist's shop.

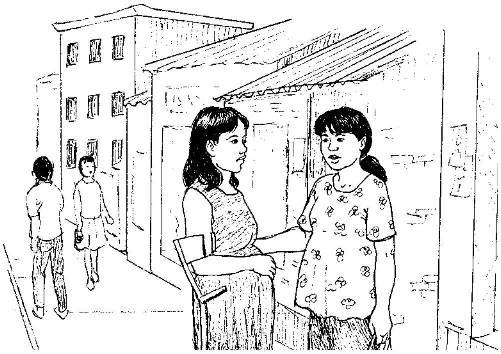
1. Put some petroleum jelly (*Vaseline*) or other greasy ointment on the skin around each wart to protect the healthy skin.
2. With a very small stick or toothpick, carefully put on a very small amount of 80% to 90% trichloroacetic acid (TCA) or bichloracetic acid (BCA) solution on the wart (see page 354). Leave the acid on until the wart turns white.
3. Wash the acid off after 2 hours or sooner if the burning feeling is very painful.

OR

Apply 20% podophyllin solution in the same way until the wart turns brown (see page 351). Podophyllin must be washed off 6 hours later.

The acid should burn the wart off, leaving a painful sore where the wart used to be. Keep the sores clean and dry. The sores should heal within a week or two. Watch them to make sure they do not get infected. Try not to have sex until they are gone, but if you must have sex, your partner should use a condom.

Several treatments are usually necessary to get rid of all the warts (it does not matter which solution you use). You can repeat the treatment after one week. Try not to get acid on a sore where a wart used to be. If there is too much irritation, wait longer before the next treatment.



Pregnancy and warts

Do not use podophyllin while you are pregnant. It will be absorbed into your skin and can harm the developing baby. Warts can spread and bleed during pregnancy, but the warts themselves will not harm the baby. Sometimes the warts will get much smaller after pregnancy .

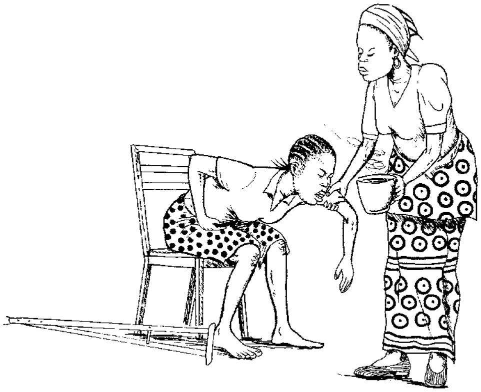
HEPATITIS (JAUNDICE, YELLOW EYES)

Hepatitis is an inflammation of the liver usually caused by a virus, but also by bacteria, alcohol, or chemical poisoning. There are 3 major types of hepatitis (A, B, and C), and it can spread from person to person whether or not there are signs of the disease.

Hepatitis A is usually mild in small children and often more serious in older persons and pregnant women.

Hepatitis B is dangerous for everyone. It can lead to permanent damage to the liver (cirrhosis), liver cancer, and even death.

Hepatitis C is also very dangerous and can lead to permanent liver infections. Hepatitis C is a major cause of death for people with HIV/ AIDS.



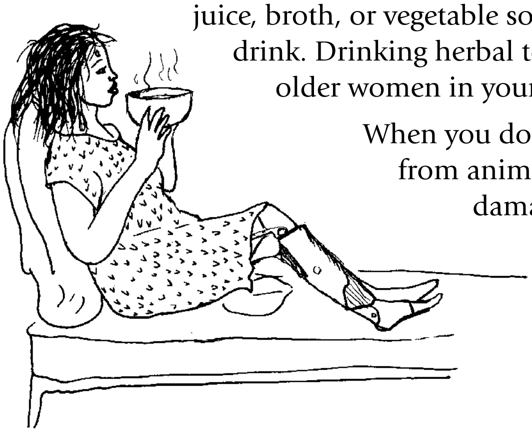
If you are pregnant and have signs of hepatitis, seek medical advice.

Signs:

- tired and weak feeling
- no appetite
- yellow eyes and/or skin (especially the palms of the hands and soles of the feet)
- pain in the belly or nausea
- dark-colored urine, and stools that look whitish
- sometimes a fever
- no signs at all

Treatment:

There is no medicine that will help. In fact, taking some medicines can hurt your liver even more.



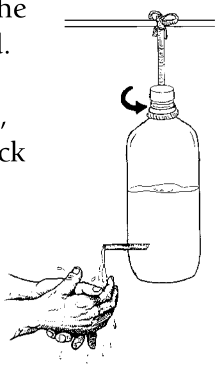
Rest and drink lots of liquids. If you just do not want to eat, try drinking fruit juice, broth, or vegetable soup. To control vomiting, sip a cola or ginger drink. Drinking herbal teas like chamomile can also help. Ask the older women in your community about which herbs work best.

When you do feel like eating, do not eat a lot of protein from animals (meat, fish, eggs) because it makes the damaged liver work too hard. Also avoid food cooked with animal fat or vegetable oil. Instead, eat mainly fruits and fresh or steamed vegetables and only a little protein. Do not drink any alcohol for at least 6 months.

Prevention:

The hepatitis B and C viruses can both pass from person to person through sex, injections with non-sterile needles, transfusions of infected blood, and from mother to baby at birth. To prevent passing hepatitis to others, always use a condom during sex (see pages 181 to 182, and pages 189 to 192) and make sure needles, syringes, and tools used for cutting or piercing the skin (such as for tattoos, circumcision, scarring, female genital cutting) are always boiled before use.

The hepatitis A virus passes from the stool of one person to the mouth of another person by way of contaminated water or food. To prevent others from getting sick, it is important to make sure the sick person's stools go down a latrine or toliet, or are buried, and to make sure the sick person is very clean. Everyone—the sick person, family members, caregivers—must try to stay clean and wash their hands often.



Vaccines are now available for hepatitis A and B, but they may be expensive or may not be available everywhere. If you are able to get a vaccination while you are pregnant, it will prevent the virus from passing from you to the baby.

WHAT TO DO IF YOU HAVE AN STI

If you or your partner have signs of an STI:

- start treatment right away. Early treatment will protect you from more serious problems later on, and will prevent the spread of infection to others.
- get tested, if possible. Go to a clinic or health center where you can be tested to know which STI you have. This way you will not have to take medicines you do not need. If it is not possible to get tested, you may have to take several medicines. Try to talk with an experienced health worker about treatment.
- help your partner get treated at the same time you do. If he does not, he will infect you again if you have sex. Urge him to take the proper medicine or to see a health worker.
- make sure you take **all** the medicine, even if your signs start to go away. Do not buy only part of the medicine. You (or your partner) will not be cured until you have taken all the required medicine (see page 327).
- practice safer sex. If you do not protect yourself, you can always get another STI (see pages 180 to 182).

What is HIV/AIDS?

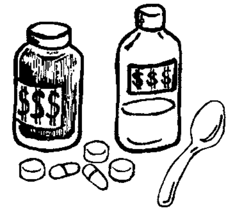
HIV (Human Immunodeficiency Virus) is a very small germ you cannot see that weakens the immune system, the part of the body that fights off infection and disease. HIV is most often spread from one person to another during sex. If a man passes HIV to a pregnant woman, or if a pregnant woman is already infected with HIV, the virus can also pass to a baby during pregnancy, during the birth, or during breastfeeding. For more information about the ways someone can and cannot be infected with HIV, see pages 170 to 171.

AIDS (Acquired Immune Deficiency Syndrome) is a disease that develops some time after a person has been infected with HIV. A person is said to have AIDS when he or she starts to get many common health problems more often than usual. Some signs of AIDS are losing weight, sores that will not heal, a bad cough, sweating at night, diarrhea, skin rashes, a fever, discharge from the vagina, or feeling very tired all the time. But all of these problems can have other causes. You cannot be sure a person has HIV/AIDS without a special blood test—see page 172.

Because the immune system of a person infected with HIV gets weaker and weaker with each illness, the person's body is less able to fight illness and recover. This goes on until the person's body is too weak to survive, and he or she dies. Anyone can get HIV/AIDS, both persons with a disability and persons without a disability.

Some people die from AIDS very quickly after they become infected with HIV. But for many people, several years can pass before they get sick with AIDS. This means that a person can be infected with HIV and not know because he or she feels healthy. Regardless of how they feel, they can pass HIV to another person as soon as they are infected. The only way to know if you are infected is to have your blood tested. This can be done at many clinics and hospitals.

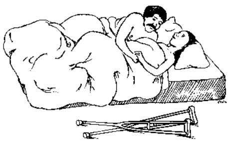
Medicines called ARVs (antiretrovirals) can help people with HIV/AIDS live longer and healthier lives. These medicines do not kill HIV or cure AIDS, but they make the sickness easier to live with. For pregnant women, ARV treatment can prevent HIV from passing from the mother to the baby. Unfortunately, ARVs can be expensive and may be difficult to get in some countries. For more information about ARV medicines, see page 176.



HOW HIV/AIDS IS SPREAD

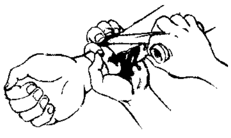
HIV, the virus that causes AIDS, lives in body fluids such as blood, a man's semen, and the fluids in a woman's vagina, of people who are infected. The virus is spread when these fluids get into the body of another person. HIV can be spread by:

sex with someone who has HIV, if the person does not use condoms.



unsterile needles or tools that pierce or cut the skin.

infected blood that gets into cuts or an open wound.



an infected mother to her baby, through pregnancy, birth, or breastfeeding.

In places where blood is not tested for HIV, people can also get HIV from blood transfusions.

For information about preventing HIV/AIDS, see pages 179 to 182.

HOW HIV/AIDS IS NOT SPREAD

HIV does not live outside the human body for more than a few minutes. It cannot live on its own in the air or in the water. This means you cannot give or get HIV by:

- touching, hugging, or kissing
- sharing food
- sharing a bed
- sharing clothes, bedding, or latrines
- insect bites

Touching does not pass HIV/AIDS.

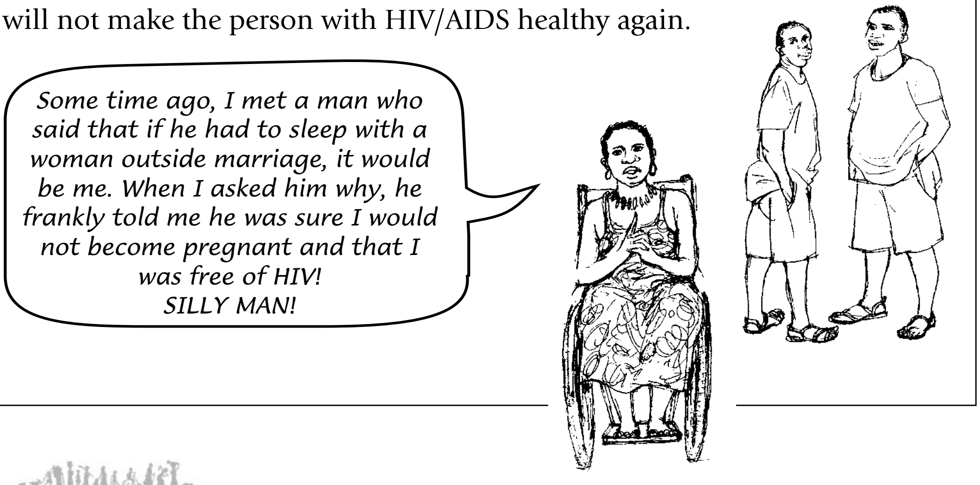
HOW HIV/AIDS AFFECTS WOMEN

Women with HIV often become sick with AIDS more quickly than men do. Poor nutrition and childbearing may make women less able to fight disease. Also, women get infected with HIV more easily than men do. When a man's semen gets into a woman's body during sex, it can easily pass through her vagina or cervix into her blood, especially if there are any cuts or sores. This can happen whether or not the woman has a disability.

Dangerous ideas about HIV/AIDS and women with disabilities

One of the most harmful and wrong ideas about HIV/AIDS is that if a person with HIV/AIDS has sex with someone who has never had sex before (a virgin), the person with HIV/AIDS will be cured. Because of this wrong idea, a man who has HIV/AIDS may seek out women with a disability if he thinks that, because she is disabled, she will be a virgin and can cure him. This is not true.

Having sex with a virgin only spreads HIV/AIDS to another person. It will not make the person with HIV/AIDS healthy again.



KNOWING IF YOU HAVE HIV

The HIV test

When HIV enters the body, the immune system starts to make antibodies right away to fight the virus. Within 2 to 4 weeks, an HIV test can detect these antibodies in the blood. This is the only way to know if a person has been infected with HIV.

A positive HIV test means you are infected with the virus and your body has made antibodies to HIV. Even if you feel completely well, you can pass the virus to others.

A negative HIV test means 1 of 2 things:

- you are not infected with HIV, or
- you were recently infected but your body has not yet made enough antibodies to HIV to test positive.

If you have tested negative for HIV but think you may be infected, you should take the test again in about 6 weeks. Sometimes a positive test also needs to be repeated. An experienced health worker can help you decide.

NOTE Testing and counseling for HIV are usually done at the same time and are becoming more available. Ask a health worker where you can be tested in your community. In many health centers and hospitals, rapid HIV testing is available at low or no cost. You can usually get test results the same day. Some testing centers have information in Braille, and some have sign language.

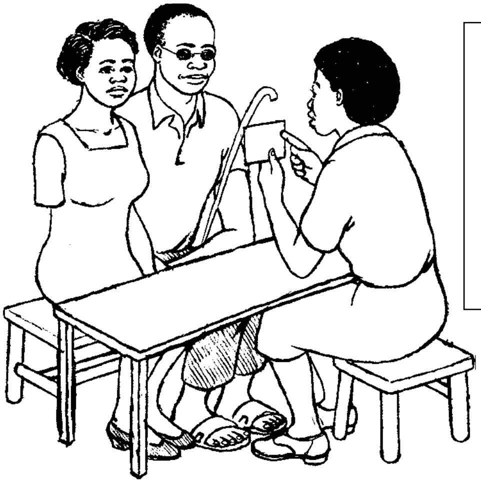
IMPORTANT You can pass HIV to others as soon as you are infected, even though you look and feel healthy. You cannot tell from looking at a person if he or she has HIV. The only way to know if you are infected is to get the HIV test.

COUNSELING

The HIV test should only be done:

- with your permission.
- with counseling before and after the test.
- with privacy. Only you and those you want to know should know the results.

A trained HIV/AIDS counselor can help you decide if you need to get tested for HIV. If your test is positive, the counselor can help you decide how to face this change in your life.



Counseling for HIV-infected people and their families can mean the difference between hope and helplessness. As an HIV-infected woman from Kenya says, "When you meet a good counselor, you feel as if you have healed."

A good counselor can help you make decisions and think about many problems and complicated situations, such as:

- how to accept that you or your partner has HIV.
- when and how to tell others (disclose) that you have HIV.
- how to continue having sex and to have sex safely when one partner has HIV and the other partner does not.
- where to get condoms and how to use them.
- where to get and how to take medicines and get treatment for illnesses caused by HIV.
- how to decide if you should get pregnant when either you or your partner is HIV positive, and how to prevent passing HIV to a baby.
- where to get food, housing, legal advice, or other help you or your family may need.

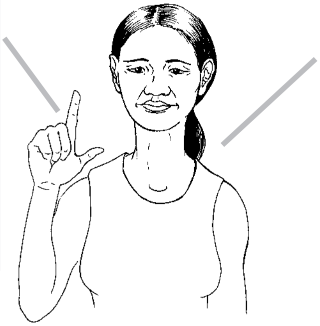
Protecting your privacy

Any woman should be able to make her own decisions about who to tell about her HIV status and how to tell them. It is important for a woman to talk with her sexual partner or partners, so they can also be tested or protect their health. Many women tell their families and others who support them. But often, women are afraid everyone in the community will find out.

It can be difficult for a woman with a disability to have a private conversation with a health worker. This may be because:

- the health worker has never learned that a woman with a disability should be treated with the same respect as any woman.
- the health worker will tell the family or friends of a woman with a disability about her health problems, including HIV or an STI, without telling the woman herself. This is especially true if the disabled woman has difficulty communicating.
- the woman's family will not let the woman see a health worker by herself.

Because I am deaf, I often have trouble with privacy, especially when I use an interpreter to speak with a health worker. The interpreter who works at the clinic I go to knows that whatever the health worker and I talk about is confidential and private. She will never tell anyone—not even another health worker—what we have talked about.



If I take my own interpreter with me, I remind her ahead of time that whatever I talk about with the health worker is private. I try to make sure the interpreter understands that the test results are private. I ask her not to tell anyone else—not even my family—without my permission.

HEALTH PROBLEMS CAUSED BY HIV/AIDS

A person with AIDS can get sick very easily from many different common health problems. Here is some general information about some of these problems, but it is best to talk to a health worker or see a book like *HIV, Health and Your Community* for more information. The most common health problems caused by HIV/AIDS are:

Fever: Fevers often come and go. It is hard to know if the fever is from an infection that can be treated, like tuberculosis, pelvic inflammatory disease (PID), or malaria, or if it is from HIV itself. If the fever is caused by an infection, then make sure the infection itself is treated.

Diarrhea: Diarrhea may come and go and can be hard to cure. The most common causes of diarrhea in persons with AIDS are infections or the side effects of some medicines.

Skin rashes and itching: It is often difficult to know what causes skin rashes and itching. Some of the skin problems related to HIV/AIDS can be caused by:

- allergic reactions to medicines.
- brown or purple patches on the mouth or skin, caused by a cancer of the blood vessels or lymph nodes called Kaposi's sarcoma.
- herpes zoster (shingles), which usually begins as a painful rash with blisters that break open. It is most common on the face, back and chest.

Nausea and vomiting: This can be caused by infections, some medicines, problems with the stomach and intestines, or the HIV infection itself.

Cough: This can be a sign of lung problems, such as pneumonia or tuberculosis (TB). The lungs make more mucus when they are irritated or infected, which causes coughing.

Tuberculosis is a serious infection caused by a germ that usually affects the lungs. The signs of AIDS and TB are similar, but they are different diseases. Most women, men and children with TB do not have AIDS. But someone with AIDS can get TB very easily because the person's body is too weak to fight it. For 1 of every 3 people who dies from AIDS, it is TB that actually kills them.

Problems with the mouth and throat: The problems can include: soreness, cracks, sores and blisters, and white patches on the tongue (thrush, see page 260).

Weight loss and malnutrition: A person with AIDS can become malnourished from constantly being sick, from diarrhea that prevents the body from absorbing the nutrients in food, from loss of appetite, and from mouth infections that make eating difficult. Weight loss is so common in people with HIV that in some areas of Africa, AIDS is called "slim disease."

TREATMENT FOR HIV/AIDS

Neither modern medicine nor traditional healing systems has found a cure for AIDS. But there are many things that can be done to help a person with AIDS. Clean water, good food, clean clothes, a clean place to rest and sleep, and loving relationships with friends and family can all help someone with AIDS stay healthy. The same foods that are good for someone who is healthy are good to eat when someone has an AIDS-related sickness (see pages 177 to 178).

Although there is no cure for AIDS, antiretroviral medicines (ARVs) are now being used successfully to treat people who are sick with AIDS. ARVs help strengthen the immune system so the person with HIV can fight off infections and stay healthy. But the HIV is not cured. Small amounts of the virus always remain in the person's body. When a person has HIV, he or she can always pass the virus to someone else.

Getting good health care is often not easy for women with disabilities, and for those who are also infected with HIV/AIDS, it can be even more difficult. Health workers may not want to test or treat them because they think disabled women cannot have sex, cannot get infected with HIV/AIDS, or will die quickly if they are infected.

But just as women with disabilities have the same risk of getting infected with HIV as other women, they will also live longer and healthier lives if they get treatment.

AntiRetroviral Therapy (ART)

Anti**R**etroviral **T**herapy, or ART, means taking a combination of 3 antiretroviral medicines at least 2 times a day. Once a person with AIDS begins ART, the medicines must be taken faithfully every day. A woman on ART will gain weight, and look and feel healthier. But if she stops ART, misses doses of medicine, or takes them at the wrong times, her HIV can become stronger and make her sick again. For more information about medicines for treating HIV/AIDS for women with disabilities, or for preventing the spread of HIV from a mother to her baby, see pages 358 to 362.

Although ART is costly, it is becoming cheaper and more available in many countries. Government health facilities and other programs may offer ART at low or no cost.

Even so, in many communities, medicines are not available for most people with HIV/AIDS. The power of large pharmaceutical companies in rich countries has often stopped other countries from making their own less expensive medicines. This has denied millions of women access to the medicines they need to treat HIV/AIDS.

Preventing some infections with medicines

For persons with HIV/AIDS, regular use of the antibiotic cotrimoxazole helps prevent pneumonia, diarrhea, and other infections. You should start taking it if you have problems with weight loss, sores or cracks around your lips, itching rashes, shingles, mouth ulcers, or frequent colds.

Treatment: Take cotrimoxazole 960 mg (double strength) by mouth every day with plenty of water. If possible, take it every day whether you feel sick or not.

IMPORTANT Allergic reactions to cotrimoxazole are more common in persons with AIDS. Stop taking it if you get a new skin rash or any other sign of drug allergy.

IMPORTANT Some women have more problems with yeast infections of the vagina when they take antibiotics. Eating yogurt or sour milk, or sitting in a bowl of water with some yogurt or vinegar in it can help. For more information on yeast infections, see pages 111 to 113.

In some countries it is also recommended that people with HIV take medicines to prevent tuberculosis (TB). Talk with an experienced health worker about this.

Eating well

AIDS affects the body's ability to digest food properly, and it also causes people to lose their appetite so they become very thin. This can also happen because of the side effects of medicines, mouth and throat problems, diarrhea, and difficulty digesting fats.

If you have HIV, it is especially important to try to eat well so you do not lose weight, and your body and immune system can be as healthy as possible. To do this, try to eat a varied or balanced diet (see page 86), drink clean water, and take a daily multivitamin. If available, you may also want to take supplements of vitamins A, C, and E, as they may slow the ability of the HIV virus to grow in your body.

Foods with vitamin A include carrots, mangos, papayas, sweet potatoes, milk, eggs, and dark green leafy vegetables (such as kale, spinach, turnip greens).

Foods with vitamin C include red and green peppers, dark leafy green vegetables (such as kale, cassava or manioc leaves, collard, turnip, mustard greens, and spinach), orange, yellow, and red fruits.

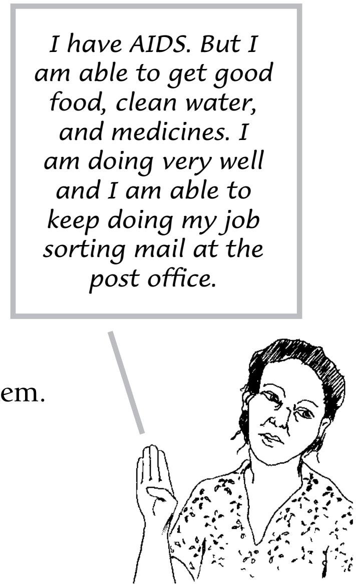
Foods with vitamin E include eggs, and oils made from almonds, corn, palm nuts, peanuts, sunflower seeds, wheat germ, and olives.

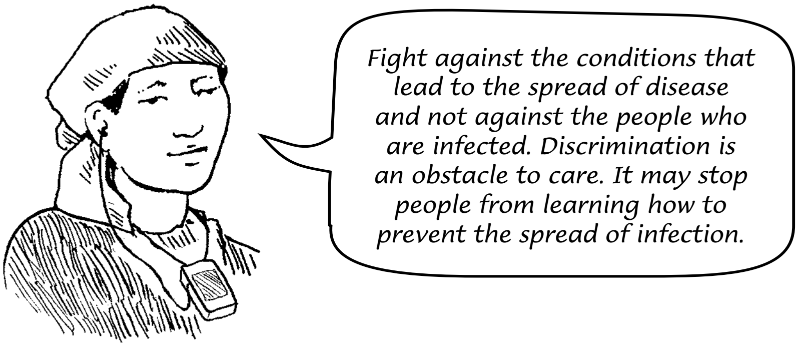
If you lose your appetite, you may find that eating a larger meal in the morning works best for you. Or you may prefer to eat 6 to 8 small meals throughout the day. Drinking cold liquids with meals can make food easier to swallow.

Living positively with HIV/AIDS

You will stay healthier if you can:

- drink and prepare food only in clean, safe water.
- avoid uncooked vegetables—they are hard for the body to digest and may have germs.
- drink a lot of liquids and watch for dehydration.
- rest whenever you are tired and sleep at least 8 hours every day.
- spend time with friends and family.
- do things you enjoy. Feeling good is part of being healthy.
- try not to worry too much. Stress can harm the immune system.
- try to keep active by doing your daily work.
- exercise as much as possible (see pages 89 to 95).
- avoid tobacco, alcohol and other drugs.
- prevent infection by washing often.
- practice safer sex to prevent new infections and unplanned pregnancies that could weaken the immune system (see page 180).
- take care of medical problems early. Each infection can weaken your immune system more.
- take cotrimoxazole to prevent diarrhea (see page 339).
- sleep under a bed net if you live where malaria is common.





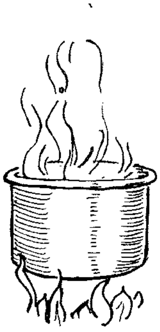
STIGMA AND HIV/AIDS

In some communities, people who are HIV-positive or have AIDS are made to feel ashamed. No one in the community will associate with them, and they think the family of someone who has HIV/AIDS has disgraced the community.

Thousands of HIV-positive people hide their status. They are frightened of rejection by friends, family, and neighbors, even though HIV/AIDS is not passed from one person to another through casual contact.

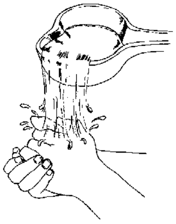
Many people with AIDS and their families do not ask for help from their communities because of the shame and disgrace they are made to feel. This can make it very difficult for someone with AIDS to get the help and treatment he or she needs, even though there are medicines available that allow people with AIDS to live longer, healthier lives.

Preventing infection at home



Many people think HIV can spread easily. This is not true. If you follow these guidelines, there is no risk of spreading HIV or hepatitis from an infected person to others around her, or of getting HIV or hepatitis yourself:

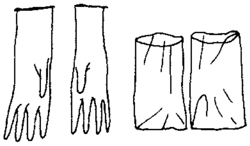
- Do not share anything that touches blood. This includes razors, needles, any sharp instruments that cut the skin, and toothbrushes. If you must share such things, boil them first in water for 20 minutes.
- Keep all wounds covered with a clean bandage or cloth. Persons with or without HIV or hepatitis should do this.
- Burn or bury soiled bandages that cannot be rewashed.



- Avoid touching body fluids with your bare hands. Use a piece of plastic or paper, gloves, or a big leaf to handle dirty bandages, cloths, blood, vomit, or stool.
- Wash your hands with soap and water after changing dirty bedding and clothes.
- Keep bedding and clothing clean. To clean soiled bedding or clothes:
    - keep them separate from other household laundry.
    - hold an unstained part and rinse off any body fluids with water.
    - wash the bedding and clothing in soapy water, hang to dry—if possible in the sun—and fold or iron as usual.
- When washing dirty laundry, it is helpful, but not necessary, to wear gloves or plastic bags on your hands.

OTHER WAYS TO PREVENT HIV

- Treat sexually transmitted infections early. Having one STI can make it easier to become infected with HIV or other STIs.
- Do not have an injection unless you are sure the instruments are sterilized first. Health workers should NEVER reuse a needle or syringe without sterilizing it first.
- Never share a needle or syringe with someone else unless it is first sterilized with bleach or boiled for 20 minutes.
- Make sure instruments for circumcision, ear piercing, acupuncture, and traditional practices such as scarring, are boiled for 20 minutes.
- Handle body fluids, like blood, vomit, stool, and urine safely.



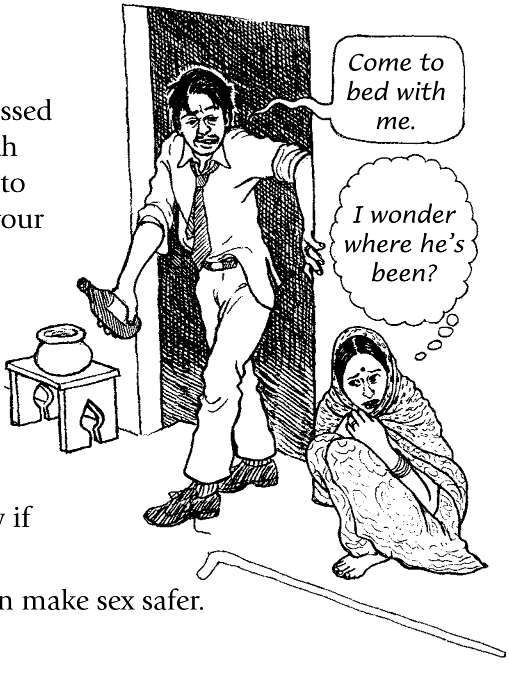
- All blood should be tested to ensure it is free from HIV and hepatitis. Even if it is tested, avoid blood transfusions except in life-threatening emergencies.

Safer sex

Most of the time, HIV and other STIs are passed from one person to another during sex. With information about safer sex, respect, access to condoms, and good communication with your partner, you can protect yourself from STIs.

But it can be hard for any woman to protect herself from sexual infections when she is not expected or allowed to make decisions about sex. You may be afraid or ashamed to ask a man to use a condom, or you may have to have sex when your partner demands it. And you may not know if your partner has sex with other people.

Every woman needs to know how she can make sex safer.



WAYS TO HAVE SAFER SEX

Having safer sex means using barriers (like condoms) to keep germs from being passed between you and your partner during sex, or having sex in ways that make infection less likely.

Sex with the penis in the vagina (sexual intercourse) is the most common way that men and women have sex. But couples can give and receive sexual pleasure by using many different kinds of talk and touch. If your partner does not want to use condoms, you can try to have other, safer kinds of sex. These practices may feel just as good for him—and be safer for you.

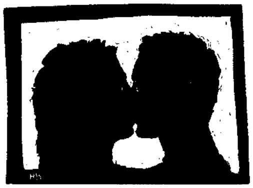
Very safe:

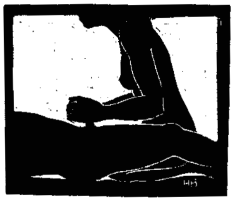
- Avoid having sex at all. If you do not have sex, you will not be exposed to STIs. Some women may find this the best option, especially when they are young. However, for most women, this choice is not possible or desirable.
- Have sex with only one partner, who you know for sure has sex with only you, and when you know for sure (through testing) that neither of you was infected by a previous partner.
- Have sex by touching each other's and your own genitals with your hands (mutual masturbation).
- Use condoms during oral sex. A barrier of latex or plastic helps prevent infection with herpes and gonorrhea in the throat. It also protects against the very small risk of infection with HIV through tiny cuts in the mouth.

Safe:

- Always use latex male condoms or plastic female condoms when having vaginal or anal sex.
- Have sex in ways that avoid getting your partner's body fluids in your vagina or anus.
- Sex using your mouth is much less likely to spread HIV. If you get semen in your mouth, spit it out.

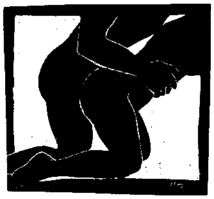
Some kinds of sex between a man and a woman are safer than others


Kissing is safe


Touching is safe


Oral sex is less safe—but safer with a condom


Vaginal sex is risky—but safer with a condom


Anal sex is very risky—but safer with a condom

Other ways to have safer sex with a man:

- Have the man withdraw his penis before he ejaculates (comes). When less semen gets inside your body, you are less likely to get HIV from him.
- Avoid dry sex. When the vagina (or anus) is dry, the skin can tear more easily, and this increases the chance of infection. Use saliva (spit), spermicide, or lubricant to make the vagina slippery. Do not use oil, lotion or petroleum jelly if you are using condoms—these can make the condom break.

SEX AND MONTHLY BLEEDING

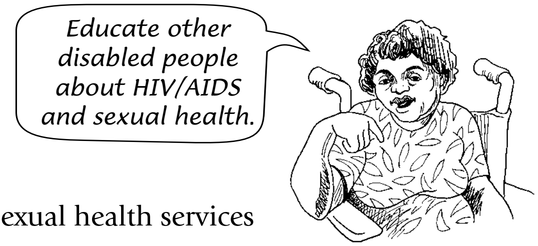
During your monthly bleeding, it is best not to have vaginal sex, unless you are absolutely certain neither you nor your partner has HIV/AIDS or any other STI. If you have HIV, the virus will be in both your vaginal secretions and blood. This increases your partner's risk of getting infected. If your partner is infected and you are not, your risk of getting infected also increases during your monthly bleeding. Using condoms will reduce the risk.

Working for change

STIs and HIV/AIDS are health problems for the whole community, including women with disabilities. Sometimes disability groups think sexual health is not something they should worry about. But sex education can save people's lives.

Good information about sexual health and about how to prevent STIs must be available to everyone, including women with disabilities. For example, information about preventing HIV/AIDS that often comes through radio or on printed leaflets should be available and accessible for deaf and blind women.

What women with disabilities can do:



- Meet with caregivers and families of women with disabilities to explain how important it is for everyone to have good information about sexual health.
- Work with health workers and other groups to make sure HIV/AIDS and sexual health services reach people with disabilities.
- If someone is taking advantage of you sexually, tell someone you trust—a family member, a neighbor, a health worker.

What families and caregivers can do:

- Make sure disabled women have information about sexual health and how to prevent HIV/AIDS and STIs. Give the information in a way that is respectful and private.
- Help other parents of disabled children understand that when their children grow up, they will want to have sexual relationships, just like people who are not disabled.

What communities can do:

It is important for everyone in the community to know how HIV/AIDS and STIs are spread and how to prevent them. With this information, people can realize that these infections can happen to anyone and they can act to prevent them. And this knowledge can help people understand that women with disabilities need the same health care services as everyone else in the community.

It is very important to fight against the conditions that lead to the spread of disease and not against the people who are infected. HIV/AIDS and STIs can best be prevented by fighting for fairer social and economic conditions so that women, including women with disabilities, will have more decision-making power, so that families do not need to separate to find work, and so that people do not need to sell their bodies for sex.

- Make sure all people—including women with disabilities—have access to information and sexual health services, including latex condoms, to keep HIV and other STIs from spreading in the community.
- Make sure medicines, clean water, and nutritious food are available for people living with HIV/AIDS.
- Educate people in your community to prevent girls and women with disabilities from being taken advantage of sexually, and to understand that having sex with them will not cure AIDS.

To the health worker:

Include women with disabilities in your health education classes, and look for opportunities to share health information with groups of disabled women who are already meeting together. Always respect the privacy of disabled women. **Never** talk about a woman's problem with others—not even with her family—unless the woman gives you permission.

- Explain how STIs and HIV/AIDS are passed and how to prevent them.
- Show how to use the condom for men and the condom for women (see pages 190 and 191).
- Learn about the possible problems some women with disabilities may have in taking certain medicines to treat STIs.
- Look for signs of sexual abuse when you see a woman for any health problem.
- Make sure women with disabilites have access to counseling and testing for HIV.

Health workers can let parents of disabled children know that children who learn about STIs including HIV/AIDS will make safe choices later on when they grow up and start to have sex.

CHAPTER 9

Family planning

Women are healthier when they can decide for themselves when to have sex and when to have children. These decisions should always be their choice, and women who use family planning are better able to make these choices. You can use family planning to:

- help you decide how many children you want to have and when to have them.
- prevent becoming pregnant unless you want to.
- help you and your partner enjoy sex more because you do not have to worry about getting pregnant.

Some family planning methods have other benefits. For example:

- condoms protect against sexually transmitted infections, including HIV/AIDS.
- hormonal methods (see page 196) can help with irregular bleeding and pain during your monthly bleeding.

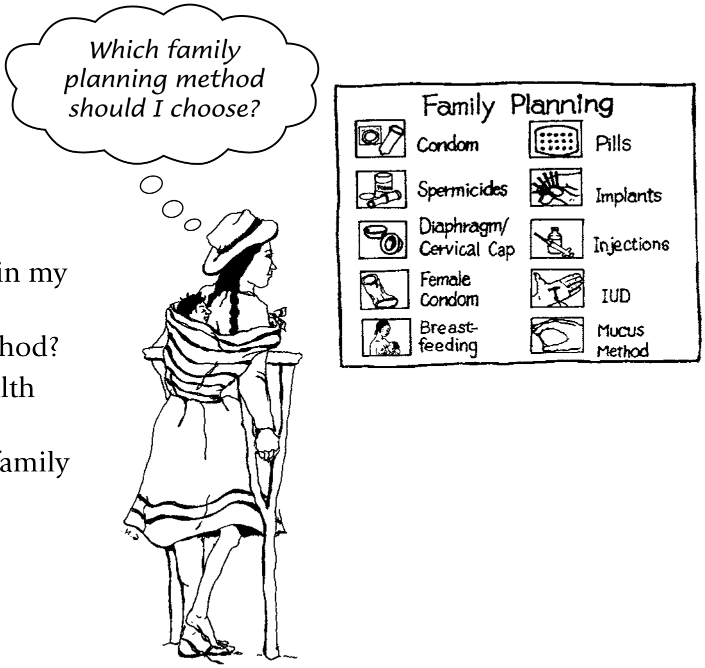
Unfortunately, many women around the world are denied access to family planning or to the methods they prefer. This happens for many reasons. Some people believe family planning is dangerous to a woman's health. But the main reason is that religious and political authorities do not believe women should decide for themselves when and how to use family planning.

It can be even more difficult for women with disabilities to get information or access to practice family planning. Many people, including some health workers, believe women with disabilities cannot have sex or become pregnant, and do not give them any information or advice.

This chapter gives information about different types of family planning methods and how to choose the best method for you.

Before you decide which method of family planning to use, look at the chart on page 188 to see how well each method prevents pregnancy. You may also want to consider the following:

- What methods are available in my community?
- How easy is it to use the method?
- Are there any risks to my health with the method?
- Is my partner willing to use family planning?
- Will my disability affect the method I use?



Where many family planning methods are available, women make choices depending on ease of use, cost, their bodies, the work they do, and what they and their partners prefer. Even if some of these methods are not available in your community, you can learn about them and talk with the local health workers about trying to make them available. You may be able to educate them!

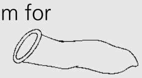
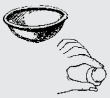
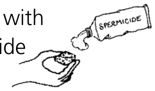
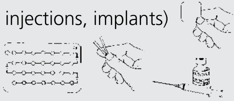
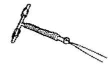
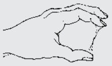
How family planning methods work

Every month, there are times when a woman is fertile and can become pregnant, and times when she is not fertile and cannot become pregnant. Most women produce one egg each month. The egg is released from the woman's ovary. The egg lives for about 24 hours (one day and one night) after it is released from the ovary. The man's sperm can live up to 2 days inside the woman's body. If the woman's egg has been released while the man's sperm is inside her body, she can become pregnant. For more information on pregnancy, see pages 77 to 80.

Family planning methods work to change a woman's fertility and prevent pregnancy in different ways:

- Barrier methods (condom for men, condom for women, diaphragm, cervical cap) stop a man's sperm from reaching the woman's egg (see page 189).
- Intrauterine devices (IUD, IUCD, IUS, Copper T, the Loop) keep a man's sperm from fertilizing the woman's egg (see page 195).
- Hormonal methods (pills, injections, implants) keep the woman's ovary from releasing an egg. Some also affect the womb or the mucus in the cervix so sperm cannot fertilize an egg there (see page 196).
- Natural methods help a woman know when she is fertile (the time in a woman's cycle when she can get pregnant), so she can avoid having sex during that time (see page 200).
- Permanent methods (sterilization) are operations that stop a man from releasing sperm, or prevent a woman's eggs from reaching her womb (see page 203).

On the next page is a chart that shows how well each method works to prevent pregnancy and to protect against STIs. The chart also shows what the possible side effects are for each method and other important information about how the method may affect your disability. Each method has stars to show how well it prevents pregnancy. Some methods have fewer stars even if they are fairly effective methods, because they are often used incorrectly. When a man and a woman use a method correctly every time they have sex, the method will work better.

FAMILY PLANNING METHOD	Protection from pregnancy	Protection from STIs	Other important information
Condom for men 	★★★ VERY GOOD	GOOD	Most effective when used with spermicide and lubricant.
Condom for women 	★★ GOOD	GOOD	May not be suitable if you have limited hand movement, cannot reach your vagina, cannot open your legs very wide, or get muscle spasms in your upper legs.
Diaphragm and cervical cap 	★★ GOOD	SOME	More effective when used with spermicide. May not be suitable if you have limited hand movement, cannot reach your vagina, cannot open your legs very wide, or get muscle spasms in your upper legs.
Sponge with spermicide 	★ SOME	SOME	May not be suitable if you have limited hand movement, cannot reach your vagina, cannot open your legs very wide, or get muscle spasms in your upper legs.
Home-made sponge 	★ SOME	SOME	May not be suitable if you have limited hand movement, cannot reach your vagina, cannot open your legs very wide, or get muscle spasms in your upper legs.
Spermicide 	★ SOME	NONE	May not be suitable if you have limited hand movement, cannot reach your vagina, cannot open your legs very wide, or get muscle spasms in your upper legs.
Hormonal methods (birth control pill, patch, injections, implants) 	★★★★ BEST	NONE	Low-dose pills are OK for women who are paralyzed if they are active or exercise every day. Women with epilepsy should use pills that contain only progestin.
IUD, IUS 	★★★★ BEST	NONE	May not be suitable if you have limited hand movement, cannot reach your vagina, cannot open your legs very wide, get muscle spasms in your upper legs, or if you have difficulty managing monthly bleeding (this is less of a problem with the IUS that contains hormones).
Fertility awareness 	★★ GOOD	NONE	May not be suitable if you have limited hand movement, cannot reach your vagina, cannot open your legs very wide, or get muscle spasms in your upper legs.
Sex without intercourse 	★ SOME	SOME	Because couples may have a hard time sticking to this method, pregnancy often results.
Pulling out (withdrawal) 	★ SOME	SOME	More effective when used with another method like spermicide or diaphragm.
Breastfeeding (during the first 6 months only) 	★★ GOOD	NONE	To use this method, a woman must give her baby only breast milk, and her monthly bleeding must not have returned yet.
Sterilization 	★★★★ BEST	NONE	After a man has been sterilized, a couple needs to use another method for about 12 weeks.

Barrier methods of family planning

Barrier methods include the condom for men, condom for women, diaphragm, cervical cap, sponge and spermicide.

CONDOM FOR MEN (RUBBER, PROPHYLACTIC)

A condom is a narrow bag of thin rubber that the man wears on his penis while having sex. The bag traps the man's sperm so it cannot get into the woman's vagina or womb.

Unfortunately, some men do not like to wear a condom during sex because they say it reduces their sexual pleasure. This is too bad, because condoms work well to prevent both pregnancy and sexually transmitted infections (STIs).

Lubricant can make sex feel better for both the woman and the man. It can also keep the condom from breaking. Use a water-based lubricant like saliva (spit), *K-Y Jelly*, or spermicide. Do not use oils, petroleum jelly (*Vaseline*), skin lotions, or butter as they can make the condom leak or break. A drop of lubricant inside the tip of the condom makes it more comfortable on the penis. A little lubricant can also be rubbed on the outside of the condom after the man puts it on. This can make sexual intercourse more comfortable for the man's partner.

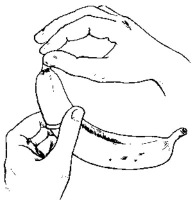
The most effective condoms are made from latex or polyurethane—not sheepskin.

A new condom must be used each time a couple has sex.

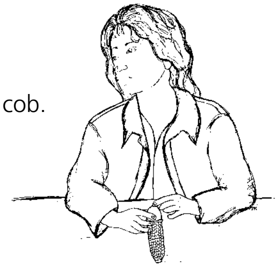
Condoms can be used alone or along with any other family planning method, except the condom for women. They can be bought at many pharmacies and markets, and are often available at health posts and through HIV/AIDS prevention programs.

If you have good movement in your hands, you can put a man's condom onto his penis. It helps to know how to do this before you are about to have sex. You can practice by:

putting the condom on a banana…

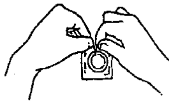


…or a corn cob.



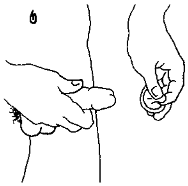
For women who are blind or who cannot see well, practicing how to put a condom on a man is an especially good idea. Then, when you have sex with a partner, you can use your hands to feel if the condom is on correctly, and you can make sure the tip of the condom is not broken or cut.

How to use a male condom

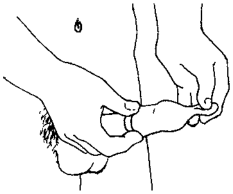


A new condom should come rolled up inside a small packet that has not been opened. Be careful not to tear the condom as you open the packet. The condom should feel smooth and slippery. If it feels stiff, hard or sticky, throw it away. It will not work.

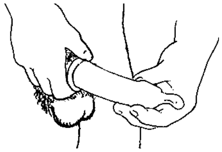
1. A condom should be put on the man's penis when the penis is hard, and before it touches the woman's genitals. An uncircumcised man should pull his foreskin back. The man should squeeze the tip of the condom and put it on the end of the penis.



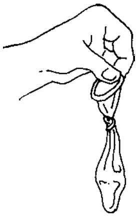
2. Unroll the condom until it covers all of the penis. Keep squeezing the tip of the condom while unrolling. Without this extra space at the tip for the semen, the condom may break.



3. Right after the man ejaculates (comes) and before his penis gets soft, he should hold onto the rim of the condom while he pulls his penis out of the vagina. Then he should carefully take the condom off.



4. Tie the condom shut. Then throw it in the garbage or a latrine, out of reach of children and animals.



CONDOM FOR WOMEN
(FEMALE CONDOM)

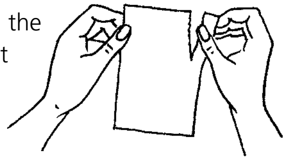
Condoms for women also prevent HIV and other STIs from passing from one person to another.

You may prefer a different method if:
- you have limited hand movement.
- you cannot reach your vagina.
- you cannot open your legs very wide.
- you get muscle spasms in your upper legs

The condom for women fits into the vagina and covers the outer lips of the genitals (vulva). It protects against both pregnancy and sexually transmitted infections, and against HIV/AIDS. Unfortunately, the female condom is more expensive and harder to get than the male condom. The female condom should not be used with the condom for men. It works best when the man is on top and the woman is on the bottom during sex.

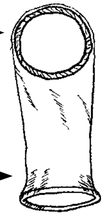
How to use the female condom:

1. Carefully open the packet without tearing the condom.

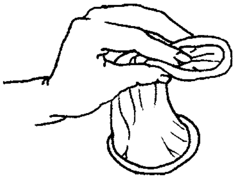


2. Find the inner ring, which is at the closed end of the condom.

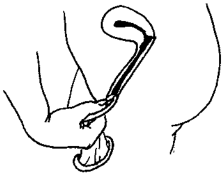
Outer ring



3. Squeeze the inner ring together.

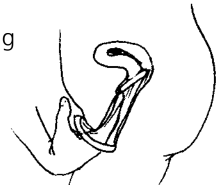


4. Put the inner ring in the vagina.

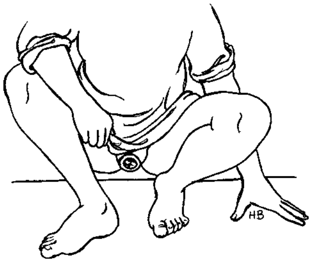


5. Push the inner ring up into your vagina with your finger.

The outer ring stays outside the vagina.



6. When you have sex, guide the penis through the outer ring.



7. Remove the female condom immediately after the man's penis leaves your body, before you stand up. Squeeze and twist the outer ring to keep the man's semen inside the pouch. Pull the pouch out gently, and then dispose of it out of reach of children and animals. Either put it into a pit latrine, or bury it.

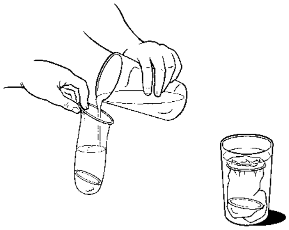
If you really want to use the female condom, but your disability makes it difficult, try sitting or lying down in different positions, or ask your partner or another person to help you.

It is best to use a new female condom every time you have sex. But, if you cannot get a new one, you can clean and reuse a female condom up to 7 times.

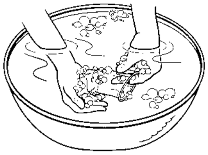
How to clean a condom for women

Before having sex, prepare a large cup of bleach (*Cloro*, *Clorox*, etc.) mixed with water (1 part powder or liquid bleach to 20 parts clean water). Bleach kills HIV.

After sex, take the condom out of your vagina. Be careful not to spill any of the man's semen. Right away, pour half the bleach solution into the condom, and then put the filled condom into the remaining bleach solution.



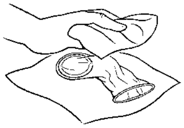
Let the condom soak for 5 minutes only. **Do not try to clean the condom in any way before putting it into the bleach.**

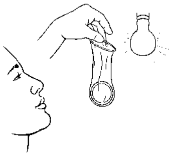


Wash your hands with mild soap, and use the soap bubbles on your hands to gently wash off the bleach and any remaining body fluids or lubrication, both outside and inside the condom, including the inner ring (do not rub a bar of soap directly on to the condom or it may break).

Use clean water to rinse off the soap bubbles from the ring and from both the inside and outside of the condom.

Dry gently the inside and outside of the condom with a clean cloth, or leave it to dry in the air.





Check the condom for holes by holding it up to the light. If there is even a tiny hole, throw the condom away and get a new one. Some change in color is OK. If there are no holes, store in a clean, dry place until next use.

Before using it again, lubricate the condom with a water-based lubricant. For the female condom you can also use vegetable oil or vegetable shortening. Because the female condom is not made from latex, it is OK to use some oils. But do not use peanut or groundnut oil, or lotions that contain lanolin or perfume, as these can all cause an allergic skin reaction.

THE DIAPHRAGM AND THE CERVICAL CAP

The diaphragm and cervical cap are both shallow cups made of soft rubber that are worn in the vagina during sex. Either one must be left in your vagina for at least 6 hours after sexual intercourse, and you can leave it in for as long as 24 hours (but no longer).

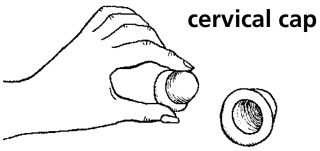
You may prefer a different method if:

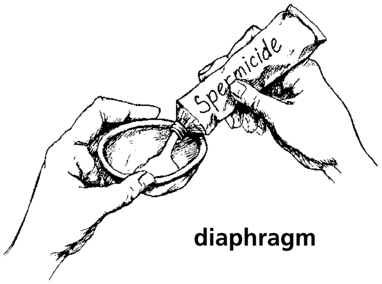
- you have limited hand movement.
- you cannot open your legs very wide.
- you cannot reach your vagina.
- you get muscle spasms in your upper legs.

Both the diaphragm and the cap are good methods to prevent pregnancy if they are used with a contraceptive cream or jelly (spermicide) every time you have sex. Diaphragms and cervical caps come in different sizes. An experienced health worker can fit you with the correct size for your body. The diaphragm is larger than the cap, and some small women say the cap fits them better. After childbirth, or if you have gained or lost a lot of weight, you may need to change the size of your diaphragm.

The diaphragm and the cap usually last a year or longer. Both must be checked regularly for holes and cracks by holding them up to the light. If there is even a tiny hole, get a new one because the man's sperm is even tinier and can get through the hole. After use, wash in warm soapy water, rinse, and dry. Keep the diaphragm or cap in a clean, dry place.

These methods are not available everywhere. But if enough women demand them, more programs and clinics will make them available.





THE SPONGE

The contraceptive sponge

The contraceptive sponge is made of soft plastic and is filled with a spermicide (nonoxynol-9). You put the sponge deep inside your vagina before having sex. Once it is in place, you can have sexual intercourse as often as you like, without having to add more spermicide. It must stay in your vagina for 6 hours after having sex, and you can leave it in for as long as 24 hours (but no longer). In many countries the sponge is not available.

You may prefer a different method if:

- you cannot open your legs very wide.
- you have limited hand movement.
- you cannot reach your vagina.
- you get muscle spasms in your upper legs.
- you have no feeling in your pelvis.

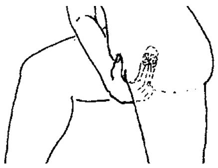
The homemade sponge

You can also use a sponge soaked in vinegar or lemon. This method is not as effective as the contraceptive sponge, but it may prevent some pregnancies. You may wish to try it when no other method is available.

How to make a homemade sponge

1. Mix: 2 tablespoons of vinegar with 1 cup of clean boiled water **or** 1 teaspoon of lemon juice with 1 cup of clean boiled water **or** 1 spoon of salt with 4 spoons of clean boiled water

2. Wet a boiled piece of sponge about the size of an egg with one of these liquids.
3. Push the sponge deep into the vagina no more than 1 hour before having sex.
4. Leave the sponge in for at least 6 hours after having sex. Then take it out.



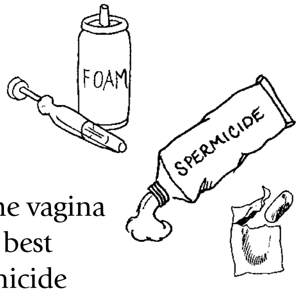
The sponge can be difficult to take out, but it cannot get lost in the vagina. It may be easier to take out if you squat and push down as if you are passing stool, while you reach into your vagina. If you have trouble taking it out, you can tie a clean ribbon or string around it for the next time.

The sponge can be washed, boiled, and used again many times. Keep it in a clean, dry place. The liquid can be made ahead of time and kept in a bottle.

The spermicide or the liquid in either sponge method may irritate the skin inside the vagina, which can make it easier for a woman to get STIs. Stop using these methods if they make your vagina dry, sore, or itchy.

SPERMICIDES

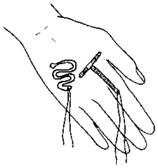
Spermicides are foam, tablets, cream, or jelly that are put into the vagina before having sexual intercourse. Spermicide kills the man's sperm before it can get into the womb. It does not protect against STIs or HIV/AIDS . Tablets should be put into the vagina 10 to 15 minutes before having sex. Foam, jelly, or cream work best if they are put into the vagina just before having sex. Add spermicide each time you have sex. After sex, do not douche or wash out the spermicide for at least 6 hours. Some spermicides can cause itching or irritation to the skin inside the vagina. The foam is the one most likely to cause an irritation. If you are sensitive to the foam, try using contraceptive jelly or cream instead.



IUD (INTRAUTERINE DEVICES: IUCD, COPPER T, THE LOOP)

You may prefer a different method if:

- you cannot manage heavy monthly bleeding.
- you cannot open your legs very wide.
- you get muscle spasms in your upper legs.



The Intra-Uterine Device (IUD) is a small object made of plastic, or of plastic and copper, that has 2 small strings attached. **The IUD does not protect against HIV/AIDS or other STIs.** A trained health worker or midwife can insert an IUD inside the womb, and the strings hang down into the vagina. The IUD prevents the man's sperm from fertilizing the woman's egg. To use an IUD safely, you need to be able to check the strings inside your vagina regularly. It is best to do this just after your monthly bleeding has stopped. If you cannot check the strings yourself, ask your partner or someone you trust to help you.

The IUD can be left in for up to 10 years. Women with IUDs should get regular pelvic exams to make sure it is still in correctly.

Common side effects

You may have some light bleeding during the first week you have an IUD. Some women also have longer, heavier, and more painful monthly bleeding, but this usually stops after the first 3 months. If you want to use an IUD, talk with an experienced health worker to see if this method will work well for you.

IUS (INTRAUTERINE SYSTEM: AN IUD WITH HORMONES)

One type of IUD called the Intrauterine System (IUS) contains the progestin hormone, levonorgestrel. The 2 most common brand names are *Mirena* and *Levonova*. The IUS reduces the amount of blood lost during monthly bleeding and is also very effective in preventing pregnancy for 5 years. Unfortunately, it is more expensive than other IUDs and is not available in as many countries. Talk with a health worker to see if it is available in your community.

WARNING! **If you have an IUD, get medical help if any of these danger signs appear:**

- late or missed monthly bleeding or unusual spotting between monthly bleeding
- pain in the belly that does not go away, or pain during sex
- signs of infection: unusual discharge or bad smell from the vagina, fever, chills, feeling ill
- IUD strings get shorter or longer, are missing, or you can feel the IUD in the vagina

Hormonal methods of family planning

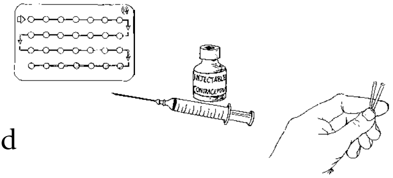
Hormones are chemicals a woman's body normally makes (see page 72). The hormones regulate many parts of a woman's body, including your monthly bleeding and ability to become pregnant. This process is no different in a woman with or without a disability. Hormonal methods of family planning prevent pregnancy by stopping your ovaries from releasing eggs into your womb. **Hormonal methods do not protect against HIV/AIDS or other STIs.**

You should not use *any* hormonal method if:

- you have breast cancer.
- you may be pregnant already.
- you have very heavy monthly bleeding or monthly bleeding that lasts for more than 8 days.

Hormonal methods include:

- pills which a woman takes every day.
- injections, which are given every few months.
- implants, which are put into a woman's arm and last several years.



Most birth control pills and some injections contain 2 hormones similar to the hormones a woman's body normally makes. These hormones are called estrogen (ethinyl estradiol), and progestin (levonorgestrel). Implants, some pills, and some injections contain only progestin.

You should not use any methods that contain estrogen *(you should use progestin-only methods)* if:

- you cannot walk or have very limited movement in your legs—unless you exercise regularly or are very active.
- you have epilepsy or take medicines for seizures.
- you have ever had a blood clot in the veins of your legs or in your brain. Swollen veins in the legs (varicose veins) are usually not a problem, unless they are red and sore.
- you have hepatitis, or yellow skin and eyes.
- you have ever had signs of a stroke, paralysis, or heart disease.

New hormonal methods are still being invented. Some newer methods are a contraceptive patch, a ring (worn on the cervix), and a hormonal IUD (see page 195).

Side effects

Hormonal methods sometimes have side effects. These effects are not dangerous, but they are often uncomfortable. Hormonal methods can make a woman have:

nausea

headaches

swelling of the breasts

weight gain

changes in monthly bleeding

These effects usually lessen after a few months. If they do not, the woman can try a different family planning method.

BIRTH CONTROL PILLS (ORAL CONTRACEPTIVES OR "THE PILL")

If you decide to take birth control pills, they should be "low-dose." That means they should have 35 micrograms (mcg) or less of estrogen, and 1 milligram (mg) or less of progestin. Do not use pills with more than 50 mcg of estrogen. There are many different brands of birth control pills (see page 355 to 356).

Taking a birth control pill at the same time every day is one of the most effective ways to avoid pregnancy. There is an increased chance of pregnancy if you forget to take even a single pill. As a rule, women who take birth control pills have lighter monthly bleeding. This may be a good thing, especially for women who have a difficult time managing their monthly bleeding. If you have trouble swallowing pills, they can be ground up in water or some other liquid, and swallowed through a straw.

Pills come in packets of 21 or 28 tablets. You should take the first pill in a packet on the first day of your monthly bleeding. If that is not possible, take the first pill any time in the first 7 days after you start your monthly bleeding. If you are using a 21-day packet, take one pill every day for 21 days. Then wait 7 days before starting a new packet. Usually, you will start your monthly bleeding after the 21st day. But even if you do not, start a new packet in 7 days. If you are using a 28-day packet, take one pill every day. As soon as you finish one packet, begin taking a new one.

If you vomit within 3 hours after taking your pill, or have severe diarrhea, your birth control pill will not stay in your body long enough to work well. Use condoms, or do not have sex, until you are well and have taken a pill each day for 7 days.

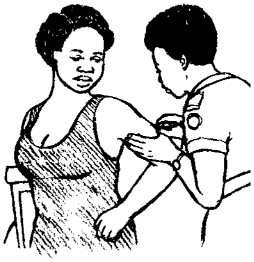
The combined pills (estrogen and progesterone) start to prevent pregnancy within 2 weeks, if you start taking them the first day of your monthly bleeding. Progestin-only pills will not prevent pregnancy for the first 4 weeks you take them. So you will need to use condoms or another method of family planning, or you may become pregnant.

WARNING! If you are taking pills and you get any of these signs, get medical advice right away:

- chest pain and shortness of breath
- strong headaches
- numbness in your arms or legs
- strong pain or swelling in one leg

These are signs that you may have a blood clot inside your body that is preventing the blood from flowing to your lungs, chest, brain, or arm or leg.

INJECTABLE CONTRACEPTIVES



With this method, a health worker gives a woman a hormone injection to keep her from getting pregnant. One injection lasts 1 to 3 months. Most injections contain only progestin. *Depo Provera* and *Noristerat* are the most common brands. These injections are safe to use while breastfeeding, and are safe for other women who should not use estrogen (see page 196).

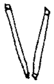
Injections are very effective. Very few women who use this method become pregnant. Another advantage to this method is that you do not have to do anything before having sex. And no one except your health worker needs to know you are using a family planning method. To use this method, you will need to see a health worker every 1 to 3 months to get another injection.

After having your first injection, you may have irregular bleeding or heavy spotting during the first few months. Then you may have no monthly bleeding at all. This is not dangerous. When you stop getting injections, it may take longer than usual (as much as a year or more) for you to get pregnant. For this reason, injections are best only if you are sure you do not want to get pregnant in the next year or more.

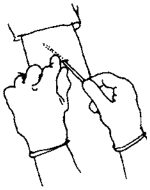
Women with epilepsy may have fewer seizures when they use the family planning injection. Also, if you use the injection for more than 6 months, try to eat more foods that contain calcium (see page 86) to keep your bones strong. Using injectable contraceptives for a long time may cause your bones to become weaker.

IMPLANTS

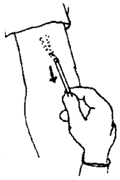
With this method, a trained health worker puts small, soft tubes of progestin under the skin of a woman's arm. The implant then prevents pregnancy for 3 to 5 years, depending on the type of implant. The implants must be removed after those 3 to 5 years are over and you will need a new implant or another family planning method right away if you do not want to get pregnant. If you want to get pregnant before that time, the implant must be removed by a health worker.



Implants



Implants are put under the skin…



…and can be removed by a trained health worker.

You cannot remove implants yourself. They can be removed only by a trained health worker. If you want to use implants, first make sure you will always be able to go to a health worker who knows how to remove them.

A woman with implants does not have to do anything before sex to prevent pregnancy. Implants contain only progestin, so they are safe for women who should not take estrogen. And they can be used safely while breastfeeding.

During the first months, the implants may cause irregular bleeding (in the middle of your monthly cycle) or more days of monthly bleeding. Or you may have no bleeding at all. This does not mean you are pregnant or that something is wrong. These changes usually go away as your body becomes used to having more progestin. If irregular bleeding causes problems for you, see a health worker. She may also give you low-dose combined birth control pills to take for a few months.

WARNING! **If you have an implant, get medical help if you have any of these signs:**

- arm pain near the implant
- pus, redness, or bleeding around the implant
- the implant comes out

Breastfeeding

In the first 6 months after birth, most women who breastfeed do not release eggs from their ovaries, so they cannot get pregnant when they have sex.

Women usually do not get pregnant if they are breastfeeding and:

1. the baby is less than 6 months old, **AND**
2. the woman has not had any monthly bleeding since giving birth, **AND**
3. the woman is giving the baby **only** her breast milk.

If you want to use this method of family planning, you must remember that you can easily get pregnant if you are giving your baby formula, water, other drinks, or if you are removing your breast milk by hand to feed the baby with a cup. Also, you may get pregnant if the baby goes longer than 6 hours between breastfeeding times. After 6 months, there is a higher risk of pregnancy, even if you are breastfeeding as before. You can get pregnant 2 weeks before your monthly bleeding starts again. So do not wait for your monthly bleeding to start again before using some form of family planning.

The breastfeeding method does not protect against HIV/AIDS or other STIs. Also, getting infected with HIV while breastfeeding creates a danger of passing HIV to the baby. If there is any chance your partner has HIV/AIDS, you should use a condom each time you have sex (see page 181).

Natural family planning

Natural family planning costs nothing and has no side effects. But it can be difficult to use. Women do not always know when they are fertile, and if they have one irregular cycle, they can easily get pregnant. These methods work best when your cycles are very regular. This means the time from the first day of your monthly bleeding to the first day of your next monthly bleeding is the same every month, and is at least 26 days and no more than 32 days.

A woman can get pregnant only during her fertile time when an egg comes from her ovary into her tubes and womb—about once a month (see page 75). To use natural family planning, you must watch your body's signs to understand when you are fertile. During the fertile time you and your partner must not have sexual intercourse without using some other form of family planning. At these times, you can try other types of sex, such as oral sex or sexual touching. Or you can prevent pregnancy by using condoms or a diaphragm during the fertile time.

Natural family planning does **not** work well for women who do not have control over when they have sex. During your fertile times, your partner must be willing to use condoms or a diaphragm, or not have sexual intercourse. This method usually works best when couples receive training before using it.

If you recently gave birth or had an abortion, do not use these methods until your cycles are regular for several months.

There are many ways to use natural family planning. In this book we talk about the mucus method and the counting days method. These methods work best when they are both used together. But one method alone is better than nothing.

Natural family planning does not protect against HIV/AIDS or other STIs.

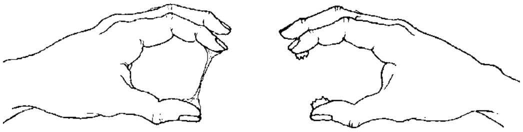
THE MUCUS METHOD

With the mucus method, you have to check the mucus from your vagina every day to see if you are fertile. On your fertile days, the mucus is stretchy and slimy, like raw egg.

To check the mucus, wipe your vagina with a clean finger, paper, or cloth. Then look or feel for mucus.

You may prefer a different method if:
- you have limited hand movement.
- you cannot reach your vagina.
- you cannot open your legs very wide.
- you get muscle spasms in your upper legs.
- you have limited feeling in your fingers.

Clear, wet, slippery mucus comes during the fertile time. **Do not have sexual intercourse.**



White, dry, sticky mucus (or no mucus) comes during other times of the month. **It is probably OK to have sexual intercourse 2 days after the first dry day.**

After 2 or 3 months of practice, you can easily recognize these changes in your mucus.

How to use the mucus method

- Check the mucus at the same time every day. Check before having sex.
- Do not have sexual intercourse on any day you feel slippery mucus. Or use a condom or diaphragm on those days.
- Do not have sexual intercourse until 2 days after the last day you have clear, slippery mucus.
- Do not douche or wash out the vagina at any time. This will wash the mucus away.

Use another method of family planning if you have a vaginal infection, or if you are not sure whether it is a fertile time. The mucus method works best when it is used with another method, like the counting days method.

THE COUNTING DAYS METHOD

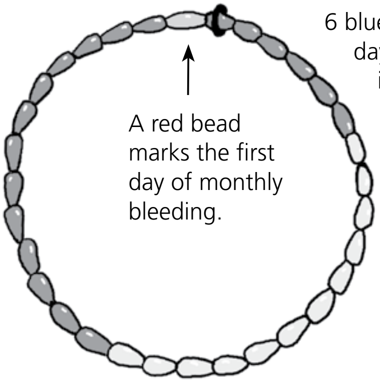
With the counting days method, a woman does not have sexual intercourse during any time she might be fertile. This method can be used only by women with regular cycles. This means you have nearly the same number of days from one monthly bleeding to the next, and each cycle is at least 26 days, and no more than 32 days.

If you have one cycle of a different length, you can easily get pregnant. It is common for a woman to have a cycle of a different length when she is sick or feeling a lot of stress. During those times, it is best for you to use a different family planning method until you are well and your cycle returns to normal.

How to use the counting days method

For this method to work, you cannot have sexual intercourse from the 8th day of your cycle through the 19th day of your cycle. If you have sexual intercourse during this time, you must use another method of family planning.

You can use beads, a chart, or some other tool to remember your fertile days. String 32 beads, of 3 different colors, into a necklace. Each color bead can represent a different part of your cycle.



A red bead marks the first day of monthly bleeding.

6 blue beads show days when sexual intercourse will not usually cause pregnancy.

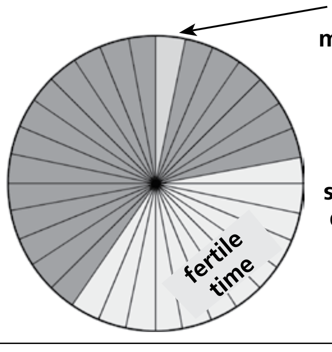
12 white beads show the fertile time—when sexual intercourse can cause pregnancy.

13 more blue beads show days when sexual intercourse will not usually cause pregnancy.

On the first day of your monthly bleeding, put a ring or string around the red bead. Each day, move the ring past one bead. When the ring is on any of the white beads, you may get pregnant if you have sexual intercourse. Whenever you start your next monthly bleeding, move the ring back to the red bead at the start.

You may be able to buy a necklace like this called *CycleBeads*.

For the counting days method, you can also make a chart with 32 sections—1 for each day of your cycle. Mark off each day on the chart to remember when you can become pregnant.



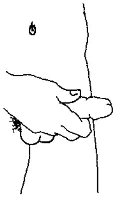
first day of monthly bleeding

sexual intercourse during the fertile time can cause pregnancy

SEX WITHOUT INTERCOURSE

There are many ways to have sex that do not cause pregnancy. Oral sex (mouth on genitals) and sexual touch (touching the genitals or other parts of the body) are both sexual activities that many couples enjoy. They have very low risk of passing HIV/AIDS and other STIs, and they cannot cause pregnancy. Anal sex also cannot cause pregnancy, although HIV/AIDS and other STIs can pass very easily this way.

Avoiding all sexual intercourse is the most sure way to prevent pregnancy and can be a good way to reduce the risk of HIV/AIDS and other STIs. Not having sexual intercourse may be very difficult for couples to practice for a long time.



PULLING OUT (WITHDRAWAL)

In this method, a man pulls his penis out of the woman's vagina and away from her genitals before he ejaculates. This helps to prevent sperm from getting inside the vagina.

This method can work almost as well as the barrier methods, if the man can pull out in time. But often men leak semen before they ejaculate. A man may not be able to pull out before the semen comes. Or he may not want to. This means the woman may get pregnant. This method is more effective when the man passes urine before sex, and when it is combined with another method like spermicide or a diaphragm.

Sterilization

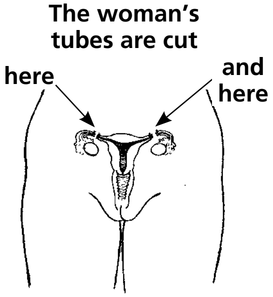
There are operations that make it almost impossible for a woman or a man to have children. Since these operations are permanent, they are good only for women and men who are certain they do not want any more children. A trained health worker or doctor can perform the operations in a health center or hospital.

The operation for women is more serious than the operation for men. The man will recover faster from the side effects of the operation. So, if possible, it is safer for a man to have the operation than a woman.

The operation for a woman (tubal ligation)

The health worker cuts or ties the tubes that carry the egg to the womb. The operation takes about 30 minutes. It does not change a woman's monthly bleeding. The operation will not affect her sexuality, and she will be able to have a normal sex life and to have sexual pleasure.

There is a small risk you can still get pregnant after the operation, so if you have signs of pregnancy, see a health worker. If your pregnancy is in the tubes, it is very dangerous (tubal pregnancy, see page 220).



Sterilization of a woman with problems learning or understanding

Many women who have trouble learning or understanding make excellent mothers and are able to take care of their children. Like all new mothers, they will need help from their families. But sometimes, families or health workers do not believe a woman who has problems learning or understanding should be allowed to become pregnant. They may decide to sterilize her without explaining what the operation means and without her permission. Even if they do this because they are concerned about her health and well-being, it is a violation of her human rights and is the wrong thing to do.

If you are a woman with learning difficulties, you might decide to be sterilized. The decision is yours to make. Other people can help you decide by talking with you about these questions:

Can you make good decisions about having sex? Sometimes a woman has trouble understanding when a man is just using her for sex and when he cares about her. Sterilization will only stop pregnancy. It will not prevent you from suffering the emotional and physical harm of sexual abuse. Living with sexual abuse is not a good reason to be sterilized. For information on what you can do about sexual abuse, see Chapter 14.

Can you make good decisions about using family planning? Sometimes a woman has trouble remembering where she is in her menstrual cycle (see page 75), or to take her birth control pills, or to use her diaphragm. If you are sterilized, you will not have to worry about any of that. But if you want to have a child later, another method such as implants, injections, or an IUD might be a better choice.

Will you be able to stay healthy during pregnancy? Sometimes when a woman is pregnant she forgets that everything she eats or drinks also affects her developing baby. Eating good food, not smoking, and avoiding alcohol and other drugs are important to prevent many problems, including some birth defects.

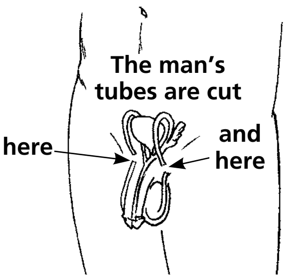
Will you be able to take care of a baby or a child? Sometimes it is difficult to remember that being a mother takes a lot of attention, patience, and work, even when you are tired, sick, or have other things to do.

Will you be able to take good decisions about safe sex? Sterilization will not prevent you from getting HIV or other sexually transmitted infections. Even if you get sterilized, you will still need to practice safe sex.

These are difficult questions for anyone to answer, and you may need a lot of discussion to answer them. Because sterilization is such an important step, it is worth making sure you understand what the operation means.

The operation for a man (vasectomy)

The tubes that carry the man's sperm from his testicles to his penis are cut. The operation takes only a few minutes to do, and it does not change the man's ability to have sex or to feel sexual pleasure. He still ejaculates (comes), but the semen does not have any sperm in it. For about 3 months, there are still sperm in the tubes, so the couple must use another method of family planning.



Emergency methods of family planning (the 'morning after' pill)

Emergency family planning is a way to avoid pregnancy after having unprotected sex. This method works by taking a larger-than-usual amount of the same birth control pills that some women take each day to prevent pregnancy. There are also emergency pills that have the dose in 1 or 2 pills.

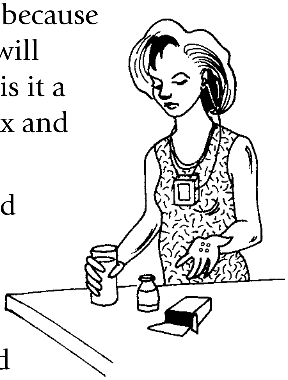
These methods work best when the pills are taken as soon as possible, within 5 days of having unprotected sex. The sooner you take the pills after unprotected sex, the more likely it is you will not get pregnant.

How this works to prevent pregnancy depends on where you are in your monthly menstrual cycle when you take it. It may prevent you from releasing an egg (see page 75).

Emergency family planning is **not** the same thing as an abortion, because if you are already pregnant when you take the pills, your pregnancy will not stop, and your developing baby will not be harmed. But neither is it a method you can use for regular family planning. If you are having sex and do not want to get pregnant, use one of the methods on page 188.

If you cannot swallow pills, or you have problems with nausea and vomiting, the pills can be put into the vagina where they will be absorbed into the body.

An intrauterine device (IUD) inserted into the womb up to 5 days after unprotected sex will also prevent a pregnancy. This method works better than pills, but should be used only by a woman who is planning to use an IUD for her regular family planning method.



Talk with local health workers about how important it is for women to have access to emergency family planning. Work with them and local pharmacists to make emergency family planning available to every woman in your community who wants it.

FAMILY PLANNING AND PARALYSIS

If you are a woman with no feeling in your lower body (from paralysis caused by polio, or a spinal cord injury), and you do not want to get pregnant, here are some guidelines to help you choose a method (some of these methods may not be available in every community):

Barrier methods (condom for men, condom for women, diaphragm, cap, sponge, spermicide). You may need assistance using the methods that are inserted into the vagina.

Hormonal methods (pills, injections, implants, IUD with hormones). You can use hormonal methods that contain estrogen if you are active every day (push your own wheelchair or cart, do exercises, do household work like sweeping, or digging in the garden). You should not use hormonal methods that contain **estrogen** if you:

- sit still all day or do not get any exercise.
- ever had a blood clot anywhere in your body.
- ever had signs of a stroke or heart disease.
- have any type of cancer.
- are over age 35.
- smoke cigarettes, or chew or snort tobacco or snuff.

If you become paralyzed as an adult, do not start using hormonal methods until 6 months after your injury.

Intrauterine device (IUD). Some of the problems that can happen with an IUD, such as the IUD coming out, or an infection, usually cause pain which lets a woman know something is wrong. As you will not be able to feel pain, it is probably best for you not to use this method. If you do want to use it, make sure you can get checked regularly by an experienced health worker.

Abortion

When something is done to end a pregnancy, it is called an 'abortion'. The unplanned loss of a pregnancy is called a 'miscarriage' or 'spontaneous abortion.' For more information about the causes of a miscarriage, see page 219.

Deciding to have an abortion can be hard. Some religions teach that abortion is wrong, and in many countries abortion it is not legal or safe. But there are many reasons a woman may try to have an abortion anyway. In making a decision, most women will benefit from warm, respectful advice and friendly support. Here are some examples of why a woman may want an abortion:

- She already has all the children she can care for.
- A pregnancy is a danger to her health or her life.
- She has no partner to help support the child.
- She wants to finish school.
- She does not want to have children.
- She got pregnant after being forced to have sex.
- Someone is forcing her to have an abortion.

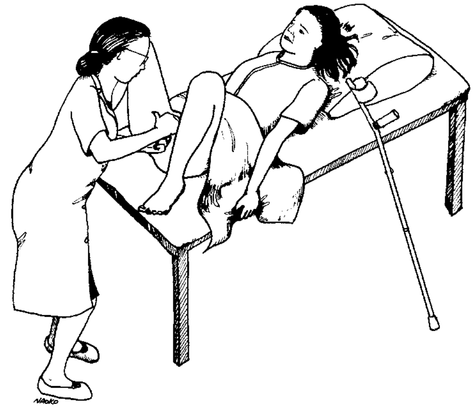
Let women make their own choices

Some women choose to have a baby whether or not they will have support. They may choose to have a baby even when they know the baby will have serious health or disability problems. Many pregnant women say: "I want THIS child!" and are determined to find ways to manage, whatever the difficulties.

For some women, the conditions of their lives or health make having a child a bad choice, and they decide to have an abortion. They may make this decision because they know they will not have enough support to care for the child. Or because they know the baby will have a disability or a serious health problem. Or they may find the idea of having a child, with or without a disability, too difficult to deal with.

Deciding to have a baby is a personal choice all women should be able to make. Whatever your own beliefs, try not to judge a woman if she does something you do not agree with. Care for her with compassion and treat her as you would want yourself or your daughter to be treated.

SAFE ABORTION



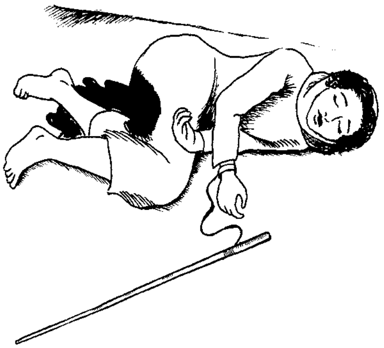
Where abortion is legal and available, a woman can have a safe abortion when it is done under clean and sterile conditions in a hospital, health center or clinic by a trained health worker. It will not usually endanger her future pregnancies. Also, abortions are safest when done in early pregnancy. There are 3 kinds of abortion that can be safe:

Vacuum aspiration. A health worker uses a machine or manual vacuum aspiration (MVA) syringe to empty the womb. If vacuum aspiration is done correctly, it is usually safe. (See *A Book for Midwives,* Chapter 23.)

D&C (dilation and curettage). A health worker empties the womb by scraping it with a sterile instrument. A woman who has had more than 3 D&C abortions may have scar tissue on the womb that can make a later pregnancy difficult.

Medical abortion. The woman takes medicines that end the pregnancy and empty the womb. Talk with an experienced health worker about the medicines that are safe and effective for this. (See *Where Women Have No Doctor,* pages 244 and 245.)

UNSAFE ABORTION



In places where abortion is illegal, a woman trying to end a pregnancy may harm herself or turn to someone who does not give abortions safely. Unsafe abortions can cause heavy bleeding, serious infection or infertility, and are often a major cause of death for women.

These unnecessary deaths can be prevented when disabled women work with other women and men to make abortion safe, legal, and accessible for all women in their communities.

If you had either a safe or unsafe abortion in the past and you became sick or injured afterward with an infection or heavy bleeding, you may have scars in your womb that could cause problems in another pregnancy or birth. If you are pregnant now, it is probably safest for you to give birth in or near a hospital or medical center. Talk with a health worker about this.

CHAPTER 10

Pregnancy

Deciding to have a baby

Getting pregnant is a personal decision, and every woman should have the right to decide for herself if and when she wants to become a mother. But all over the world, women are often pressured by their partners, families and communities to have children, often as many children as possible.

For women with disabilities, however, the opposite is most often true. They are encouraged **not** to get pregnant. Many disabled women are sterilized against their will, so they can never get pregnant. Others who do get pregnant are pressured to have abortions, even where abortions are illegal. This happens because people often believe a woman with a disability cannot be a good mother, or that babies born to her will also be disabled. These ideas are wrong.

There is no reason why most women with disabilities cannot have a safe pregnancy, give birth to a healthy baby, and be a good mother (see Chapter 12). However, there are precautions women with some disabilities must take when they are pregnant, and some women will need more assistance than others.

This chapter has information that will help you understand some of the changes that can happen during pregnancy, how they may affect different disabilities, and how to plan for a safe pregnancy and birth.

Naomy's story: How I became a mother

When I was young and my women friends used to talk about having babies, they all used to tell me that because of my disability, I would not be able to get pregnant. And if by some miracle I did conceive, they said the baby would have to be delivered by caesarian operation and would probably be disabled in one way or another.

I really did not understand what my friends meant, because I knew I was a woman, just like them. But because I walked differently from them, I believed what they said. Also, I had not been examined by any doctors to confirm this. I used to feel very sad, because I loved little children. Every time any of my friends had a baby, I wished it was mine.

In 1987, I started feeling strongly that I needed to try and see if I could have a baby, despite the possible problems. I had a boyfriend and one day I just thought, well, why not? And it happened. On 27 December, 1987, I became pregnant.

When I realized I was pregnant, I was delighted, but at the same time I worried. Because I am a polio survivor, I went to see a doctor, a gynecologist, to prove I was pregnant and to find out if it was true there would be complications during my pregnancy and delivery.

The doctor was shocked to hear I was pregnant. Before he even examined me, he told me that because of the way I walked, I was not going to be able to carry the pregnancy to full term. He said I would lose it within the first 3 months. He advised me not to wait for the 3 months, but to have an abortion right away. I agreed and made an appointment for 27 February, 1988. It was very expensive, but I somehow managed to raise the money.

I had not yet told anyone I was pregnant or about how worried and afraid I was. Abortion is illegal in Kenya, so I did not want anybody to know I was planning to have one. I also did not know how my friends would react. Would they laugh at me or be disappointed with me? I therefore kept the whole thing a secret.

I spent many sleepless nights, and felt sad and afraid all the time. First, I could not stand the idea of not having a child in my life. Second, abortions were dangerous and I had known a number of young women who had lost their lives from having an unsafe abortion. Third, I am a Christian and believe that abortion is a sin. And finally, I was not married and pregnancy outside marriage is not culturally accepted. So you can imagine how troubled I was.

Well, life had to go on. I gathered courage and prepared for the abortion. When the day arrived, I went to the hospital and sat outside the doctor's office waiting to be called in. This was the most trying moment of my life. Courage failed me, and I found myself worrying again about what was going to happen to me. I was sure I was going to die. I started praying for forgiveness and courage.

Suddenly I remembered the doctor saying that I was going to lose the pregnancy anyway at 3 months. This excited me, and I realized there was no need for me to have an abortion. It would be safer, cheaper, and there would be no stigma if I had a miscarriage instead of an abortion. So I went back home to wait for the baby to come out. However, I was not quite sure I had made the right decision.

My first 4 months of pregnancy were horrible. I lost a lot of weight, I had no appetite, and I vomited all the time. Above all, I lived in fear and expected the worst to happen at any time. When I first felt the baby move, I was scared. I thought the time had come for the baby to come out.

For quite some time I was afraid of going for a medical checkup, even though I knew it was necessary. But one day I decided to go to the nearest health center, where I met a doctor who examined me and assured me I was going to carry the pregnancy to full term and that I was going to deliver the baby normally. He did advise me, however, to give birth in hospital.

I felt confident and started going for frequent checkups at the antenatal clinic. The staff told me that all was going well. The nurses also gave me books to read on pregnancy, delivery, and taking care of a newborn baby. These gave me good information and helped give me strength to carry on. All I wanted was to have a baby, see how it would look, see if it was going to be disabled, and above all be called a mother, just like my friends.

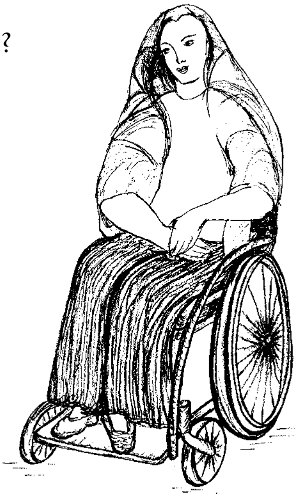
To everyone's surprise, I carried the pregnancy to full term—9 months—and delivered normally a healthy, non-disabled beautiful baby girl after 36 hours of labor. My 'baby,' Ann, is now 18 years old, a very healthy girl, and doing well in her studies in form 4 in secondary school.

QUESTIONS TO ASK BEFORE BECOMING PREGNANT

Every woman needs to make plans and decide how many children to have and when to have them. A woman's age, health, and personal living situation can affect her decision to become a mother.

Before getting pregnant, it may help to think about these questions:

- Do you want to have children?
- If you already have children, can you take care of any more?
- Has your body recovered from your last pregnancy?
- Can you care for a child by yourself?
- Do you have a partner or family to help you support and care for the child?
- Is someone forcing you to have a baby?
- Will a pregnancy have any affect on your disability?



WILL MY BABY BE BORN WITH A DISABILITY?

Most disabilities are not passed from mother to child (inherited or familial disability). But there are some that are passed—sometimes by the father, sometimes by the mother, and sometimes by both. See page 14 for more information about some of the disabilities that are passed in families.

If you think your baby might be born with one of these disabilities, it is best for you to arrange to give birth in a hospital in case there are any complications.

WILL THE BABY BE A BOY OR A GIRL?

It is the man's sperm that makes a baby either a boy or a girl. About half of a man's sperm will produce a baby boy and the other half will produce a girl. Only one sperm will join with the woman's egg. If it is a boy sperm, the baby will be a boy. If it is a girl sperm, the baby will be a girl. This is no different for a disabled woman than for a woman without a disability.

In communities where families prefer having boys, women are often blamed if they do not have sons. This is unfair both to girls, who should be valued as much as boys, and to women, because it is the man who determines the baby's sex.

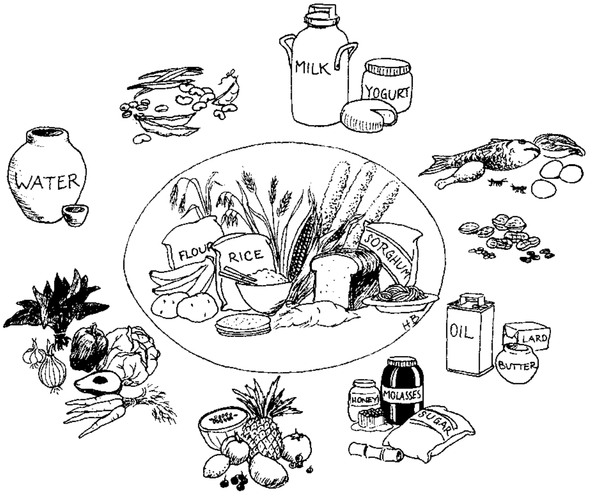
Planning your pregnancy and birth

Around the world, most women give birth at home with the help of a local midwife. These births can be safe and healthy for both the mother and the baby, especially if the midwife is experienced. For women with disabilities, care during pregnancy and birth with a midwife is also usually safe and healthy. But even if the midwife is skilled, there are times when women and babies need hospital care.

Some women with disabilities who have a greater risk of complications need medical care that is usually only provided in a hospital. For example, if you:

- **have a disability that prevents you from opening your legs wide** such as cerebral palsy, rheumatoid arthritis, or severe muscle spasms. During the birth, you will need to keep your legs open wide for 2 to 3 hours, either by yourself, or with someone's help, or you may need to deliver the baby through an operation.
- **are a woman of short stature (dwarf).** The bones in your pelvis may not be wide enough for the baby to come out safely without an operation. Also, because you have less blood in your body, you may need a blood transfusion, depending on how much you bleed during childbirth.
- **have a high spinal cord injury (T6 and above)** you are at risk for getting dysreflexia, a deadly high blood pressure (see pages 117 to 119).

While you are trying to get pregnant



To make sure you and your baby will be as healthy as possible, eat regularly and try to eat a variety of healthy food, especially the foods that can help prevent birth defects (see pages 86 and 216). Healthy habits like eating good foods, not smoking, and avoiding drugs and alcohol are important because many problems start early in pregnancy—before you even realize you are pregnant.

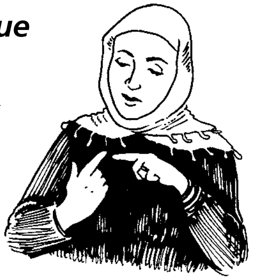
MAKE A BIRTH PLAN

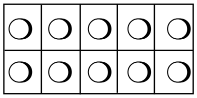
Even though it can be difficult for women with disabilities to get the medical treatment they need, every pregnant woman should make a birth plan. You should begin having *prenatal* (also called *antenatal*) checkups as soon as you think you are pregnant. If possible, try to find a midwife, doctor, or other health worker you trust, and take a friend or family member with you when you go for your first checkup. Together you can talk about any possible problems that may happen, what can be done about them, and where you can get the best advice. You can use this information to help make your birth plan. For example:

- Which will be the safest place for you to have your baby: at home, a birthing clinic, or a hospital?
- Will you have transport to a hospital or clinic if you need it?
- If you take medicines regularly, will they have any effect on your developing baby? You may need to change some of the medicines you take to others that are safer in pregnancy. This is especially true for anti-seizure medicines (see page 231).
- Will your disability affect your health while you are pregnant, or the health or development of your baby?
- Is your disability likely to cause problems during labor or delivery?
- Can complications be prevented or treated safely?
- Do you know how to stay healthy during your pregnancy (eating well and exercising)?

How to know when a baby is due

Add 9 months plus 7 days to the date when your last normal monthly bleeding began. Your baby will probably be born any time in the 2 weeks before or after this date.





A woman can know when her baby will be born by counting the passing of 10 moons since her last period.

Staying healthy during pregnancy

If you can take good care of yourself while pregnant, you are more likely to have a safe pregnancy and birth, and a healthy baby. Try to:

- Sleep and rest whenever you can.
- Go for prenatal (before-birth) checkups.
- If you have never had a tetanus immunization, get one as soon as you can. Get at least 2 before the end of your pregnancy.
- Keep clean. Bathe or wash regularly and clean your teeth every day.
- Practice squeezing exercises, if you can, so the muscles in your vagina will be stronger. This will help them recover more quickly after the birth (see page 101).
- Drink at least 8 glasses of water or juice each day and pass urine frequently to prevent bladder and kidney infection.
- Exercise daily.
- Get treatment if you think you have a sexually transmitted infection (STI) or other infection.
- Avoid taking modern or plant medicines, unless a health worker who knows you are pregnant says it is OK.
- Do not drink alcohol, smoke, or chew tobacco. They are bad for you and will harm the baby.
- Avoid pesticides, herbicides, or factory chemicals.
- Stay away from a child with a rash all over its body. The rash may be caused by German measles (rubella), which can harm the baby.
- If you use a bowel program to pass stool, do it regularly (see page 107).

EAT A VARIETY OF FOODS

If you are pregnant or breastfeeding, you need to eat more than usual. The extra food will give you enough energy and strength, and will help your baby grow.
As much as possible, try to eat different kinds of food: main foods (carbohydrates), grow foods (proteins), glow foods (vitamins and minerals), and go foods (fats, oils, and sugar), along with plenty of fluids. (For more information about eating well, see page 86.)

Prevent anemia (weak blood)

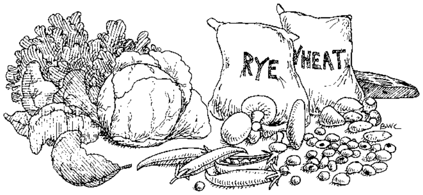
It is especially important for you to get enough food with iron so your blood will be strong. If a pregnant woman has anemia and she bleeds heavily during childbirth (hemorrhage), she is more likely to become seriously ill or even die. For more information about anemia, see pages 87 to 88.

Folic acid (folate)

Not getting enough folic acid can cause anemia and can also cause severe birth defects in the baby, such as growths on the spine or in the brain. To prevent these problems, it is most important for you to **get enough folic acid before you get pregnant and in the first few months of pregnancy.**

These foods contain a lot of folic acid:

- dark green leafy vegetables
- meat (especially liver, kidney, and other organ meats)
- peas and beans
- sunflower, pumpkin, and squash seeds
- whole grains (brown rice, whole wheat)
- fish
- eggs
- mushrooms



Some women also take folic acid pills.

Folic acid pills

Take 0.5 to 0.8 mg (500 to 800 mcg) folic acid by mouth, 1 time each day.

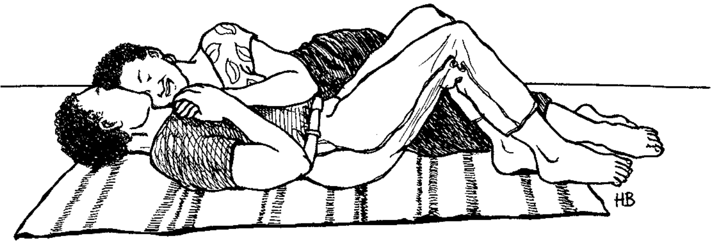
Women who have spina bifida should take 800 mcg folic acid by mouth, 1 time each day.

SEX DURING PREGNANCY

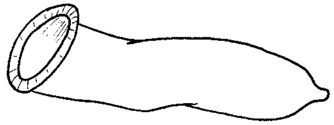
Some women do not want much sex when they are pregnant. Others want sex more than usual. Both feelings are normal. Having sex and not having sex are both OK for the woman and her baby. Sex is not dangerous for the baby.

Sometimes sex is uncomfortable in pregnancy. Depending on your disability, you can try different positions until you find something that is comfortable for you. It may feel better with you on top, or in a sitting or standing position, or if you lie on your side.

Of course, couples can be close and make each other happy in ways other than sex. Some couples touch and massage each other's bodies. Some talk about their hopes and dreams for the future.



Safer sex



Condoms are a good way to prevent infection during pregnancy.

If you are pregnant and have sex, it is important to avoid infection by making sure that anything put inside your body is clean. This includes the penis and hands. A man who is having sex with more than one woman must always use condoms—including with his pregnant partner. Condoms are a good way to prevent infections, HIV/AIDS, and other illnesses. See pages 189 to 192 to learn more about condoms.

Sex and early labor

If you have had a baby before, and you went into early labor, it is probably best for you not to have vaginal sex after the 6th month. This may help prevent you from going into labor too soon.

The 9 months of pregnancy

A pregnancy usually lasts for 9 months and is divided into 3 parts that each last about 3 months. During each of these 3-month parts, a woman's body goes through many changes.

MONTHS 1 TO 3

When you first become pregnant, and the baby starts to grow, your breasts begin to swell and may be tender. You may feel more tired than usual and also have nausea and some vomiting. (In some places, this is called 'morning sickness').

MONTHS 4 TO 6

Many women enjoy the 4th, 5th, and 6th months of a pregnancy. Usually they stop feeling sick in the stomach, stop feeling tired, and have a lot more energy. This is also the time when the belly gets bigger, the baby starts to move, and you can hear the baby's heartbeat.

MONTHS 7 TO 9

This is an exciting time during your pregnancy. You will feel the baby move every day. At the same time, your belly is getting bigger and bigger and, depending on your disability, you may be having more difficulties or problems getting through the day. If you experienced difficulties during the first 6 months, these may continue and may even get worse.

During the last month, about 2 weeks before birth, the baby often drops lower in the belly, especially first babies, and you may find it easier to breathe.

What to expect

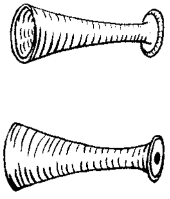
Feeling the baby move

For most women, feeling the baby move inside the belly is the most exciting part of being pregnant. And most women, regardless of their disability, seem to be able to notice the movement, although the sensation can be difficult to recognize at first. Many women describe it as a fluttering movement, and others compare it to gas in the stomach or intestines. Some notice a feeling of pressure inside the belly and then use their hands to feel the movement.

When the baby starts to move in the 4th month, the movements will be very soft and you may not feel them every day. But by the 5th month, you should feel them every day (not all day long—there will be periods of rest in between movements). If you are concerned because you have not felt the baby move for several hours, eat or drink something and then lie on your side in a quiet place for about 30 minutes. During that time you should feel the baby move at least 3 times. If you do not feel or notice any movement, talk with a midwife or health worker.

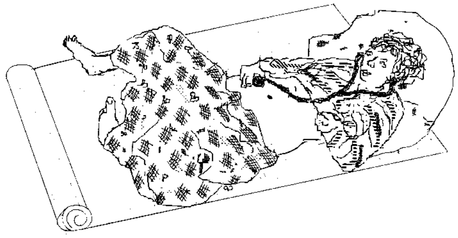
Hearing the baby's heartbeat

This can be done after about 5 months and gets easier to do as the pregnancy gets more advanced. A baby's heartbeat is very quick and quiet. It is not an easy thing to hear, even for someone with better-than-average hearing, and it is even harder to feel. A birth attendant or health worker can use a fetoscope to listen to the baby's heartbeat. It is difficult for the mother herself to do unless she has a stethoscope (like the one used for taking blood pressure).



Fetoscopes

A one-ear fetoscope can be used to hear the baby's heartbeat.



The baby's heartbeat is quiet and quick. It may sound like a watch ticking under a pillow, only faster. The baby's heartbeat is about twice as fast as a healthy adult heartbeat. You can listen to it yourself with a stethoscope.

Losing a pregnancy (miscarriage)

Women with disabilities are no more likely to have a miscarriage than women who are not disabled. Losing a pregnancy is hard for anyone who wants to have a baby, but it can be especially hard for a woman with a disability. Many people may not think she should get pregnant anyway, and when she does, she will face disapproval in her community. If she has a miscarriage, people assume it is because of her disability. She may think that too.

Miscarriages most often happen during the first 3 months of pregnancy. A miscarriage can happen for many reasons, such as:

- unhealthy eggs or sperm
- a problem with the shape of the womb
- growths (fibroids) in the womb
- infection in the womb or vagina
- an illness, such as malaria
- heavy work or accidents
- poisons
- malnutrition
- emotional stress or trauma

Losing a pregnancy is common. If it happens to you, it does not mean you cannot have a healthy pregnancy the next time.

If you have a miscarriage, take good care of yourself for a few days. This can help prevent you from getting an infection and will help your body heal faster. Try to:

- Drink plenty of fluids and eat nutritious food (see page 86).
- Rest often.
- Avoid heavy work for 7 days.
- Bathe regularly, but do not wash out your vagina (douche), or sit in a tub of water until a few days after your bleeding stops.
- Use clean cloths or pads to catch any blood, and change them often.
- Do not put anything inside your vagina, and do not have sexual intercourse, for at least 2 weeks, and not until a few days after you stop bleeding.
- Wait until you have had your monthly bleeding 3 times before trying to get pregnant again. If you wait, there is less chance of having another miscarriage.

Having a miscarriage, whether early or later in a pregnancy, can cause enormous emotional pain and sadness. It can be worse because the people around you may expect that when the pains in your body have gone, you will be fine again. They may not realize how sad you may feel.

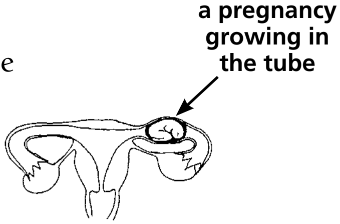
Give yourself time to feel sad and cry. Spend time with friends who understand how you feel and don't force yourself to 'be happy.' Some people may suggest you try to get pregnant again right away. Take time to feel ready for another pregnancy.

PAIN IN THE LOWER BELLY (ABDOMEN)

Strong, constant pain in the first 3 months may be caused by a pregnancy growing outside the womb in the tube (a tubal, or ectopic, pregnancy). As the tube stretches, it causes pain. If the pregnancy grows large enough, the tube will burst and bleed. This is very dangerous. You will bleed inside your abdomen and may die.

Signs of tubal pregnancy:

- missed monthly bleeding
- pain in the lower abdomen on one side
- slight bleeding from the vagina
- feeling dizzy, weak, or faint



If you have some of these signs, go to the nearest hospital.

BLEEDING DURING PREGNANCY

Do not worry if you spot or bleed a little during the first 3 months. This is not unusual, especially if there is no pain or cramps.

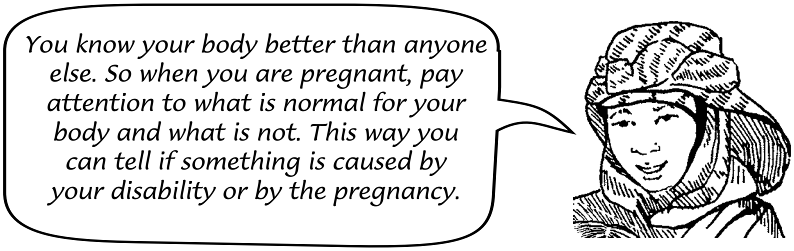
But you must **go to a hospital for medical help right away if you have:**

- bleeding as much as monthly bleeding at any time during your pregnancy.
- bleeding with pain at any time during your pregnancy.
- bleeding with no pain after the first 3 months.

Discomforts during pregnancy

Many women experience discomfort during pregnancy. For some disabled women, the discomforts of their disability get worse, and for some they lessen.

Some discomforts of pregnancy, such as tiredness or back pain, are common to all women, including women with disabilities. What can be different for a disabled woman, though, is knowing if a problem is caused by her pregnancy or her disability. Be aware of what is normal for your body so you can tell the difference. Then you will be better able to get help when you go to see a health worker.



If you tend to get certain problems because of your disability, such as infections of the urine system because you have a spinal cord injury, then you may have these problems more often during pregnancy. Problems may improve or worsen at any time during your pregnancy, depending on your body and the baby's development.

Each and every woman makes adjustments in her life to accommodate her pregnancy.

Here are some changes that women with some disabilities might go through and suggestions for how to deal with them.

FEELING TIRED AND SLEEPY

Most women feel tired and sleepy during the first 3 or 4 months of pregnancy. For more complete information about other possible causes, read about:

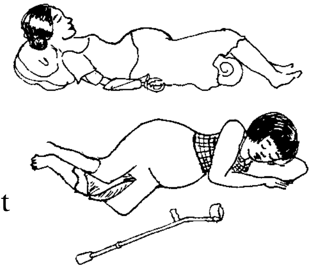
- *anemia* (*Where Women Have No Doctor* page 172).
- not eating enough of the right kinds of food (*malnutrition*), (*Where Women Have No Doctor* page 165).
- emotional problems (*Where Women Have No Doctor* page 416).

SLEEPING DIFFICULTIES

Many women have trouble sleeping at night during the last few weeks of pregnancy. This can happen because they need to pass urine during the night, or because of leg cramps (see pages 222 and 225), or because the baby starts to move and kick. It can be difficult to find a comfortable sleeping position. If possible, try to rest during the day to make up for the loss of sleep.

It is important to find a comfortable sleeping or resting position, but avoid sleeping flat on your back. This can cause your womb to press on the blood vessels in your belly and cause circulation problems. It can also cause problems with digesting food, with back strain, and with breathing.

What to do:



- Drink a little warm milk or hot soup before trying to sleep.
- Sleep sitting up a little, or with something behind you to support your head and shoulders, and put rolled-up cloth or newspaper under your knees.
- Sleep on your side. If possible, lie on your left side as this is the best position for blood circulation. Place something comfortable like rolled-up cloth or newspapers between your knees and ankles.
- Eat nutritious food, making sure to get enough protein, and use only a little salt in your food (but do use a little).

SWOLLEN FEET AND LEGS

Many women have problems with swollen feet and legs during pregnancy, especially in the afternoon or in hot weather. Swelling of the feet is usually not dangerous, but severe swelling when you wake up in the morning, or swelling of your hands and face anytime, can be signs of pre-eclampsia (toxemia of pregnancy, see page 232).

To help with swollen feet and legs, try to lie down on your side for 30 minutes, 2 or 3 times a day. It does not matter which side you lie on. Just sitting with your feet up is not enough. It is best to lie down on your side.

To help prevent pre-eclampsia, eat nutritious food, make sure to get enough protein, drink plenty of water, and use only a little salt in your food (but do use a little).

MOVEMENT AND BALANCE

During the 9 months of your pregnancy, your body shape will change so much it will probably affect how you move about. This happens to almost all women, whether or not they have a disability. You may find that you start to lose your balance and fall easily. Or that you have problems with bending and picking things up. Because of this, many women with disabilities that affect body movement start to use aids to help with walking and moving about until the baby is born.

AMPUTATED LEG

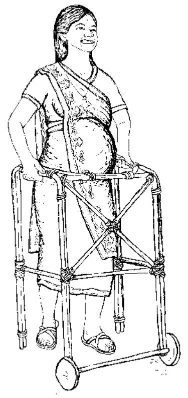
If your leg or part of your leg is amputated, and you use an artificial leg, you may find that the prosthesis will not fit properly because your body is heavier and the skin above your amputation has become swollen. If possible, talk with the person who made your artificial leg to see if it can be adjusted. If not, you may need to use crutches, a walker or a wheelchair while you are pregnant.

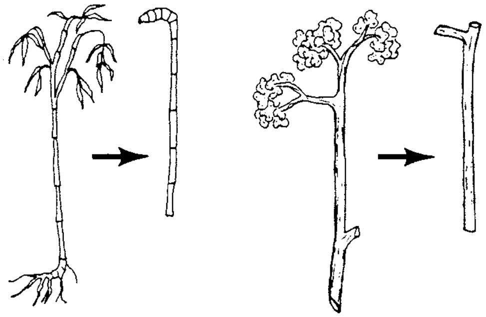
Some women who do not usually use a wheelchair will have to use one while pregnant. You may find it difficult at first to use a wheelchair, but with practice you will find it more comfortable than trying to get around without one.

What to do:

A 'walker' can be made from cane, rattan, bamboo or wood. Tie the joints with any strong string, twine or ribbon, or with strips of car tires or bicycle inner tubes.

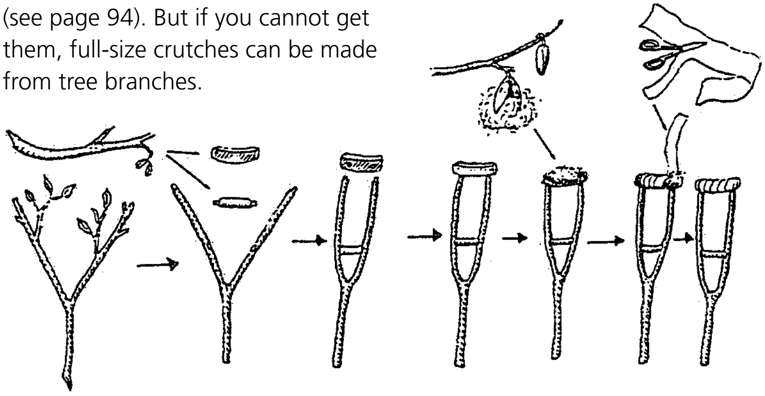
A walker with 2 front wheels is easier to move than a walker with no wheels, and is more stable than a walker with 4 wheels.

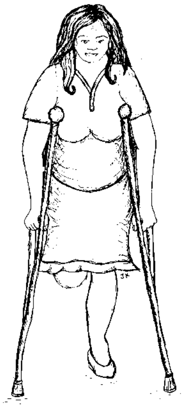




A cane or walking stick can be made from forest plants.

Elbow crutches are the best to use (see page 94). But if you cannot get them, full-size crutches can be made from tree branches.



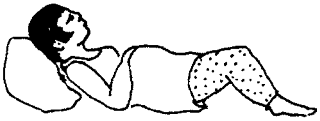


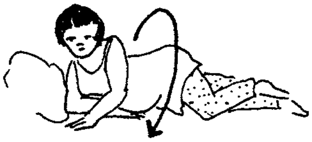
Moving during the last weeks of pregnancy

Even women who are not disabled often have difficulties with balance and with moving about during the last weeks of pregnancy. The difficulties are even worse for women with physical disabilities such as paralysis of the lower body, or limited control of muscles. Your large belly will affect daily activities such as washing yourself, dressing, and moving from place to place.

What to do:

Getting up from a lying down position will be easier if you:



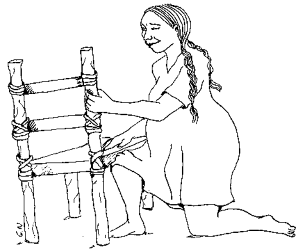


Turn to the side…

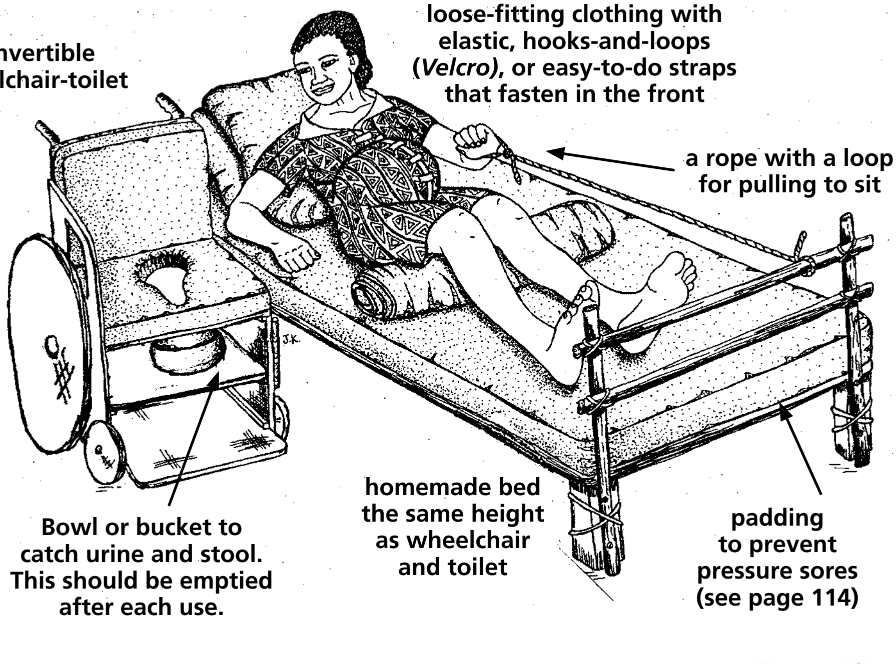
...then push up on the knees...

…then stand up.

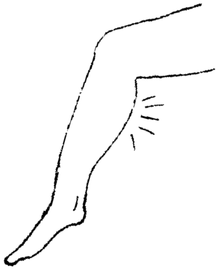
Also, getting up will be easier if you have a heavy chair or box close by to use for support.



A few simple aids can help many women with physical disabilities during the last weeks of pregnancy when movement is the most difficult.



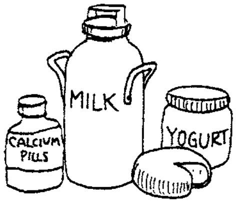
MUSCLE CRAMPS



These are strong, painful contractions of a muscle, usually in the lower leg, especially at night. If you touch the cramped muscle, it may feel like a hard lump. Leg cramps may be caused by not having enough calcium in the diet.

What to do:

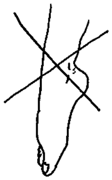
- Do not point the toes—even when stretching.



- Do stretching exercises regularly (see pages 90 to 95).
- Eat more foods with calcium, such as milk, cheese, yogurt, sesame seeds, and green leafy vegetables. Also, eat bananas.
- Sleep on your side with something soft like rolled-up cloth or newspaper between your knees and with your legs slightly bent.
- Do not lie down or sleep under heavy bed covers, and do not tuck covers tightly around your body.

If your foot or leg cramps:

point your toe up,



not down,

then stroke your leg.

Soaking your legs in warm water, or putting a cloth soaked in warm water on the cramping area may also help.

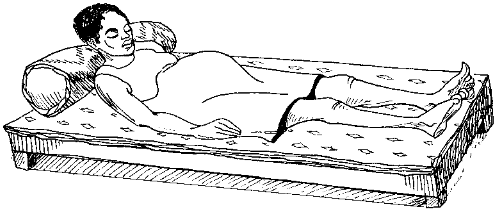
MUSCLE SPASMS

These are tightening or pulling of muscles that make it difficult for a person to control her movements. They happen most often to people with cerebral palsy or a spinal cord injury. Women with these injuries can have muscle spasms during labor (see page 243).

What to do:

- Do not pull or push directly against the tight muscles. This will make them worse.
- Gently hold and support the affected part until the muscle relaxes.

If the back or the whole body is affected by muscle spasms, put something under the head and shoulders to bend them forward a little. This helps to relax stiffness in the whole body.



- Apply warm soaks to the tight muscles or, if possible, sit or lie in warm water. Be careful not to burn the skin or overheat the body, especially if you cannot feel hot or cold things against your skin. Too much heat can cause damage to the unborn baby.
- Gentle stretching exercises done 2 to 3 times each day can help reduce tight muscles.
- Weight-bearing exercise, like standing up, also helps keep muscles strong and reduces muscle tightness.

Sitting in clean, warm water will help muscle spasms relax.

IMPORTANT As a general rule: **Do not massage spastic muscles.** In some countries, people and even therapists use massage or rubbing to relax spastic muscles. Although massage often helps relax muscle cramps, or tight muscles from other causes, in spasticity, massage usually increases the muscle tightness.

BACK PAIN

Most pregnant women, whether or not they have a disability, get back pain, especially in the weeks just before the baby is born when the belly is very big and heavy. Most often this is because the muscles in the belly are stretched and weakened during pregnancy, and the back muscles have to work harder.

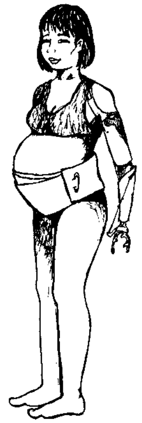
Women with some physical disabilities seem to get back pain that is more severe and that happens earlier in the pregnancy. Even women who have no feeling in the lower body often notice back pain while they are pregnant.

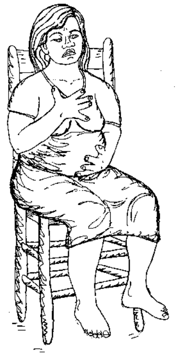
What to do:

- Exercise before, during, and after pregnancy to stretch and strengthen the muscles in the lower back and to keep the muscles in the belly strong. Swimming is a good way to reduce back pain and to stay strong.
- Sit in a straight-backed chair.
- Rest, heat, and massage on the painful area can help reduce back pain.

A binder of cloth may help to support your belly so it does not pull so much on your back muscles.

- Wind a piece of clean, thin cotton cloth, about 4 to 5 feet long (1½ meters) around your belly like this.
- Do not wind it so tight that it is uncomfortable.
- You can keep it in place with a safety pin, or you can tuck in the end of the cloth.





BREATHING DIFFICULTIES

As the baby grows, it pushes against the mother's lungs and she has less room in her chest to breathe. This is normal in pregnancy. But women with some physical disabilities, such as short stature (dwarfism) or paralysis of the chest muscles, can get short of breath earlier in the pregnancy than other women. The baby gets oxygen from the mother's lungs, so a pregnant woman must keep her lungs clear and healthy for the developing baby to get all the oxygen it needs.

What to do:

- Sleep sitting up a little. You will be more comfortable if you put something under your knees.
- Drink water often, at least 8 glasses a day. This will help mucus in the lungs stay loose so it is easier to cough up. Mucus in the lungs can cause an infection.
- Get regular exercise.
- If you start coughing up phlegm (mucus with pus), see a health worker. You may need to take medicine, like antibiotics. A health worker can help you decide which antibiotic or other medicine is safe to take while you are pregnant.

IMPORTANT If a mother is having difficulty breathing and is also weak and tired, or if she is short of breath all the time, she should see a health worker. She may have heart problems and need medical care. Or she could have anemia (see page 87), a poor diet, an infection, or she may be depressed (see page 54).

ACHES AND PAINS IN THE JOINTS

A pregnant woman's body gets soft and loose to make room for the baby to grow and to get ready to give birth. Sometimes her joints also get loose and uncomfortable, especially the hips. This usually happens during the last few weeks of the pregnancy. It is not dangerous and will get better after the birth.

What to do:

- Rest the painful joints. Move a little from time to time so that the joints will not get stiff, but your movements should be gentle.
- Applying cold or heat to the painful joint often reduces pain and makes movement easier. Usually cold works best on hot, inflamed joints, and heat on sore, stiff joints. Experiment to see which works best for you. If you cannot feel hot or cold things against your skin, be careful not to burn or freeze yourself.

For cold: Use ice wrapped in a cloth or towel for 10 to 15 minutes.

For heat: Use a thick cloth that has been soaked in clean hot water (squeeze out the extra water) and wrap it around the sore joint. Cover the cloth with a piece of thin plastic, and wrap with a thick dry cloth or towel to hold in the heat. When the wet cloth starts to get cool, put it back in the hot water and repeat.

Or fill a bottle (ceramic, plastic, or glass) with hot water, close it securely, wrap it in a cloth, and hold it against the painful area.

Heat will help ease sore and stiff joints.

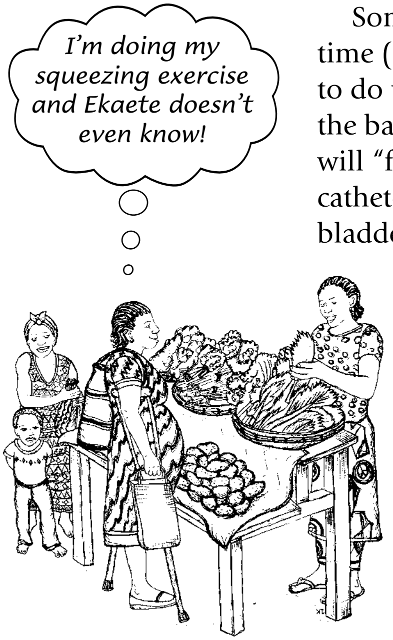
- Take paracetamol (acetaminophen) for pain, 500 mg every 3 to 4 hours. But do not take more than 8 tablets (4000 mg) in 24 hours (see page 350).

LEAKING URINE

Many women find that as their belly gets bigger, it gets harder to control leaking urine. During pregnancy, women with physical disabilities such as limited muscle control and paralysis or loss of feeling in the lower body often have more problems than other women with leaking urine.

As the baby grows and the mother's belly gets bigger, the baby may push against the bladder, leaving less room for urine. This can make urine leak out at times, especially when the woman coughs or sneezes. Sometimes the urine comes out so suddenly that it is hard to tell if it is urine or if the 'bag of waters' has broken. You may be able to tell by the smell if it urine or not. If this happens, watch for other signs of labor, and ask a health worker or midwife for advice.

If you normally use a catheter each time you want to pass urine, continue to do this if it does not cause you any problems. But if you find it too difficult to put a catheter in more times than usual, try using thick pads of cloth to catch the urine. These pads must be changed, washed and dried often to prevent a rash or an infection on the skin around your genitals (see pags 111 to 113). Make sure the pads are clean and dry before using them again.



Some women change to a catheter that is left in all the time (a 'fixed' or Foley catheter). But, if possible, try not to do this, because it may be difficult to change back after the baby is born. The muscles that control your bladder will "forget" how to hold the urine inside. Also, having a catheter in all the time can increase the risk of getting a bladder infection.

If you have trouble with leaking urine at night, use pads, or keep a bowl, bucket or something else close by to pass urine into. A convertible wheelchair-toilet may be a good solution (see page 224).

If you are able to use the muscles in the lower belly, the squeezing exercise (see page 101) sometimes helps to make the muscles around the bladder stronger. For more information on urine problems, see pages 105 to 106.

DIFFICULTY PASSING STOOL (CONSTIPATION)

Many pregnant women have trouble passing hard stools. Pregnancy can make the bowels work more slowly, and this can make the stool more difficult to pass. See page 108 for information on how to reduce and prevent constipation.

Women who use a 'bowel program' (see page 107) to pass stool may need to remove the stool more often while they are pregnant. Hard stool that is not removed can cause dysreflexia (see pages 117 to 119), which is very dangerous.

WARNING! **Pregnant women should not take medicines called laxatives or purgatives for constipation.** These work by making the bowels tighten or contract—and they may cause labor to start too soon. Some can harm the baby.

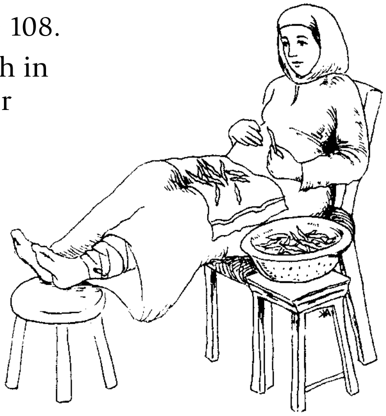
Also, pregnant women should not wash out the bowels with water (enema). This could also start labor too soon.

PILES (HEMORRHOIDS)

Hemorrhoids are swollen veins in and around the anus. They often itch, burn or bleed, and they can be very painful. Hemorrhoids sometimes look like large 'blood blisters.' Straining to pass stool when you are constipated makes them worse. Many women, both disabled and non-disabled, get hemorrhoids while they are pregnant. Sitting for a long time seems to make them worse.

What to do:

- Follow the advice for preventing constipation on page 108.
- To help shrink the hemorrhoids, soak some clean cloth in a drying (astringent) plant juice, such as witch hazel or cactus, and put it on the painful area.
- Use a cushion when sitting to reduce pressure.
- Try to move at least once every hour.
- If you lie down all the time, try to lie on your side, and have someone help you change position regularly.
- Sit or lean back with your feet and legs up. This will help your blood circulate better and heal the hemorrhoid more quickly.

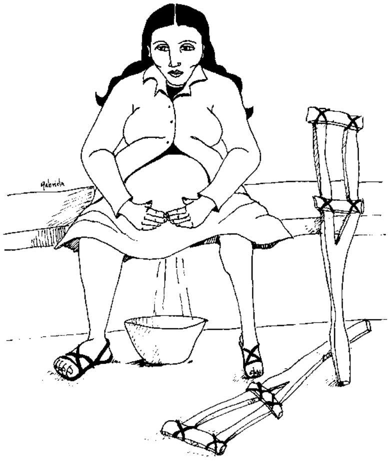


Common health problems

BLADDER INFECTIONS

During pregnancy, all women are more likely to get a bladder infection than at other times. As the womb grows larger, it presses against the bladder and may prevent all the urine from coming out. Germs can grow in the remaining urine and cause an infection.

Women with disabilities, such as limited muscle control, and paralysis or loss of feeling in the lower body, tend to have more problems than other women with leaking urine and infections of the bladder and kidneys. Bladder problems are a common cause of dysreflexia (see pages 117 to 119).



If you usually push on your belly to make urine come out, it is still OK to do this while you are pregnant. You will not harm the baby.

Women who use a "fixed" catheter may find that the urine stops coming out. This can happen if the expanding womb presses on the catheter and stops the urine flow. See a health worker.

If you can take care of a bladder infection right away, you may be able to prevent more serious problems, such as kidney infection and early labor. Watch carefully for signs of infection, and see a health worker if necessary.

To prevent urine infections while you are pregnant:

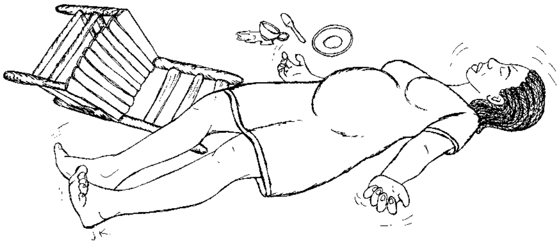
- drink plenty of water or fruit juices—at least 8 glasses a day.
- keep your genitals clean.
- pass urine after having sex.
- always wash your hands before using a catheter.
- clean your catheter more often (see pages 102 to 104).

One way to know if you are drinking enough liquid is to try to notice the color of your urine. If it is a dark yellow, you are probably not drinking enough. The urine should be light yellow, almost like water. Drinking lots of tea or coffee will not help because the caffeine in them will make you lose more fluid than you drink.

For more information on bladder and kidney infections, see pages 105 to 106.

SEIZURES (CONVULSIONS, "FITS," EPILEPSY)

It is hard to say whether a woman who has epilepsy will have more or fewer seizures while she is pregnant. If you are someone who gets seizures, you will know best how often you get them and how severe they are. Some antiseizure medicines, especially phenytoin (diphenylhydantoin, *Dilantin*), may increase the risk of birth defects when taken by a pregnant woman. But do not stop taking anti-seizure medicines while you are pregnant. This can make seizures worse and may even kill you. Talk with an experienced health worker or doctor who understands epilepsy and can help you decide about the best medicine to take. Phenobarbital (phenobarbitone, *Luminal*) is probably the safest anti-seizure medicine to take during pregnancy.



TOXEMIA OF PREGNANCY (PRE-ECLAMPSIA)

Some swelling in the legs and ankles is normal in pregnancy. But swelling of the hands and face can be a sign of pre-eclampsia (also called toxemia of pregnancy), especially if you also have headaches, blurred vision, or pains in your belly. Sudden weight gain, high blood pressure, and a lot of protein in the urine are also signs of toxemia. Toxemia can cause convulsions (seizures or 'fits'), and both you and the baby can die. Convulsions are different from the seizures caused by epilepsy (see page 231).

You may be at risk of toxemia if you or your mother or sisters have had it, or if it is your first pregnancy, or you are pregnant for the first time by a new partner. Toxemia is also more common for women who have high blood pressure, diabetes, kidney problems, for severe headaches, for women over 35, and for women expecting more than one baby.

If you have any signs of toxemia, go to a midwife or healthworker who can test you to see if you are in danger.

What to do:

- Stay quiet and in bed. Eat good, nutritious foods, especially foods rich in protein, but with only a little salt. Avoid salty foods.
- **If you do not get better quickly**, or if you have trouble seeing, or the swelling increases in your face, or if you have a seizure, **get medical help fast**. Your life is in danger.

PRESSURE SORES (BED SORES)

Women who sit or lie down most of the time can develop pressure sores easily if too much time passes without moving or changing position. This is especially true for women who are paralyzed and cannot feel pain. When you are pregnant, the extra weight puts even more pressure on the body parts where sores are the most likely to develop.

What to do:

Try to move or change your position more often than usual—at least once every hour. Check your skin over the pressure-sore areas more often than before you were pregnant. Also, see page 116 for information on preventing pressure sores.

HIV/AIDS and pregnancy

Although there is still no cure for HIV/AIDS, there are medicines that can help people with HIV/AIDS live much longer. They are the same medicines (called ARVs) that help prevent a pregnant woman from passing HIV to her baby during pregnancy, at birth, or while breastfeeding (see pages 358 to 362).

If you have HIV and you are pregnant, it is important for you to get treated for your disease as well as getting normal care for your pregnancy. Women who are infected with HIV can have more problems in their pregnancies, such as:

- miscarriage.
- fevers and infections.
- yeast infections of the vagina, mouth, or stomach.
- sexually transmitted infections.
- problems after the birth, such as bleeding and infection.

Try to find out if medicine is available to treat you, to prevent your baby from getting HIV, or to treat the baby early. If there is a well-equipped medical center in your area, it may be better for you to give birth there.

Working for change

What families and caregivers can do:

- Help us get enough food and rest.
- Be positive about the pregnancy.
- Make sure we get prenatal care and go with us to get exams.
- Be of assistance any time.

Women with disabilities have much the same concerns as other women who are pregnant. We want to have a healthy pregnancy and give birth to a healthy baby.

What midwives, doctors, and other health workers can do:

Health workers will be able to help us if we start going to see them early in our pregnancy, or even before we are pregnant. Because very few doctors, nurses, midwives, and other health workers have experience caring for women with disabilities, we can help them learn what is natural for us and how our disabilities may (or may not) affect pregnancy. Health workers can also:

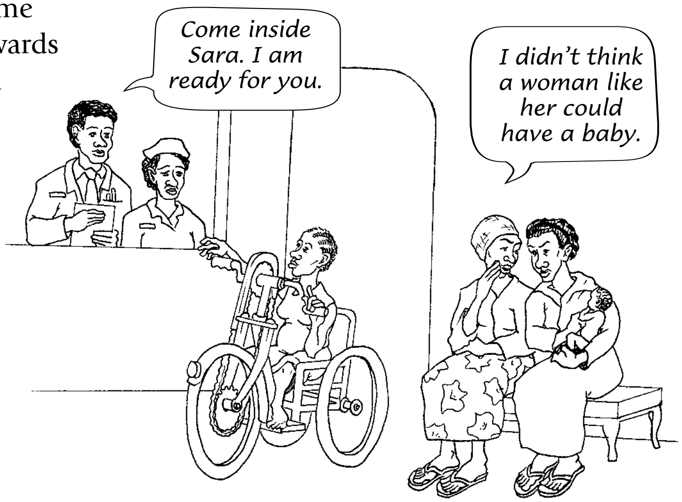
- learn about possible problems a woman with a disability may (or may not) have during pregnancy.

- be aware of things we can do. For example, do not assume we cannot have a vaginal birth. Remember, that just because a woman may have a disability, it does not mean her womb is damaged. Even if her body and legs are paralyzed, her womb will still be able to contract and push out a baby.
- organize a group for women with disabilities for advice on eating well, medicines and health exams during pregnancy.
- make sure we have easy-to-use health care during pregnancy.

Women with disabilities improve health access in Uganda

The Disabled Women's Network and Resource Organization in Uganda (DWNRO) works to help health professionals become more aware of the needs of women with disabilities. Their main concerns are accessibility, availability, and attitude. For example, when pregnant women with disabilities are treated poorly by hospital staff, they lose self-confidence and do not go back for prenatal care. They can have problems with the pregnancy later, or with the birth, that could have been prevented with regular checkups.

The DWNRO held regional workshops for doctors and midwives on the lack of access to hospital wards and services, such as postnatal care, weighing scales, exam tables, and adequate communication with deaf and blind women. Some hospitals have made wards more accessible, and a deaf women's group recently trained a groups of midwives in sign language. The DWNRO is now working to make women with disabilities aware of these services so they will demand them.



CHAPTER 11

Labor and birth

Giving birth is different for every woman. For most women it takes a lot of strength and concentration, and it is not unusual to feel exhausted after the baby is born. But the joy of holding the new baby makes most women forget the pain or discomfort they may have had.

Most babies are born without problems. So trust in your natural ability to give birth. But problems can arise and if they do, you will need skilled care.

In advance of the birth, speak with the person who will be delivering your baby to let her know of any special needs or concerns you may have. If you need help with daily care or communicating, you will need the same help during labor and birth.

Even after all the changes from pregnancy, you are still the person who understands your body the best. You can prevent many problems by learning about what will happen during birth, practicing ways of breathing during labor (see page 240), and trying different positions to find what is comfortable for you (see pages 240 to 241).

Try to have someone with you

Going through labor alone is hard for any woman. Try to have someone who knows you well (partner, family member, friend) with you from the beginning of labor until the baby is born. This person can:

- help reassure you that you are doing well.
- help you with your breathing.
- help you try different positions that feel the most comfortable for you.
- help explain to the midwife or doctor any concerns or problems you may have.

Labor and birth

Birth starts when the womb begins to contract and open. The time this takes can vary a lot. When it is the mother's first birth, this usually lasts 10 to 20 hours or more. In later births, it often lasts from 7 to 10 hours. When the cervix is fully open, it usually takes less than 2 hours to push the baby out. Birth ends when the after birth (placenta) comes out.

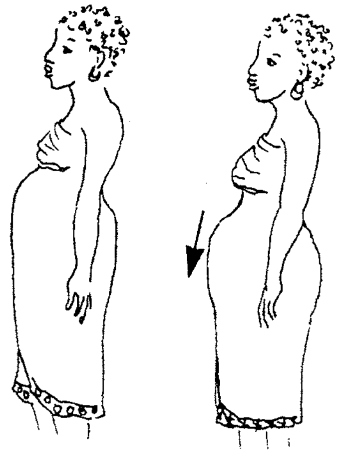
The length of time it takes for a woman with a disability—any disability—to give birth is no different from the time it takes any other woman, usually from 3 to 24 hours. What may be different is how she can tell that labor has begun, and the position she may need to be in during the delivery.

HOW TO TELL YOU ARE IN LABOR

Labor usually starts when you have been pregnant more than 8 months. The baby will drop lower in your belly, and you may find it easier to breathe.

During the last few weeks of pregnancy, most women feel the womb getting tight a few times a day, or maybe only a few times each week. These tight feelings are practice contractions and are not real labor. They may feel strange and last a few minutes. But they do not usually hurt, and they do not follow a regular pattern.

Even women who are paralyzed and have no feeling in the belly can usually tell when the baby is ready to come out. Although paralyzed women may not have real pain, the belly will feel different enough for them to know that something is changing.



About 2 weeks before birth, the baby often drops lower in the belly, especially first babies.

> ***To midwives and other health workers caring for women who have trouble learning or understanding:***
>
> Giving birth will be easier if you can help the mother-to-be prepare someone—her husband, mother, sister, aunt, or a good friend—to be with her during labor and birth. They can help with everything on page 235, as well as:
>
> - Hold her hand, ask how she feels, and help her understand what is going on.
> - Help her understand what the midwife wants her to do.
> - Help her practice different kinds of breathing during her pregnancy so she can do this during her labor (see page 240).

Signs that labor is near

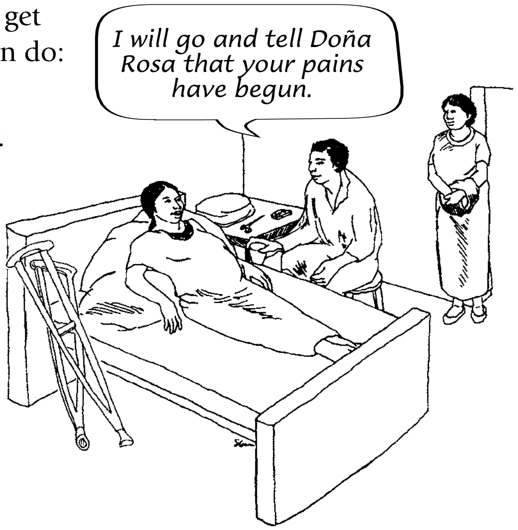
These 3 signs show that labor is starting or will start soon. They may not all happen, and they can happen in any order. If you have any of these signs, tell your birth attendant (health worker, midwife, doctor).

1. Clear or pink-colored mucus comes out of the vagina. During pregnancy, the opening to the womb (cervix) is plugged with thick mucus. This protects the baby and womb from infection. When the womb starts to open, it releases this plug of mucus and also a little blood.
2. Clear water comes out of the vagina. This is from the bag of waters that has surrounded and protected the baby in the womb. The bag of waters can break before labor begins, or at any time during labor.
3. The womb begins to contract and pains in the belly start. During a contraction, the womb will squeeze up and become hard, and then it will relax and become soft again. At first contractions may come 10 or 20 minutes apart or more. When contractions become regular (have about the same amount of time between each one), real labor has begun.

Contractions are usually painful, but if you have no feeling in your belly, you can usually see or feel the changes like this:

When any one of these signs occurs, it is time to get ready for the birth. Here is a list of things you can do:

- Let your midwife know that labor is starting.
- Make sure the supplies for the birth are ready.
- Wash yourself, especially your genitals.
- Continue to eat small meals.
- Drink plenty of fluids (water or juice).
- Rest while you can.
- Apply heat to your lower back, such as a warm cloth or towel. Or ask a friend to massage your back.



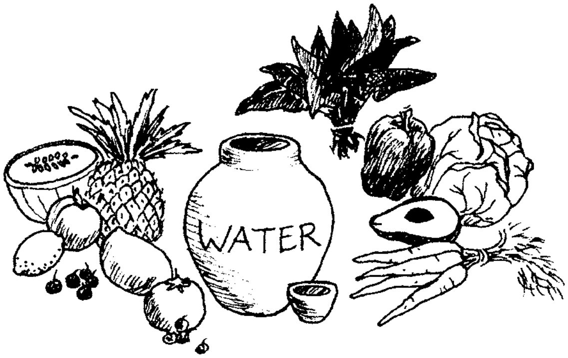
IMPORTANT INFORMATION ABOUT DYSREFLEXIA FOR WOMEN WITH SPINAL-CORD INJURY

If you have a fairly high spinal-cord injury (usually T6 and above), you can get a sudden, dangerous increase in blood pressure with pounding headaches and severe sweating (see pages 117 to 119). You may get these signs when you are in labor.

What to do:

See a health worker or midwife regularly so your blood pressure can be checked. This should be done at least once every week for the first 7 months, and then **every day for the last few weeks, before your labor starts**. This way they will be able to see if your blood pressure starts to get high.

Take care of your bowel program. This is especially important during pregnancy. Drink a lot of water and eat foods that will help you have easy bowel movements. Too much stool in your body can cause dysreflexia.



Make sure your bladder stays empty, because a full bladder can cause dysreflexia. If you use an indwelling (Foley) catheter, make sure it does not become twisted or bent and prevent the urine from coming out.

Look and feel for contractions a few times each day during the last weeks before the baby is due and watch for other signs that labor is starting (see pages 236 to 237).

As soon as you have any signs your labor is starting, go to a hospital or maternity clinic right away to give birth. You will need to have anesthesia injected in your spine. This is called an "epidural" and will prevent dysreflexia caused by labor contractions.

To midwives and other health workers caring for women with spinal-cord injury during pregnancy, labor, and birth:

Dysreflexia is a medical emergency. For more information, see pages 117 to 119. The high blood pressure can cause seizures or deadly bleeding inside the brain. Because of this, during the last 2 months of her pregnancy, make sure to check her blood pressure every day. Also, before her labor starts, it is best for a pregnant woman with a spinal cord injury to go to a hospital or clinic that can take care of the medical problems she may have during labor and birth.

To prevent dysreflexia during labor, she must have anesthesia injected in her spine (an epidural*)*. Also, it is important to:

- make sure she is not left alone.
- make sure she is not lying down flat, and that her head and shoulders are supported and her knees bent.
- measure her blood pressure frequently, at least once every 10 minutes.
- If she needs to pass stool, be very careful if you remove the stool with a finger, or give her an enema to remove stool. Removing the stool can start dysreflexia. Apply lidocaine gel (2% to 4%) to the rectum first.
- keep her bladder empty. If necessary, put in a catheter to drain the urine (see pages 103 to 104). Apply lidocaine gel to the urine hole before putting in the catheter.

HOW TO MAKE LABOR EASIER

Make sure you pass urine. Try to pass urine at least once every hour. You will be more comfortable if your bladder is empty. Also, women with a spinal cord injury will be less likely to get dysreflexia if a catheter is left in place all during the labor and delivery so that urine can drain out.

You will probably sweat a lot during labor. So it is important to drink water, juices, or herbal tea when you can so you do not become dehydrated.

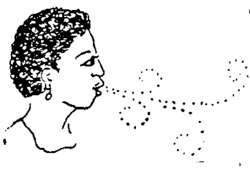
Change your position several times, at least once every hour. Practice ahead of time moving from one position to another so that when labor starts, you can change position more easily between contractions. Ask someone to help if necessary. The more comfortable and relaxed you are, the more relaxed your muscles will be, so it is less likely that they will cramp or spasm. Also, when you change your position often, you will be less likely to develop pressure sores.

Walk around between contractions if you can. Walking helps the womb open and the baby move down.

Breathing during labor

The way you breathe can have a strong effect on how your labor will feel. You can practice different ways of breathing throughout your pregnancy so you will be ready when labor starts. For example:

- **Slow, gentle breathing:** Breathe in through your nose to take a long, slow breath. To breathe out, make a kiss with your lips and slowly blow.



- **Hee breathing:** Take a slow deep breath and then blow out short, quick breaths while you make soft "hee, hee" sounds.
- **Panting:** Take quick, shallow breaths.
- **Strong blowing:** Blow hard and fast.

During labor you can choose whichever breathing methods help you the most.

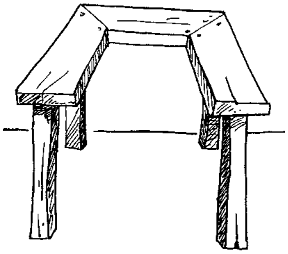
Birthing positions

These positions can be used during both labor and birth:

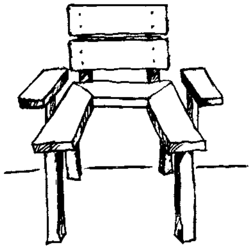
If you have little or no leg or arm control, you can sit on a lap.

Or you can rest on cushions in a half-sitting position.

If you have good arm and hand control, you can use a birthing chair like this. (For another example, see Fatuma's story on page 242.)

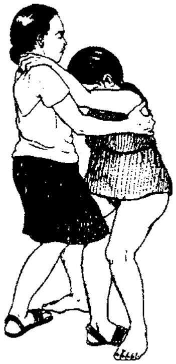


Or you can use a birthing chair with arm and back support, like this.

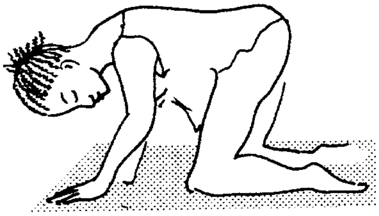


With help, a woman with some leg control can squat...

...or stand.



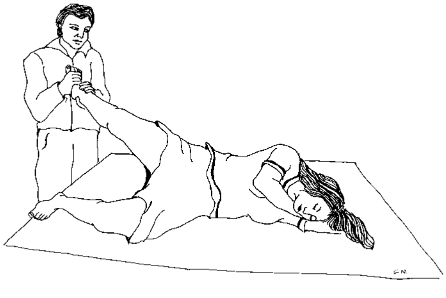
The person or object that supports you must be strong and balanced. You can also hold onto the back of a chair. The squatting or standing positions can help bring the baby down when the birth is slow, or if the mother is having trouble with pushing.



If you have some leg and arm control, you may want to try the hands-and-knees position. This position sometimes also helps prevent and control muscle spasms.

If you have little or no leg control, you can lie on your side while someone holds your top leg, with your legs bent...

....or straight.

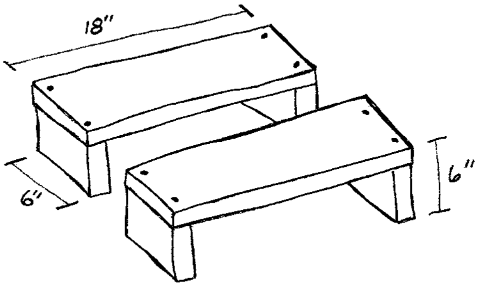


If you are blind or have poor balance, you may feel safer lying on the floor. Most hospital and health centers have special beds for women giving birth. These beds have knee supports and can be useful for women with poor leg control.

Fatuma's birthing stool

Fatuma Achan lives in Uganda and is paralyzed in both legs from having had polio as a child. When Fatuma became pregnant, like most disabled women, she was told by the doctors at the local clinic she had to give birth by an operation (a Cesarean section, or c-section).

Fatuma was determined not to have an operation but to go through normal labor. Other women in her community sometimes gave birth by squatting. Because her legs were paralyzed, Fatuma knew that she would not be able to hold herself in the squatting position. But she also knew her arms were very strong from pushing her wheelchair all the time. So she built a birthing stool which enabled her to stay in the squatting position. This way her baby could still be born through the vagina.

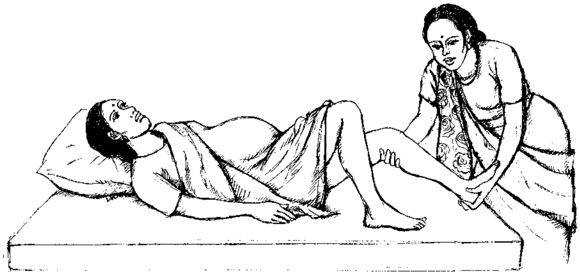


An easy-to-make wooden birthing stool

Even though Fatuma is paralyzed, her womb is still strong and can squeeze itself (contract) to push out a baby. The position of her body on the birthing stool helps the baby drop down gently out of her body through the vagina, just as it does for other women who squat during birth.

For muscle cramps and spasms (sudden stiff muscles) during labor and birth

Women with cerebral palsy, a spinal cord injury, or who are paralyzed from polio can get cramps or tight spastic muscles at any time during labor and delivery. Tight muscles in any part of the body are affected by the position of the head and body. Pulling or pushing directly against the spastic muscles will cause them to tighten more. Here are some suggestions for softening spastic muscles during labor:

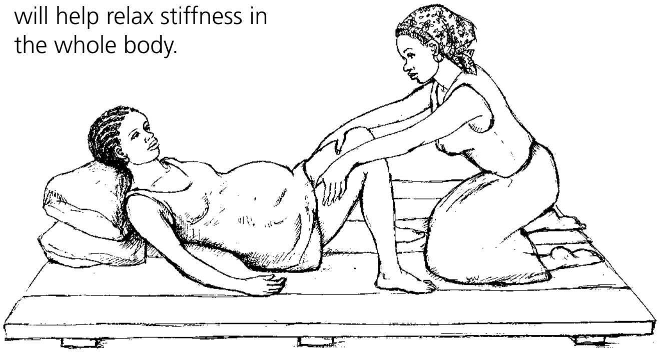


Throughout labor, do range-of-motion exercises (see page 95) between contractions. If necessary, have someone help. The exercises will keep muscles loose and help prevent cramps and spasms.

To help the muscles relax, sit in a bath of clean warm water, but only before the bag of waters has broken.

Cloth soaked in clean, warm water may help.

Put something under the head and shoulders to bend them forward. This will help relax stiffness in the whole body.



Do not try to pull a woman's legs apart at the ankles. This will make her legs pull together more tightly. Instead, after lifting her head and shoulders, bend her legs. To separate her legs, first bring the knees together. This may unlock the legs. If not, hold the legs above the knees and they will open more easily.

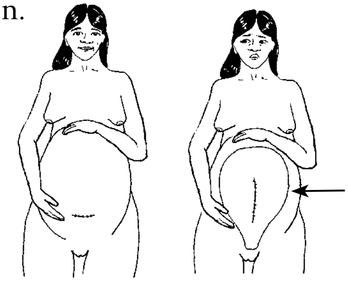
Birth by operation (Cesarean section, c-section)

When complications make it dangerous for a woman or her baby to go through normal labor and birth, a doctor may make a cut in the woman's belly and womb and bring the baby out. The doctor then sews the womb and belly closed (the womb is not removed). The operation leaves one scar on the womb and a second scar on the belly. This operation is called a Cesarean section, or c-section.

Most pregnant women with physical disabilities, especially those who are paralyzed, are told by doctors and health workers that they MUST give birth by c-section. This is not always true. With a little help, it is possible for most women who have a physical disability, or have no feeling in the belly, to give birth through the vagina. No matter what sort of disability a woman has, the muscles of the womb will still contract by themselves to push the baby out. For information on particular disabilities that may cause problems during childbirth, see page 213.

Sometimes it is necessary for a woman to have a c-section, especially if:

- the baby is big or in a difficult birth position.
- the woman has a pelvic deformity.
- she has a curve in her spine.
- she is unable to move her legs apart.
- her pelvis is small, and the baby is big.
- she is not strong enough for labor.



A scar on the womb like this is more likely to open up in labor.

A scar that goes one way on the outside...

...may be hiding a scar on the womb that goes another way.

Even though a c-section is sometimes necessary, if possible it is best to avoid this operation. It is most often done because it is easier for the doctor. In addition, it is expensive, there is always a possibility that something will go wrong, and it takes longer to recover than from a regular birth.

Many women who have had a baby delivered by c-section are able to give birth the next time through the vagina. This is especially true if the cut from the c-section was made across the lower belly from side to side, and not up and down. An up-and-down scar is more likely to open up during labor.

Even with the scar across the belly, there is a very small chance that the scar on the womb will tear open during labor. If this happens, the woman can bleed inside and die. Although she may not need another operation to give birth, **it is safest for a woman with a past c-section to give birth in a hospital**, in case there are problems. If this is not possible, she should try to give birth near a hospital. And before the birth, try to arrange to have hospital care in case there are any problems during the labor.

FEMALE GENITAL CUTTING (FGC, FEMALE CIRCUMCISION)

In some communities—mostly in Africa, but also in parts of South Asia, the Middle East, and other parts of the world—girls and young women are cut on their genitals. Like many cultural practices, female genital cutting is a way that girls' bodies are changed so they are considered beautiful, acceptable, or clean. But while this tradition may be meaningful for the community where it is practiced, female genital cutting has serious harmful effects on the health and well-being of the girls who are cut. In the long term, female genital cutting can lead to urinary infections, emotional damage, loss of sexual sensation or ability to have sex as an adult, and long, difficult labors which can lead to death of the baby or the mother. If you are a woman who has had your genitals cut and then sewn partially closed, talk with an experienced midwife or health worker. Your genitals will need to be cut open before you give birth.

Danger signs during labor

Most women, including women with disabilities, give birth safely. But when something goes wrong during labor and birth, it is very important for a woman to get the care she needs to save her life. (For more information about safe labor and birth and the problems that can arise, see *A Book for Midwives.*) Here are some of the danger signs that can let you know when to get help:

Waters break but labor does not start within 24 hours

Go to a health center or hospital. When the waters have broken, the risk is much higher that you or your baby could get a serious infection. You may need to get fluids or medicines in the vein (intravenous, IV).

Baby lying sideways

Go to a hospital. Do not try to change the position of the baby once labor has started. This can tear the womb or separate the placenta from the womb wall. A baby lying sideways cannot be born without an operation.

Bleeding before the baby is born

Go to the hospital right away. If you are bleeding bright red blood, it could mean the placenta is separating from the womb wall or is covering the opening of the womb. This is very dangerous.

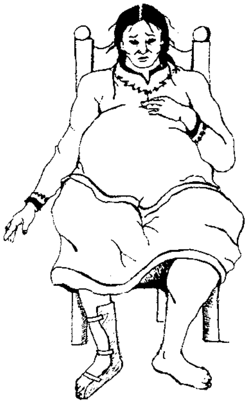
Fever

Fever is usually a sign of infection. If your fever is not very strong, you may just need fluids. Drink plenty of water, tea, or juice, and try to pass urine every few hours.

If your fever is very high and you have chills, **go to a health center or hospital**. You need antibiotic medicines right away.

Too long labor

Go to a health center or hospital. When labor lasts longer than 1 day and 1 night, or if you are pushing hard for more than 2 hours, you may need medicines or an operation for the baby to be born.



A woman in labor should not see the sun rise twice. —Proverb from Niger

Green or brown waters

If it is still early labor, or if the mother has not started pushing, it is best for this baby to be born in a hospital. When the bag of waters breaks (see page 237), the water should be clear or a little pink. Brown or green waters mean the baby has probably passed stool inside the womb and could be in trouble.

If the mother is far along in her labor and the baby is going to be born soon, have the mother push as hard as she can and get the baby out quickly. As soon as the baby's head is out, and before it takes its first breath, ask the mother to stop pushing. Wipe the baby's mouth and nose with a finger wrapped in a clean cloth, or use a suction bulb to suck out the mucus. Once the nose and mouth have been cleaned out, the mother can push the rest of the baby's body out.

Pre-eclampsia (toxemia of pregnancy)

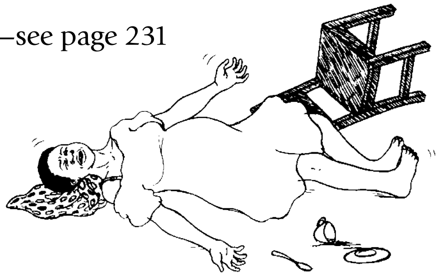
Pre-eclampsia can lead to seizures and even death. If the mother has any of these danger signs, **go to a hospital right away:**

- strong headache
- blurred or double vision
- sudden, steady severe pain at the top of the belly, just below the high point between the ribs
- overactive reflexes
- high blood pressure
- protein in the urine

If the mother starts to have a seizure and you know she does not have epilepsy:

- Put something under her head to protect it, and put her on her left side if possible. But do not try to hold her down.
- Keep her cool.
- **Take her to the nearest hospital.**

A woman who has epilepsy can also get toxemia—see page 231 for more information about epilepsy.



Danger signs for the mother in the first few days after birth

Bleeding

Start breastfeeding your baby right away. This will help you stop bleeding sooner.

Bleeding that starts more than a day after the baby is born is usually caused by pieces of the placenta that have been left in the womb. **Get medical help.**

Danger signs of too much bleeding:

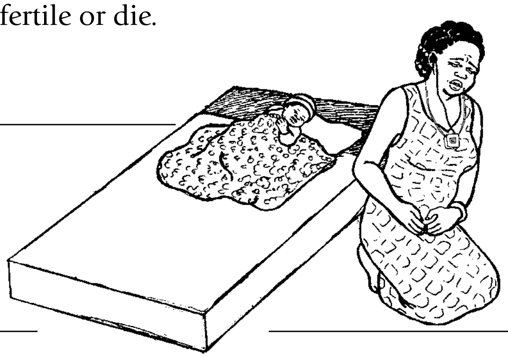
- soaks more than 2 pads or thick rags in an hour during the first day after birth
- soaks more than 1 pad or thick rag in an hour after the first day
- a continuous small flow of blood

What to do:

1. Rub the top of her womb until it gets very hard and the bleeding stops. Have the baby suck on her breasts, or have someone roll her nipples.
2. Give 0.2 mg of ergonovine by mouth every 6 hours as needed, but no more than for 4 to 7 days.
3. If the bleeding will not stop, get medical help. Continue to rub her womb as you take her to the hospital.
4. If she has signs of infection, give the same antibiotics as for womb infection on page 248.

Womb infection

Infection of the womb is very dangerous. If not treated, a woman can become infertile or die.



Danger signs of womb infection:

- fever and chills
- pain and tenderness in the belly
- bad-smelling fluid from the vagina

If the mother complains that she does not feel well, watch her carefully for signs of infection.

Medicines for womb infection

Medicine	How much to take	When to take
ciprofloxacin	500 mg	by mouth, 2 times a day
and doxycycline	100 mg	by mouth, 2 times a day
and metronidazole	500 mg	by mouth, 2 times a day

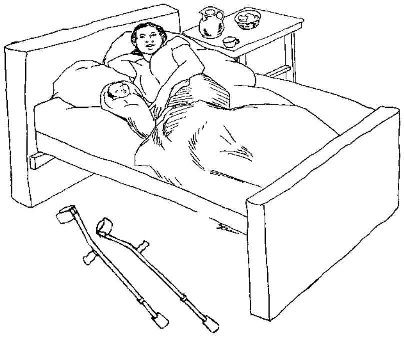
Continue giving all of the medicines for 2 more days after the fever is gone. But if she does not start to feel better after 1 day, take her to the nearest hospital. She may need other medicines by injection or in the vein (IV).

IMPORTANT Encourage her to drink a lot of fluids. Do not drink alcohol during the time you are taking metronidazole.

Care for a new mother

Mothers need care after birth just as the baby does. People are often so busy looking after the baby that the mother's needs may be forgotten. Share this information with your family or caregivers so they can help you get the care you need.

- **To prevent infection,** do not have sex or put anything in your vagina until your bleeding stops. Bathe as often as you usually do, but do not sit in water until 1 week after the birth. It is good for you to wash and to keep your genitals very clean.
- **Get a lot of rest for at least 6 weeks.**
- **Eat more food than usual**. You can eat any kind of food: fish, meat, eggs, beans, grains, vegetables, and fruit will all help you heal from the birth and will give you energy to care for your baby and yourself. Eating food high in fiber will help prevent constipation.
- **Drink plenty of fluids.** This will also help prevent constipation.
- Be as active and move about as much as you can.



- If your breasts become very swollen, hard, and sore, feed the baby as often as possible, both day and night (every 1 or 2 hours, and on both breasts). Also, place warm, wet cloths on your breasts for 15 to 20 minutes before each feeding. You can take paracetamol for pain (see page 350).
- If you do not plan to breastfeed, do not try to remove the milk from your breasts. If you do, your body will keep making more milk. Instead, wrap a length of cloth firmly around your body, over your breasts, and apply cold cloths or ice. You can also take paracetamol for pain (see page 350).
- If you have any tears in your genitals or vagina, wash them every day with mild soap and clean water to prevent infection. Apply a hot, damp cloth and honey to the tear to help it feel better and heal more quickly. After a week, you can also sit in a bowl of clean, warm water with a little salt in it. If the tear causes burning, pour water over your genitals while you pass urine.
- If you use plant medicines to help your genitals heal, make sure the plants are very clean (boiled is best). **Do not put plant medicines, or anything else, inside your vagina.**
- Start using a family planning method before you have sex again, or you could become pregnant again right away. You can get pregnant 2 weeks **before** your monthly bleeding starts again. If you are feeding your baby nothing but your breastmilk, the breastfeeding will usually protect you from getting pregnant again for about 6 months. For information on family planning, see Chapter 9.

IF YOU FEEL VERY UPSET OR SAD

Most women feel strong emotions after giving birth. If you feel this way, health workers and your family may think it is because you have a disability, especially if you find it harder than usual to take care of yourself and do not seem to be able to take care of your baby. They may not realize any new mother may feel sad or worried for a few days, weeks, or even months. When these feelings are very strong, and if you are not able to sleep or eat very well, and cry a lot, it is called depression. A woman who had feelings like this after a previous birth is more likely to feel depressed again.

You will feel better if you can talk to someone you trust about your feelings. You may also need extra help to take care of yourself, your home, and your baby.

There are also some traditional rituals and remedies, as well as modern medicines, to help you feel better. The modern medicines are expensive and can cause other problems, so they should be taken only in extreme cases. Talk to your midwife or health worker. For more information about mental health, see Chapter 3.

Care for a new baby

Breastmilk is the best food for your baby. Keep your baby warm and clean and let it suckle as often as it likes.

Babies often have a little yellowish mucus coming from their eyes in the first weeks after birth. You can wash out the eyes with breast milk or cool, boiled water and a clean cloth. If the baby's eyes get red, swollen, or have a lot of pus in them, take the baby to a health worker.

Care of the cord

Keep the cord stump on the baby clean and dry. If possible, clean it with alcohol and a clean cloth with every diaper (nappy) change. It will turn black and fall off during the first week. You do not need to cover it with anything unless there are flies or dust. Then you can use a very clean piece of gauze or cloth to cover it loosely.

If you notice redness or pus around the cord, the baby may have an infection. Take the baby to a health worker for medicines right away. Watch for signs of tetanus, an infection babies can get if the cord is cut with something that is not clean.

TETANUS OF THE NEWBORN

Take the baby to a health center or hospital right away. If the hospital is more than 2 hours away, give the baby an injection of 100,000 Units of benzylpencillin before leaving.

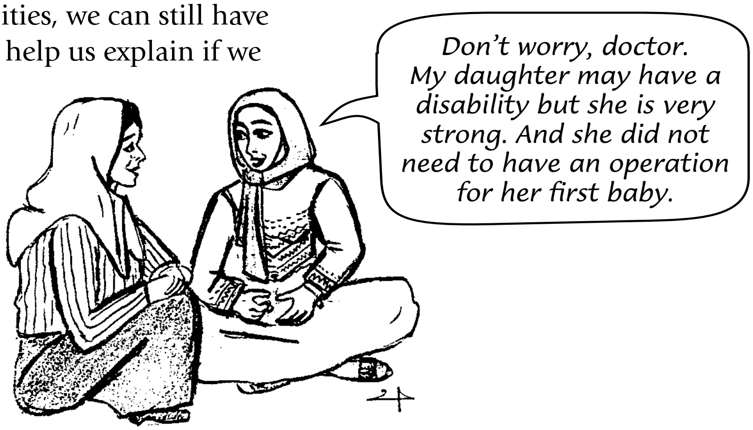
Danger signs of tetanus in the newborn

- fever
- baby cannot suckle the breast
- baby cries all the time
- fast breathing
- baby's body gets stiff

Working for change

What families and caregivers can do:

After ourselves, our families understand our disabilities better than anyone else. This means they can be a great help to us during both labor and birth. They can make sure the midwife or health worker delivering the baby understands that just because we may have disabilities, we can still have vaginal births. They can also help us explain if we need to try alternative positions for the birth. And when the baby is born, they can make sure we can hold and bond with the baby, no matter how much assistance we may need.



What midwives, doctors, and other health workers can do:

- Make sure the rooms or spaces where women give birth in the clinic or hospital are easy for us to get to. For example, if the birthing room is upstairs, make a room on the ground floor available for births.
- Make sure all beds and exam tables are low to the ground and do not have wheels.
- Make sure the baby of a deaf or blind woman stays very close to her. Then, even if the mother cannot hear or see her baby, she will know if he needs to be fed or comforted.
- Both the mother and baby will benefit from the care of a health worker after the birth. Visit a new mother and her baby at least 2 times—the day after the birth, and then again at least once in the following week.
- Help the new mother with the legal requirements in her community to register the birth of her child.

CHAPTER 12

Caring for your baby

The constant attention and care a new baby needs can be very tiring and frustrating. Almost all mothers rely on family, friends, neighbors, child-care workers, and teachers to help.

Some women with disabilities will learn quickly to take care of a baby. But if your disability means you need help with your daily work, you will probably also need help caring for the daily needs of your baby. Newborn babies need to be fed and changed often. So do not get discouraged if you need to ask for help. All new mothers get assistance if they can to help with the baby.

No matter how much help you may need, you are still your baby's mother. Allowing someone to help you care for your baby does not make you any less of a mother. Even when you ask another person to be your eyes, ears, arms, or legs, you are the one deciding about how to meet your baby's needs, her safety, and her well-being. That is what a mother does. Keeping the baby close to you, day and night, so she can see your face, hear your voice, and feel and smell your body, will assure that your baby knows who her mother is—you!

BUILDING A RELATIONSHIP FOR LIFE

The relationship a baby develops with her mother or main caregiver affects the baby's physical and emotional development. As a close relationship is formed, a baby learns to find security in it and it will be easier for the baby to form new relationships with other people later on. While other family members can help you look after the baby, it is important for you to be recognized as the main caregiver so you can form this deep bond with your baby.

Women who have trouble learning or understanding

Many women who have trouble learning or understanding are good mothers. You can discuss with your family what things you may need help with to be a good mother to your baby.

Things to think about

Small babies need to be fed and cared for day and night, and you will not be able to get much sleep. So even though your baby will probably wake you up several times during the night, and you will most likely feel very tired during the day, your baby will still need to be taken care of. Will you be able to ask for help to:

- keep the baby clean.
- know when the baby needs medical care.
- measure medicines, if necessary.
- make sure the baby is safe from:
    - — falling.
    - — getting burned.
    - — animals.
    - — poisons.
    - — swallowing something and choking.
    - — accidents that may break a bone or cut the skin.

If you can breastfeed, there will be no need to prepare formula. But if you do not breastfeed, you will need to make sure bottles are clean and the formula or alternative milk is prepared properly.

Breastfeeding the baby

Breast is best!

If possible, breastfeed your baby. Colostrum, the first yellow-colored milk that comes out of the breasts for the first 2 or 3 days after birth, is the best possible food for the baby. It is good for the baby's stomach, has all the nutrition a new baby needs, and protects against disease. Babies who breastfeed as often as they want **do not need herbs or teas or sugar water**. If possible, give your baby nothing but breast milk for the first 6 months. If it is too difficult to breastfeed your baby, remove the milk from your breasts by hand (see pages 257 to 258) so it can be fed to the baby by another method.

Feeding a baby breast milk is important because:

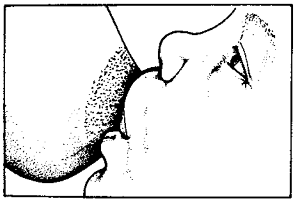
- breast milk is the perfect food to help a baby grow healthy and strong.
- breastfeeding helps the mother's womb stop bleeding after birth.
- breast milk passes on to the baby the mother's defenses against illnesses such as diabetes and cancer, and infections like diarrhea and pneumonia.
- breastfeeding helps the mother and baby feel close and secure.
- breastfeeding can prevent some women from becoming pregnant again during the first 6 months (see page 199).
- breast milk is free.

Most women with disabilities can breastfeed their babies. Some disabled women need help holding the baby in a good position. Others may not produce enough milk. Some disabilities make women feel too weak and tired. You must decide for yourself whether or not you can breastfeed your baby.

HOW TO BREASTFEED

Most babies are born knowing how to suck. But they may need help getting enough of the nipple in the mouth. The baby should have a big mouthful of the breast with the nipple deep inside.

This baby has a good mouthful of breast.



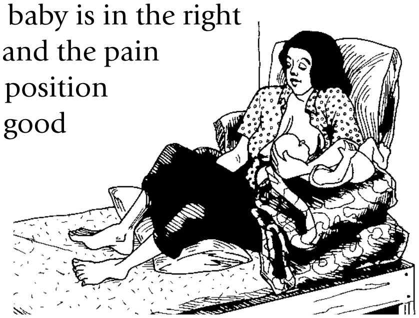
This baby does not have enough breast in its mouth.

HOW TO HOLD THE BABY

Breastfeeding can be painful at first. But if the baby is in the right position, you will get used to the baby's sucking and the pain should go away. If it does not, try changing your position or the baby's position. Make sure the baby has a good mouthful of the breast. If breastfeeding is still painful, talk with a health worker. There could be another problem.

Most women learn to breastfeed their babies by watching other women in the family and community. If another woman in the community has your disability and is already a mother, ask her for advice.

Many disabled women can breastfeed their babies if they find a comfortable position.

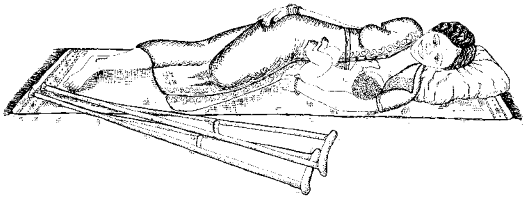


Some women find breastfeeding easier if they sit in a chair or bed where they can lean back a little and also support their arms. It also helps to rest your feet on something. Make sure the baby is well supported too.

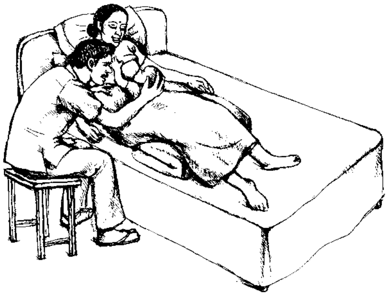
Use pillows or some rolled-up cloth under the baby.

If you have good use of your arms and upper body, you should be able to breastfeed the baby with no problems. Make sure the baby, especially the baby's head, is well supported and that you sit or lie in a position that is comfortable for you.

If you have limited use of your arms and upper body, try to find at least one comfortable position for breastfeeding. Ask someone to help you if necessary. Here are some suggestions:

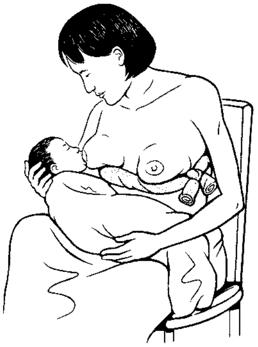


Many women find it easier to lie on their sides with their babies beside them supported by pillows or rolled-up cloth.



If you cannot use your arms and upper body, you can breastfeed with help from family members or friends. Explain to them how to position the baby so that you can breastfeed. If necessary, ask them to hold the baby in position, especially the baby's head. Even though you are not holding the baby in your arms, the baby will still be able to see your face and feel the warmth and familiar smell of your body.

If it is difficult for you to hold your breast, wear a bra (brassiere) with a wide hole cut around the entire nipple. You may be able to buy a 'nursing bra' made to support the breasts and with a way to cover and uncover the nipple for breastfeeding. Or you can wrap some cloth around your chest and across your breast with a hole cut out to expose the nipple. You can also tie a length of rolled-up cloth around your upper body under your breasts.

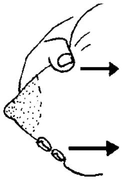


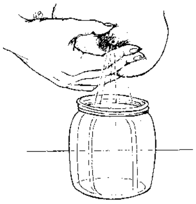
If you cannot breastfeed

If you are unable to breastfeed your baby, you may be able to remove milk from your breasts by hand and feed it to your baby using a bottle or a cup. If you cannot remove the milk by yourself, ask someone you trust to help you.

How to remove milk by hand:

1. Wash a jar and lid with soap and clean water, and leave them in the sun to dry. If possible, pour some boiling water into the jar and then pour it out just before using it. This will kill germs in the jar and keep the milk safe for the baby.
2. Wash your hands well.
3. Put your fingers and thumb at the edge of the dark part of the breast (areola), and press in toward the chest.





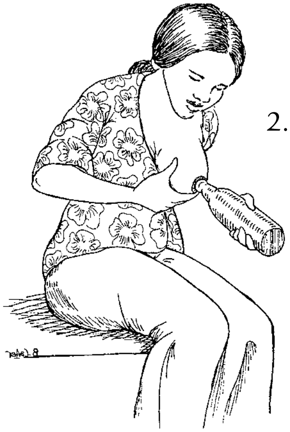
4. Gently press the fingers together and roll them toward the nipple. Do not pinch or pull the nipple. Removing milk should not hurt.
5. Move your fingers all the way around the areola so the milk can come out of the whole breast. Do this with each breast until it is empty.

At first, not much milk will come out, but with practice, more will come. If possible, try to remove milk every 3 to 4 hours, at least 8 times in 24 hours to make sure there is a good supply. You can usually remove more milk if you are in a quiet, calm place and feel relaxed. Thinking about your baby while you remove your milk may help the milk flow for you. If it is hard to start the flow, try putting warm, moist cloths or towels on your breasts and massage them before trying to remove the milk.

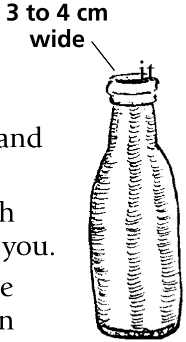
You may be able to get a breast pump to help you remove milk more easily. Some clinics and medical centers loan or rent out electric pumps. They may also sell simple hand pumps at low cost.

Warm-bottle method to remove milk

This method may work best if the breasts are too full or very painful. This may happen right after birth, or if you get a cracked nipple or a breast infection. If you cannot hold your breast or the bottle, ask someone you trust to help.



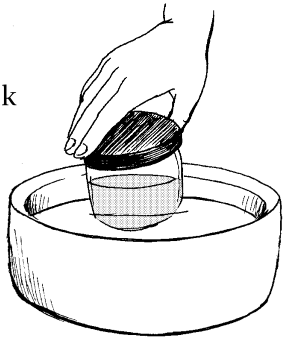
1. Clean a large glass bottle that has a 3 to 4 cm wide mouth. Warm it by filling it with hot water. Fill it slowly so the bottle does not break. Wait a few minutes and then pour the water out.
2. Cool the mouth and neck of the bottle with clean, cool water so that it does not burn you.
3. Fasten the bottle mouth over your nipple so that it makes a seal. Hold it firmly in place for several minutes. As it cools, it will gently pull the milk out.
4. When the milk flow slows down, use your finger to loosen the seal around the breast.
5. Repeat on the other breast.



How to store breast milk

Keep your milk in a clean, closed container. You can store milk in the same jar used to remove the milk. Keep the milk in a cool place away from sunlight.

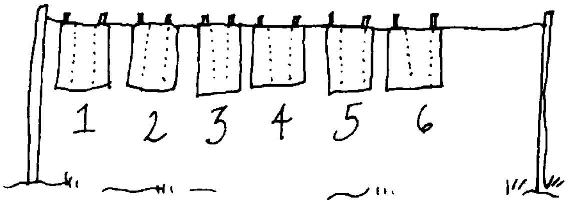
You can keep milk cool by keeping the container in cool water, or burying the closed container in wet sand, or keeping it wrapped in a cloth that is kept wet all the time. Cool breastmilk will keep for about 12 hours.



The container can be stored longer in a cool place such as a clay pot with cool water in it.

If you have a refrigerator, keep the milk there. Milk can be kept in a glass jar in a refrigerator for 2 or 3 days. The cream in the milk will separate, so before giving it to the baby, shake the container to mix the milk. Then gently heat the container with the milk by putting it in a pot of hot water. Test the milk to make sure it is not too hot by shaking a few drops onto your arm. The milk should not be hot, but should feel the same temperature as your skin.

WARNING! Milk that cannot be kept cold will spoil and should be thrown out. **Spoiled milk can make a baby very sick.**



The baby is getting enough breastmilk if he gains weight and passes urine at least 6 times a day.

Problems with breastfeeding

PAINFUL BREASTS

Pain in the breast can be caused by a sore nipple or breasts that get very full and hard. The pain will often go away in a day or two. It is important to keep breastfeeding the baby even it if hurts, and to let the baby suckle often. It also helps to change the baby's position each time she nurses.

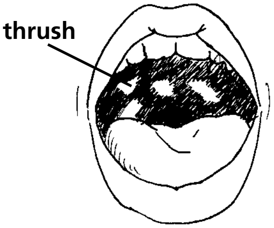
Sore or cracked nipples

Sore or cracked nipples can develop when the baby sucks only the nipple instead of taking the nipple and part of the breast into her mouth when she is breastfeeding (see page 255).

Prevention and Treatment:

- Let the baby feed as long and as often as she wants.
- When the baby has stopped feeding, squeeze out a few drops of milk and rub them on your nipples.
- Do not use soap or cream on your breasts, unless you have an infection. Your body makes a natural oil that keeps the nipples clean and soft.
- Avoid tight or rough clothing.
- If the pain is too great when the baby suckles, remove your milk by hand and feed the baby with a cup and spoon. A crack in your nipple should heal in 2 days.
- Do not let your breasts get hard and overfull. If you have more milk than the baby can drink, cover your breasts with warm cloths or towels and empty your breasts by hand (see pages 257 to 258) after the baby is full. After a few weeks you body will usually make just the right amount of milk, and your breasts will not get too full.

Thrush



If a baby is in a good position while suckling and you still have pain in the nipples that lasts for more than a week, it may be caused by thrush (a yeast infection on the nipple or in the baby's mouth). Your nipples may itch or you may feel a stabbing, burning pain. The baby may have white spots or redness in her mouth. She will be fussy if her mouth hurts.

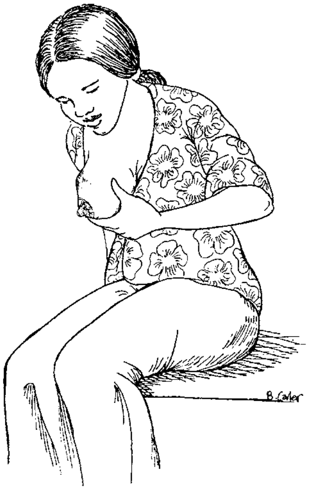
Thrush can lead to sore and cracked nipples and breast infection. Both mother and baby should be treated.

How to treat thrush

Mix gentian violet (see page 344) and water to make a 0.25% solution. For example, if you have a solution of 1% gentian violet, mix 1 teaspoon with 3 teaspoons of clean water.

Use a clean cloth or a finger to paint your nipples and the white spots in the baby's mouth once a day for 5 days. Gentian violet will stain clothing and will turn the baby's mouth and your nipples purple—this is normal. You should keep breastfeeding. If the thrush does not get better in 3 days, stop using gentian violet and get medical advice.

BREAST INFECTION (MASTITIS)



Painful breasts and sore or cracked nipples can lead to an infection inside the breast.

Signs:

- Part of the breast becomes hot, red, swollen, and very painful.
- Fever or chills.
- Lymph nodes in the armpit are often sore and swollen.
- Abscess (painful lump in the breast) that sometimes bursts and drains pus.

Treatment:

Keep breastfeeding frequently, giving the baby the infected breast first, or milk the infected breast by hand, whichever is less painful. The infection will not pass to the baby.

- Rest and drink lots of liquids.
- Use hot compresses on the sore breast for 15 minutes before each feeding. To reduce pain, use cold compresses on the sore breast between feedings.
- Gently massage the sore breast while the baby is nursing.
- Take paracetamol for pain (see page 350).
- Use an antibiotic. Dicloxacillin is the best antibiotic to use (see page 341). Take 500 mg by mouth, 4 times each day, for 7 to 10 days. If you cannot find this or are allergic to penicillin, use erythromycin (see page 343). Take 500 mg by mouth, 4 times a day for 7 days.

HIV/AIDS and breastfeeding

For general information about HIV/AIDS, see page 169.

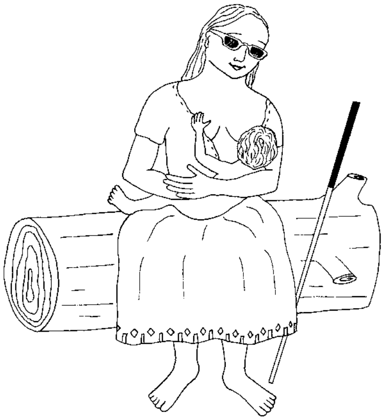
Some mothers with HIV pass the infection to their babies through breast milk. Other mothers with HIV breastfeed their babies, and their babies do not become infected. No one knows exactly why HIV is passed to some babies and not others. HIV probably passes more easily during breastfeeding when:

- the mother recently became infected with HIV.
- the mother is very sick with AIDS.
- the mother gives formula or other fluids along with breast milk.
- the mother has cracked nipples or a breast infection.
- the baby has thrush in her mouth.

For most mothers, even mothers with HIV, breastfeeding is the safest way to feed their babies. In places where water is not always safe, many babies get sick and die from diarrhea. And when people cannot always afford enough formula, babies die from malnutrition.

Whatever you choose to do, do not blame yourself if your baby becomes infected with HIV. At the moment, there is no way to know for sure how to protect your baby.

Breastfeeding if you have HIV



A woman who is being treated with medicines for HIV is less likely to pass the virus to her baby while breastfeeding. But even if you are not taking ART medicines, you can make breastfeeding safer:

- Give only breast milk for the first 6 months. Babies who also get formula, teas, or other foods or drinks are more likely to become infected than babies who drink only breast milk. Other foods or liquids are harder for a small baby to digest and may irritate the lining of the baby´s stomach. This may help HIV to pass more easily.
- Stop breastfeeding after 6 months, but do not stop suddenly. It usually takes several days to wean a baby (see page 265).
- Position the baby correctly to avoid cracked nipples.
- Treat thrush, cracked nipples, and breast infections right away.
- Do not feed the baby from a breast that has mastitis or an abscess—instead, remove the milk and throw it away. Feed the baby with milk from the other breast, until the infection heals.

To kill HIV in breast milk, you can also heat the breast milk almost to boiling (pasteurize), and then cool it and feed it to the baby through a cup or a bottle. This takes work, but it can be done if you have clean water, fuel, and support.

To pasteurize breast milk

1. Place a jar of breast milk in a pot of water.
2. Bring the water to a boil.
3. Immediately remove the pot from the heat.
4. Let the milk cool before feeding it to the baby.

The milk should be used within a few hours of pasteurizing. Breast milk should not be boiled.

Using other kinds of milk

Breastfeeding a baby is best. But if it is not possible for you to breastfeed, formula (artificial milk) may be a safe alternative to breast milk.

If you cannot afford formula, perhaps a relative or friend who does not have HIV/AIDS can breastfeed your child, or you can give the baby animal milks.

To feed a baby with animal milk

For cow, goat, or camel milk, mix 100 ml fresh milk with 50 ml clean water and 10 g (2 tsp) sugar.

For sheep or buffalo milk, mix 50 ml fresh milk with 50 ml clean water and 5 g (1 tsp) sugar.

Bring the mixture to a boil and then remove it from the heat. Let it cool and then feed immediately.

Animal milks do not have all the vitamins a growing baby needs—so the baby should be given a wide variety of mashed vegetables, fruits, and other foods starting at about 6 months of age.

FEEDING A BABY WITH A CUP OR BOTTLE

If you cannot breastfeed, you can use a cup or bottle to feed a baby breast milk, animal milk, or a baby formula. If you cannot hold the cup, ask someone to help you while you support the baby.

Feeding a baby with a cup

1. Use a small, very clean cup. If boiling is not possible, wash the cup with soap and clean water.
2. The baby should be upright or almost upright on your lap.
3. Hold the cup of milk to the baby's mouth. Tip the cup so the milk just reaches the baby's lips. Rest the cup lightly on the baby's lower lip. Let the edges touch the baby's upper lip.
4. Do not pour milk into the baby's mouth. Let the baby take milk into its mouth from the cup.

Feeding the baby from a bottle

Feeding a baby with a bottle is never safe unless you can answer "YES" to all these questions:

- is there is a constant source of clean water in the community?
- is there is a constant supply of fuel to boil the water?
- do you or your family have enough money to buy several new bottles and nipples?
- do you or your family have enough money to buy enough infant formula, tinned milk, or clean animal milk for at least 6 months?
- do you or your family know how to properly clean the bottles and nipples, and prepare the other milks?

When you give formula or animal milk, everything must be kept very clean. The cup, spoon, bottle, rubber nipples, and any containers used for milk or formula should be washed thoroughly and boiled for 20 minutes before each use. Prepared formula, tinned milk that has been opened, and animal milk should never be left at room temperature for more than 2 hours. They will spoil and could make the baby very sick. Formula can sit in a cold refrigerator for up to 12 hours.

HELPING THE BABY BURP (WIND)

During feeding, some babies swallow air, which can make them uncomfortable. You can help a baby bring up this air if you can hold it on your shoulder or chest and rub its back, or rub its back while it sits or lies on your lap.

If you have only one arm or limited strength in one arm, hold the baby on your knees with the baby facing away from you and your good arm across its chest. Then rock forward and backward until the baby burps and relaxes.

Feeding an older baby

When the baby is 6 months old, you can start giving her other foods in addition to breast milk. Always give the breast milk first, and then the other foods. It is good to start with a gruel or porridge made from your main food (see page 87). These new foods need to be well cooked and mashed. At first they can be mixed with a little breast milk to make them easier for the baby to swallow.

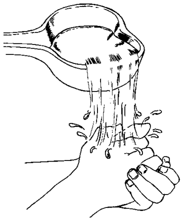
After a few days, start adding other helper foods (see page 87). But start with just a little of the new food, and add only 1 at a time or the baby may have trouble digesting them. Most important is to add foods that give extra energy (such as oil), and—whenever possible—extra iron (such as dark green leafy vegetables). For more information on feeding your baby healthy foods, see *Where There Is No Doctor*, page 107.

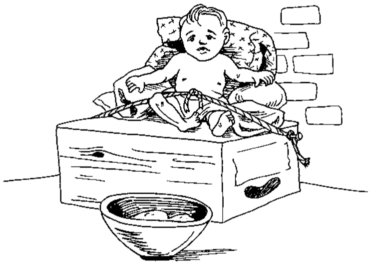
Remember, a young child's stomach is small and cannot hold much food at one time. So feed her often, if possible 5 to 6 times a day, and add high-energy helper foods to the main food.

The baby will be happier and calmer if you plan ahead and have everything ready when it is time for him to eat. If you wait until the baby is hungry and crying, it will be hard for you to stay calm while you get ready to feed him. When you get ready to feed the baby:

If you cannot see well

Always remember to wash and rinse your hands with soap and clean water.



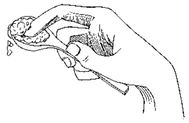


Sit the baby in a comfortable and safe place so he will not topple over. Put the food in a sturdy bowl or container and position it so the baby cannot kick it over.

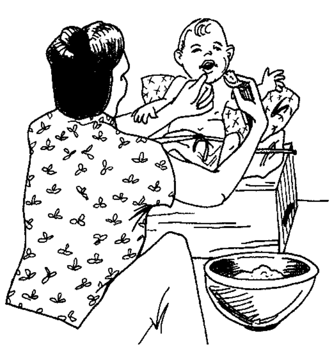
To feed a baby with your fingers and without a spoon, give only a small amount each time that feels no larger than a pea or bean.

To feed a baby with a spoon

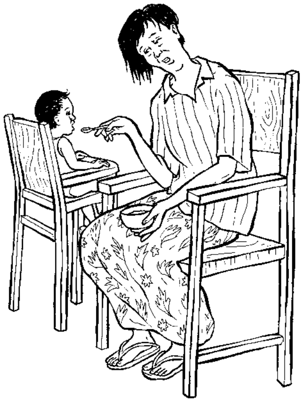
1. Use one hand to put a small amount of food onto a small spoon. Hold the spoon close to the round eating end, and push off any excess food from the spoon with another finger of the same hand.



2. Place the thumb of your other hand on the baby's chin, just under the mouth. Using your thumb as a guide, put the spoon containing the food into the baby's mouth.



When the baby is old enough to feed himself, he will probably make a lot of mess at first. You may need to ask a family member, friend or neighbor to let you know where the food has been spilled so you can clean it up. Try to be patient. As the baby gets older and more sure of himself, he will spill less and less food



If you have limited upper body strength and coordination

You may be able to feed your baby if you sit to the side of the baby. This way you will not have to reach forward so much to feed him. But if you cannot feed the baby yourself, you can sit as close to him as possible and talk to him while someone else gives him food. This will help him think of you as one of the people who gives him food when he is hungry.

When a baby is 1 year and older

When your baby is 1 year and older, he can eat the same foods as adults, but he should continue to breastfeed or drink milk whenever possible.

Every day, try to give the child plenty of the main food that the people in your community eat, together with 'helper' foods that give added high energy, proteins, vitamins, iron, and minerals, so that he will grow up strong and healthy.

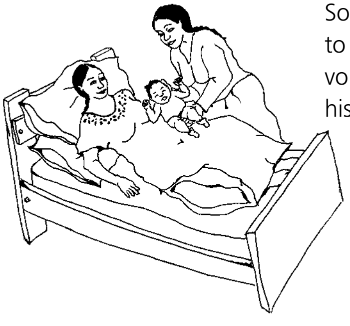
To make sure the child gets enough to eat, serve him in his own dish, and let him take as long as he needs to eat his meal.

Comforting the baby

For a baby to feel safe and close with its mother, it is important for the mother to comfort the baby when the baby is unhappy. If your baby starts to cry, and you cannot get to her quickly, someone else can bring her to you. Then your baby can see your face and hear your voice saying comforting words—even if you cannot pick up or hold the baby yourself.

If you have no use of your arms or cannot hold your baby

Here are two ways you can comfort your baby:



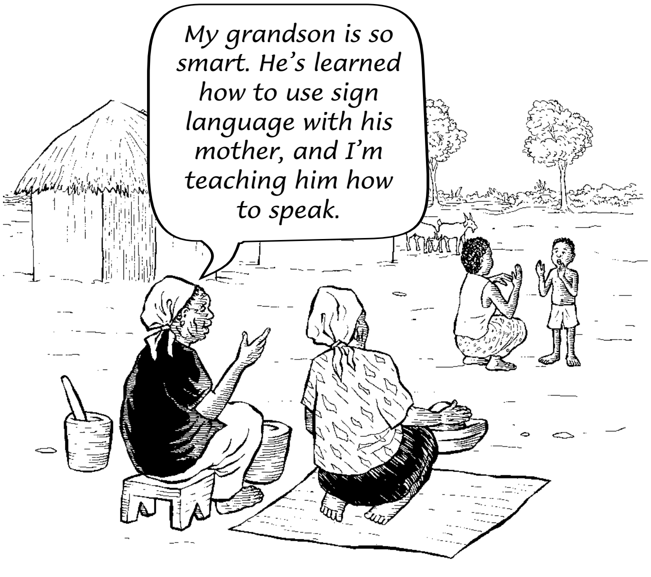
Someone can hold the baby close to you so the baby can hear your voice and recognize your smell as his mother.

Or someone can sit behind you and hold the baby in front of you so you can comfort him with your voice.

If you cannot hear well

A healthy baby usually makes a lot of noise when he is hungry or not feeling well. So, if you do not hear well, you will need to stay close to your baby as much as possible so you will see when your baby needs your attention. At night, sleep with the baby as close to you as possible so that you can feel him move. And during the day, keep the baby close to you.

To know how he is feeling, you will probably carry your baby more than most women. He will quickly get to know how you smell and feel, and the sound of your voice. This will make him feel very close and secure with you.



If you use sign language and not a spoken language to communicate, use sign language with your baby, even if your baby is not deaf. This way you and your baby will be able to communicate throughout life. Also, let your baby spend time with family members and friends who are not deaf so the baby will learn to speak.

If the baby is fussy

During the first few months, some babies can be very fussy, especially in the evening. This is less common with babies who have been breastfed, but it can still happen. You can help calm your baby by offering her the breast, burping her, singing or talking to her, and walking or rocking her. Babies love to move. A fussy baby can be exhausting and frustrating for any mother. The baby's father, or other family members or caregivers, can all help with the baby when she is fussy so you have more time to rest.

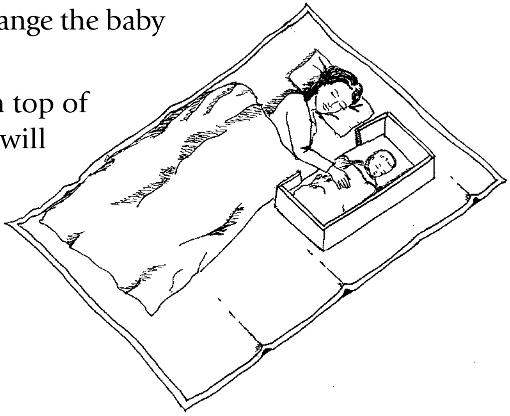
Sleeping with the baby

Most mothers of small babies rest better sleeping with the baby next to them. It is easier to breastfeed when the baby wakes up hungry, and you can comfort the baby without getting up. If you cannot see or hear well, you will always know if your baby needs to be fed or changed.

If you have difficulty walking, keep a supply of nappies, diapers or cloth and clean clothes close by so you can also change the baby during the night without having to get up.

If your disability is such that you may roll over on top of the baby, or if you need to sleep sitting upright, you will need to do something else. Here is an example:

If you think you may roll on top of your baby, make a small wooden bed with sides that the baby can sleep in beside you. Leave one side partly open so you can easily reach inside. Smooth the wood or cover it with cloth so that you and the baby do not get any splinters.



Changing and dressing the baby

A healthy baby becomes an active, wriggling baby very quickly. Changing his clothing can become more and more difficult as he grows. Try to use clothes that are easy to put on and take off. For example, zippers or strips of *Velcro* (a strong, fuzzy plastic tape that sticks to itself) are easier to fasten and open than buttons.

If you have physical disabilities

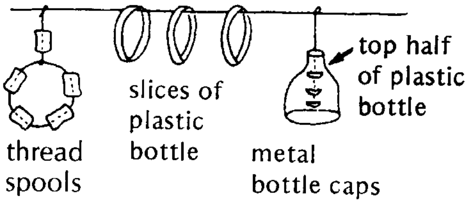
Many women with physical disabilities can safely change and dress their babies on a table or bed, especially if they can sit down. But some women do not have enough balance or body strength to do this. Here are 2 examples of simple wooden tables that will hold the baby safely, and will also not hurt your body. A table can be made to the height that you need.

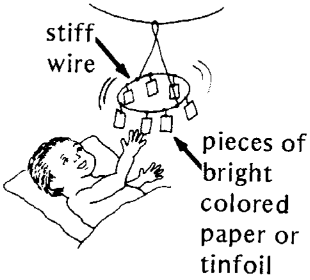
Smooth the wood or cover it with a cloth so you and the baby won't get any splinters.

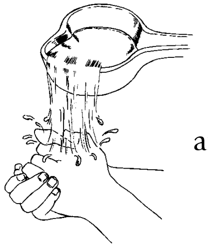
Cleaning the baby

It helps to have a small toy for the baby to play with while you clean her so she will not move about so much. Try to collect about 10 playthings that the baby can touch and hold so you can give a different one to the baby each time you change her. A new toy will hold the baby's attention better. Many simple things in the home can be used as toys, or can be turned into them. For example, a noisy seed pod, a bell, a small cloth doll, a mirror, a bracelet of colored beads, or colored paper. When you have gone through all 10, start with the first one again so it will seem new to the baby. Here are some examples of simple toys:

Make sure the objects or toys have no sharp edges, and are not so small the baby could swallow them.







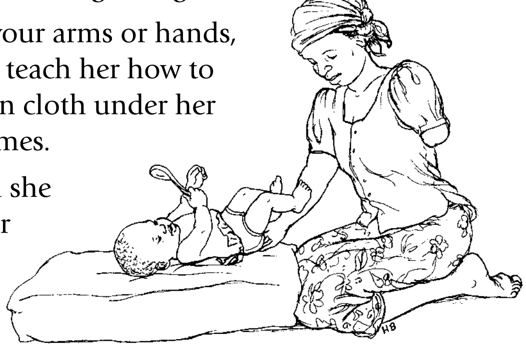
Always wash your hands after cleaning or changing the baby, and after helping a child use a latrine or toilet.

If you have limited use of your hands

Many women who have limited movement in their hands can clean the baby's bottom and genitals. But often they cannot put on a nappy or diaper—especially if it needs safety pins to hold it closed. You may have to rely on a family member or helper to do this. If you cannot clean and change the baby yourself, make sure the place where the baby is changed is close beside you so that the baby can always hear your voice and see your face as she is being changed.

If you have only one arm or limited use of your arms or hands, when your baby is about 1 month old you can teach her how to help you put on her nappy. As you place a clean cloth under her bottom, lift or bounce her bottom up 2 or 3 times.

Do this each time you change her, and soon she will start to lift her bottom up herself whenever she feels you touching her there. This will make it easier for you to get the cloth placed underneath her.



A nappy or diaper can be held on a baby without pins by putting panties over the top. The panties will probably get wet with urine too, so they must also be changed each time the baby is changed. Wash and dry them the same way that you clean the diapers. Also, strips of *Velcro* can be used to hold the baby's diaper closed.

If you are blind or cannot see well

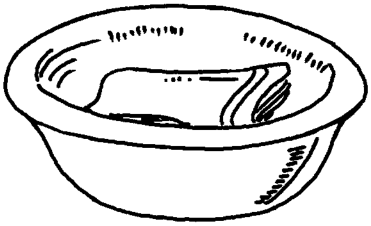
It can be hard to know if all the stool has been cleaned off the baby's bottom. Here are some suggestions:

If you have enough water available, hold the baby securely with one hand and wash the stool off the baby's bottom in a bucket or bowl of clean water.

Hold the baby securely over the edge of a table and pour clean water over its bottom.

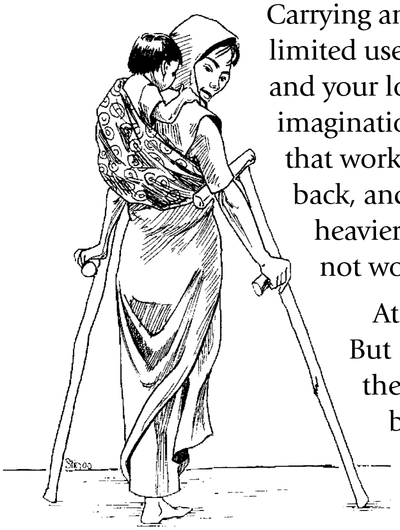
If you do not have much water, wipe off the baby's bottom with a thin, damp cloth. Do not use a thick cloth or you will not be able to feel where the stool is. Afterward, wash the cloth well with soap and water, and hang it in the sun to dry.

When you bathe the baby, put a piece of cloth inside the basin or bowl for the baby to sit or lie on. This will prevent the baby from sliding under the water.



If your baby is constipated, put a little cooking oil up the rectum. Or you can also put some grease or oil on your finger and gently break up and remove the hard stool. Do not give oils, like castor oil, or vegetable oil, or laxatives to a baby or small child.

Carrying and moving about with the baby



Carrying and moving about with a baby can be difficult if you have limited use of your arms and legs. It may be hard to keep your balance, and your lower back may hurt. You will probably have to use your imagination and try many different methods until you find something that works for you. Some women find it easier to carry their baby on the back, and others find it easier on the front. Your baby will be getting heavier and more active all the time, and what works one month may not work the next month.

At first your balance will be affected by the weight of the baby. But if you start while the baby is small, you will soon get used to the feel of your baby. As the baby grows bigger and heavier, your body and balance will adjust to the increase in weight.

If you use crutches or a stick to help with walking, it may be difficult for you to carry your baby in your arms. You can probably carry your baby best on your back.

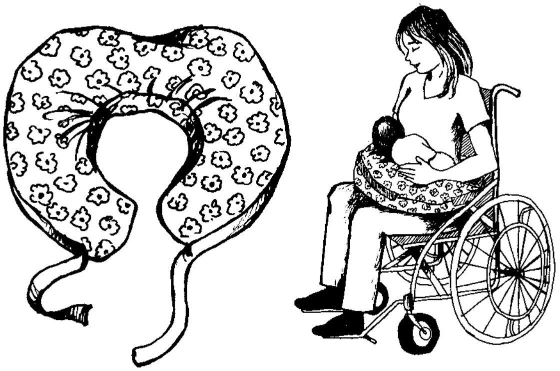
If you have limited use of your arms

This cushion-sling will help distribute the baby's weight better so it does not put so much strain on your arms and shoulders. You can use it to carry your baby in front or on your back.

If you use a wheelchair or a cart

It can be difficult to hold a baby in your arms or on your lap if you use both your hands to push your wheelchair. But if you can wear a sling around your neck, you can hold the baby safely in it as you roll. Tie the sling to your waist with a strap so that the sling does not bump the baby around.

When the baby grows, you can use a harness that supports the baby while she sits on your lap.

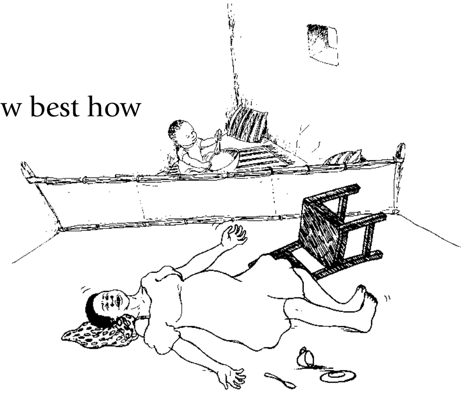


A baby cushion like this, that ties around your waist, will help you to hold your baby safely in your lap.

If you use sign language

If you are a mother who uses sign language to communicate, you can also use a sling to hold your baby so your hands are free to sign.

If your have seizures ("fits," epilepsy)



If you are someone who gets seizures or "fits," you will know best how often you get them and how severe they are. If you have a seizure while you are holding a small baby and you drop her, she could be badly hurt or even killed.

If possible, try to always have someone who does not have seizures with you and the baby. If you live by yourself, or are sometimes alone with the baby, make a safe space in the room or house and keep the baby there all the time. Do not walk around with the baby, and make sure there are no sharp edges on things like chairs or tables. This way, if you have a seizure while you and the baby are alone, the baby will be safe until the seizure is over. It will also be safer to put the baby on the floor when you feed, bathe, or dress her.

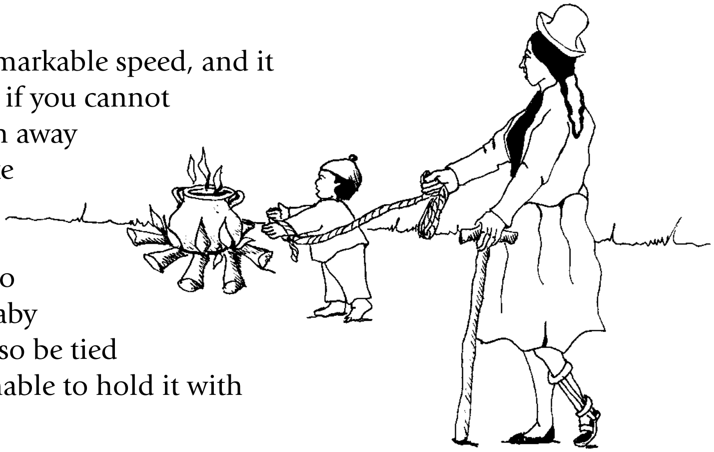
When the baby is a little older and can crawl or walk, put a gate or barrier across an open doorway or any steps, so that the baby is safe even if you have a seizure and are recovering.

Keeping up with the baby

When babies first learn to crawl and walk by themselves, it can be difficult for any mother or father to keep up! Running and walking is a healthy thing for growing babies to do. And when they are first learning, they fall down a lot. Do not be concerned about this. It is a normal part of a young child's development.

If you cannot move quickly

Small babies can move with remarkable speed, and it is easy for them to get hurt. So, if you cannot run after your baby to keep him away from dangerous situations—like running in front of a car or into the cooking fire—tie a string around the baby's wrist so that you can quickly pull the baby back to safety. The string can also be tied around your waist if you are unable to hold it with your hand.

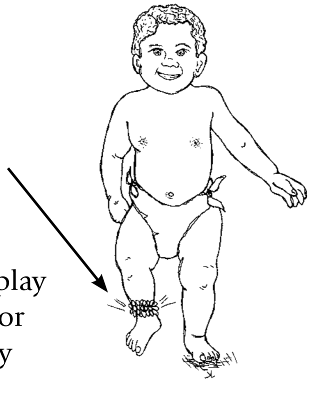


If you have trouble seeing or you are blind

When the baby is very small, sleep together with him in the same bed. This way you will always know what he needs and where he is.

As the baby grows and starts to move about by himself, by crawling and then walking, tie something that makes a noise onto the baby's ankle or wrist (such as a small bell or a seed pod). Then you can always hear him and know where he is.

Also, make a space where the baby can move around and play without hurting himself. Make sure there are no sharp edges or corners on anything in the space. Put a barrier in the entryway between rooms and at any steps or doors leading out of the house so the baby cannot leave his safe space by himself.



Protecting children's health

In children, sicknesses often become serious very quickly. An illness that takes days or weeks to severely harm or kill an adult can kill a small child in hours. So it is important to **notice early signs of sickness and attend to them right away.**

Diarrhea (loose or watery stools) is more common and more dangerous in babies and small children than it is in adults. If your baby or small child gets diarrhea, **act quickly and:**

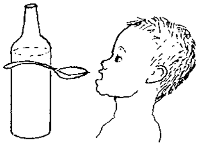
- keep giving breast milk—often.
- keep giving food.
- give lots of liquids to drink.

Rehydration drink helps prevent or treat dehydration, especially if the baby or child has severe watery diarrhea:

There are 2 ways to make rehydration drink:

1. **With sugar and salt** (raw sugar or molasses can be used instead of sugar)

In 1 liter of clean **water**, put half of a level teaspoon of **salt**. Make sure it tastes less salty than tears. Then add 8 level teaspoons of **sugar**. Mix well and start giving the drink to the child.



2. **With powdered cereal and salt** (powdered rice is best, or use finely ground maize, wheat flour, sorghum, or cooked and mashed potatoes)

In 1 liter of clean **water**, put half a teaspoon of **salt**. Make sure it tastes less salty than tears. Then add 8 heaping teaspoons (or 2 handfuls) of powdered **cereal**. Boil for 5 to 7 minutes to form a liquid gruel or watery porridge. Cool the drink quickly and start giving it to the child.

Taste the drink each time you give it to make sure it is not spoiled. Cereal drinks can spoil in a few hours in hot weather.

Add to either drink one half cup of fruit juice, coconut water, or mashed ripe bananas, if available. This provides potassium which may help the child accept more food and drink.

IMPORTANT Adapt the drink to your area and adjust the quantities to your local forms of measurement. If you give cereal gruels to young children, add enough clean water to make it liquid, and use that. Look for an easy and simple way.

There are 3 important ways to help children grow up to be healthy and protect them against many sicknesses:

- Nutritious food
- Cleanliness
- Immunizations

Nutritious food

It is important that children eat the most nutritious food they can get, so they grow well and do not get sick. Above all, children should get enough to eat—several times a day (see pages 265 to 266).

Cleanliness

Children are more likely to be healthy if they and their homes are kept clean. Here are some guidelines:

- Wash children and change their clothes often.
- Teach children to always wash their hands when they get up in the morning, after they pass stool, and before they eat or handle food.
- Teach children how to use latrines or toilets.
- Where hookworm exists, do not let children go barefoot; use sandals or shoes.
- Teach children to brush their teeth every day and do not give them a lot of sweets or carbonated drinks.
- Cut fingernails very short.
- Do not let children who are sick or have sores, scabies, lice or ringworm sleep with other children or share clothes or towels.
- Treat children quickly for scabies, ringworm, intestinal worms, and other infections that spread easily from child to child.
- Do not let children put dirty things in their mouths, or let dogs, cats or other animals lick their faces.
- Keep pigs, dogs, and chickens out of the house.
- Use only clean, boiled, or filtered water for drinking. This is especially important for babies.
- To protect babies and children from malaria, if possible, have them sleep under mosquito netting or bed nets that have been treated with insecticide.

Immunizations (vaccinations)

Vaccines give simple, sure protection against many dangerous diseases. If health workers do not give immunizations in your community, take your children to the nearest health center to be immunized. It is better to take them for immunizations while they are healthy, than to take them for treatment when they are sick or dying. Immunizations are usually given free. (Different countries use different schedules.) The most important vaccines for children are:

Immunization	When given	Note
DPT *for diphtheria, whooping cough (pertussis), and tetanus*	Given at 2 months, 4 months, 6 months, and 18 months.	In some countries one more injection is given when a child is between 4 and 6 years old.
POLIO *(infantile paralysis)*	In some countries 1 dose is given at birth, and 3 more doses are given at the same time as the DPT injections.	In other countries the first 3 doses are given at the same time as the DPT injections, the 4th dose between 12 and 18 months of age, and a 5th dose at 4 years old.
BCG *for tuberculosis*	At birth or anytime afterward.	
MEASLES	1 injection no younger than 9 months, and often a second injection at 15 months or older.	In many countries, a '3 in 1' vaccine called MMR (measles, mumps and rubella—German measles) is given between 12 and 15 months, and a second injection between 4 and 6 years.
HepB (Hepatitis B)	3 injections are usually given at the same time as DPT.	In some countries the injections are given at birth, 2 months, and 6 months.
Hib *for Haemophilus influenza type b, which is a germ that causes meningitis and pneumonia in young children*	3 injections given together with the first 3 DPT injections.	
Td or TT (Tetanus toxoid), *for tetanus (lockjaw) for adults and children over 12 years old*	1 injection every 10 years. In some countries this is done between 9 and 11 years (5 years after the last DPT vaccination), and then every 10 years.	Pregnant women should be immunized during each pregnancy so their babies will be protected against tetanus of the newborn (see page 251).

Immunize your children on time.

Be sure they get the complete series of each vaccine they need.

CHAPTER 13

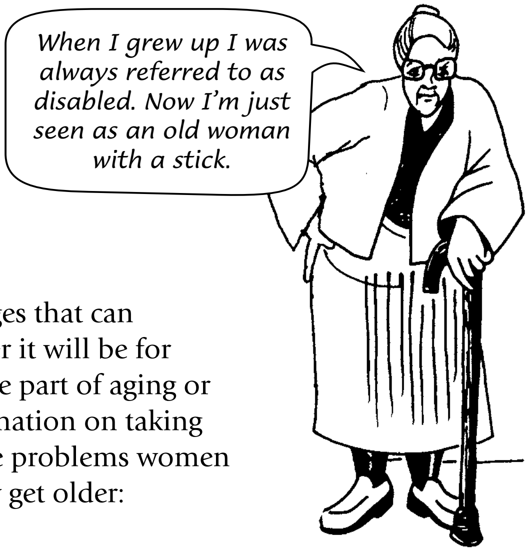
Growing older with a disabilty

Growing older can be a time when you gain more respect in your family and community. However, it can also be a time when you become more vulnerable to poverty, mistreatment, and health problems. Whether or not you have a disability, you will experience many changes as you grow older.

As your body ages, you will probably have to change the way you do many things. Some activities will have to stop because you can no longer do them. You may develop health problems or disabilities you did not have when you were younger. Some women may start using a cane or wheelchair to get around because they do not walk as well any more. Some may start to need glasses or use a hearing aid.

Whether you were disabled as a child or became disabled later in life, this chapter has information on how some disabilities can develop or change and how you can care for your health as you age.

Health problems caused by aging



Women often do not think about themselves as growing older until their children are grown or until their bodies start to change. You may also notice that your body gets tired more often, that you are not as strong as you used to be, or that it is not as easy for you to move about.

The better you understand the changes that can happen as women grow older, the easier it will be for you to know if changes in your body are part of aging or are caused by your disability. For information on taking care of your body, see page 85. Here are problems women with some disabilities may have as they get older:

Weaker or painful muscles and joints

If your disability means that part of your body does not work as well as another part, over time you have probably overused the part that works better to make up for the part that does not work as well. For example:

- if one of your legs is paralyzed, you probably use the 'good leg' more than someone who has use of both legs, and the joints may become weak from overuse.
- if you use a wheelchair or crutches for a long time, the joints in your hands, arms, and shoulders can become painful from overuse and start to wear out.
- if you are a very small woman (dwarf), you may find you start to get pains in your shoulders, knees, and hips from all the reaching and climbing you have done over the years.

If you are using a wheelchair or spending more time in bed, it is very important to move around and change positions as much as you can to prevent pressure sores (see page 116).

For women who use wheelchairs

Women who use wheelchairs usually get less exercise as they age. Ask other people to help you stand or use a standing frame so you can put weight on the bones in your legs. Also try to keep the bones in your arms strong by lifting things. For more exercise ideas, see pages 88 to 95.

Post-polio syndrome

If you had polio earlier in your life, you may start to have severe weakness, tiredness, pain, and trouble breathing many years after the polio virus has gone. This means you must be very careful when you exercise. Using your muscles too much may damage them and make your weakness worse. Instead, do gentle stretching and movement to help keep your body from getting stiff.

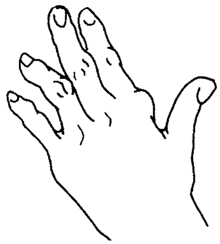
Walking and balance

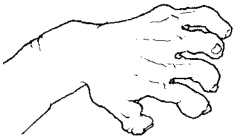
If you use an artificial leg (prosthesis), you may need to get it adjusted because it may not fit as well any more, especially if you do not move about or exercise as much as you used to and your muscles get weaker and softer.

If you are used to walking with no aids, you may need to start using a cane, crutches, or a wheelchair. Many women wait a long time before deciding to use aids that will help them. But starting to use a stick or wheelchair early can protect you from falls and injuries, and help you move about more easily. The better you can get around, the more you can take part in the life of your community.

Arthritis

Arthritis is a painful swelling and stiffness of the joints. It affects many people and can make many daily tasks painful or more difficult. If the arthritis is in the hands, it can cause special problems for people with some disabilities. For example:





deformity of the hand from leprosy and arthritis

- If you are blind and use your hands to 'see' or to read things by touch, you may not be able to do this as well.
- If you are deaf, you may not be able to use sign language as well.
- If you use a catheter to pass urine, or a bowel program to pass stool, it may be more difficult for you to do this by yourself.
- If you have leprosy (Hansen's disease) and your hands are already affected, arthritis will make using your hands even more difficult.

Skin problems

Your skin will become thinner as you get older, and you may find that you bruise more easily. This happens to most women.

- If you sit or lie down for most of the day, thinner skin means you can get pressure sores more easily (see page 114).
- If you use artificial legs or arms, check your skin more often where it touches the prosthetic to make sure it does not become red and irritated.
- If you have leprosy (Hansen's disease), check your skin every day. Thinner skin will make it easier for you to get sores and infections.
- If you have a spinal cord injury or a paralysis and have no feeling in your skin, ask someone to check your skin every day to prevent pressure sores, especially in areas you cannot see, such as your back (see page 117).

Eyesight and hearing

Many older people cannot see as well as when they were young. If you are deaf, it will be difficult for you to understand if someone is speaking to you in sign language or if you are used to lip-reading.

If you have leprosy, aging may cause an inflammation in your eyes that can cause blindness if it is not treated.

If you are blind and also start to lose your hearing, communicating and moving around safely will be more difficult.

Ask your family to make changes that will help you see, hear and move around more easily. For example, if you do not see as well, try to make the house lighter inside by painting the walls white, or getting a brighter light bulb. Mark steps and doorways with different colors so you can see them better and not trip or bump into them.

If your hearing gets worse, ask people to sit facing you when talking and to speak clearly but not shout. Turn off radios or televisions when speaking so you can hear better.

Weak bones (osteoporosis)

After your monthly bleeding stops, your body starts to make less of the hormone estrogen (see page 72) and your bones may become weaker. Weak bones break more easily and heal slowly. If your balance is affected by aging, or if you have epilepsy seizures or cerebral palsy you have a greater risk of falling and breaking weakened bones. You can prevent weak bones by:

- eating foods rich in calcium (see page 86), with foods that have vitamin C, such as fruits and yellow-colored vegetables.
- doing regular exercise that puts weight on your bones (see pages 88 to 90).

Mental confusion

Some older people have difficulty remembering things or have difficulty concentrating. For most people, this is not a serious problem. But some people develop more serious problems with memory or thinking (Alzheimer's disease, dementia, senility) and eventually become so confused they no longer recognize friends and family members. They can become very frightened and confused by everyday things they used to know well.

An older person with Down syndrome may become confused more easily and may start to have epileptic seizures.

Find new ways to do things

The changes that come with growing older may mean you will need to find new ways to do things and to get other people to help you. And you may need to use more aids, like a hearing aid, a walking stick, or a wheelchair. As you feel your body begin to change, start now to find the best way to do things. Knowing what to expect can help you take better care of your body and continue to remain as healthy as possible as you grow older.

Seek assistance

If you find it is getting harder to do certain things, such as eating, bathing, dressing, or getting up from lying down, show or explain to friends, family members, caregivers, and to others you trust how they can help you. You might also arrange to have a relative or friend come to live with you. For her assistance, the person will get a place to live.

If you find you are forgetting things, it may help to make a list of the things you want to do each day, and cross them off when they are done. Or each day talk with your family members about things you want to do that day so they can remind you of them.

Depression
(extreme sadness or feeling nothing at all)

Some people start to feel unhappy and depressed as they grow older. This is often because of loneliness, changes in health, or not being able to do as much as they used to. Some women with disabilities who suffer from low self-esteem may feel even more lonely and depressed as they grow older.

Some of the signs of depression are:

- feeling sad most of the time
- difficulty sleeping or sleeping too much
- difficulty thinking clearly
- loss of interest in pleasurable activities, eating, or sex
- physical problems, such as headaches or intestinal problems, that are not caused by illness
- slow speech and movement
- lack of energy for daily activities
- thinking about death or suicide

What to do to help prevent depression

Try to stay as active as possible, to exercise, and to eat well. Above all, try not to be alone too much. Help take care of younger children in your community. Meet with other older women with disabilities to talk and to pass time together. If you are often feeling sad or are unable to sleep, talk to someone in your family you trust or with a health worker. For more information about mental health, see Chapter 3.

When monthly bleeding stops (menopause)

Usually monthly bleeding stops gradually over 1 or 2 years, most often between 45 and 55 years old. This happens because your ovaries stop making eggs, and your body makes less of the hormones estrogen and progesterone. Women with Down syndrome often stop their monthly bleeding earlier than other women.

Signs

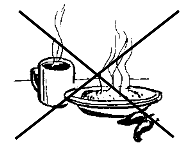
- Your monthly bleeding changes and you may bleed more often for a while. Or you may stop bleeding for a few months and then bleed again.
- At times you may suddenly feel very hot or sweaty ('hot flashes').
- Your vagina may become less wet and smaller.
- Your feelings change easily.

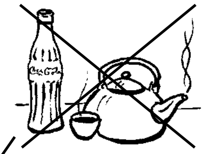
These signs will start to go away as your body gets used to less estrogen.

If you have discomfort during the end of monthly bleeding (menopause)

If you are feeling uncomfortable, try the following:

- Dress in clothes that are loose, comfortable, and made of cotton. If possible wear clothes you can take off easily when you begin to sweat.





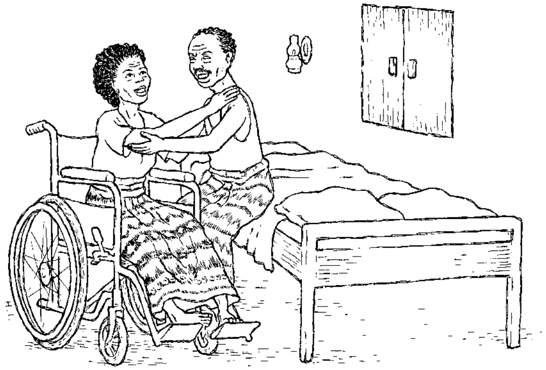
- Avoid hot or spicy foods or drinks. They can cause hot flashes.
- Get regular exercise.
- Do not drink much coffee, tea, or soft drinks (pop, soda, cola). They contain caffeine, which can make you feel nervous and prevent you from sleeping.
- If you drink alcohol, drink only small amounts. Alcohol can increase bleeding and hot flashes.

- Stop smoking, sniffing, or chewing tobacco. It can cause unusual bleeding and make problems with weak bones much worse.
- Explain to your family that your feelings may change easily. It may also help to discuss how you feel with other women who are also going through menopause.
- Ask about the use of traditional remedies in your community. Often women who have already been through menopause will know ways to help you feel better.

In the past, doctors recommended that women take medicines called hormone replacement therapy (HRT) to help manage changes and discomfort during menopause. Unfortunately, HRT has been shown to increase women's risk of breast cancer, heart disease, blood clots, and stroke. It is better to avoid using these medicines.

Sexual relations after the end of monthly bleeding

For some women, menopause means freedom from the sexual demands of a relationship. Other women become more interested in sex, perhaps because they no longer fear an unwanted pregnancy. All women, though, continue to need love and affection.



There is no reason you cannot enjoy sex for as long as you live.

As you grow older, some of the changes in your body may affect your sexual relations. You may take longer to become excited during sex (this also happens to men). And because your body no longer makes as much of the hormone estrogen, your vagina may be more dry. This can make sex with a man uncomfortable, or more easily lead to infections of the vagina or the urine system.

Also, the skin inside your vagina will also get thinner, so make sure to take more time before having sex so your vagina can make its own natural wetness. You can also use spit (saliva), vegetables oils (corn oil, olive oil), or water-based lubricants.

If you are having sex with a man and it is difficult for him to get his penis hard (erection), try to learn what he likes. Touching him may help make him excited.

IMPORTANT

- Do not use oils for lubrication if you are using condoms. Oil will weaken the condom and it may break.
- Do not use petroleum jelly (*Vaseline*) or oils that contain perfumes to increase wetness in the vagina. These can cause irritation.
- Do not use anything in your vagina to make it dry. This can also cause irritation in the vagina, which can make it easier to get HIV or other infections (see page 169).
- To prevent urine problems, pass urine before having sexual intercourse and as soon as possible afterward. This will help flush germs out of the urethra that may otherwise get into the bladder and cause an infection.

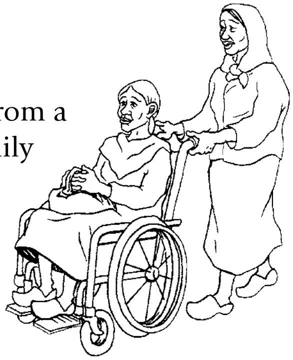
Protect yourself against pregnancy and sexually transmitted infections (STIs)

You can still become pregnant until your monthly bleeding has stopped for one full year. To prevent unwanted pregnancy, you should continue to use a family planning method until you have no monthly bleeding for one whole year (12 months) (see page 188).

If you are using a hormonal method of family planning (the pill, injections, or implants), stop using it around the age of 50. Use another method of family planning without hormones until 12 months have passed since your last monthly bleeding.

Unless you are certain neither you nor your partner has an STI, including HIV/AIDS, be sure to use a condom each time you have sex with a man—even if you can no longer become pregnant.

Live an active life



Try to live your life as actively as you can. With assistance, either from a person or with an aid, you can take a more active part in your family and community and do more things you enjoy. Move around the community and keep yourself mentally and physically active.

You can help to keep your mind active by reading or by playing games with other people. Card games, games with stones (Mancala), games with words (Scrabble), chess, or other games popular in your community give you an opportunity to enjoy yourself and to talk and be with other people. Help young people learn to read, understand the history of their community, or with their school work.

You have a lifetime of wisdom and experience. Working together with families, caregivers, and other elders in the community, older women with disabilities can be very powerful.

Time to learn new things

Imelda from the Pallisa district in Uganda is 67 years old. Recently she joined a universal primary education program and went back to school. Now she can write and speak English. The students at school like her and call her Grandmum.

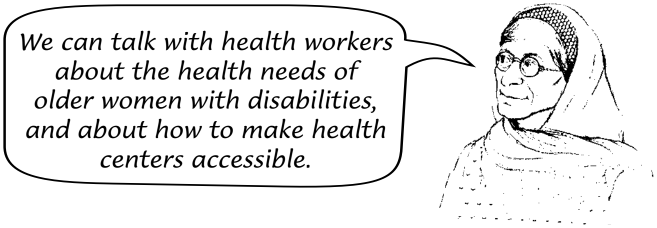
Working for change

Even though your disability may get worse as you grow older, find activities you can do to continue to be an active participant in your community. With your wealth of experience, you can do many things to improve conditions for women with disabilities.

What older disabled women can do

- Many governments provide monthly income (pensions), housing, and health care for older persons with disabilities. If our government does not, we can work with other women with disabilities, and with our mothers, sisters, daughters, and neighbors to change these laws. This kind of change takes time.

- We can form groups of disabled women who live together to lower living expenses and to help each other. A blind woman, for instance, can be the ears for a deaf woman, and a deaf woman the eyes for a blind woman.



- We have rich life experiences, and we can share this information with young disabled women and girls. We can probably help them with problems they are having because we had the same problems when we were younger.

CHAPTER 14

Abuse, violence, and self-defense

Abuse can happen to any woman. Around the world, many women are treated badly by strangers and by people they know. They may be beaten, raped, shamed, sexually assaulted, hurt or abused in other ways, or even killed. Many times no one knows about the abuse because women feel ashamed or afraid to speak about it. They think no one will care or they are afraid they will be blamed for having caused the abuse.

Many women are treated badly because they have less power than the person abusing them, or because they are alone, weak or vulnerable. Disabled women and girls are even more likely to be abused, hurt, or sexually assaulted than non-disabled women. They are seen as even weaker and less important. A woman's disability **never** makes violence, abuse, or neglect OK. Women with disabilities deserve to live in safety, with people who care about them and treat them well.

A disabled woman or girl can be abused by men or women—by members of her family, by her husband or partner, by others in her household, or by her caregivers. She can be abused by a neighbor, a family friend, an employer, a co-worker, or a stranger.

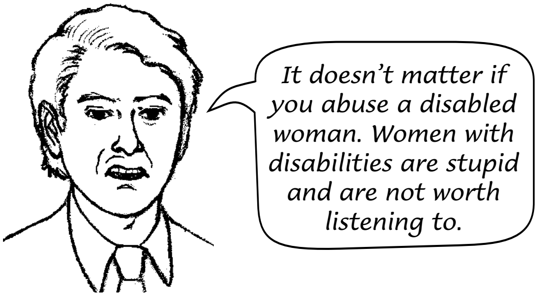
If the abuser is someone the woman knows, she may feel she has no one else to turn to, especially if she relies on that person to help her with her daily activities. But when a woman keeps silent about abuse, she becomes more isolated and more vulnerable. Reaching out to someone she trusts can help a woman resist violence and get support.

Abuse and violence against any woman is never OK. Because disabled women often get little respect, they are sometimes seen as not worth protecting. This teaches people that abuse against disabled women is not a problem and that there is no need to respect their rights.

Harmful idea:

The truth: A disabled girl has a right to be cared for just as other girls. No one is 'lucky' to experience abuse.

Harmful idea:



The truth: It is never OK to abuse a disabled woman. No one should ever be abused—especially a woman who has trouble learning. Abuse in any form—whether it is neglect, emotional abuse, not giving care, not allowing her to go to school, making decisions for a woman without consulting her, physical abuse or sexual violence—must be stopped.

Different kinds of abuse

When most people think of abuse, they usually imagine someone being violently assaulted—hurt, beaten, raped, sexually assaulted, or even killed. While women with disabilities are vulnerable to physical violence, they are also vulnerable to other forms of abuse.

For example, women who are dependent on someone assisting them with their daily care may be shamed; deprived of food, water, or medicine; left so long that they wet or soil themselves; or not be given the care they need. Some people may force women to exchange sexual favors for care. Some girls and women with disabilities are rarely allowed to meet other people or go out of the house. Others may be left alone, abandoned, or abused in other ways.

A disabled woman may suffer abuse from someone else who is also disabled. If a disabled man feels powerless and angry because of his disability, he may act out his anger by beating his partner as a way to assert his power over her.

Physical abuse—as well as other kinds of abuse and violence—can cause mental health problems. Women who have been abused often become afraid or sad, and sometimes they suffer from depression. When a woman is abused, her body needs to heal—and so do her mind and spirit.

EMOTIONAL ABUSE

Emotional abuse happens when someone insults a woman, threatens her, makes her feel frightened, abandons or isolates her, or treats her as though she is worthless. Some people abuse disabled women by saying they would be better off dead, or they are a burden and do not deserve to live.

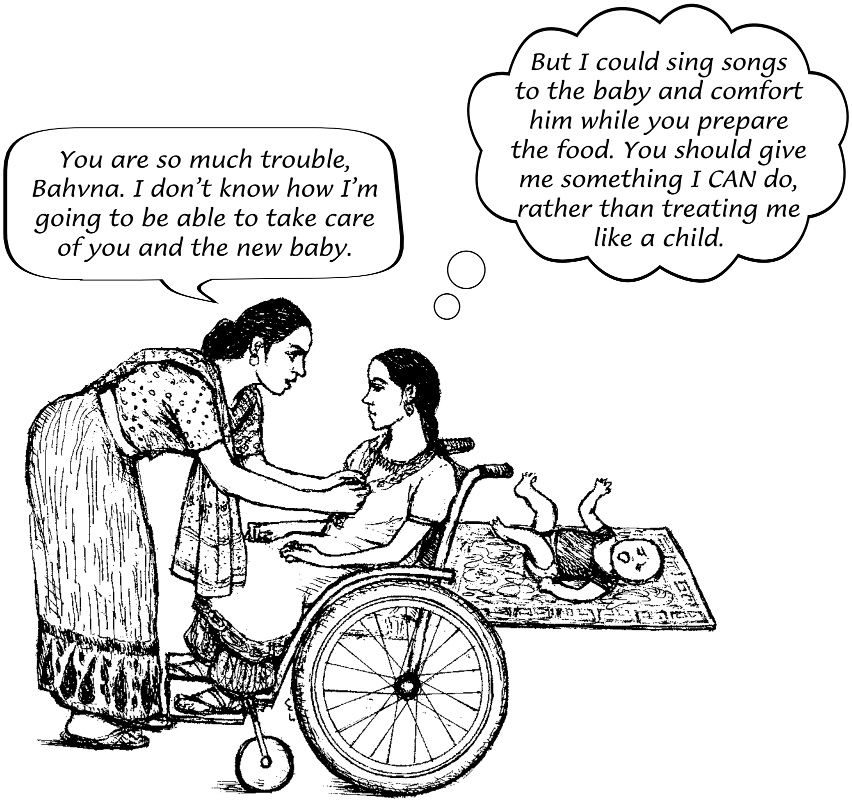
Emotional abuse can also happen when someone:

- speaks badly about a deaf woman with people who are not deaf.
- calls her names or shouts at her for doing things differently.

Emotional abuse makes a woman weak

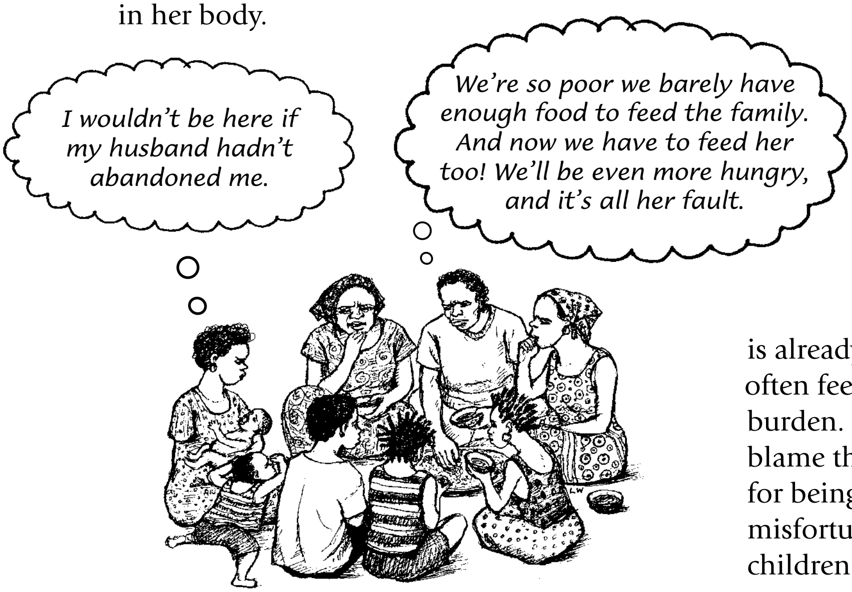
Emotional abuse makes it hard for a disabled woman to stay strong. A woman who is abandoned may feel as if she has lost her place and her role in society. It can be easy for her to feel sad and weak.

If a woman is always insulted or called names, she will start to feel stupid or sad. And if someone makes fun of her in front of her friends or neighbors, she may feel ashamed and be less likely to go out. After a while, the woman herself will believe she is not able to do anything worthwhile. A woman who is emotionally abused often suffers from mental health problems or depression. For more information, see Chapter 3 on Mental health.



ABANDONMENT

Sometimes people abandon or refuse to care for a disabled person. A family may abandon a disabled child if they are ashamed or if they think they will not be able to give the child the care she needs. A woman who becomes disabled may be abandoned by her husband or family because they are unable to accept the change in her body.



Many disabled women who are abandoned move in with relatives who may make her feel bad. When there is a lot of work to be done or if the family is already poor, disabled women often feel as though they are a burden. Sometimes relatives blame the disabled woman for being the 'cause' of their misfortune, especially if she has children.

ISOLATION

Keeping a disabled woman shut inside a room alone is one of the worst forms of abuse.

When a community does not respect or excludes people with disabilities, then some people are ashamed to have a disabled woman or girl in the family. They may try to keep other people from finding out about disabled women and girls in their families, or pretend they do not exist. Often, disabled women and girls are not allowed to get an education or participate in community events or religious services.

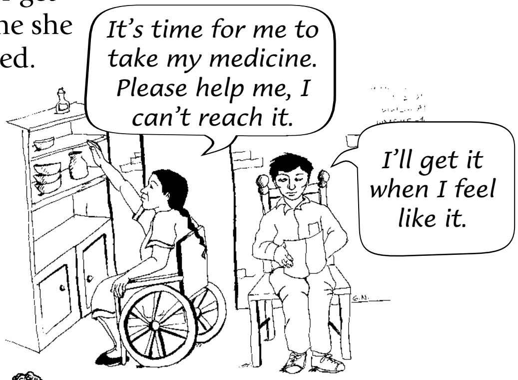
In some communities, disabled women are isolated because other people are afraid that being around them will make them disabled too. And some people believe if a pregnant woman touches a disabled woman, her baby will be born with a disability. None of this is true. You cannot catch a disability from someone else.

NEGLECT

Neglect happens when someone who should be caring for a disabled woman ignores her or does not help her. For example, if someone:

- does not give her food, or feeds her roughly.

- refuses to help her get medicine she may need.



- does not help her with the toilet.

Other examples of neglect are:

- leaving a disabled woman in bed for a long time.
- not helping her get dressed or wash herself.
- not helping her move or reposition her body to prevent pressure sores.
- not changing soiled sheets or wet clothes.

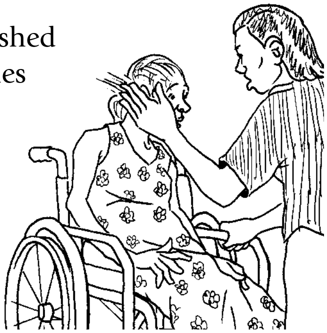
People also neglect disabled women by leaving them at home, or by denying them good education, proper food, or clothing.

Neglect can hurt a woman, as well as make her lonely and afraid. She can get pressure sores if she stays in bed too long or cannot move on her own. For information on preventing pressure sores, see page 116.

Physical abuse

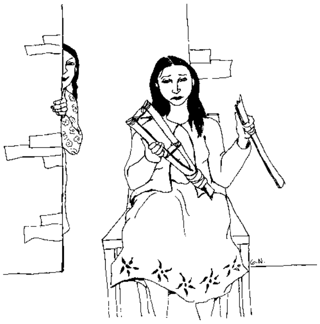
Physical abuse includes being beaten, pushed down, pinched, slapped, or hit. Sometimes people threaten a disabled woman's children. She may be even more afraid because she feels she cannot protect her children from violence.

In addition to beatings and assault, a disabled woman is being physically abused when:



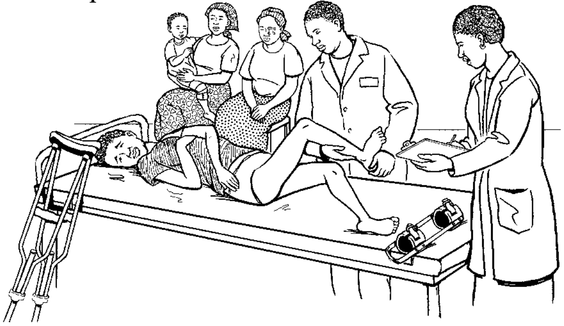
Women with disabilities can be physically abused and treated roughly in many different ways and places: in clinics, schools, residential homes, at their workplace, on public transportation, or even at home.

- someone deliberately breaks equipment she uses, such as her hearing aid, or her crutches.



- someone deliberately moves a blind woman's furniture to make it harder for her to get around.

- she is forced to be naked in front of strangers during an exam in a public clinic or hospital.

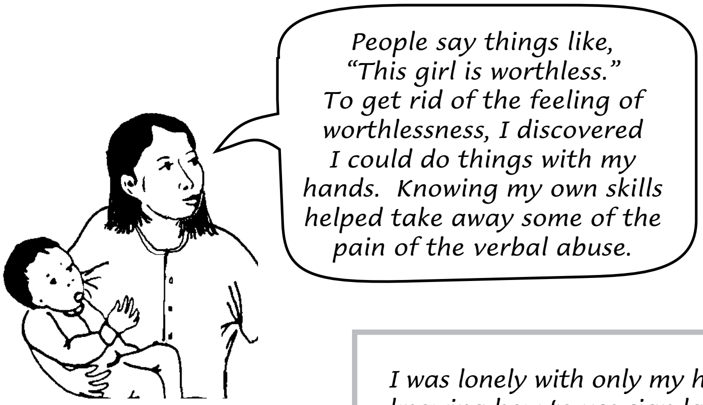


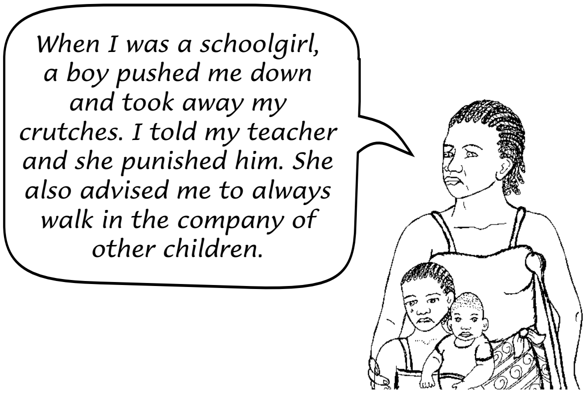
Health workers can prevent this kind of situation by covering her body as much as possible with her own clothes or a sheet. Or they can examine her in a private room, if one is available.

Preventing abuse

One of the ways women with disabilities can be safer from abuse is to become more involved in the community. Talking with others can help you find support.

- **Communicate with more than one person.** If at first other people find it hard to understand your speech, they will understand you better with practice. Drawing simple pictures can also help.
- **Talk about abuse with other women you trust.** It can be hard to explain what happened, and you may be ashamed or afraid that your abuser will find out. You may also worry that no one will believe you. Sometimes you might feel worse after you talk, especially if the person you are telling does not listen. But talking with someone is usually the best way to get help. For more information about support groups, see page 65.





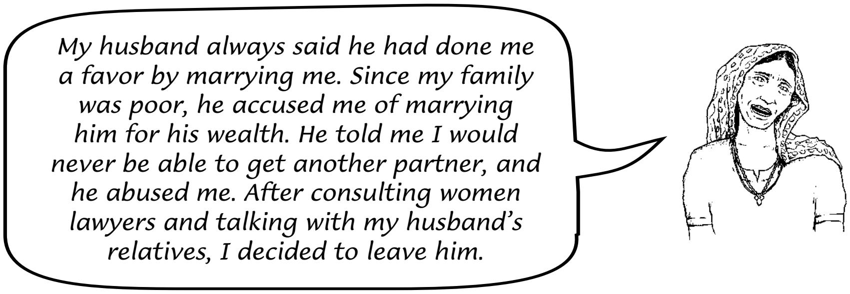
I was lonely with only my husband knowing how to use sign language. Teaching some sign language to other women in the community helped me make friends and do more things with other people. Now I have the support of other women and I can ask for help when I need to.

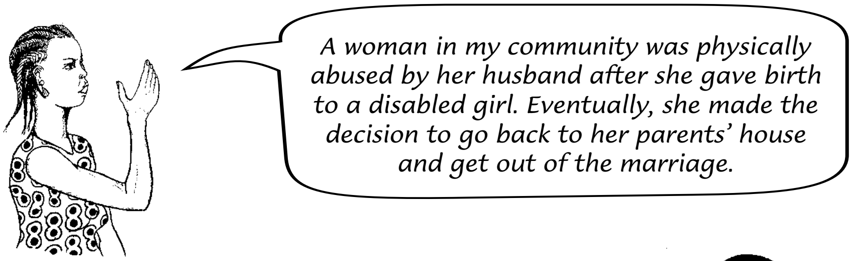
Women with different abilities can exchange or trade work if they each do something they are good at.

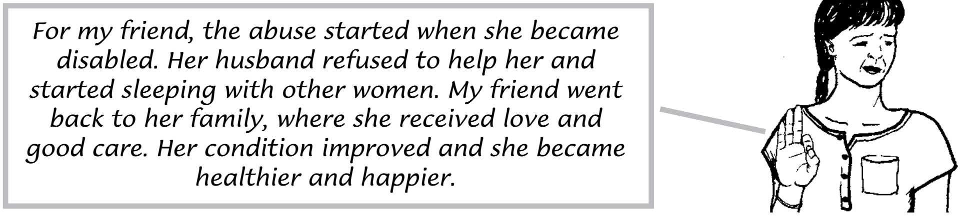
- **Do your work with other women.** People are less likely to threaten you or treat you badly where other people can see. If you are hurt in a public place, other women may be too scared or ashamed to do anything. But you might be able to get help from these women later.
- **Reach out for support** from other women and with community groups if you or someone you know has been abused.
- **Talk with a health worker** if you have been physically hurt.

Abusers often break down a woman's self-esteem, making her believe she (and her children) will be unable to survive without the abuser. Remember, you can survive without the abuser.

See page 308 for ways you can defend yourself against violence.



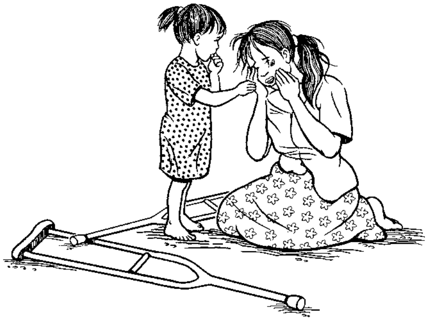




Support for women leaving violent partners

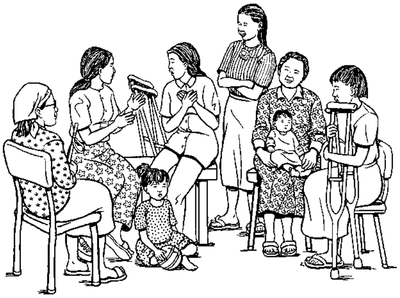
Because women have organized to be safe from abuse, in many places laws and courts have been established to protect us against violence. In other places, the people who are supposed to enforce the laws, especially the police, lawyers, and judges, cannot be trusted to help a woman. But in all communities, women are best protected when they work together. Here is an example:

If your partner has been beating you…



…and you decide you want to leave him…

…talk about it with someone you trust (a neighbor, a friend, or a relative).



Then try to get together with other women in the community to talk about your problems. You will probably find that some of them have the same problems.

Then you can all go together and talk to the man. If he does not say he will change his ways, go together to a village elder...

...or to the police and report him. They will be more likely to take your complaint seriously if you are with a group.

Sexual abuse

Girls are especially at risk for sexual abuse because they are smaller, weaker, and less aware of the social rules and practices around sex in their communities. Girls may be abused by a father or mother, an uncle or other relative, or by a brother or by other children. If a girl tells someone about abuse in the family, the family often protects the abuser—and blames the girl. But it is never right to blame the person who has been abused, especially not a child.

Girls and women with disabilities are at even greater risk for being abused—especially if they are weakened by their disabilities, have difficulty communicating, or are not fully accepted by their communities. This can make the abusers believe women with disabilities are easy targets and their communities will not care about what happens to them.

A disabled woman can be sexually abused by her husband, by other family members, by someone who takes care of her, or by a stranger. Most often, a woman is raped by a man she knows. And because a disabled woman's family may not have allowed her to be in social situations where she could make friends and learn about sexual relationships between men and women, she may think she has no other choice but to accept abuse. She may even think that no one but the abuser will be attracted to her.

There are many ways sexual abuse happens, but only sometimes do people think of them as sexual assault or rape. Sexual abuse means any sexual contact a woman does not want. A woman or girl is sexually abused when she:

- has been raped or forced to have sex she does not want.
- is touched on her breasts or genitals, or on other parts of her body, without her permission.
- is forced to have sex with someone so she can keep her job, or with a teacher so she can get a passing grade.
- is forced to have sex in exchange for care.
- has sex in exchange for money or food, because she has no other way to support herself.
- has to pose for sex pictures (pornography) in exchange for money, food, or care.
- has to hear or watch sex between other people.
- is teased or talked to sexually, or has to listen to jokes or sexual language that make her uncomfortable.
- is made to look at pornography.

Sexual abuse can happen to any girl or woman. It is never her fault.

Talk about sexual abuse with women who have problems with learning or understanding

All children are taught to obey adults. As they grow older, they learn when not to obey. But women who have learning difficulties have often only been taught to trust other people, to be 'good' by being quiet, not arguing, and by doing what they are told. This can make them easy targets for people who may try to take advantage of them, including sexually.

Talk about sexual abuse with girls and women who have problems learning and help them understand they have a right to be safe from abuse. Make sure they know they can talk to you or someone they trust if they are being touched or abused, and that they will be believed and kept safe.

Also, make sure women who have learning difficulties learn how to defend themselves.

Sexual assault and rape

Sexual assault means forcing a woman to have sexual contact she does not want. Rape is the most violent form of sexual assault. Rape happens any time a man puts his penis, finger, or any object into a woman's vagina, anus, or mouth without her consent.

Sexual assault and rape of girls

Sexual assault and rape is extremely harmful to anyone. But the effect it has on girls can be especially hard and long-lasting. Because girls are not sexually mature and may not understand exactly how to explain what was done to them, they often have a difficult time getting anyone to believe them. In some communities, a girl who has been raped will never be 'acceptable' to marry.

In places where there is a strong military presence, girls are sometimes forced to be servants or 'sex slaves' for soldiers or armed groups. These girls are often disabled physically and emotionally as a result.

In some places, people believe that having sex with a virgin will cure AIDS, and many very young girls, and even babies, have been raped because of this belief. Because their bodies are small, their genitals get badly damaged and they are more easily infected with HIV and other sexually transmitted infections.

Getting help if you are raped or assaulted

Every woman's experience with rape is different. But there are some things you can do to help yourself recover. First, ask yourself these questions:

- Who can you ask for help?
- Do you want to tell the police about the rape?
- Where can you go for medical care?
- Do you want to try to punish the rapist?

A disabled woman who is raped needs the same help as any other woman. It is important to tell someone you trust who can go with you to see a health worker, and help you decide if you want to tell the police. You may feel sad, hurt, scared or angry for a long time, so you will also need someone to talk with about your feelings. Choose someone who cares about you, is strong and dependable, and who you trust will not tell others. Your family or usual helpers may be too upset to be able to give you all the support you need.

The stigma of rape

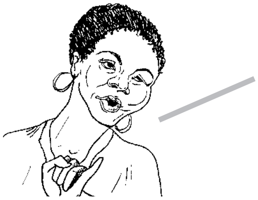
In some places, a woman who has been raped is treated as if she has brought shame or disgrace to her family or the whole community. She is unfairly blamed not only for the attack on her, but for the moral failing of the entire community. This is called stigma. Because of stigma, a woman who was raped may be afraid to tell other people. She may fear her community will treat her differently if they know about the rape. Or, a woman's family may not want anyone to know because they think it will dishonor the family. The stigma can be worse for a disabled woman, because it usually adds to the stigma that people already direct toward others who are disabled or have disabled people in the family.

A woman who has been raped is **never** to blame for the rape. A woman who has been raped needs support from her family and her community. Stigma is a barrier to a woman healing and a community preventing sexual assault in the future.

If you speak differently, you may find it hard to explain what happened, especially if you are upset. If you are ashamed or frightened, the words may be harder for you to say. Sometimes it helps to draw a picture to explain what happened.

If you are deaf

Women who are deaf or have trouble speaking can have a harder time getting help if they are raped or abused. Even though she may be able to describe her attacker, if no one understands her sign language, she will have a difficult time explaining to others what happened to her and who did it.



When I went to the police because my husband was beating me, they did not understand my sign language and they were impatient with me. My co-wife defended my husband, and no one believed me.

If someone you know has been raped or abused

If you are talking with a woman who has been abused or raped, reassure her that you will listen to her. Tell her to take as much time as she needs to explain what happened.

- Reassure her that it is not her fault.
- Be supportive. Listen to her feelings, help her decide what she needs, and reassure her she can go on with her life.
- Respect her wishes for privacy and safety. Do not tell anyone unless she wants you to.
- Go with her to see a health worker, to report the rape or abuse to the police, to talk with someone trained to listen and support her, to see a lawyer, and to go to court if she wants to do those things.
- Do not protect the rapist if you know him. If possible, let other women know about the man. He is a danger to every woman in the community.

If you go to the police

In most places, rape is a crime. But it may take a long time and be very difficult to prove you were raped. Make your decision to go to the police carefully. Have the police helped other women in your community who have been raped? If you want the rape to remain private, will the police keep others from learning about it?

Never go to the police alone. In some communities, a woman who goes to the police alone is at risk for being raped again by the police. Be sure someone else can go with you.

If you want to report the rape to the police, you must go as soon as possible. Do not wash, shower, or bathe before you go, and do not change the clothes you were wearing. This can help prove you were raped. The police may ask you to have a medical exam from a doctor who works with the police. The exam can also help prove you were raped.

If the rapist is arrested, you will have to identify him in front of the police or in front of a judge in court. Going to court for a rape is never easy. Describing what happened may make you have the feelings of being raped all over again. Not everyone will understand. Some may try to blame you or say you were lying.

And some people will not listen to you because of your disability. They may believe a disabled woman cannot be a truthful or convincing witness. But some women with disabilities have been successful in court, especially when they have support from their community. When you decide to go to court, make sure you always go with someone you trust.

HEALTH PROBLEMS CAUSED BY RAPE

After a rape, it is best to see a health worker, even if you are not badly hurt. Tell the health worker you have been raped. She can help prevent and treat common health problems caused by rape.

Pregnancy

You can prevent pregnancy if you act quickly and use emergency family planning. Speak with a health worker about this. Use emergency family planning as soon as possible after the rape, but no later than 5 days (120 hours). See page 357.

Even if you use emergency contraception, if you do not get your next monthly bleeding on time, have an exam right away to make sure you are not pregnant. If you think you are pregnant, see a health worker. In some countries, abortion is legal if a girl or woman has been raped.

Sexually transmitted infections (STIs) and HIV/AIDS

The man who raped you may have had a sexually transmitted infection (STI) or HIV/AIDS and passed it to you. A health worker can give you medicines to prevent STIs such as gonorrhea, syphilis, and chlamydia even if you do not think you were infected. It is better to prevent an STI than to wait for signs of infection.

You should also try to have an HIV test in 2 to 4 weeks (see page 172). Until you have a negative test result, it is best to use condoms if you have sex to protect your partner from possible infection. If you live in an area where many people have HIV/AIDS, you may want to talk with a health worker about taking medicines to reduce your risk of becoming infected.

Tears and cuts

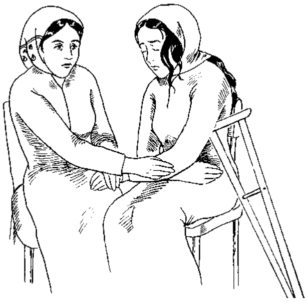
Rape can damage the genitals by causing tears and cuts. These can cause pain, but will go away in time. If there is a lot of bleeding, see a health worker who can stitch tears and give you medicine to prevent infection. For small cuts and tears:

- Soak your genitals 3 times each day in warm water that has been boiled and cooled. You can put chamomile flowers in the boiling water to help with healing. Or you can put the liquid from inside the leaves of an aloe plant on the cuts and tears.
- Pour water over your genitals when you pass urine so it will not burn. Drinking a lot of liquid makes the urine burn less.
- Watch for signs of infection: heat, yellow liquid (pus), a bad smell, and pain that gets worse.

Bladder or kidney infections

After violent sex, it is common for a woman to have a bladder or kidney infection. If you have pain when you pass urine, or if there is blood in your urine, see a health worker. You may need to take medicine. It helps to drink a lot of water, at least 8 glasses a day (see pages 105 to 106).

To the health worker:



If you see someone who has been raped or abused:

Treat her with kindness and understanding. Encourage her to tell you what happened, listen carefully, and let her know you believe her. Do not blame her. She may find it difficult for you to see or touch her. So before you touch her, explain how you will examine her and wait until she is ready. Remember that her feelings about the rape and violence may last for a long time, even years.

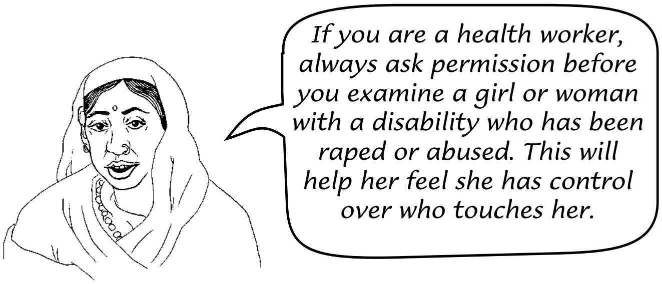
Treat her health problems. Give her medicines to prevent STIs and pregnancy, and to lower her risk for getting HIV/AIDS. If she became pregnant because of the rape, help her to decide what to do.

Write down who raped her and exactly what happened. If your clinic does not keep records, make one and keep it somewhere safe. Draw a picture of the front and back of her body and mark the places where she has been hurt. Show or tell her what you have written and explain that it can be used to support the fact she was raped if she reports the rape to the police or brings legal charges against the rapist.

Treat her emotional and mental health needs. Ask her whether she has someone to talk to. Help her to respect herself again and to gain control of her life.

Help her to make her own decisions. If she wants to report the rape to the police, help her find legal services. Help her find other services in the community for women who have been raped.

Help her tell her partner or her family. If they do not know already, offer to help her tell them. You can help them find ways to support her until she recovers. Remember that family members usually also need help to overcome their feelings about the rape.



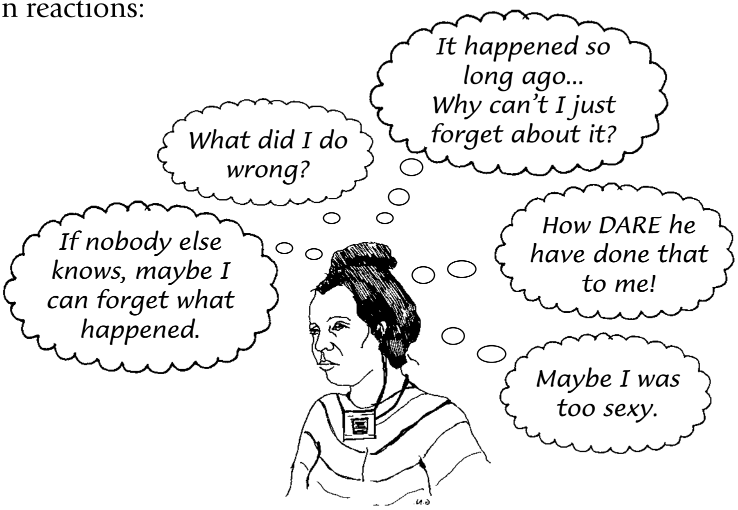
SEXUAL RELATIONS AFTER RAPE

You can have normal sexual relations after rape. You will need to wait until your genitals no longer hurt and any tears have healed. For many women, having sex makes them think about the rape. If this happens to you, talk with your partner about why sex no longer feels the same, why it frightens you, and why you need to wait. Ask your partner to help you overcome your fear by gentle hugging and caressing that avoids touching your genitals. As you feel safer, you may be able to start having sexual intercourse again. But this takes time, and you will both need to be patient.

A woman's partner can make a big difference in helping a woman who has been raped, by being kind and understanding. But sometimes a woman's partner may reject her after she has been raped. He may be ashamed and angry, especially if he believes that her rape dishonors him or if the community holds that belief. It may help to find someone in the community he can talk with about his feelings.

HOW YOU FEEL AFTER THE RAPE

The rape may still bother you long after your body has healed. Here are some common reactions:



It is important for a woman who has been raped to talk to someone, or to do things that will help her feel better after the rape. Every woman finds her own way to heal. Some women perform a ritual. Others try to punish the rapist, or work to prevent other women from being raped. Whatever you do, be patient with yourself and ask others to be patient, too. For more information, see Chapter 3, Mental health.

Abuse in institutions

Sometimes when a family finds it hard to care for a disabled woman, they decide to place her in an institution or a residential home. They feel the institution will be able to care for their daughter or mother better than they themselves can. Many people who live in institutions or residential homes also get a feeling of belonging and have a community of people around them. Even though many people with disabilities have survived because of the care they get in residential schools, hospitals, and orphanages, they can also be abused there.

Because people who live in institutions are often isolated, lonely, and powerless, they are more vulnerable to being abused. Many times they are living far away from their families, or they have no families at home who can care for them.

Disabled people in institutions often have little control over their own lives. They are usually told what to do, and cannot make many decisions on their own. Women who have learning difficulties may be particularly isolated in institutions because of their difficulties in understanding or making themselves understood.

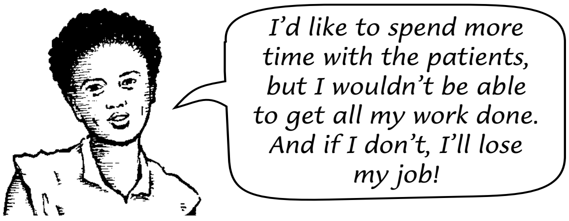
Other problems for people in institutions result from the way the institution is managed. Many institutions have too many residents and not enough money. Often, the people who work there are overworked, frustrated, and exhausted. Sometimes the people who work in institutions are given too much power: they make rules, provide the care, and are expected to keep order.

In addition to the kinds of abuse mentioned earlier, women with disabilities can face other kinds of abuse and violence in institutions:

- forced sex with workers, caretakers, or other residents
- being beaten, slapped, or hurt
- no activity for work or pleasure, and always being bored
- forced sterilization or abortions
- being locked in a room alone
- ice baths or cold showers as punishment
- forced medication (tranquilizers)
- having to undress or be naked in front of other people
- watching other people be abused or hurt
- being tied down or put in restraints (unable to move)

People who work in institutions

Many people who work in institutions that care for women with disabilities have good intentions. But some people who work in institutions may treat people with disabilities badly. These people like having power over others. Other people who work in institutions may get upset at how women with disabilities are treated in the institution and may want to do things differently. These caregivers usually work long hours with low pay. They are usually expected to do what they are told, and they rarely have the power to change the conditions in which they work.



Sometimes caregivers do not say anything because they do not know who to tell. Or they are afraid of losing their jobs. If caregivers complain about abuse they might be told it is not their problem, or they may be threatened or laughed at. Many times the caregivers end up believing that bad care is just how things are.

The people in charge of the institution may not know about the abuse, or if they know, they may pretend nothing is happening, or they may say that violence against disabled people does not matter.

Bad conditions and the abuse of people with disabilities in institutions are issues for the whole community. People in institutions need enough resources for good care and to make sure they are not abused.

WORKING TO CHANGE INSTITUTIONS

If you know someone who has been sent to live in an institution, and you think the person is not being treated well, here are some ideas to work for change:

- Form a parent's or family group, and speak with the people in charge. They will be more likely to pay attention if you go as a group than if you go alone.
- Build community involvement with the institution and residents by offering residents opportunities for meaningful activity and interaction with the community outside.
- Campaign for visiting hours and conditions that allow residents to go out with a visitor, or spend time privately with people who come to visit.
- Advocate for community programs and stay-at-home services, so that people do not have to go to institutions.

What you can do to be safer from violence

SELF-DEFENSE

Having a disability does not mean you have to accept that you are weak and must always depend on others. You can learn to defend yourself against the many ways you may face abuse, violence or sexual assault.

Never believe you are alone. You are part of a world-wide movement of women and men who are working to end violence against women.

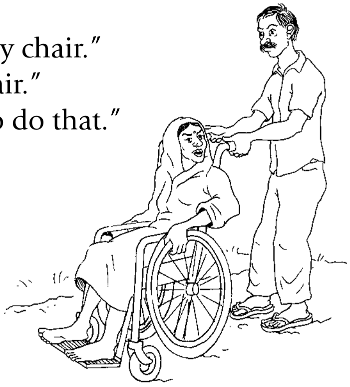
You can begin by preventing people from giving you 'help' you don't want or need. This is one way you can show people your strength and your ability to speak for yourself and make your own decisions. Although the person offering "help" may not be trying to harm you, do not be afraid to tell them to stop, even if they seem annoyed. If there are other people nearby, speak loud enough so they can hear you too. Practice being firm but not necessarily rude to people who may offer you genuine but unwanted help.

When men believe they are free to touch you, they may think they can easily take even more advantage of you. If someone touches you without your permission, say the following 3 things to the person:

1. "You are touching me."
2. "I don't like that."
3. "Take your hands off me."

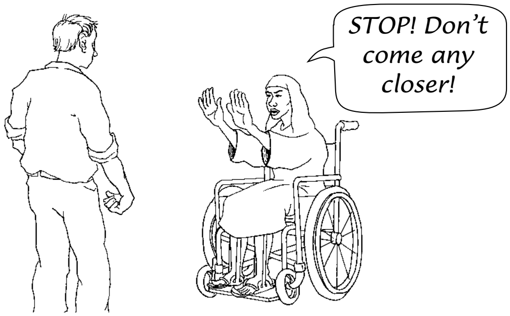
If the person holds your arm, or starts pushing your wheelchair, say firmly and loudly:

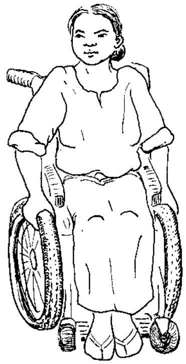
"You are pushing my chair."
"Don't push my chair."
"I don't want you to do that."



"You are holding my arm."
"Don't hold my arm."

If someone is coming toward you and you think they may hurt you, try this:




This woman looks confident and assertive.

Many times this action is enough to make the person go away. He will think you will be too much trouble to try to take advantage of. If he keeps coming closer, scream for help.

Attackers usually pick people who look easy to hurt. And a disabled woman, no matter what disability she has, can look especially easy, particularly if she looks as though she is lost or does not know where she is. So acting in an assertive way with a lot of self-confidence is just as important as knowing what to do physically. Being assertive is often a woman's best protection. When a woman is assertive, she moves, speaks, and acts as if she has a right to be wherever she is. She acts confidently and carries herself like a strong, proud woman. For information on self-esteem, see pages 62 to 65.

WHAT TO DO IF YOU ARE ATTACKED

If a woman resists someone who tries to hurt her, she is often able to avoid rape. Some people think that trying to stop rape will make an attacker more angry. But an attacker is already dangerous. Resisting rape may allow you to get away, because it can show an attacker that trying to rape you will be too much trouble.

It is impossible to know how you will react if someone tries to rape you. Some women are filled with anger and feel strength they did not know they had. Others feel like they cannot move. But remember, if you are raped, it is not because you failed to defend yourself. Rape is **never** your fault.

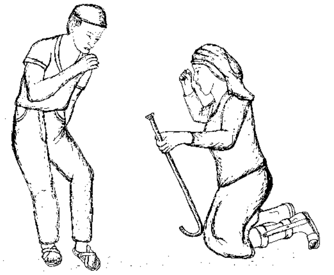
If someone attacks you or tries to rape you, do whatever you can to get away:

- Do something he finds disgusting, such as drool or spit.
- Hurt the soft parts of his body such as his eyes, nose, or testicles (balls) by scratching, hitting, or kicking him.
- Roll your wheelchair into the person as hard and fast as you can.

Make noise, scream, or yell "NO!" Shout as loud as you can: "HELP!"

Throw chili powder, pepper, or dirt into his eyes. It will blind him for a while and be very painful. You may be able to get away.

If you lose your balance easily, it is best to sit down before you start defending yourself or fighting back.



Sitting or kneeling down is a safer defense position for women who use crutches, whose legs are weak, or who are unsteady on their feet. Once you are sitting down, poke him with your crutch or cane.

When your attacker bends down, hit him in the nose or eyes. You can also use your head to hit his nose.

If you use a stick or cane, you may be disoriented if it is knocked away. If you think you are about to be attacked, turn your stick so the short, thick end points toward the man. Poke him with the stick as hard as you can. Do not swing your stick like a baseball or cricket bat. That makes it easier to grab or to knock away.

It is better to poke someone with the short end of your stick than to swing the long end.

If you use crutches, use them as a weapon to hit him.

If you are blind

Blind women can lose their bearings when someone attacks them. But you can use the attacker's body to help you. Try to find the place where the shoulder meets the neck. It is one of the easiest places to find quickly and it gives you good information about the position of the rest of his body. Then you can hit him in his soft spots.

Ask a friend to help you practice finding the shoulder quickly, and then finding the tender parts of the body. Your friend can also help you practice finding a cane that is knocked away.

Lift your knee, and push it as hard and fast as you can into his testicles (balls).

Practice your skills

Practicing self-defense can help you feel safer and more confident, even if you are never assaulted. Practice having a strong, assertive attitude. Think about different ways to defend yourself and try them with other women. You can organize a group so you can all learn together. In some self-defense classes, women practice hitting as hard as they can. They can hit a dummy or another woman padded with extra clothes or pillows. This is very useful for women who are not used to fighting.

FAMILIES AND CAREGIVERS CAN PREVENT ABUSE

Girls and women who grow up with disabilities are regularly touched, examined, and moved around by family members, helpers, and health workers. Often this happens without asking permission. Any woman, whether or not she has a disability, has the right to say who can touch her.

Families and caregivers can work to prevent sexual abuse by helping a girl learn the difference between 'good touch' and 'bad touch.' Always ask for permission before touching her. If she needs help with personal care and daily activities, always allow her to tell you what she wants you to do. Let her tell you how to touch or move her body in ways that are more comfortable. Teach disabled girls to say 'NO' to touches they do not like.

Talk to disabled girls about rape and sexual abuse, and make sure they learn to defend themselves.

When you raise a disabled child with love and respect, she will grow up into a confident, assertive woman and other people will be less likely to treat her badly.

COMMUNITIES CAN PREVENT VIOLENCE AND ABUSE

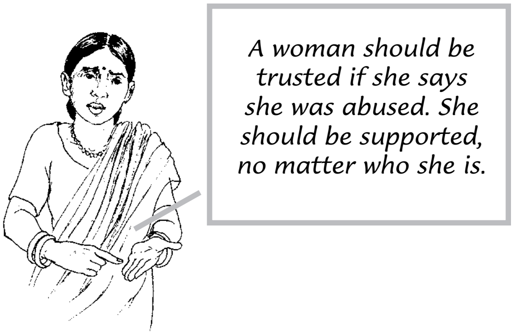
When a community believes that abuse is a terrible thing, it is rare for a woman to be abused. When disabled women are important members of the community, few disabled women are abused. But in places where communities believe that disabled women are not worth much, many more women with disabilities are abused.

Provide help for women who have been abused, especially women with disabilities. Rape crisis centers, emergency homes, shelters, and other programs against abuse and violence can include special programs to help women with disabilities. Make sure the buildings are accessible and that appropriate information is available for blind and deaf women, and for women with learning difficulties.

Health centers, schools, counseling centers, churches or elders in the community can help care for the mental health of people who have suffered abuse. Counseling can help people who have been abused regain their confidence, self-esteem, and well-being.

Educate and involve men in discussions about why abuse is wrong. Make sure the police and other community officials understand it is never OK to abuse disabled women. Employ people who know the local sign language in all community services, such as police stations, clinics, and hospitals.

Learn about the laws in your country that protect women who have been abused and explain them to others. Arrange public meetings of women, including women with disabilities, to discuss and protest violence and abuse against women. When women with disabilities, health workers, and others in the community talk openly about these problems and work to end violence, it makes all women safer from abuse.




Abuse is not just a family matter. Abuse is a social and community health problem.

CHAPTER 15

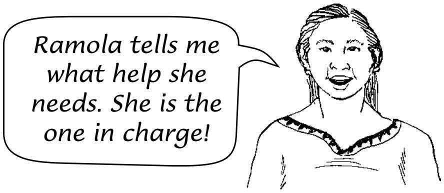
Support for caregivers

Everyone needs help sometimes. It is rare that we can go through a day without getting help from—or giving help to—family members, neighbors, or even strangers. It is human nature to help each other.

A disabled woman often needs assistance in a daily, ongoing way. When she gets the help she needs, she can live a healthier and happier life, and can contribute to her family and community.

Assisting a woman with disabilities can be rewarding work, but it can also be stressful, especially if she needs a lot of care. This chapter is mainly for families and others who assist women with disabilities in caring for themselves. It will also help disabled women better understand the needs of the people who help them.

MAKE DECISIONS TOGETHER



Above all, anyone who assists a woman with a disability must remember she is a grown woman and not a child. If she can, let her tell you what she needs help with, and then together you can decide the best way to do it.

As much as possible, the disabled woman should be in charge of her care and her life. Caregivers should encourage the disabled woman to regard herself as the captain of the 'team.' That way she can get the help she needs, and not assistance given in a way she finds unnecessary, not helpful, or lacking respect.

As far as possible, talk with the disabled person about what she expects. Ask her what responsibilities she can share, and what a caregiver needs to do or not do. She may not feel good asking for help to do things she would rather be doing herself. It will be easier to give good care if you and the woman can talk about this openly. If that is not possible, try putting yourself in her place and imagine what she might be feeling.

If she is deaf and uses sign language to communicate, make sure you learn how to sign with her as soon as possible.

If she is blind, let her tell you how she wants you to help her find her way around. Do not just take hold of her arm or hand and start to lead her. Let her take your arm first. Also, if she uses a stick or cane to find her way around, make sure it is always close by her side.

What women with disabilities can do

If you are a woman with a disability and you need help with daily activities, such as bathing, dressing, eating, or getting up from lying down, talk with the person who will assist you before they begin to help you. Make sure they understand how much assistance you do or do not need.

Be patient. It may take time for the person to realize there are many things you do not need help with.

Caregivers need respect. Most caregivers and assistants work very hard. They need a little time to themselves every day as well as a whole day off at least once a week. If your caregiver is rested, he or she will be better able to assist you.

Make decisions together. Although you know best the sort of assistance you need, listen to the ideas the caregiver may have. Sometimes her ideas may work better.

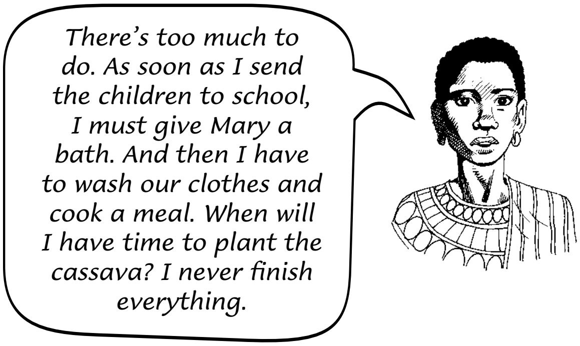
Meet with other disabled women to share ideas about the best way to use the help of a personal caregiver.

The community must value caregivers

Both women with disabilities and caregivers—whether they are family members or paid assistants, whether they are men, women, or children—are valuable members of our communities. They need to be supported in real and warm relationships within the families and communities where we live, work, and share our joys and suffering. But like most domestic work, assisting women with disabilities is seldom valued, appreciated, or seen as important. Sometimes a helper feels that even the disabled woman herself takes the assistance for granted!

Women as caregivers

Most often, women and girls assist family members who are sick or have a disability. And they do this while they continue to do their other work at home and in the community. For many women, their daily work begins before dawn and is not done until late in the day. When women are also helping care for another person, they have even more work to do.



Children as caregivers

It is easy to forget that children—especially daughters who assist their mothers—have their own needs. Children need to spend time with other children, to learn and to play.

Instead of always relying on their daughters, mothers with disabilities can also get help from other adults. If the mother can explain to everyone the help she needs, perhaps the entire family can work together as a team to assist her.

Men as caregivers

Sometimes it is the man or boy in a family who is the caregiver for a wife, sister, or mother. If so, he may need help from other women in the family, as well as the person he is assisting, to understand why life for a woman with a disability might be different than it is for a man. The differences between male and female bodies are important, but the differences in the ways men and women are raised and treated in the family and community are even more important.

PAID PERSONAL ASSISTANTS

Sometimes a woman with a disability can pay a personal assistant whose work helps her have more freedom and be more independent. In some communities, the government provides money for people with disabilities to hire someone to assist them with daily care or will pay family members and friends to assist them. Sometimes a disabled woman gives her assistant food or a place to stay.

Although the work that assistants do, such as taking care of daily hygiene including bladder and bowel care, is very important to a person's health, it is usually considered a low-status job and often pays very little. Many personal-care assistants say that family members sometimes want to control them and make unreasonable demands on their time, or dismiss them without explanation. And if disabled people are isolated, they may not understand how badly the attendant is being treated.

Paid caregivers, like other workers, need fair wages, time off, vacations, and sick leave.

Organizations and community groups that train and provide jobs for personal assistants can:

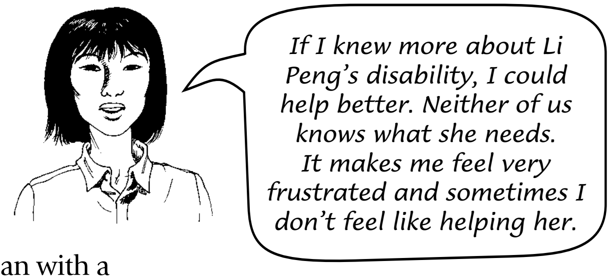
- help set standards for working conditions.
- educate about ways to prevent and reduce conflicts.
- offer training in counseling skills to better meet the emotional needs of women with disabilities.
- teach skills for lifting, helping someone exercise, and preventing infection.

Community workers make time for caregivers

In Ghana, a group of community workers who help older people gathered a group of caregivers together to talk about how to make things easier for them. They started the group because when the community workers traveled to different villages in Ghana, looking in on older people and assisting them with everyday tasks, they realized that in addition to helping older people, they also needed to look out for the people who help the older people every day. Now, whenever a community worker goes to visit an older person, she also makes time to talk to the person's caregivers. She listens to their feelings and problems. She also helps them with their tasks if they need it, and makes sure the caregiver gets a break for a little while.

Caregivers need help too

UNDERSTAND YOUR FEELINGS

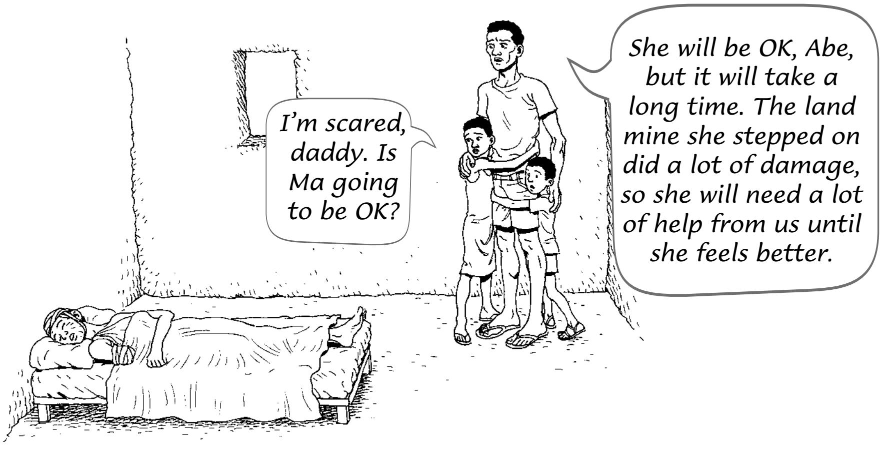


Caregivers stay busy trying to make things better for the person with the disability. They often focus on how that person is feeling. But, if you are a caregiver, it is also important to take time to notice your own feelings. Even if you are glad to assist a woman with a disability, you will sometimes get tired, experience stress, or feel frustrated or upset. As a caregiver, you may work in many different ways—as a nurse, a counselor, a driver, a cook, an accountant, and a housekeeper—all at the same time. If you look after a person who is very ill or depressed, you may experience more stress.

It is natural for family members and others who assist women with disabilities to feel ashamed or guilty for being frustrated, tired, angry, or upset. Even a person who cares for a close relative or a spouse can experience uncomfortable feelings and strong emotions. Do not feel guilty or ashamed for wanting to get away sometimes.

If you can notice and think about what makes you feel angry, frustrated, or helpless, then you can try to find a way to change the underlying causes of your feelings.

A sudden disability affects the whole family

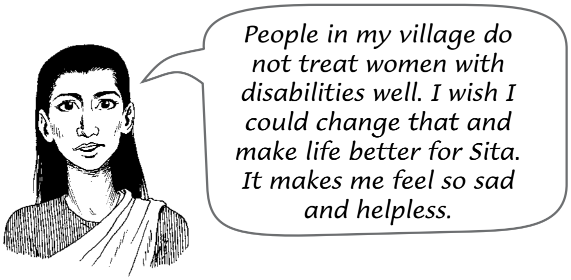


When someone close to you becomes disabled suddenly, because of an accident or an illness, everyone gets injured in a way. The unexpected change in your life can be frightening, and can cause you and other family members to feel very sad or angry.

Understanding your feelings can move you to actions that make both your life and the life of the woman with disabilities better.

Feeling angry may give you energy to help organize a group of caregivers and others to persuade the government to make it easier for women with disabilities to get good health care, transport, and access to public buildings.

Feeling frustrated, helpless, or lonely may help you reach out to other people in your community who live with women who have disabilities, or who are themselves disabled. They may be able to help you.



Healthy ways to talk about feelings

When people who spend a lot of time together do not talk about how each other feels, they can become frustrated and angry with each other. Even if talking cannot find a way to change the underlying reasons for your feelings, it can help both of you to change how you act on them.

People show their feelings in different ways. There are healthy ways of expressing feelings and unhealthy ways. For example:

This is a dangerous and unhealthy way to talk about feelings.

This is a safe and healthy way to talk about feelings.

A mother in Nigeria tells how she cares for her disabled daughter

My daughter is a polio survivor. When she was a young girl, we could not afford to buy a wheelchair or to employ anyone to help us. So I used to carry her on my back to school every day, even up to the 12th grade. It was hard for me and I would get very tired as she got bigger and heavier. When she got to university she also got a wheelchair, and now she even has her own car. So I can rest more compared to what it was like a few years ago.

But now she needs emotional help because she becomes erratic in her behavior sometimes. I understand that this has to do with what she is going through, so I try to help her. But if I could afford to employ someone to help her become more emotionally stable, then I would be able to look after myself better and not be so exhausted all the time.

Take care of yourself

Some caregivers devote themselves completely to fulfilling the needs of the people they care for. They get so good at helping other people that they forget to take care of their own needs. Sometimes they sacrifice their own well-being and their enjoyment of life. After a while, helpers who never think about themselves may begin to get frustrated and angry at the people they help. This can hurt both the helper and the person she assists.

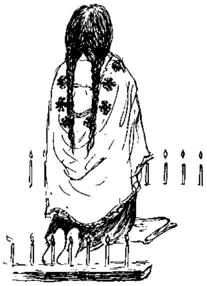
If you do not take care of yourself, you stop having energy to help others. To take good care of someone, you must get enough sleep and rest, look after your own physical needs, and continue to have fun and other relationships.

Practice traditions that calm the body and mind and build inner strength such as yoga, prayer, meditation, T'ai Chi, and others. Practicing these traditions regularly can help you cope with the stress of caring for someone.

Take care of your own health

- Eat good food so your body stays strong.
- Get enough sleep so you will have enough energy during the day.
- Get more exercise than just your work as a caregiver.
- Massage can help you relax your body. It can also help relieve stress and upset.

yoga

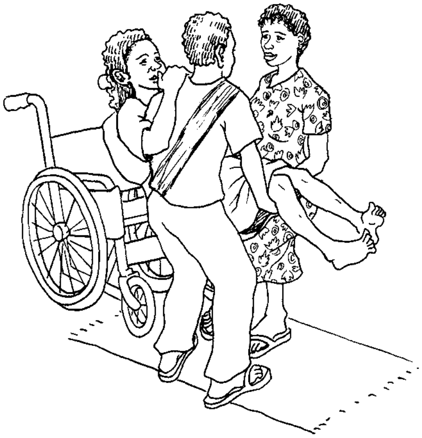


prayer

Make time to put your work aside and do something you enjoy. It is important for a woman with a disability and her caregiver to both have friends and interests away from each other. To have a full and satisfying life, each of you needs to spend time with other people.

Be careful not to injure yourself

The job of caring often involves physical work, such as lifting the person you are helping. This can cause injuries to your back. To lift or carry someone or something safely:



- Use your leg muscles, not your back muscles. When you lift something heavy from the ground, kneel or squat to pick it up rather than bending over.
- Keep your back, shoulders, and neck as straight as possible as you straighten your legs.
- Ask someone to help you lift the person you are caring for. It may seem quicker to do it yourself, but if you injure your back, later on you may not be able to help at all.

ASK OTHERS FOR HELP

Being a caregiver can be isolating. When a disabled person relies on just one helper all the time, everyone else may feel that the 'expert helper' is the only person who knows the right way to assist. But no one should be a disabled woman's only helper. Other family members, friends and neighbors can assist by bringing or cooking a meal, going to the market, cleaning, or just coming to visit. This will help you rest and have more energy later.

GIVING AND RECEIVING HELP

Look for ways a disabled woman can do things as part of the family's daily routine. Then, she can give help instead of just receiving it. Have good, realistic expectations. Expect a woman to be the best she can be. Encourage her to try new things and develop her skills.

Start a caregiver's group

One important way to improve health for caregivers is to talk with each other. Both caregivers and people with disabilities need support from others who have similar experiences. Talking with others about your needs and feelings can help you feel less isolated. You can also share ideas with other caregivers about how to make things easier and build support systems for you and all the disabled people you assist.

If there is not a group already, and you know there are other caregivers in the community, it may be up to you to start one. Some of the strongest and most active groups began because of one person's idea. A group working together can solve problems and do more than if they each work alone.

To start a group:

Find 2 or more caregivers who want to start a support group. If you do not know any families in which someone is disabled, a health worker may know of other families in nearby communities.

Plan when and where to meet. It helps to choose a place where everyone will be comfortable talking, perhaps a room in a health center, community center, cooperative, or place of worship. At the first meeting, discuss why you are meeting and what you hope to do.

Probably one person will be the leader of the first few meetings. But it is important that no one person makes decisions for the group. Everyone should have a chance to talk. Try to keep the discussion focused on the main reasons for the meeting. After the first few meetings, take turns leading the group. Having different people lead each meeting will help shy members participate.

Together we help our children and ourselves

In a poor community in Bangalore, India, several families of disabled children and adults have formed a support group. They meet once a week to talk and to make plans to promote and demand services in the community for persons with disabilities. They also own and operate several auto-rickshaws (3-wheel motorcycle taxis) to take children with disabilities to and from school.

LEARN TO SUPPORT EACH OTHER IN THE GROUP

Often, people who are always assisting others are too busy to think about their own feelings. Or they think they have no right to feel upset, or that only the woman with a disability should feel upset. Even when people know each other well, it may take time to feel comfortable talking about feelings, experiences, and the challenges of being a caregiver.

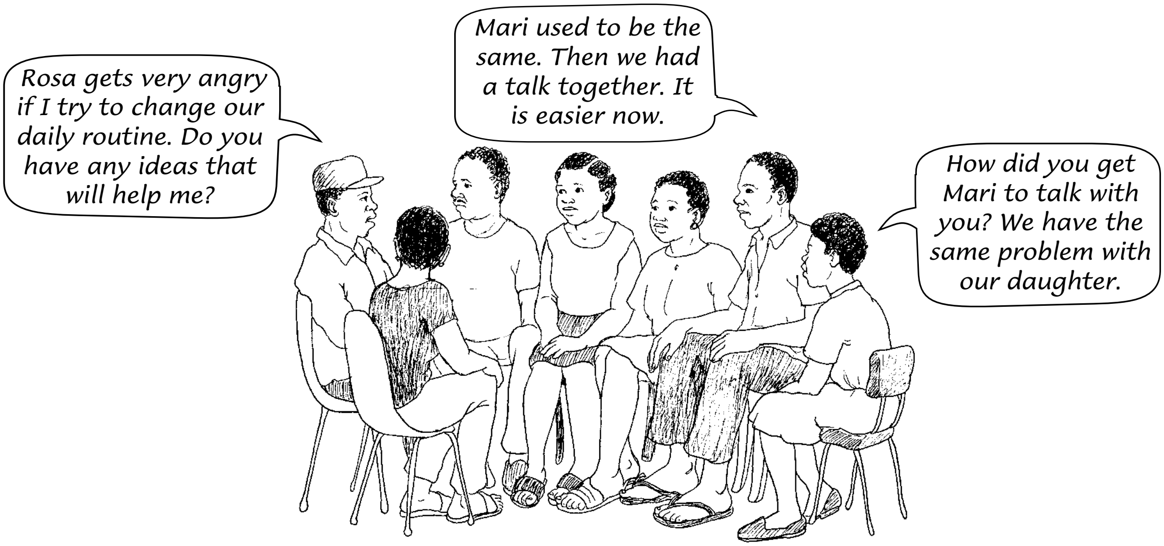
It is easier for some people to speak in a group than it is for others. But speaking is not the only way people can express their thoughts and feelings. Try different activities, such as singing songs, creating poems, or telling stories to help each person participate in a way that feels comfortable for them. Some people may best express themselves by drawing or painting pictures.

Here are some suggestions to help group members feel comfortable and trust each other:

Listen to what others say. Think about how you want others to listen to you, and then try to listen to them in the same way.

Try not to tell other people what to do. You can help others understand how they are feeling, and share your own experiences. But everyone must make their own decisions about the best way to assist people with disabilities.

The support group can be a place where a caregiver can show anger or cry from frustration. By sharing experiences and ideas, you can help each other find ways to change the causes of these feelings.



PLANNING FOR ACTION

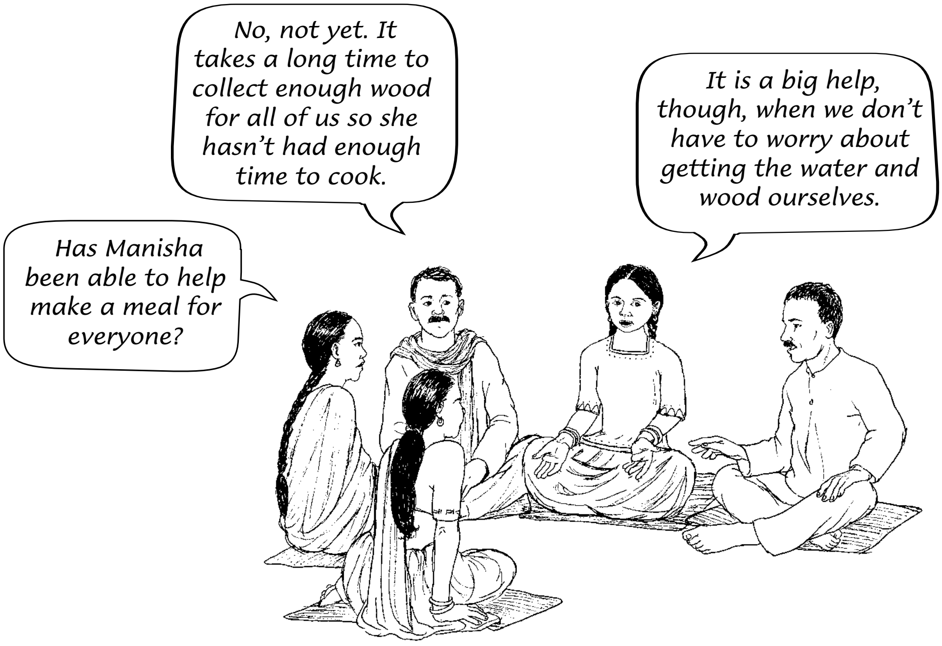
A group working together can take action to solve many problems. Here are some useful steps for taking action.

1. Choose a problem that most people in the group feel is important. Although many changes are probably needed, your group may be more effective if it works on one problem at a time. At first, pick a problem that your group has a good chance of solving quickly. Then, as the group learns how to work together, you can work on more complicated problems.

2. Decide how you want to solve the problem. List many ways the problem could be solved and pick the one that best uses your group's strengths and resources.

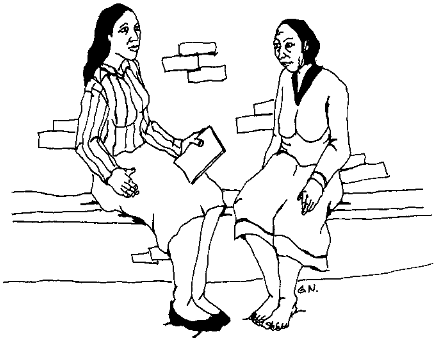
3. Make a plan. Members of the group will need to do different things to get the job done. Try to set a date when each should be finished.

4. When you meet again together, talk about how the work is going. Adjust your plan as needed if difficulties arise.



To the health worker:

Health workers can help caregivers. When you treat a woman with a disability, try to discuss with her the relationship she has with her caregiver. If her caregiver comes with her, talk with them both about their relationship and about what each needs from the other.



Talk with the caregiver to see if she has any problems you can help her with.

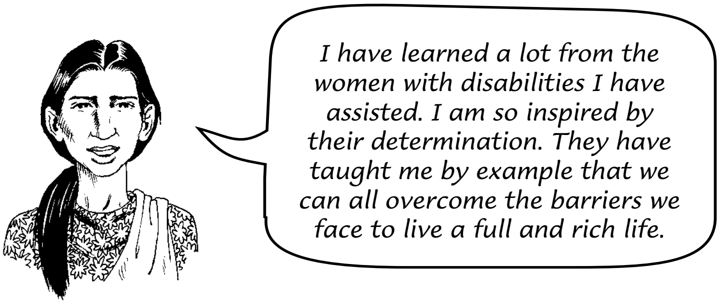
Encourage the caregiver to talk about her own feelings. Listen to the caregiver and let her talk. Do not scold her for feeling frustrated or upset. Assisting another person is hard work. Remind the caregiver that it is natural to sometimes feel sad, angry, or frustrated.

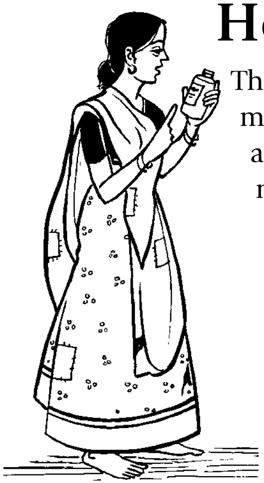
Ask the caregiver about her own needs. Encourage her to take care of herself as well as the person she helps.

Try to find someone who can give the caregiver a break. Everyone needs some time for themselves. See if you can find another person in the family or in the community who could help out for a little while.

If necessary, teach the caregivers in your community any health care and counseling skills they may need to take better care of the woman with a disability they are assisting.

IMPORTANT There is a difference between a person feeling frustrated, and hurting the person they help. Sometimes caregivers get so stressed and angry that they are dangerous to the person they are taking care of. Always be alert for signs of abuse when you examine a disabled woman (or any woman), and try to talk to her alone to make sure she is not being abused by her caregiver in any way. See Chapter 14 for more information about abuse and violence toward women with disabilities.





How to use the green pages

This section gives information about the modern medicines mentioned in the book. If you want to use traditional medicines, ask a traditional healer where you live to help you find remedies that may work for your problem. Traditional medicines vary a lot from one place to another, so a remedy used in one place may not be available or may not work anywhere else.

HOW TO TAKE MEDICINES SAFELY

Use medicines only when they are needed

Many people believe that if they do not receive medicines when they are sick, they will not get well. This is not true. Some problems, like colds, are best cured by time and rest. Other problems are best solved by eating enough good foods and drinking clean water. Be suspicious of health workers who always want you to take more and different medicines.

Take the full course of medicines

Even if you begin to feel better, continue to take the medicines for as long as recommended. Sometimes, taking less than the full amount can allow the sickness to return. It may even cause drug resistance, which means that the same drugs will no longer work against the illness.

Do not take too much

Taking more than the recommended amount will not make you well faster, and it will probably make you even more sick.

Know and watch for signs of problems

Some medicines can have harmful side effects or cause allergic reactions that can be very dangerous (see page 329).

Learn as much as you can about a medicine

Ask a health worker or a pharmacist about the medicines you take or other medicines you may need. You can also find information in the Green Pages in this and other Hesperian books (such as *Where Women Have No Doctor* and *Where There Is No Doctor*).

Medicines by mouth (tablets, capsules) are usually safer than injections

In this book, we suggest medicines to be taken by mouth. Only if they cannot be taken by mouth do we give information about medicines that must be injected. If you need an injection, see a health worker. Information on how to inject safely can be found in *Where Women Have No Doctor* on pages 542 to 544.

Single medicines are safer and less expensive than combined medicines

But some medicines, especially those for HIV/AIDS, are easier to take in combination.

IMPORTANT

- If possible, take medicines while standing or sitting up. Also, try to drink a glass of liquid each time you take a medicine.
- If you vomit and can see the medicine in the vomit, you will need to take the medicine again.
- If you vomit within 3 hours after taking a birth-control pill, take another one to make sure you will not get pregnant.

TAKING OTHER MEDICINES TOGETHER WITH YOUR DISABILITY MEDICINES

If you take medicine regularly for your disability, it may not combine well with some of the medicines listed in this book. Other medicine may make your disability medicine not work as well, or your disability medicine may change how the other medicine works. For example, if you take phenytoin for epilepsy, you should not use birth control pills that contain both estrogen and progestin because your seizures may become worse. Talk with an experienced health worker or pharmacist to find out if your regular medicines will interact with any new ones you must take, and if so, what other medicines you might take instead.

Luckily, not every medicine listed in this book has interactions. For the few medicines that do have interactions, you will find the information listed for each medicine under the heading 'Interactions with other medicines' with this symbol:

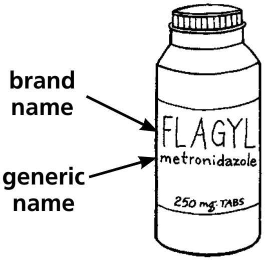
ALLERGY

Some people are allergic to certain medicines. When a person is given that medicine, her body has a reaction. The reaction may be uncomfortable (such as skin rash, itching skin or eyes, swelling of the lips or face, wheezing), or it may be very serious and endanger her life (such as pale, cold or sweaty skin; weak or rapid pulse or heartbeat; difficulty breathing; low blood pressure; or loss of consciousness).

If a person goes into allergic shock, she needs medical help immediately. Give epinephrine (see page 342).

Do not take a medicine you are allergic to and do not take other medicines from the same family. (For information on antibiotic families, see pages 330 to 331).

MEDICINE NAMES



Medicines usually have 2 names. The *generic* (or scientific) name is the same all over the world. Some companies that make medicines give each medicine they make a brand name. The same medicine made by 2 different companies will have 2 different brand names. In this book we use generic names. You may substitute one medicine for another if the generic names are the same—any brand will do. Some brands cost less than others.

HOW MUCH MEDICINE TO GIVE

Most tablets, capsules, inserts, and injectable medicines are measured in grams (g), milligrams (mg), micrograms (mcg), or Units (U):

1000 mg = 1 g (one thousand milligrams is the same as one gram)
1 mg = 0.001 g (one milligram is one one-thousandth part of a gram)

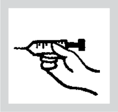
Some medicines, such as birth control pills, are weighed in micrograms (mcg or ucg):

1 ucg = 1 mcg = 1/1000 mg = 0.001 mg
This means there are 1000 micrograms in a milligram.

Injectable medicines may be measured in Units (U) or International Units (IU).

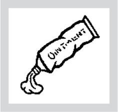
FORMS OF MEDICINES

Medicines come in different forms, and in this book we use pictures to show how a medicine should be given:



Inject medicines when we show this picture.

Take tablets, pills, capsules, or inserts when we show this picture.



Use ointment or cream when we show this picture.

Use drops when we show this picture.

Use syrup when we show this picture.

Usually, it is best to give medicines by mouth to avoid the risks of injections. But in an emergency, injecting the medicine may be better because it will make it work more quickly.

WARNING!

These pictures appear with the word *WARNING!* when pregnant women or women who are breastfeeding need to take special care.

KINDS OF MEDICINE

There are several different kinds of medicine listed in this book. One group of medicines, antibiotics, needs explanation as a group.

Antibiotics

Antibiotics are used to fight infections caused by bacteria. **Antibiotics do not cure illnesses caused by viruses, such as colds, hepatitis, or HIV/AIDS.** Antibiotics that are similar to each other are said to come from the same family. Antibiotics from the same family can often treat the same problems. So if you cannot get one antibiotic, another one from the same family may work instead. If you are allergic to one antibiotic, you will probably be allergic to other antibiotics in the same family, so do not take any antibiotics from that family.

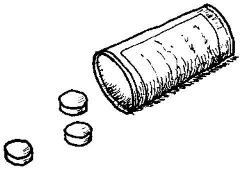
Here is a list of some antibiotics and their families:

Penicillins: amoxicillin, ampicillin, benzathine penicillin, benzylpenicillin, dicloxacillin, procaine penicillin, and others

Macrolides: azithromycin, erythromycin, and others

Tetracyclines: doxycycline, tetracycline

Sulfas (sulfonamides): sulfamethoxazole (part of cotrimoxazole), and others



Aminoglycosides: gentamicin, streptomycin, and others

Cephalosporins: cefixime, cephalexin, and others

Antibiotics are used much too often. Use antibiotics only when necessary and use them safely (see page 327).

PROBLEM LIST

This is a list of health problems discussed in this book that can be treated with medicines. The problems are listed in order of the alphabet in the left column. The middle column has the numbers of the pages where you can read about each problem before taking any medicine. The right column has medicines that can be used to treat each problem on the left. To learn more about a medicine, look it up in the medicine tables that start on page 333.

If you are not sure about which medicines to take, or if the medicine you take does not seem to work, talk with an experienced health worker or pharmacist. They can help you find out if other medicines that may work better are available in your community.

Problem	See pages	See medicines
allergic shock	329	epinephrine, dexamethasone
arthritis	279	aspirin, ibuprofen
bacterial vaginosis	113	metronidazole, clindamycin
bleeding from the vagina		
after childbirth	247	ergometrine
chancroid	164	azithromycin, ciprofloxacin, erythromycin
chlamydia	160	amoxicillin, azithromycin, doxycycline, erythromycin, tetracycline
dysreflexia	117	lidocaine gel, nifedipine
emergency family planning	205, 357	low-dose birth control pills, emergency pills
fever		
after childbirth	248	ampicillin, ciprofloxacin, clindamycin, doxycycline, metronidazole
during labor	246	ampicillin, metronidazole, procaine penicillin
fungal infection		
mouth (thrush)	175,260	clotrimazole, gentian violet, nystatin
skin	111, 260	clotrimazole, gentian violet, miconazole, nystatin
vagina	111	gentian violet, clotrimazole, miconazole, nystatin, vinegar

gonorrhea	160	cefixime, doxycycline,
herpes sores	165	acyclovir
infection (prevention)		
for people with HIV	177	cotrimoxazole
infection (treatment)		
bladder	105	amoxicillin, cotrimoxazole, nitrofurantoin
breast	260	dicloxacillin, erythromycin
after childbirth	248	ciprofloxacin, doxycycline, metronidazole, tetracycline
eye	99	erythromycin eye ointment, tetracycline eye ointment
kidney	106	amoxicillin, cefixime, ciprofloxacin, cotrimoxazole, norfloxacin
skin	114	ampicillin, dicloxicillin, doxycycline, erythromycin, penicillin, tetracycline
newborn eye care	99, 343	erythromycin eye ointment, tetracycline eye ointment
pain, fever, and swelling		
mild to moderate	93	aspirin, paracetamol, ibuprofen
pelvic inflammatory disease (PID)	161	amoxicillin, azithromycin, cefixime, clindamycin, doxycycline, erythromycin, metronidazole, tetracycline
pneumonia prevention,		
for people with AIDS	177	cotrimoxazole
sores, infected	114	dicloxacillin, doxycycline, erythromycin, gentian violet, penicillin
on the genitals	163	azithromycin, benzathine penicillin, ciprofloxacin, doxycycline, erythromycin, tetracycline
syphilis	163	benzathine penicillin, doxycycline, erythromycin, tetracycline
tetanus in newborn	251	benzylpenicillin
toxemia/seizures	246	diazepam
trichomonas	159	clindamycin, metronidazole
warts on the genitals	165	podophyllin, trichloroacetic acid
womb infection	248	amoxicillin, ampicillin, doxycycline, metronidazole, penicillin, procaine penicillin, tetracycline
yeast, thrush	111	clotrimazole, gentian violet, miconazole, nystatin, vinegar

The medicines in this section appear under their generic names, in the order of the alphabet:

A B C D E F G H I J K L M N O P Q R S T U V W X Y Z

acetaminophen or paracetamol

(*APAP, Panadol, Tempra, Tylenol,* others)

Acetaminophen and paracetamol are 2 names for the same medicine that is used to ease pain and lower fever. See *paracetamol*, page 350.

WARNING!

acyclovir

(*Zovirax*)

Acyclovir is a medicine that kills viruses and is used to fight herpes, which can cause painful blisters on the genitals and anus, and in the mouth.

Important: Acyclovir will not stop herpes from coming back, but it makes it less painful and keeps it from spreading.

Side effects: May sometimes cause headache, dizziness, nausea, vomiting

Often comes in: Tablets of 200, 400, or 800 mg; 5% ointment

The tablets are much more effective than the ointment and usually cost less. Take with lots of water.

How to use:
For genital herpes infection (see page 165), take 200 mg by mouth 5 times a day for 7 to 10 days; or apply ointment 6 times a day for 7 days. Wash hands immediately.

WARNING: Do not take this medicine if you have kidney problems.

adrenaline or epinephrine

Adrenaline and epinephrine are 2 names for the same medicine. It is used for severe allergic reactions or allergic shock, and for severe asthma attacks. See ***epinephrine,*** page 342.

amoxicillin

(*Amoxifar, Amoxil, Himox, Megamox, Sumoxil*)

Amoxicillin is an antibiotic of the penicillin family used to treat many kinds of infections. Because of high levels of drug resistance, it is less useful than previously.

Important: Take with food. If you do not start to get better in 3 days, get medical help. You may need a different medicine.

Side effects: Diarrhea, rash, nausea, vomiting. May cause yeast infection in women, or rash on a baby or child's bottom.

Often comes in: Tablets of 250 and 500 mg

How to use:
For bladder infection (see page 105), take 500 mg 3 times a day for 3 days.

For chlamydia, take 500 mg by mouth 3 times a day for 7 days.

For drug combinations for vaginal discharge, see page 162.

For kidney infection (see page 106), take 500 mg by mouth 3 times a day for 7 days.

For infection of the womb after childbirth, take 1 gram 3 times a day for 10 days (also use other medicines, see page 248).

Other medicines that may work:
For bladder or kidney infection: cefixime, ciprofloxacin, cotrimoxazole, nitrofurantoin, norfloxacin

For womb infection after birth: ampicillin, doxycycline, metronidazole

WARNING: Do not use if allergic to medicines of the penicillin family.

ampicillin

(*Amcil, Ampicin, Omnipen, Penbritin, Polycillin*)

Ampicillin is an antibiotic of the penicillin family used to treat many kinds of infections. Because of high levels of drug resistance, it is less useful than previously.

Important: Take ampicillin before eating. If you do not start to get better in 3 days, look for medical help. You may need another medicine.

Side effects: May cause stomach upset, diarrhea, and rash.

Often comes in: Tablets or capsules of 250 and 500 mg

How to use:
For womb infection during pregnancy, take 500 mg 4 times a day until you can get medical attention.

For infection during labor, give 2 g by mouth 4 times a day for 7 to 10 days.

For infection after birth (see page 248), give 2 g by mouth 4 times a day until fever has been gone for 48 hours. Give other antibiotics too.

Other drugs that may work:
For womb infection during pregnancy: metronidazole

For womb infection after birth: amoxicillin, doxycycline, metronidazole

WARNING: Do not use ampicillin if you are allergic to medicines of the penicillin family.

WARNING!

aspirin

(acetylsalicylic acid, ASA)

Aspirin works against swelling, pain—including joint pain of arthritis—and fever.

Important: Try to take aspirin with food or milk or a large glass of water.

Side effects: May cause stomach upset, stomach pain, or bleeding problems.

Signs of taking too much: Ringing in the ears, headache, dizziness, confusion, fast breatvhing.

Often comes in: Tablets of 300 or 600 mg and other sizes.

How to use:
For pain, swelling or fever, take 300 to 600 mg by mouth no more than 6 times a day as needed.

Other medicines that may work:
For pain or fever: paracetamol

For pain, fever, or swelling: ibuprofen

Interactions with other medicines:
with valproic acid: May increase the concentration of the valproic acid

with phenytoin: May increase the concentration of the phenytoin

WARNING: Women should not take aspirin during the last 3 months of pregnancy. People with stomach ulcers or bleeding problems should not take aspirin. Do not use before surgery. Do not use if breastfeeding in the first week of the baby's life. Do not give to children. If the ears begin to ring (an early sign of poisoning), stop taking aspirin until the ringing stops. Then take it again, but in a slightly lower dose.

azithromycin

(*Zithromax*)

Azithromycin is an antibiotic of the macrolide family, used to treat many STIs. It is expensive and often hard to find, but it works well against STIs when other antibiotics do not.

Important: Take at least 1 hour before eating or at least 2 hours after eating. Azithromycin is an excellent treatment for STIs that cause discharge or genital sores. It is good for treating STIs where there is resistance to other medicines.

Side effects: Diarrhea, nausea, vomiting, abdominal pain

Often comes in: Capsules of 250 mg

How to use:
For chlamydia, chancroid, or PID, take 1 g by mouth one time only

Other medicines that may work:
For chlamydia: amoxicillin, doxycycline, erythromycin, tetracycline

For chancroid: ciprofloxacin, erythromycin

For PID: see page 162.

WARNING: Do not take if you are allergic to erythromycin and other antibiotics of the macrolide family.

benzathine penicillin

(*Bicillin L-A, Penadur L-A, Permapen*)

Benzathine penicillin is a long-acting antibiotic of the penicillin family used to treat syphilis, genital ulcers, and other infections.

Important: Is always given as an injection into a large muscle.

Side effects:
In some people: Itchy raised spots or rashes

Rarely: A dangerous reaction called allergic shock. Soon after penicillin is injected, the person suddenly gets pale (cold sweat), weak, rapid pulse or heartbeat, difficulty breathing, loss of consciousness. *Epinephrine* (see page 342) must be injected at once.

Often comes in: Powder for mixing injections of 1.2 or 2.4 million Units in a 5 ml vial.

How to use:
For syphilis, if there is a sore, inject 2.4 million Units into a large muscle one time only. If there is a blood test, or the sores have already disappeared, then inject once every week for 3 weeks.

Other medicines that may work:
For syphilis: doxycycline, tetracycline, erythromycin

WARNING: Have ephinephrine on hand whenever penicillin is injected. Watch for allergic reactions and allergic shock, which could start within 30 minutes.

benzylpenicillin

(*Celinex, Hi-Do-Pen*, penicillin G potassium or sodium)

Benzylpenicillin is an antibiotic of the penicillin family used to treat many serious infections.

Important: Be ready to treat an allergic reaction (see p. 329).

Side effects: May cause yeast infection in women or diaper rash in children.

Often comes in: Powder for mixing for injection of 1 or 5 million Units

How to use:
For tetanus in newborns, inject 100,000 Units/kg into muscle 1 time only and get medical help.

WARNING: Watch for allergic reactions and signs of shock. Do not give to people who are allergic to medicines of the penicillin family.

cefixime

(*Suprax*)

Cefixime is an antibiotic of the cephalosporin family used to treat many infections including gonorrhea, pelvic inflammatory disease (PID), and kidney infection.

Important: Watch for allergic reaction.

Side effects: Upset stomach, diarrhea, headache

Often comes in: tablets of 200 or 400 mg; liquid of 100 mg in 5 ml

How to use:
For gonorrhea, take 400 mg by mouth, one time only.

For drug combinations to treat vaginal discharge or PID, see page 162.

For kidney infection, take 500 mg by mouth 2 times a day for 10 days.

Other medicines that may work:
For gonorrhea: doxycyline

For kidney infection: ciprofloxacin, cotrimoxazole

WARNING: People who have liver problems should be careful when taking cefixime. Do not use if you are allergic to antibiotics of the cephalosporin family.

WARNING!

ciprofloxacin

(*Ciloxan, Cipro, Ciprobay*)

Ciprofloxacin is an antibiotic of the quinolone family, used to treat skin and kidney infections, and some STIs like chancroid.

Important: Drink lots of water. You can eat while taking ciprofloxacin, just avoid dairy products.

Side effects: Nausea, diarrhea. vomiting, headache

Often comes in: Tablets of 250, 500, or 750 mg

How to use:
For chancroid, take 500 mg by mouth 2 times a day for 3 days.

For infection after childbirth, take 500 mg by mouth 2 times a day.

For kidney infection, take 500 mg by mouth 2 times a day for 10 days.

Other medicines that may work:
For gonorrhea: cefixime

For chancroid: azithromycin, erythromycin

For kidney infection: cefixime, cotrimoxazole

WARNING: This medicine reacts with caffeine (in coffee, chocolate, cola drinks, etc.), making the caffeine even stronger. Do not take with dairy products. Do not use if you are pregnant, breastfeeding, or younger than 16 years old.

WARNING!

clindamycin

(*Cleocin, Dalasin*)

Clindamycin is an antibiotic of the lincosamide family that is used to treat infections of the vagina, pelvis, and skin.

Important: Using this medicine with erythromycin or chloramphenicol can make both medicines less effective. If you have your monthly bleeding while using the cream, do not use a tampon because it will absorb the medicine.

Side effects: Nausea, vomiting, and diarrhea can happen within a few weeks of using this medicine. If clindamycin gives you a skin rash, stop using it and see your health worker.

Often comes in: Capsules of 25, 75, 150, and 300 mg; cream 2%

How to use:
For bacterial vaginosis, take 300 mg by mouth 2 times a day for 7 days. ***Or,*** put 5 g of cream high in the vagina each night at bedtime for 7 nights.

For trichomonas, take 300 mg by mouth 2 times a day for 7 days.

For drug combinations to treat vaginal discharge or PID, see page 162.

Other medicines that may work:
For bacterial vaginosis: metronidazole

WARNING: Using for more than 30 days can lead to thrush and yeast infections, and can harm people with kidney or liver problems. The vaginal cream can weaken condoms for up to 3 days after use. If you are breastfeeding and this medicine gives your baby diarrhea, stop using it.

clotrimazole

(*Canesten, Gyne-Lotrimin, Mycelex*)

Clotrimazole is an anti-fungal medicine used to treat yeast and other fungus infections in the vagina, mouth, and skin.

Important: Avoid having sex for 3 days after using clotrimazole for vaginal infections. It can weaken condoms and diaphragms. Be sure to keep it out of your eyes, and stop using clotrimazole if it irritates you.

Side effects: Irritation, stomach upset (with lozenges).

Often comes in: Cream at 1%, 2%, 10%; inserts of 100 mg, 200 mg, and 500 mg; lozenges of 10 mg

How to use:
For yeast infections of the vagina:

100 mg inserts or 1% cream: Put 1 insert or 5 g of cream high in the vagina every night for 7 nights.

200 mg inserts or 2% cream: Put 1 insert or 5 g of cream high in the vagina every night for 3 nights.

For yeast infections of the mouth (thrush): Take 1 lozenge 5 times a day for 14 days. Suck on the lozenge, do not chew or swallow it whole.

For skin infections: Lightly rub cream onto the infected area 2 times a day for 2 to 8 weeks.

Other medicines that may work:
Gentian violet, nystatin, miconzaole

WARNING!

cotrimoxazole

(trimethoprim + sulfamethoxazole)

(*AzoGantanol, Bactrim, Coptin, Gantanol, Pologrim, Septra, Sulfatrim, TMP/SMX, Trimpex,* others)

Cotrimoxazole is a combination of 2 antibiotics (one from the sulfa family) that is used to treat bladder and kidney infections, vaginal discharge caused by gonorrhea, and chancroid. It also helps prevent diarrhea and pneumonia, and other infections for people with HIV.

Important: Take with lots of water.

Side effects: Stop taking if it causes allergic reactions such as itching or rashes. Also may cause nausea and vomiting. Sign of taking too much are nausea, vomiting, diarrhea, confusion and sweating.

Often comes in: Tablets of 120 mg (20 mg trimethoprim + 100 mg sulfamethoxazole); tablets of 480 mg (80 mg trimethoprim + 400 mg sulfamethoxazole—called "single strength"); tablets of 960 mg (160 mg trimethoprim + 800 mg sulfamethoxazole—called "double strength"); liquid of 240 mg (40 mg trimethoprim + 200 mg sulfamethoxazole) per 5 ml

How to use:
For bladder infection, take two 480 mg tablets by mouth 2 times a day for 3 days.

For kidney infection, take two 480 mg tablets by mouth 2 times a day for 10 days.

For prevention of pneumonia and diarrhea for people with HIV, take two 480 mg tablets every day.

For bloody diarrhea for people with AIDS, take two 480 mg tablets by mouth 2 times a day for 10 days.

cotrimoxazole *continued*

For pneumonia for people with AIDS, take four 480 tablets by mouth 3 times a day for 21 days.

Other drugs that may work:
For bladder and kidney infections: cefixime, ciprofloxacin, nitrofurantoin

For diarrhea for people with AIDS: norfloxacin, metronidazole

Interactions with other medicines:
With phenytoin: The levels of phenytoin may increase and cause difficulty controlling body movement (ataxia), or eye movement (nystagmus), and confusion.

With dapsone: May increase the levels of trimethopin and may increase the risk of anemia.

WARNING: Women in the last months of pregnancy should avoid this drug. Do not take cotrimoxazole if you are allergic to sulfa antibiotics.

WARNING!

diazepam

(*Anxionil, Calmpose, Valium*)

Diazepam is a tranquilizer used to treat and prevent convulsions and seizures. It also relieves anxiety and helps promote sleep.

Important: Diazepam is a habit-forming (addictive) medicine. Avoid taking with other drugs that will make you sleepy, especially alcohol.

Side effects (signs of taking too much): Sleepiness, loss of balance, confusion

Often comes in: Tablets of 5 to 10 mg; liquid for injections of 5 mg per 1 ml, or 10 mg per 2 ml

How to use:

For convulsions during pregnancy, give 20 mg of injectable diazepam in the rectum using **a syringe without a needle.** After 10 minutes, repeat if needed, using 15 mg after convulsions. Use crushed up tablets in water if you do not have injectable diazepam

WARNING: Frequent or large doses of diazepam during pregnancy can cause birth defects. This medicine also passes through breastmilk, so breastfeeding mothers should avoid it except in emergencies.

dicloxacillin

Dicloxacillin is an antibiotic of the penicillin family used to treat breast and skin infections.

Important: Be ready to treat an allergic reaction.

Side effects: Nausea, vomiting, diarrhea. May cause yeast infection in women, or a rash on a baby or small child's bottom.

Often comes in: Capsules of 125, 250, and 500 mg; liquid of 62.5 mg per 5ml

How to use:

For breast or skin infection, take 500 mg by mouth, 4 times a day for 7 to 10 days.

Other medicines that may work: erythromycin, penicillin.

WARNING: Do not take dicloxacillin if you are allergic to medicines in the penicillin family.

WARNING!

doxycycline

(*Biocolyn, Doryx, Monodox, Vibramycin, Vibra-Tabs*)

Doxycycline is an antibiotic of the tetracycline family used for many infections, including STIs, and pelvic and skin infections.

Important: Do not take with milk, other dairy products, or antacids. Do not take just before lying down. Take while sitting up and with lots of water to prevent the irritation this medicine can cause.

Side effects: Diarrhea or upset stomach. Some people get a rash after staying in the sun. May cause yeast infection in women, or a rash on a baby or child's bottom.

Often comes in: Tablets of 50 and 100 mg

doxycycline *continued*

How to use:
For chlamydia, take 100 mg by mouth 2 times a day for 7 days.

For syphilis when the genital sore is still visible, take 100 mg by mouth 2 times a day for 14 to 21 days.

For drug combinations for vaginal discharge or PID, see page 162.

For pressure sores or other skin infections, take 100 mg by mouth 2 times a day for 14 days.

For infection after childbirth, take 100 mg by mouth 2 times a day until fever has been gone for 2 full days.

Other medicines that may work:
For syphilis: benzathine penicillin, erythromycin, tetracycline

For gonorrhea: cefixime, ciprofloxacin

For chlamydia: amoxicillin, azithromycin, erythromycin, tetracycline

For skin infection: dicloxacillin, erythromycin, penicillin, tetracycline

For infection after childbirth: ampicillin, metronidazole

WARNING: Pregnant and breastfeeding women should not take doxycycline. Do not use doxycycline that has been in the sun or has passed the expiration date.

epinephrine or **adrenaline**

(*Adrenalin*)

Epinephrine and adrenaline are two names for the same drug. It is used for allergic reactions or allergic shock, for example, allergic shock caused by penicillin.

Important: Take the person's pulse before injecting. Do not give more than 3 doses. If the pulse goes up by more than 30 beats per minute after the first injections, do not give another dose.

Side effects: Fear, restlessness, nervousness, tension, headaches, dizziness, increased heart rate

Signs of taking too much: High blood pressure, fast heart beat, stroke

Often comes in: ampules for injection of 1 mg in 1 ml

How to use:
For moderate allergic reaction or allergic shock, inject ½ mg (½ ml) just under the skin (not into muscle) of upper arm. If needed, a second dose can be given after 20 to 30 minutes, and a third dose after another 20 to 30 minutes.

WARNING: Be careful never to give more than the recommended amount. Avoid injecting this into the buttocks; instead use the back of the upper arm.

ergometrine maleate, methylergonovine maleate

(*Anurhage, Ergonovine, Ergotrate, Methergine,* methylergonovine)

Ergometrine causes contractions of the womb and its blood vessels and is used to control heavy bleeding after childbirth. Ergometrine and methylergonovine are the same drug. After giving this medicine, get medical help.

Side effects: Nausea, vomiting, dizziness, sweating

Often comes in: Tablets of 0.2 mg

How to use:
For heavy bleeding after childbirth, after the placenta has come out, give 1 tablet (0.2 mg) by mouth every 6 to 12 hours as needed.

WARNING: Do not use ergometrine to start or speed up labor or to cause an abortion.

Do not give this drug before the baby and the placenta have come out.

erythromycin

(*E.E.S, E-Mycin, Ery-max, Ethril, Ilosone, Ilotycin*)

Erythromycin is an antibiotic of the macrolide family used to treat many infections, including some STIs and skin infections. It can be used safely during pregnancy and is widely available.

Important: Erythromycin works best when taken 1 hour before or 2 hours after a meal. If this upsets your stomach too much, take it with a little food.

Do not break up the tablets. Tablets are often coated to prevent strong stomach juices breaking down the medicine before it can begin to work.

Side effects: May upset stomach, or cause nausea, vomiting, diarrhea.

Often comes in: Tablets or capsules of 200, 250, or 500 mg; ointment 1%; powder for solution of 125 mg per 5 ml

How to use:

For chlamydia, take 500 mg by mouth 4 times a day for 7 days.

For drug combinations to treat vaginal discharge or PID, see page 162.

For chancroid, take 500 mg by mouth 4 times a day for 7 days.

For syphilis, take 500 mg by mouth 4 times a day for 14 to 21 days.

For breast infection, take 500 mg by mouth 4 times a day for 7 days.

For pressure sores or other skin infections, take 250 mg by mouth, 4 times a day for 7 to 10 days.

For eye infection (conjunctivitis), put a little ointment inside the lower lid 3 to 4 times a day for 2 to 3 days.

For newborn eye care, put a little 1% ointment in each eye within 2 hours of birth.

erythromycin *continued*

Other medicines that may work:

For chlamydia: amoxicillin, azithromycin, doxycycline, tetracycline

For chancroid: azithromycin, ciprofloxacin

For syphilis: benzathine penicillin, doxycycline, tetracycline

For breast infection: dicloxacillin

For skin infection: dicloxacillin, doxycycline, penicillin, tetracycline

For baby eye care: tetracycline eye ointment

WARNING: Do not take erythromycin if you are allergic to medicines in the macrolide family.

gentian violet

(*Crystal Violet,* methylrosanilinium chloride)

Gentian violet is a liquid disinfectant used to help fight infections of the skin, mouth, and vagina.

Important: After putting this in an infant's mouth, turn the baby face down so it does not swallow too much. Gentian violet will stain your skin and clothes purple.

Side effects: Long-term use causes irritation. Use on a sore or on broken skin may stain that skin purple when it heals.

Often comes in: Liquid in 0.5%, 1%, 2%; tincture in 0.5%; crystals of 1 teaspoon in ½ liter of water makes a 2% liquid

How to use:
For vaginal yeast infections, soak clean cotton with 1% liquid and place high in the vagina overnight for 3 nights. Be sure to remove the cotton every morning.

For yeast infections in the mouth (thrush), rinse the mouth with 1% liquid for 1 minute 2 times a day, but do not swallow.

gentian violet *continued*

For skin infections, first wash with soap and water, and dry. Then paint on skin, mouth, or vulva 3 times a day for 5 days.

For skin infections for people with AIDS, first wash with soap and water, and dry. Then paint on skin, mouth, or vulva 2 times a day until rash is gone.

Other medicines that may work:
For skin infections: antibiotic ointments, iodine

For thrush in the mouth:
lemon (not for babies), nystatin

For vaginal yeast infections:
nystatin, miconozole, clotrimazole

WARNING: Do not have sex while you are using gentian violet for a vaginal infection to avoid passing the infection to your partner. Stop using gentian violet if it starts to irritate you. Keep away from the eyes.

hydrocortisone or **cortisol**

(*Eczacort, Hyocotil, Solu-Cortef,* others)

Hydrocortisone is an anti-swelling and anti-itch skin cream used to treat rashes. It is also useful for treating hemorrhoids (piles).

Important: Do not cover the cream with a bandage. Pregnant and breastfeeding women can safely use cream, but should use tablets with caution.

Side effects: Cream may cause thinning and scarring of skin if used for more than 10 days.

Often comes in: Cream or ointment in many strengths, often 1%

How to use:
For rash, itching, or piles, apply cream directly on skin 3 or 4 times a day

WARNING!

ibuprofen

(*Actiprofen, Advil, Genpril, Motrin, Nuprin, Rufen,* others)

Ibuprofen works against pain, swelling, and fever. It is very useful to relieve discomfort during monthly bleeding and pain from arthritis and AIDS.

Important: Causes less irritation to the stomach if taken with food, especially dairy products.

Side effects: May cause stomach irritation or pain, ringing in the ears, constipation.

Often comes in: Tablets of 200 mg and larger; liquid in 100 mg per 5 ml

How to use: Take 200 to 400 mg 4 to 6 times a day. Do not take more than 2400 mg daily.

Other medicines that may work:
For pain, swelling and fever: aspirin

For pain and fever: acetaminophen

Interactions with other medicines:
with phenytoin: May cause liver problems.

WARNING: Avoid taking within a week before or after surgery. Avoid using during the last 3 months of pregnancy.

lidocaine

(*Topicaine, Xylocaine*)

Lidocaine gel is used on the skin to prevent and relieve pain caused by minor skin irritations, minor burns, minor cuts, and insect bites.

Side effects: Changes in skin color (these usually go away quickly), fluid-filled bumps on the skin.

Often comes in: Ointment 2% to 4%

How to use:
To help prevent dysreflexia, insert a small amount into the anus before removing hard stools by hand. Or apply to the urine hole before putting in a catheter.

WARNING!

mebendazole

(Vermox)

Mebendazole is a medicine that works against many different worm infections, including hookworm.

Side effects: There may be some belly pain or diarrhea, but side effects are not common.

Often comes in: Tablets of 100 mg

How to use:
For hookworm, take 100 mg by mouth 2 times a day for 3 days.

Other medicines that may work:
albendazole

WARNING: Do not use if you are pregnant. Do not give to children under 2 years old.

WARNING!

metronidazole

(*Flagyl, Methoprotostat, Metro, Metroxyn, Satric*)

Metronidazole is used for PID, vaginal and skin infections, and amebic dysentery.

Important: Your sexual partner should also be treated. Do not drink any alcohol while you are taking metronidazole. It will make you feel very nauseous.

Side effects: Metallic taste in the mouth, dark urine, nausea or upset stomach, headache.

Often comes in: Tablets of 200, 250, 400, and 500 mg; inserts of 375 and 500 mg

How to use:
For infection of the womb after childbirth, take 500 mg metronidazole by mouth 2 times a day until fever is gone for 2 days.

For bacterial vaginosis or trichomonas, take 2 grams by mouth 1 time only, but not if you are pregnant. **If you are pregnant,** take 400 to 500 mg by mouth 2 times a day for 7 days.

For drug combinations to treat vaginal discharge or PID, see page 162.

For bloody diarrhea in people with AIDS, with or without fever, take 500 mg by mouth 3 times a day for 7 days.

Other medicines that may work:
For diarrhea for people with AIDS: cotrimoxazole, norfloxacin

WARNING: Stop taking it if you feel numb. Try not to use metronidazole during the first 3 months of pregnancy. If you must, do not take the 1 large dose during pregnancy. But if you are breastfeeding, the 1 large dose is safest. People with liver problems, such as jaundice, should not use it.

WARNING!

miconazole

(*Daktarin, Fungtopic, Micatin, Monistat*)

Miconazole is an anti-fungus medicine used to treat yeast and other fungus infections in the vagina, or on the skin.

Important: If miconazole irritates you, stop using it. Avoid having sex for 3 to 4 days while using miconazole to avoid passing the infection to your partner. Keep it out of your eyes.

Side effects: Irritation

Often comes in: Cream 2%; inserts of 100 and 200 mg

How to use:
For yeast infections of the vagina:

Cream: Put 5 g in the vagina every night for 7 nights.

100 mg inserts: Put 1 high in the vagina every night for 7 nights.

200 mg inserts: Put 1 high in the vagina every night for 3 nights.

For yeast infection on the skin, apply cream to affected area 2 times a day until infection is gone.

Other medicines that may work:
For all yeast infections: gentian violet, nystatin, clotrimazole

WARNING: Do not use miconazole during the first 3 months of pregnancy.

nifedipine

(*Adalat, Nelapine, Nifecard, Nifed, Procardia*)

Nifedipine is a medicine used to lower high blood pressure very quickly.

Important: Do not drink grapefruit juice with nifedipine The medicine will not work as well.

Side effects: Headache, dizziness, rash, flushing of the face

Often comes in: Capsules and tablets of 10 mg

How to use:

Only for sudden high blood pressure caused by dysrelexia:

Capsule: Bite into the capsule and swallow it, or make a hole in the capsule and put under the tongue.

Tablet: Crush and mix with clean water into a soft paste and put under the tongue, or chew the tablet and swallow it with some water.

Interactions with other medicines:

With carbamazepine, phenobarbital or phenytoin: These medicines may not work as well while taking nifedipine.

WARNING: Nifedipine should be used only for dysreflexia by someone with a spinal-cord injury (see page 117). It should not be used for ongoing high blood pressure, hypertension, or heart problems.

WARNING!

nitrofurantoin

(*Furadantin, Macrobid, Macrodantin*)

Nitrofurantoin is an antibiotic used to treat bladder infections.

Side effects: Nausea or vomiting, headaches, passing gas. To limit these, take with food or milk.

Signs of taking too much: Vomiting, chest pains. Urine may turn dark yellow or brown.

Often comes in: Tablets of 25, 50, or 100 mg; suspension of 25 mg/5 ml

How to use:

For bladder infections, take 100 mg 2 times a day for 3 days

Other medicines that may work:

For bladder infections: amoxicillin, cotrimoxazole, norfloxacin

WARNING: People with kidney problems should not take this medicine. Women in their last month of pregnancy should not take this medicine.

WARNING!

norfloxacin

(*Lexinor, Noroxin, Uritracin*)

Norfloxacin is an antibiotic of the quinolone family used to treat bladder and kidney infections, and serious cases of diarrhea.

Side effects: May cause lightheadedness and increase the effects of caffeine. To limit these effects, take either 1 hour before eating or 2 hours after eating.

Often comes in: Tablets of 400 mg

How to use:
For bladder infections, take 400 mg by mouth 2 times a day for 3 days

For kidney infections, take 400 mg by mouth 2 times a day for 10 days

For diarrhea for people with AIDS, take 400 mg by mouth 2 times a day for 4 to 7 days.

Other medicines that may work:
For bladder infections: amoxicillin, cotrimoxazole, nitrofurantoin

For kidney infections: amoxicillin, cefixime, ciprofloxacin, cotrimoxazole

For gonorrhea: cefixime, doxycyline

For diarrhea in people with AIDS: metronidazole, cotrimoxazole

WARNING: Take with lots of water. Do not take this drug while using antacids or vitamins that contain iron or zinc. If norfloxacin or quinolone antibiotics give you an allergic reaction, do not use it. Women who are pregnant, breastfeeding, or under 16 years old should not take norfloxacin.

nystatin

(*Dermodex, Mycostatin, Nilstat, Nystat*)

Nystatin is an anti-fungus medicine used to treat yeast infections in the mouth (thrush), the vagina, or the skin.

Important: Nystatin works only against candida yeast infections, while miconazole works against other fungal infections as well. Clotrimazole may be less costly and easier to use.

Often comes in: Inserts of 100,000 U; lozenges for the mouth of 200,000 U; cream 100,000 U per gram; liquid in 100,000 U per ml

How to use:
For mouth or throat infections, 3 or 4 times a day, put 1 ml of liquid in mouth, swish around both sides of mouth for 1 minute and swallow. Do this for 5 days.

For skin infections, keep area dry and apply cream 3 times a day until rash is gone.

For vaginal infections, put cream inside the vagina twice daily for 10 to 14 days; or put 100,000 U insert high inside the vagina at bedtime for 14 nights.

Other medicines that may work:
miconazole, clotrimazole, vinegar, or gentian violet

WARNING: If nystatin causes you irritation, stop using it. Avoid having sex while using nystatin so you do not pass the infection to your partner.

paracetamol or **acetaminophen**

(*APAP, Panadol, Tempra, Tylenol,* others)

Paracetamol and acetaminophen are 2 names for the same drug that is used to ease pain and lower fever. It is one of the safest pain killers. It does not cause stomach irritation and so it can be used instead of aspirin or ibuprofen by people with stomach ulcers. It can also be used by pregnant women, and is safe at lower doses for children.

Important: Paracetamol does not cure sickness, it only eases pain or fever. It is important to find the cause of the pain and fever and treat that.

Signs of taking too much: Nausea, vomiting, pain in the stomach

Often comes in: Tablets of 100, 325, and 500 mg; liquid in 120 and 160 ml per 5 ml; inserts of 80, 120, 300, 325, or 650 mg; drops of 80 mg per 0.8 ml

How to use:
For pain or to lower fever, take 500 to 1000 mg by mouth every 4 to 6 hours as needed.

Other medicines that may work:
For pain, fever, or swelling: aspirin or ibuprofen may work, but do not use either during pregnancy.

WARNING: Do not take if you have liver or kidney damage. It can cause damage if taken regularly during or after drinking alcohol.

penicillin

(*Bentapen VK, PenVee K,* phenoxymethyl penicillin)

Penicillin is an antibiotic used to treat mouth, tooth, skin, womb, and many other infections. Unfortunately, a lot of resistance to penicillin has developed and it is less useful than previously.

Important: Watch for allergic reactions and allergic shock.

Side effects: Rash

Often comes in: Tablets of 250, 500 mg; liquid of 125 or 250 mg per 5 ml

How to use:
For womb infection after childbirth, take 250 mg (which is the same as 400,000 U) by mouth 4 times a day for 7 days.

For skin infection or sores, take 250 mg by mouth 4 times a day for 10 days.

Other medicines that may work:
For womb infection after childbirth: amoxicillin, ampicillin, ciprofloxacin, doxycycline, metronidazole

For skin infection: dicloxicillin, doxycycline, erythromycin, tetracycline

WARNING: Do not take if you are allergic to any of the medicines in the penicillin family.

WARNING!

podophyllin

(*Condylox, Podocon-25,* podophylom resin)

Podophyllin is a liquid that can be put directly on genital warts to shrink them.

Important: Podophylin is very irritating to healthy skin. Use only a little bit (½ ml or less) at a time. Protect the area around the wart with petroleum jelly (*Vaseline*) before using podophyllin.

Side effects: Can be very irritating to the skin.

Often comes in: Liquid in 10% to 25%

How to use: Apply liquid to warts with a cotton swab, a toothpick, or a clean cloth rolled to a fine point. After 4 hours, wash it off carefully with soap and water. Use once a week for 4 weeks.

Other medicines that may work:
For genital warts: trichloracetic or bichloracetic acid.

WARNING: Do not put on bleeding warts, birthmarks, moles, warts with hair, or in the mouth. If severe skin irritation occurs, do not use it again. Do not use if you are pregnant or breastfeeding.

WARNING!

probenicid

(*Benemid, Probalan*)

Probenicid is used with some antibiotics of the penicillin family to make the penicillin stay inside the body longer. This makes the treatment more effective.

Important: Do not give probenicid to children under 2 years old.

Side effects: Sometimes causes headache, nausea, or vomiting.

Often comes in: Tablets of 500 mg

How to use: Take 500 mg to 1 gram by mouth each time you use an antibiotic from the penicillin family.

WARNING: Use with caution during pregnancy and breastfeeding, or if you have a stomach ulcer.

procaine penicillin

(*Benzylpenicillin Procaine, Bicillin C-R, Crysticillin, Duracillin AS, Penadur, Pfizepen AS, Wycillin*)

Procaine penicillin is an antibiotic used to treat womb and other infections, such as infected pressure sores, and gonorrhea that is not resistant to penicillin.

Important: When taken with probenicid (see page 351), the amount of penicillin in the blood increases and lasts longer, making the treatment more effective.

Side effects: May cause yeast infection in women, and a rash on a baby or small child's bottom.

Often comes in: Vials for injection of 300,000 and 400,000 and 600,000 Units; powder for mixing injections of 1 gram = 1 million Units.

How to use:

For fever during pregnancy,
inject 1.2 million Units into muscle every 12 hours while you take the woman for medical treatment.

Other medicines that may work:
For fever during pregnancy: ampicillin, metronidazole

WARNING: Procaine penicillin can cause asthma attacks in people who have asthma. Never use this drug with tetracycline. Do not use procaine penicillin if you are allergic to antibiotics in the penicillin family. Never inject this into the vein.

tetanus toxoid

(Tetavax)

Tetanus toxoid is an immunization given to prevent a tetanus infection. It can be given during or after pregnancy, or after a miscarriage. If a woman gets 2 injections (or better still, 3 injections) when pregnant, it will also prevent this deadly infection in her newborn baby.

Important: Tetanus immunizations should be given to everyone, starting in childhood.

Side effects: Pain, redness, warmth, slight swelling

Often comes in: Liquid for injection of 4, 5, or 10 U per 0.5 ml

How to use: To be safe from tetanus for your entire life, you must get 5 immunization injections, and then one injection every 10 years.

For each immunization: Give 1 injection of 0.5 ml into the muscle of the upper arm.

WARNING!

tetracycline

(Achromycin, Sumycin, Terramycin, Theracine, Unimycin)

Tetracycline is an antibiotic of the tetracycline family. It is used to treat many infections, including chlamydia, syphilis, pelvic inflammatory disease (PID), kidney and bladder infections. Doxycycline works for all the same infections, costs less, and is easier to take (see page 341).

Important: Tetracycline does not fight common colds or prevent STIs.

Side effects: If you spend time in the sun, tetracycline can cause skin rashes. It may cause diarrhea or upset stomach.

Often comes in: Capsules of 100, 250, or 500 mg; ointment 1%

tetracycline *continued*

How to use:
For chlamydia, take 500 mg by mouth 4 times a day for 7 days.

For syphilis, take 500 mg by mouth 4 times a day for 14 days.

For PID, take 500 mg by mouth 4 times a day until fever is gone for 2 days. (For drug combinations for PID or vaginal discharge, see page 162.)

For skin infection, take 250 mg by mouth 4 times a day for 14 days.

For baby eye care, put a little ointment in each eye at birth, one time only.

Other medicines that may work:
For chlamydia: azythromycin, doxycycline, erythromycin

For syphilis: benzathine penicillin, doxycycline, erythromycin

For PID: see page 162

For skin infection: dicloxicillin, doxycycline, erythromycin, penicillin

For baby eye care: erythromycin ointment

WARNING: Do not take within 1 hour of eating dairy products or antacids. Do not use tetracycline that it has been in the sun a long time or is past its expiration date. Pregnant or breastfeeding women should not use tetracycline.

trichloroacetic acid (TCA), bichloroacetic acid (BCA)

Either trichloroacetic acid or bichloroacetic acid can be used to treat genital warts.

Important: First protect the area around the wart with petroleum jelly (*Vaseline*). Then put on trichloroacetic acid. It will hurt for 15 to 30 minutes. If it spills onto healthy skin, wash it off with soap and water. You can also put baby powder (talc) or baking soda on spills.

Side effects: Trichloroacetic acid will hurt or destroy normal skin if spilled.

Often comes in: Liquids in strengths between 10% and 35%

How to use: Put only on wart once a week for 1 to 3 weeks as needed.

Other medicines that may work: podophyllin

WARNING: Use very carefully. It can burn normal skin badly enough to cause a scar.

ORAL CONTRACEPTIVES ('THE PILL,' BIRTH CONTROL PILLS)

Interactions of oral contraceptives with other medicines: Some medicines make combined birth control pills (ones that contain both estrogen and progestin) work poorly or not at all. Do not use combined birth control pills if you regularly take:

- carbamazepine *(Tegretol)*
- phenobarbital (phenobarbitone, *Luminal*)
- phenytoin (diphenylhydantoin, *Dilantin*)
- valproic acid *(Depakene)*

See page 196 for information about which oral contraceptives (and other hormonal methods of family planning) should be avoided by women with certain disabilities. Birth control pills come in different strengths of each hormone and are sold under many different brand names. We list only a few brands in the chart below.

Usually, brands that contain a smaller amount of both hormones are the safest and work best for most women. These 'low-dose' pills are found in Groups 1, 2, and 3.

Group 1 - Triphasic pills

These contain low amounts of both estrogen and progestin in a mix that changes throughout the month. Since the amounts change, it is important to take the pills in order.

Brand names:
Logynon
Synophase
Tricyclen
Trinordiol
Trinovum
Triquilar
Triphasil

Group 2 - Low dose pills

These contain low amounts of estrogen (35 micrograms of the estrogen 'ethinyl estradiol' or 50 micrograms of the estrogen 'mestranol') and progestin in a mix that stays the same throughout the month.

Brand names:
Brevicon 1 + 35
Noriday 1 + 50
Norinyl 1 + 35, 1 + 50
Ortho-Novum 1/35, 1/50
Ovysmen 1/35
Neocon
Norimin
Perle

Group 3 - Low dose pills

These pills are high in progestin and low in estrogen (30 or 35 micrograms of the estrogen 'ethinyl estradiol').

Brand names:
Lo-Femenal
Lo-Ovral
Microgynon 30
Microvlar
Nordette

To assure effectiveness and minimize spotting (small amounts of bleeding at other times than your normal monthly bleeding), take the pill at the same time each day, especially with pills that have low amounts of hormones. If spotting continues after 3 or 4 months, try one of the brands in Group 3. If there is still spotting after 3 months, try a brand from Group 4.

But if a woman misses her monthly bleeding for months or is disturbed by the very light monthly bleeding, she can change to a brand with more estrogen from Group 4.

For a woman who has very heavy monthly bleeding or whose breasts become painful before her monthly bleeding begins, a brand low in estrogen but high in progestin may be better. These pills are found in Group 3.

Women who continue to have spotting or miss their monthly bleeding when using a brand from Group 3, or who became pregnant before while using another type of pill, can change to a pill that has a little more estrogen. These 'high dose' pills are found in Group 4.

Group 4 - High dose pills

These pills are higher in estrogen (50 micrograms of the estrogen 'ethinyl estradiol') and most are also higher in progestin.

Brand names:

Eugynon
Femenal
Neogynon
Nordiol
Ovral
Primovlar

Women who are breastfeeding, or who should not use regular pills because of headaches or mild high blood pressure, may want to use a pill with only progestin. These pills in Group 5 are also called 'mini-pills.'

Group 5 - Progestin-only pills

These pills, also known as 'mini-pills,' contain only progestin.

Brand names:

Femulen
Micronor
Micronovum
Nor-Q D

Microlut
Microval
Neogest
Neogeston
Ovrette

← **these brands can also be used for Emergency Family Planning— see next page**

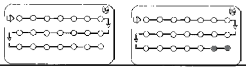
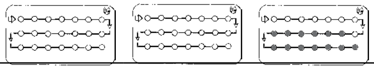
Progestin-only pills should be taken at the same time every day, even during the monthly bleeding. Menstrual bleeding is often irregular.

EMERGENCY FAMILY PLANNING (EMERGENCY CONTRACEPTION)

It is OK to take emergency family planning pills, even if you would not normally use pills for family planning (see page 355). Because you take them for such a short time, they will not interact with your disability medicines.

You can use emergency pills or regular birth control pills to prevent pregnancy within 5 days after unprotected sex. The number of pills you need depends on the amount of estrogen or progestin each pill contains. This chart lists only a few common brands for each type of pill. Since some brand names are used for more than one type of pill, check the amount of hormone in the pills before you use them in an emergency.

How to take pills for emergency family planning

Pills for emergency family planning	**First dose** 	**Second dose (12 hours later)** 
High-dose pills containing 50 mcg ethinyl estradiol (Ovral, Ogestrel)	Take 2 pills ⊖ ⊖	Take 2 more pills ⊖ ⊖
Low-dose pills containing 30 or 35 mcg ethinyl estradiol (Lo-Femenal, Lo/Ovral, Microgynon, Nordette)	Take 4 pills ⊖ ⊖ ⊖ ⊖	Take 4 more pills ⊖ ⊖ ⊖ ⊖
Low-dose pills containing 20 mcg ethinyl estradiol (Alesse, Lessina, Lutera)	Take 5 pills ⊖ ⊖ ⊖ ⊖ ⊖	Take 5 more pills ⊖ ⊖ ⊖ ⊖ ⊖
Special emergency pills containing ethinyl estradiol and levonorgestrel (Tetragynon)	Take 2 pills ⊖ ⊖	Take 2 more pills ⊖ ⊖
Progestin-only pills (mini-pills) containing 75 mcg levonorgestrel (Ovrette, Neogest)	Take 40 pills, one time only, or 20 pills in one dose and 20 more pills 12 hours later 	
Progestin-only pills (mini-pills) containing 30 mcg levonorgestrel (Microlut, Microval, Norgeston)	Take 50 pills, one time only, or 25 pills in one dose and 25 more pills 12 hours later 	
Special emergency pills containing 1500 mcg levonorgestrel (Postinor 1)	Take one pill, one time only ⊖	
Special emergency pills containing 750 mcg levonorgestrel (Postinor, Postinor-2, Plan B, Pill 72, Post-Day)	Take 2 pills, one time only ⊖ ⊖	

With a pack of 28 pills, use any of the first 21 pills for emergency contraception. Do not use the last 7 pills in a 28-day pack, because these pills do not contain any hormones.

Progestin-only pills and special emergency pills have fewer side effects (headaches and nausea) than combined pills used for emergency family planning.

MEDICINES FOR AIDS—ANTIRETROVIRAL THERAPY (ART)

Medicines to treat AIDS are called antiretroviral medicines (ARVs). These medicines can help a person with AIDS live a longer and healthier life. Taken as a combination of at least 3 medicines, this is called AntiRetroviral Therapy, or ART. In this section you will find information about some common medicine combinations for ART. Look in the individual medicine charts (see pages 361 to 362) to see if there is an interaction between your regular disability medicine and the medicines for AIDS.

HIV Care and ART Programs

HIV/AIDS is a complicated disease that affects every part of your body. As soon as you have a positive HIV test, try to find an HIV care program where trained health workers can see you regularly and help you stay healthy. HIV care programs can provide medicines to prevent and treat HIV illnesses, counseling and other support. They can help you start ART, treat any side effects, and change your ART if it is not working for you. Getting drugs from an ART program is more reliable and less costly than buying them from a private source.

When is ART needed?

People infected with HIV who still have healthy immune systems do not need ART. Only people who test positive for HIV and show signs of AIDS, or whose immune system is no longer working well, need ART. A blood test called a CD4 count can show how well the immune system is working. If this test is available, and your CD4 count is below 500, you and your health worker can decide when you should start ART. The goal is to start ART before HIV can damage your immune system.

Before starting ART, it is important to discuss with your health worker:

- Have you ever taken any ARVs before? This may affect what medicines you should take now.
- Do you have any illnesses or other conditions, like TB, serious infections, or fever? They may need to be treated first.
- What are the benefits, risks, and possible side effects of ART? Try to talk to someone who is already using ART as well as your health worker.
- Are you ready to take medicines every day, at the correct times? This is necessary for ART to work.
- Will you have the support of a person you trust or an HIV/AIDS support group who you can turn to for information and help?

Be sure you know where to get help if you have problems getting your ART medicines, have problems with side effects, or need treatment for other health problems.

Do not start taking ARVs on your own. They may be the wrong ones for you and can have serious side effects.

Do not share ARVs with anyone, including a partner or child. Taking less than the recommended dose can cause the medicines to stop working, harming you and the person you share them with.

Do not buy ARVs from someone who is not part of an approved HIV care or ART program.

ARV combinations (ART regimens)

ARVs are effective only if they are taken in combinations (regimens) of at least 3 medicines. We list 4 common combinations on page 360, and then give more information about each medicine. As more is learned about HIV and how to slow or stop it, drug regimens will change. Ask your health worker what medicines are available and work best where you live.

The 4 regimens in the box below are the easiest to take. They can be taken with or without food. They are also the least costly and most available. Some combinations (all 3 medicines, or sometimes just 2 of the 3) are available in one pill, called a 'fixed dose combination.'

How to Take ART

- Whatever combination you use, take all 3 medicines every day, at the same times of day.
- If the medicines need to be taken 2 times a day, there should be 12 hours between the 2 doses. For example, if you take the morning dose at 6:00, then the second dose should be taken at 6:00 in the evening. If you leave more than 12 hours between doses, having too little medicine in your body for some hours can cause *drug resistance.*
- If you forget to take a dose on time, try to take it within 5 hours. If it is more than 5 hours late, wait until it is time for the next dose.
- Do not stop taking any medicine that is part of an ART regimen without seeing a health worker to find out if your medicines should be stopped separately or all at once.

Side effects of ART

ART has helped many people live longer, healthier lives. But like many medicines, ARVs can have side effects for some people. Many people find that as their body gets used to the medicine, the side effects lessen and may go away completely. Some common side effects for ART are diarrhea, tiredness, headaches, and stomach problems such as nausea, vomiting, stomach pain, or not feeling like eating. Even if you feel bad, keep taking all your medicines until your health worker tells you to change or stop.

Some side effects are signs that the medicine needs to be changed. Serious side effects include tingling or burning feelings in the hands and feet, fever, rashes, yellow eyes, tiredness with shortness of breath, anemia and other blood problems, and liver problems. If you have serious side effects, see a health worker right away.

ARV regimens for adults and adolescents (not for children)		
d4T *(stavudine)*, 30	+ 3TC *(lamivudine)*, 150 mg	+ NVP *(nevirapine)*, 200 mg
These 3 medicines come combined in one pill called *Triomune.*		
or		
d4T *(stavudine)*, 30	+ 3TC *(lamivudine)*, 150 mg	+ EVF *(efavirenz)*, 600 mg, one time a day
or		
AZT *(ZDV, zidovudine)*, 300 mg	+ 3TC *(lamivudine)*, 150 mg	+ NVP *(nevirapine)*, 200 mg
AZT and 3TC come combined in one pill called *Combivir.*		
or		
AZT *(ZDV, zidovudine)*, 300 mg	+ 3TC *(lamivudine)*, 150 mg	+ EVF *(efavirenz)*, 600 mg, one time a day
AZT and 3TC come combined in one pill called *Combivir.*		

IMPORTANT

Some ART medicines seem to cause more serious side effects than others. One of these is stavudine (d4T). **The World Health Organization (WHO) recommends d4T-based treatment should be slowly phased out.** In many countries, people with AIDS do not take stavudine any more. In other countries this is not always possible because there are no other medicines available or because other drugs are more expensive. If you have AIDS and you want to take ART medicines, talk with an experienced HIV/AIDS health worker in your community to see if other medicines are available.

HIV/AIDS MEDICINES

WARNING!

efavirenz

(*EFV, EFZ, Sustiva*)

Efavirenz is an antiretroviral (ARV) medicine used in combination with other ARVs to treat AIDS.

Side effects: EFV may cause dizziness, confusion, mood changes, and strange dreams, but these will usually go away after a few weeks. If not, discuss with a health worker. **Seek care immediately** for yellow eyes or severe confusion.

Often comes in: Capsules of 50, 100, 200 mg; tablets of 600 mg; oral solution of 150 mg/ 5 ml

How to use :
Take 600 mg, by mouth, one time a day.

Interactions with other medicines:
With rifampicin: the effectiveness of efavirenz is reduced. You may need to take a higher dose of EFV (800 mg instead of 600 mg).

WARNING: Women in the first 3 months of pregnancy should not take EFV. It can cause birth defects. Women taking EFV who may become pregnant should use a reliable family planning method.

lamivudine

(*3TC, Epivir*)

Lamivudine is an antiretroviral (ARV) medicine used in combination with other ARVs to treat AIDS. It has very few side effects.

Often comes in: Tablets of 150 mg; oral solution of 50 mg/ 5 ml

How to use:
Take 150 mg, by mouth, 2 times a day.

nevirapine

(*NVP, Viramune*)

Nevirapine is an antiviral (ARV) medicine used in combination with other ARVs to treat AIDS. NVP is also used to prevent mother-to-child transmission of HIV in pregnancy and during birth.

Side effects: **Seek care immediately** for yellow eyes, skin rash, fever, tiredness with shortness of breath, poor appetite.

Often comes in: Tablets of 200mg; oral suspension (liquid) of 50mg/5ml

How to use:
To reduce the chance of side effects when starting NVP as part of an ART regimen, take only a half dose for 2 weeks—200 mg of NVP once a day. After 2 weeks, take 200 mg of NVP 2 times a day.

Interactions with other medicines:
With rifampicin: may reduce the effectiveness of nevirapine.

WARNING!

stavudine

(*d4T, Zerit*)

Stavudine is an antiretroviral (ARV) medicine used in combination with other ARVs to treat AIDS.

Side effects: Tingling, numbness, or burning feeling in the arms or legs. **Seek care immediately** for nausea, vomiting, severe abdominal pain, tiredness with shortness of breath, changes in body fat.

Often comes in: Capsules of 15, 20, 30, 40 mg; powder for oral solution of 5 mg/5 ml

How to use:
Take 30 mg 2 times a day.

WARNING: Pregnant women and women who are heavy should not take stavudine if other medicines are available. See the chart and the note below it on page 360.

zidovudine

(*AZT, ZDV, Azidothymidine, Retrovir*)

Zidovudine is an antiretroviral (ARV) medicine used in combination with other ARVs to treat AIDS. It is also used to prevent mother-to-child transmission of HIV in pregnancy and during birth.

Side effects: Tiredness and shortness of breath. **Seek care immediately** for pale skin or other signs of anemia.

Often comes in: Capsules of 100 or 250 mg; tablets of 300 mg; oral solution or syrup of 50 mg/5 ml; solution for IV infusion injection of 10 mg/ml in a 20 ml vial

How to use:
Take 300 mg 2 times a day

Interactions with other medicines:

With dapsone: may cause anemia

With valproic acid: the levels of zidovudine may increase and cause nausea, vomiting, and fatigue

With rifampicin: may reduce the effectiveness of the zidovudine

Take care of your equipment

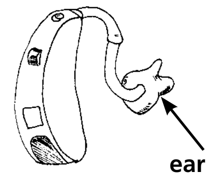
This chapter has information about how women with certain disabilities can take care of their equipment so it will work well and last as long as possible.

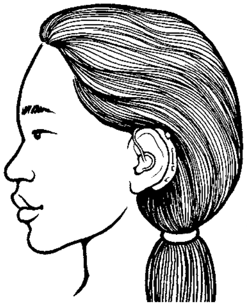
Hearing aids

Hearing aids are expensive to begin with, but buying the aid is not the only cost. The ear mold **must** fit well, otherwise the hearing aid will not work correctly. If your ear mold starts to crack or get smaller (shrink), it will need to be replaced. Ear molds do not usually last more than 2 years. Also, all hearing aids need batteries to make them work.

The 2 most common hearing aids are the:

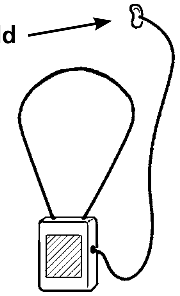
Behind-the-ear (BTE) aid

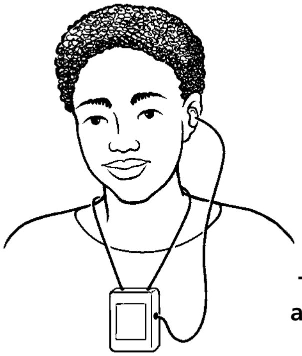




This is how a BTE aid is worn.

Body aid



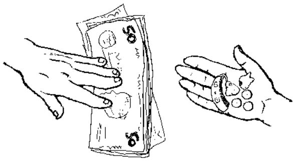


This is how a body aid is worn.

These 2 hearing aids may need new batteries every week or every 2 or 3 months. How often you need new batteries depends on how many hours each day you wear your hearing aid, the type of hearing aid you have, and the kind of batteries you use.

An organization in Botswana, southern Africa, has found a way to make a hearing aid with batteries that can be used over and over (rechargeable). See page 377 for more information.

Some countries provide hearing aid batteries and ear molds free. Contact the Ministry of Health in your country to see if they are available.



Getting new ear molds and batteries can be very costly.

HOW TO TAKE CARE OF A HEARING AID

No matter what type of hearing aid you have, it will last longer and give better sound if it is given regular care. Here are some tips for taking care of a hearing aid:

- When you are not using it, keep your hearing aid far away from electrical equipment, such as refrigerators and televisions.
- Do not let it get very hot or very cold.
- Keep it dry—sweat or water will damage it. During the day, remove it from time to time and wipe off any sweat or moisture. Remove the hearing aid before bathing, swimming, or when out in the rain. At night, put the hearing aid in a container with silica gel (a material that absorbs moisture). Do not use perfumes or any sort of spray on the hearing aid.

Cleaning

- Use a soft dry cloth to clean it. Never use any cleaning fluid.

Ear mold

- Check for wax in the ear mold regularly.
- Clean the ear mold with warm water, and make sure it is dry before using it again.

Battery

- To make the battery last longer, turn off the hearing aid when it is not being used.
- Keep the battery clean, and remove it when the hearing aid is not being used for a length of time—for example, while sleeping at night.
- Change the battery regularly. To check if it is time to change the battery, turn the sound to the highest setting. If it makes a whistling noise, the battery is okay. If not, it is time to get a new battery. Ask someone to help you if necessary. If the battery loses power faster than usual, it may be a sign of a problem with the hearing aid.
- Store batteries in a cool, dry place. Bring a battery that has been kept in the refrigerator to room temperature before using.
- Try to have the hearing aid checked at a hearing aid clinic or store from time to time.

Hearing aids may need repair. Usually hearing aid repair can be done only in big cities. But deaf organizations have started training deaf people to take ear impressions, to make ear molds, and to repair hearing aids.

Using a stick to get around

If you are blind or have difficulty seeing, using a stick to get around can give you confidence, especially for walking in places you are not familiar with. The longer the stick, the faster you will be able to walk, because the stick will help you feel the area ahead of your steps.

The stick should be made from wood that is strong, but not too heavy or thick, so it is easy to carry all day. The top of the stick, where you hold it, should be thicker and can be curved or straight. You can also attach a cord to the handle that will fit loosely around your wrist. This will help prevent the stick from getting dropped or lost.

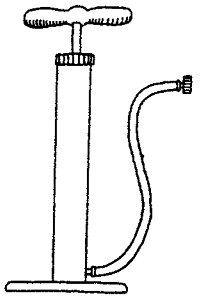
Each day, before leaving home, check your stick for any breaks or cracks by feeling along the whole length. Ask someone to help if necessary.

The best length for a stick is one that reaches from the ground to halfway between your waist and shoulders.

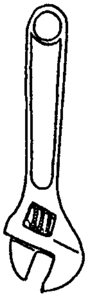
Taking care of your wheelchair

Your wheelchair will last longer and give you a smoother ride if you take good care of it. To do this yourself, you will need some basic tools (see the box below). These pages (366 to 368) are a general guide to help you care for your wheelchair. How much maintenance your chair will need can depend on how rough or smooth the roads or pathways are where you live and ride your chair.

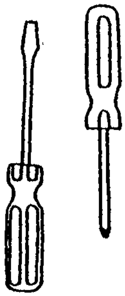
Tools for taking care of a wheelchair



bicycle pump

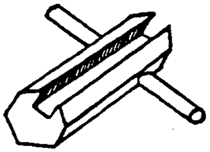


adjustable wrench

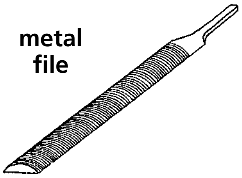


screwdriver

spoke wrench



metal file



It also helps to have some:

- medium weight machine oil
- soft wax—the kind used to shine a car, or wax made from the jojoba plant or shea tree, or lanolin made from sheep's wool, or cocoa butter made from roasted cocoa beans. Candle wax will not work because it is too brittle.

DAILY

- Clean any dirt off the wheelchair frame with a damp cloth.
- Try to keep water and dirt from getting into the bearings in the front and rear wheels (do not store your wheelchair where it will get wet).
- Check the tires to make sure they are still hard. Use the bicycle pump to add air if necessary. The tires should be very hard when you press on them.

Be kind to your wheelchair, and it will be kind to you.

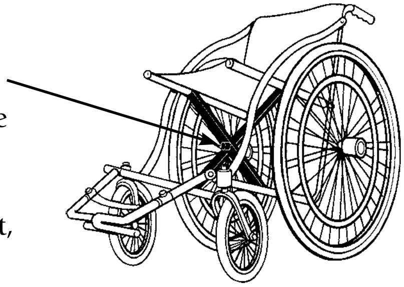
EVERY WEEK

- Check the tires for weak or worn tread and punctures. If there is a nail or tack stuck in your tire, do not pull it out until you are ready to get the tube fixed. Change the tire if necessary. If your wheelchair uses bicycle tires, they can be repaired or replaced in a bicycle shop. It is not very difficult to patch a puncture in the tube inside the tire. Ask someone in a bicycle shop to show you.
- Check the rear wheels to see if they spin freely. If they wobble or make an unusual noise, the ball bearings may be worn and might need to be replaced. Also, tighten any parts that feel loose (you may need to visit a mechanic to borrow bigger wrenches). After you tighten the nuts, you may have to loosen them a little bit so that the wheels can spin freely.
- If the front forks do not turn from side to side easily, make sure they are not bumping into the footrests. If the whole fork wiggles a lot, tighten the top nut down tight, and then loosen it just enough so that it can turn easily.
- If the front wheels do not spin freely, they may need new bearings. It is best to have them checked in a wheelchair shop.
- Clean any dirt or hair out of all 4 wheel axle housings using a damp cloth with a few drops of oil on it.
- Wiggle the spokes in the large back wheels. Use the spoke wrench to tighten any that are loose. Replace any broken ones.

MONTHLY

- Wax the wheelchair frame to make it easier to clean, open, and close.
- Ball bearings in the center of the wheels may be factory sealed. If they are not, take them out, clean them with solvent, dry them, and put them back in with new grease. If water gets into the bearings, it can cause rust, and the wheelchair will not roll smoothly.
- Check arm rests, leg rests, and hand rims for rough spots or sharp edges. File them smooth.
- Check the screws and bolts on your chair and tighten any loose ones. Look for screws on the seat back and bolts on the seat, hand rim, x-brace, footrests, front axles, rear axles, brakes, front caster (front small wheel), and pivot (turning point). The front caster pivot bolt should be tight but not too tight, or the chair will be hard to steer.
- Check the wheelchair frame for cracks or dents. A crack may cause the frame to break. Some cracks can be welded together.

EVERY 4 TO 6 MONTHS



- Oil the center and bottom of the x-brace with medium-weight machine oil. Oil the other pivot points on the chair.
- Check the seat fabric and replace it if it is torn or sags too far. This is very important, because sagging or torn seats can lead to pressure sores.
- If you are using a foam cushion, check to make sure it is still springy. A foam cushion that has lost its bounce can also lead to pressure sores.

IMPORTANT The front tires, whether they are solid rubber or filled with air, may need to be replaced in a wheelchair shop.

If your wheelchair breaks, you may need to have it repaired in a wheelchair shop. If there is no wheelchair shop in your area, a bicycle repair shop or metalwork shop may be able to help.

Sign language for health

In most communities around the world, deaf people have created their own sign language. They use signs to communicate as well and nearly as fast as hearing people do. The signs shown here are from several countries. The sign for the same word can be different in different places. Use these signs as a guide. If you are a health worker, family member, or caregiver, ask the deaf women in your community to teach you the signs they use, how you should change and adapt these signs, and to teach you other signs. Sign language can help you make sure deaf women in your community get good health care.

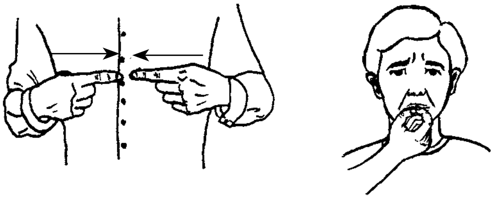
SIGNS HEALTH WORKERS NEED TO KNOW

Here are examples of some signs a health worker needs to know to provide good health services for deaf women. Sometimes signs are based on gestures, and sometimes by finger-spelling letters of the alphabet.

Signs that point at the body

Body parts can be pointed at to show where a pain is. For example, to show a pain in the belly, make the sign for pain and then point to the belly.

Pain

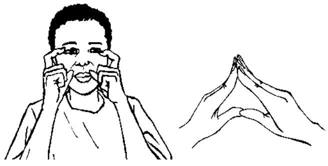
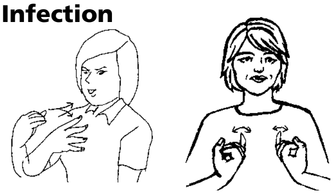
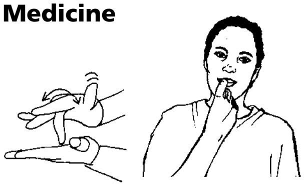
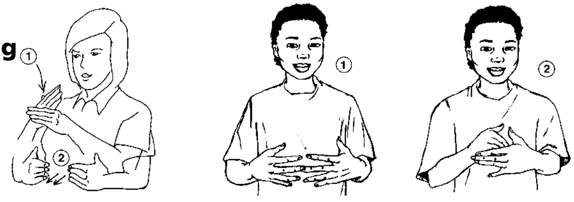
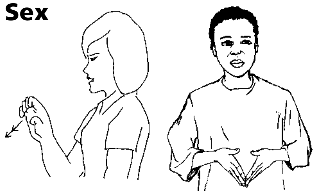


from Great Britain

from China

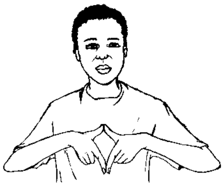
Signs that use gestures

Here are examples of other signs to use in a health setting. These signs mostly use gestures:

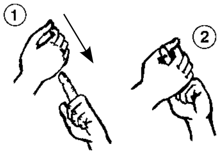
AIDS  from Kenya from China	**Infection**  from Vietnam from Great Britain	**Medicine**  from the US from Kenya
Family planning  from Vietnam from Kenya		**Sex**  from Vietnam from Kenya

Vagina


from Vietnam


from Kenya

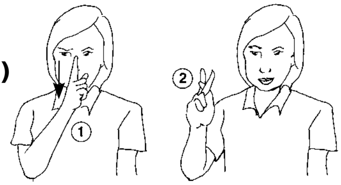
Condom



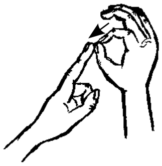
from Vietnam


from Kenya

Monthly bleeding (menstruation)



from Vietnam

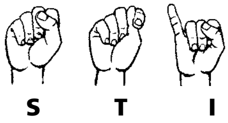

from Great Britain


from Kenya

Signs that use finger spelling

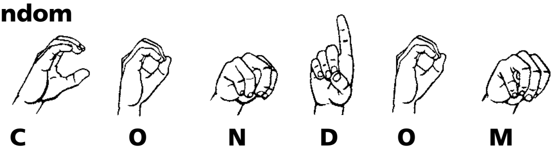
Many words can be understood by using finger spelling. For instance:

STI



from the US

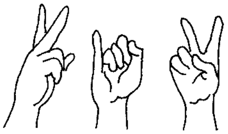
Condom



from the US

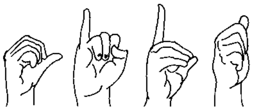
Condom


from China


from Vietnam

HIV


from China


from Vietnam


in Arabic Sign Language

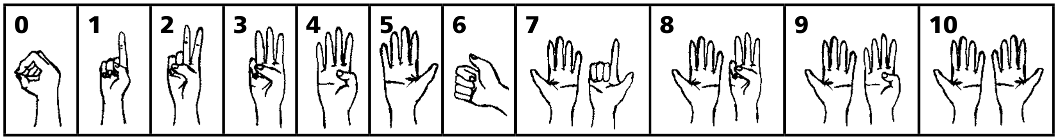
Other useful words to learn signs for

Here are suggestions for other words it would be good for a health worker to learn in a local sign language:

abortion
abuse
anus
birth
blood/bleeding
blurred vision
breast
breastfeeding
breathing problems
burning
changes in color
contractions
cough
chills
clean/wash
cramps
cuts/sores/tears
depression
diarrhea
discharge
dizzy
drugs
dry
exams (*examination*)
exercise
faint
no feeling (*numb*)
fever
growth (*on skin or inside body*)
itchy
labor
lump
medicines
miscarriage
mucus
nausea (*feeling sick*)
nervous
passing stool
passing urine
pelvis
penis
pregnant
rape
sleeping problems
sweating
swollen
tenderness
vomiting
weak
womb

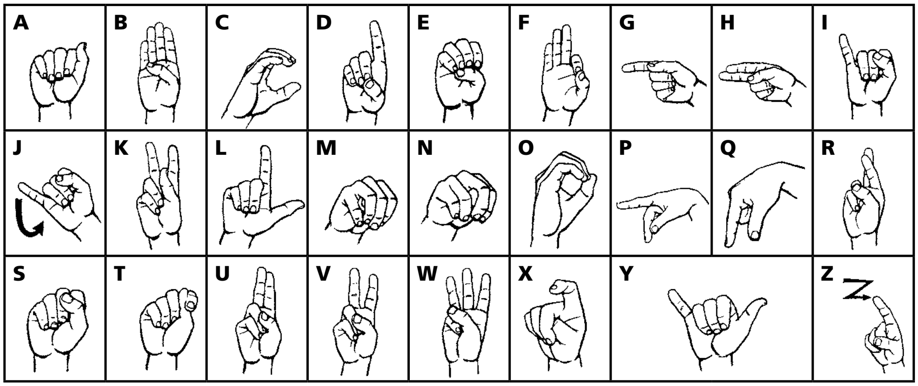
Signs for numbers

Numbers can be used to say how long the person has had a problem (how many times, how many days, weeks, or months). Numbers from 1 to 5 can also be used to say how bad a pain is, with 1 as the smallest amount of pain, and 5 as the largest.



Examples from British Sign Language

Sign alphabet



Examples from one-handed American Sign Language alphabet

List of difficult words

Here is a list of words that may be difficult to understand. Knowing what these words mean can help you use this book better.

Some of the explanations here in this vocabulary also contain words written in *slanted letters*. This is because an explanation for these words can also be found in this list.

This vocabulary is listed in the order of the alphabet:

A B C D E F G H I J K L M N O P Q R S T U V W X Y Z

A

abdomen The part of the body that contains the stomach, liver, guts, and reproductive organs. The belly.

abnormal bleeding Bleeding that is different from what is usual, natural, or average. Not normal.

access When health services and other public services are available, and the services are easy for a woman with a disability to get to and use.

acute When something happens suddenly, lasts for a short time, and is usually serious or strong—for example, acute pain or acute infection (compare with *chronic*).

afterbirth See *placenta*.

allergy, allergic reaction, allergic shock A problem—such as itching, sneezing, hives or rash, and sometimes difficulty breathing or shock—that affects certain people when specific things are breathed in, eaten, *injected*, or touched. Allergic shock is a severe form of allergic reaction.

antibiotic Medicine used to fight infection caused by bacteria. (Antibiotics DO NOT fight infections caused by viruses.)

antibody A substance the body makes to fight infection.

antiretrovirals Medicines used to help people with AIDS stay healthier and live longer. They do not cure AIDS.

atrophy A progressive wasting or weakening of the muscles that comes from a problem in the nerves (compare with *dystrophy*).

B

biopsy When a piece of *tissue* or fluid is taken from somewhere on or in the body and examined to see if it is healthy or diseased.

birth control See *family planning*.

birth defects Physical problems, or problems with understanding or learning, that a child is born with.

birth spacing Using *family planning* methods to space your children.

blood pressure The force or pressure of the blood upon the walls of the blood vessels (arteries and veins). Blood pressure varies with the age and health of the person.

blood transfusion When someone's blood is given to another person, in a vein and using a special needle, to replace blood the person may have lost.

brand name The name for a medicine that is given by the company that makes it. Compare with *generic*.

C

caliper An aid which gives support to a weak or injured leg. Another word for 'brace.'

cancer A serious disease that causes *cells* to change and grow in an abnormal way, causing growths. Cancer can affect many different parts of the body.

cell The smallest unit of living matter in the body.

chart A file where information about a person's illnesses and treatments is kept.

chronic Something that lasts for a long time, or that occurs often. Compare with *acute.*

contaminated When medical supplies or food contain harmful germs.

contracture Reduced range of motion in a joint, often due to muscle shortening.

convulsion An uncontrolled seizure, 'fit.' A sudden jerking of part or all of the body.

D

date rape When a woman is forced to have sex by a man she is dating or courting.

douche Washing out the vagina. This can cause harm because it washes out the natural healthy wetness in the vagina.

dystrophy A progressive muscle weakness that comes from a problem in the muscles themselves (compare with *atrophy*).

E

enema A solution of water put up the anus to make a person pass stool or to increase the amount of fluid in the body.

estrogen A female *hormone.*

F

family planning When a woman uses methods to prevent pregnancy so she can have the number of children she wants, when she wants them.

G

gang rape When someone is raped by more than one man.

gender role The way a community defines what it means to be a woman or man.

generic The name of the main ingredient in a medicine. Compare with '*brand name.*'

H

hemorrhoids Small, painful bumps or lumps at the edge of the anus or inside it. They are a type of swollen veins that may burn, hurt, or itch.

hepatitis A serious disease of the *liver* caused by a virus, bacteria, alcohol, or chemical poisoning. Some forms of hepatitis can be sexually transmitted.

home remedies Traditional ways of healing.

hormones Chemicals the body makes that tell it how and when to grow. *Estrogen* and *progesterone* are the most important hormones for women.

I

immunization See *vaccination.*

infant formula Artificial milk for babies used instead of breast milk. Infant formula and other replacement foods do not have the same nutrition or health benefits as breast milk.

infection A sickness caused by bacteria, viruses, or other organisms. Infections may affect part of the body or all of it.

injections When medicine or other liquid is put into the body using a *syringe* and needle.

intramuscular injection (IM) *Injection* deep into the muscle.

intravenous (IV) When medicines or fluids are put into a vein.

J

jaundice Yellow color of the skin and eyes. Jaundice can be a sign of *hepatitis* or of newborn jaundice.

L

ligament Tough strips or bands inside the body that hold joints and bones together. Ligaments join bones with other bones, while tendons or cords join bones with muscles.

liver A large organ under the lower right ribs that helps clean the blood and get rid of poisons.

M

massage A way of touching the body to relieve pain, tension, or other signs. Massaging the belly can help the womb *contract* and stop heavy bleeding after birth, miscarriage, or abortion.

midwife Someone with special training or experience to help a woman give birth.

N

nerves Thin fibers along which messages travel in the body. Nerves are the 'messengers' of the body. Some nerves let us feel things, and tell us when something hurts. Other nerves let us move parts of the body when we want to.

O

operation When a doctor makes a cut in the skin in order to repair damage inside, or to change the way the body functions.

orthopedic Aids, procedures, or surgery to help with the prevention or correction of injuries or disorders of the bones and skeletal system, and associated muscles, joints, and ligaments.

P

paraplegia Paralysis or loss of movement in the muscles of both legs (sometimes with slight involvement elsewhere) caused by disease or injury to the spinal cord.

physical therapist, physiotherapist A person who designs and teaches exercises and activities for people with physical disabilities.

placenta (afterbirth) A spongy organ in a woman's womb that gives the baby everything it needs to grow during pregnancy. The baby is connected to the placenta by the cord. After the baby is born, the placenta also comes out of the womb.

plant medicines Flowers, leaves, roots, and other parts of plants that can be used to treat diseases.

progesterone A female *hormone.*

progestin A *hormone* made in a laboratory that is similar to the *progesterone* made naturally in a woman's body. It is found in some hormonal *family planning* methods.

pus White or yellow fluid that is filled with germs, often found inside an *infected* tear or wound.

Q

quadriplegia (tetraplegia) Paralysis or loss of movement in the muscles of both arms and legs caused by disease or injury high up in the spinal cord, close to or in the neck.

R

rectal exam Checking the rectum for growths or other problems. A rectal exam can also give information about the wall or lining of the vagina.

resistance The ability of something to defend itself against something that would normally harm or kill it. Bacteria, biruses, and parasites can become resistant to the effects of certain medicines, especially *antibiotics* and *antiretrovirals*, so these treatments no longer fight disease.

S

scar A cut or wound that leaves the skin or *tissue* rough and raised after it has healed.

scrotum The bag between a man's legs that holds his testicles or ('balls').

seizures See *convulsion*.

sepsis A serious infection that has spread into the blood.

shock A dangerous condition with severe weakness or loss of consciousness, cold sweats, and fast, weak pulse. It can be caused by dehydration, heavy bleeding, injury, burns, or a severe illness.

side effects When medicines or *hormonal methods* cause changes in the body other than those needed to fight disease or prevent pregnancy.

spasticity Uncontrolled tightening or pulling of muscles that make it difficult for a person to control her movements. Spasticity often occurs with cerebral palsy, spinal cord injury, or brain damage.

stress The result of activities or events that put pressure on a woman, causing tension in her body and mind.

stroke A sudden loss of consciousness, feeling, or ability to move caused by bleeding or a clot inside the brain.

subcutaneous injection An *injection* into the fatty *tissue* under the skin, not into the muscle.

syringe An instrument used to *inject* medicine.

T

temperature The degree of heat of a person's body.

thermometer An instrument used to measure how hot a person's body *temperature* is.

tissue The material making up the muscles, fatty areas, and organs of the body.

toxemia A dangerous condition during pregnancy, which can lead to *convulsions*.

V

vaccinations or vaccines Medicines that are *injected* to give protection against specific diseases like tetanus.

Velcro The brand name of a strong, fuzzy plastic tape that sticks to itself. (The surface of one piece of the tape has little plastic hooks that catch onto the curly hairs on the other piece of the tape.) Useful to use instead of buttons, buckles, or laces on clothes, braces and shoes—especially for people with limited use of the hands.

W

weight-bearing Supporting the weight of the body on a particular joint or limb. For example, weight-bearing on the knee is possible if the strength of the thigh muscle is good, but not if it is poor.

X

x-rays Pictures of parts of the inside of the body, such as the bones or the lungs, which are created by rays sent through the body. The body does not need to be cut open.

Index

The Index lists topics covered in the book in the order of the alphabet.

A B C D E F G H I J K L M N O P Q R S T U V W X Y Z

To learn more

Here is a small selection of organizations, printed materials and internet resources that can provide useful information for women with disabilities, organizations for and by people with disabilities and information about the rights of persons with disabilities. We have tried to cover as many of the topics in this book as possible, and to include groups working in all areas of the world. Many of the printed materials are easy to adapt and often include other helpful resource lists.

ORGANIZATIONS

Many of the organizations listed here do most of their work with disability communities around the world. Contact them to see if they have projects or programs in your country. Some organizations provide general health information.

AIFO (Associazione Italiana Amici di Raoul Follereau)
Via Borselli 4-6, 40135 Bologna, Italy
Tel: (39-051)439-3211; Fax: (39-051)434-046
Email: info@aifo.it
Web: www.aifo.it

AIFO, an Italian NGO, provides support to projects in the global South. At present AIFO is involved in over 180 projects in 57 countries, supporting projects on leprosy and primary health care; rehabilitation of disabled persons; and support for vulnerable children.

ABILIS
Aleksanterinkatu 48 A, 00100 Helsinki, Finland
Tel: (358-9)612-40333
Email: abilis@abilis.fi
Web: www.abilis.fi

ABILIS is part of the international Independent Living and Disability Rights Movement. They give grants for projects run by disabled people in developing countries that focus on human rights and women with disabilities.

Action on Disability and Development (ADD)
Vallis House 57 Vallis Road
Frome Somerset, BA11 3EG, UK
Tel: (44-137)347-3064; Fax: (44-137)345-2075
Email: add@add.org.uk
Web: www.add.org.uk

ADD supports active networks of disabled people in several countries. Many of ADD's staff have disabilities themselves.

Arab Resource Collective
Lebanon: PO Box 13-5916, Beirut, Lebanon
Visiting Address: 5th Floor, Dkeik Building
Hanra, Beirut, Lebanon
Tel: (9611)742-075; Fax: (9611)742-077
Email: arcleb@mawared.org

Cyprus: PO Box 27380, Nicosia1644, Cyprus
Tel: (357)2277-6741; Fax: (357)2276-6790
Email: arccyp@spidernet.com.cy
Web: www.mawared.org/english/

Written and audio-visual materials on general health care, community development, and skills training for grass-roots organizations in the Middle East.

CBM (Christoffel-Blindenmission/ Christian Blind Mission)
Nibelungenstraße 124
64625 Bensheim, Germany
Tel: (49-6251)131-392; Fax: (49-6251)131-338
Web: www.cbm.org

CBM supports community-based rehabilitation programs run by local partner organizations in developing countries.

Danish Council of Organizations of Disabled Persons (DSI)

Kløverprisvej 10B
DK-2650 Hvidovre, Denmark
Tel: (45)367-517-77; Fax: (45)367-514-03
Email: dsi@handicap.dk
Web: www.handicap.dk/english

***DSI** supports organizations in the global South to improve their organizational structures, educate representatives of disability organizations and develop negotiation structures between authorities and disability organizations.*

Disability and Development Partners (*formerly* Jaipur Limb Campaign)

404 Camden Road, London N7 0SJ, England
Tel/Fax: (44-207)700-7298
Email: info2006@disabilityanddevelopmentpartners.org
Web: www.disabilityanddevelopmentpartners.org

***Disability and Development Partners (DDP)** works with local partner organizations in developing countries to bring social and economic benefits to people with disabilities—especially to those who have lost limbs or the use of limbs through war, accidents, or preventable diseases.*

Disability India Network

Disability India Network
c/o Society For Child Development
Cottage 15, Oberoi Apts, 2 Sham Nath Marg
Delhi 110 054, India
Email: vijay@disabilityindia.org
Web: www.disabilityindia.org

***Disability India Network** has a website with comprehensive information related to disability, and works for the empowerment of persons with disabilities and equal access to healthcare, education and employment.*

Disabled Peoples' International (DPI)

902-388 Portage Avenue, Winnipeg
Manitoba, R3C 0C8 Canada
Tel: (1-204)287-8010; Fax: (1-204)783-6270
Email: info@dpi.org
Web: www.dpi.org

***DPI** promotes the human and economic rights, and social integration of people with disabilities. Information on issues including women's health care, human rights, independent living, and social justice. Special focus on grass-roots development. Has local offices in over 110 countries.*

Disabled People of South Africa (DPSA)

Office of the Secretary General
P.O. Box 3467, Cape Town, 8000, South Africa
or
Room 705, 7th Floor, Dumbarton House
1 Church Street, Cape Town, South Africa
Tel: (0-21)422-0357; Fax: (0-21)422-0389
Email: info@dpsa.org.za
Web: www.dpsa.org.za

***DPSA** is a cross-disability umbrella body of disability organizations in South Africa. Programs include the **Disabled Women's Development Programme**, which promotes disabled women's participation through leadership and self-help skills development.*

Global Fund for Women

1375 Sutter Street, Suite 400
San Francisco, CA 94109, USA
Tel: (1-415)202-7640; Fax: (1-415)202-8604
Email: gfw@globalfundforwomen.org
Web: www.globalfundforwomen.org

Gives small grants to community-based women's groups, especially those working on controversial issues and in difficult conditions. Areas of special interest are human rights, communications technology, and economic independence.

Godisa

P.O. Box 142
Otse, Botswana
Tel: (267)533-7634; Fax: (267)533-7646
Email: mwb@info.bw
Web: www.godisa.org

The only hearing aid maker in Africa, Godisa distributes low-cost, durable, solar rechargeable hearing aids for people in developing countries.

Handicap International
Waterman House101-107, Chertsey Road
Woking, Surrey GU21 5BW, England
Tel: (44-0870)774-3737
Email: hi-uk@hi-uk.org
Web: www.handicap-international.org.uk

***Handicap International** works in over 50 countries to help people disabled by natural disasters, violence, and armed conflict, including land-mine victims.*

Healthlink Worldwide (*formerly* **AHRTAG)**
56-64 Leonard Street, London, EC2A 4JX, UK
Tel: (44-207)549-0240; Fax: (44-207)549-0241
Email: info@healthlink.org.uk
Web: www.healthlink.org.uk

***Healthlink Worldwide** works to strengthen the provision, use and impact of health information, to increase social inclusion of people working on issues such as disability and HIV/AIDS. Their partners publish **Disability Dialogue** (earlier called CBR News).Together with the Overseas Development Group, they publish a series of disability research papers as part of the **Disability Knowledge and Research Programme**.*

Helen Keller International
352 Park Avenue South, 12th Floor
New York, NY 10010, USA
Tel from US (toll free): (1-877) 535-5374
Tel: (1-212) 532-0544; Fax: (1-212) 532-601
Email: info@hki.org
Web: www.hki.org

Has programs in 25 countries. Material on blindness from lack of vitamin A. Information on blindness prevention and visual chart.

Inclusion International
Inclusion International administrative office
c/o The Rix Centre, University of East London
Docklands Campus, London E16 2RD, England
Tel: (44-208)223-7709; Fax: (44-208)223-7411
Email: info@inclusion-international.org
Web: www.inclusion-international.org

***Inclusion International (II)** is a global federation of family-based organizations advocating for the human rights of people with intellectual disabilities. **II** represents 200 member federations in 115 countries.*

International Disability and Development Consortium (IDDC)
IDDC Administrator
c/o Handicap International, Waterman House
101-107 Chertsey Road, Woking
Surrey GU21 5BW5, England
Tel: (44-0870)774-3737
Fax: (44-0870)774-3738
Email: administrator@iddc.org.uk
Web: www.iddc.org.uk

***IDDC** is an international network on disability and development. Members in over 100 countries implement programs, and fund, disseminate information and advocate human rights of people with disabilities.*

International Federation of Anti-Leprosy Associations (ILEP)
The Teaching and Learning Materials Coordinator
234 Blythe Road, London, W14 OHJ, England
Email: ilep@ilep.org.uk
Web: www.ilep.org.uk

***ILEP** coordinates support to leprosy programs. Their website includes a large list of funders as well as international partners.*

International HIV/AIDS Alliance
Queensberry House, 104-106 Queens Road
Brighton BN1 3XF, England
Tel: (44-0127)371-8900
Fax: (44-0-127)371-8901
Web: www. aidsalliance.org

*The **International HIV/AIDS Alliance** works to reduce the spread of HIV and meet the challenges of AIDS in developing countries. It channels funds and provides technical and organizational support to community-based groups. It also produces and distributes useful information on HIV/AIDS.*

Latin American and Caribbean Women's Health Network
Simón Bolivar 3798, Ñuñoa, 6850892
Casilla 50610, Santiago 1, Santiago, Chile
Tel: (56-2)223-7077; Fax: (56-2)223-1066
Email: secretaria@reddesalud.org
Web:www.reddesalud.org

Promotes women's health and women's human rights through cultural, political and social transformation.

Leonard Cheshire International (LCI)

30 Millbank
London, SW1P 4QD, England
Tel: (44-207)802-8224
Fax: (44-207)802-8275
Email: m.ekanger@london.leonard-cheshire.org.uk
Web: www.lcint.org

*The work of **LCI** includes projects in education, employment, economic empowerment, rehabilitation and day care services, short and longer-term residential care, and community programs. Their website lists resources and training materials.*

Mobility International USA (MIUSA)

132 E. Broadway, Suite 343
Eugene, Oregon 97401, USA
Tel: (1-541)343-1284; Fax: (1-541)343-6812
Email: info@miusa.org
Web: www.miusa.org

***MIUSA** works to empower people with disabilities through international exchange and development to achieve human rights. **MIUSA's website has** a comprehensive listing of international disability organizations.*

Mobility International India

1st and 1st A Cross, 2nd Phase, JP Nagar
Bangalore 560 078, India
Tel: (91-80)2649-2222; Fax: (91-80)2649-4444
Email: E-mail@mobility-india.org
Web: www.mobility-india.org

Promotes community-based rehabilitation and mobility for persons with disabilities, especially in rural areas. Trains women with disabilities to make artificial limbs and provide rehabilitation services in their communities.

Motivation

Brockley Academy, Brockley Lane, Backwell
Bristol, BS48 4AQ, England
Tel: (44-0127)546-4012
Fax: (44-0127)546-4019
Email: info@motivation.org.uk
Web: www.motivation.org.uk

***Motivation** designs and provides low-cost mobility products (wheelchairs, tricycles and artificial limbs). **It** also trains people to meet the needs of their local disabled communities.*

Musasa Project

Physical address: 64 Selous Ave
Cnr 7th Street, Harare, Zimbabwe
Postal address: PO Box A712, Avondale Harare, Zimbabwe
Tel: (263-04)725-881, (263-04)734-381
Fax: (263-04)794-983
Email: musasaproj@africaonline.co.zw

Provides information and support to abused women and education programs on domestic violence and rape.

National Union of Women with Disabilities of Uganda (NUWODU)

Plot No. 62 Ntinda Road, Ntinda
P.O. Box 24891, Kampala, Uganda
Tel: (256)41-285240; Mobile: (256)77-475186
Fax: (256)41-540178
Email: nuwodu@infocom.co.ug
Web: www.disability.dk/site/countryindex.php?section_id=28

An umbrella promoting equal rights and opportunities for women and girls with disabilities. Provides information on grassroots groups of women with disabilities and assists development of newly formed groups.

Teaching Aids at Low Cost (TALC)

P.O. Box 49, St. Albans, Herts AL 1 5TX, England
Tel: (44-0172)785-3869
Fax: (44-0172)784-6852
Email: info@talcuk.org
Web: www.talcuk.org

Low-cost books, slides, and accessories in English, French, Spanish, and Portuguese on health care and development for use in poor communities. Free booklist and CD libraries.

The Southern Africa Federation of the Disabled (SAFOD)

PO Box 2247, 19 Lobengula Street
Bulawayo, Zimbabwe
Tel: (263-9)69356; Fax: (263-9)74398
Email: safod@netconnect.co.zw
Web: www.safod.org

Human rights organization in Zimbabwe by disabled people for disabled people.

Swedish Organizations of Disabled Persons International Aid Association (SHIA)

Liljeholmstorg 7A, 11763 Stockholm, Sweden
Tel: (46-8)462-3360; Fax: (46-8)714-5922
Email: shia@shia.se
Web: www.shia.se

***SHIA** aims to strengthen the efforts of persons with disabilities to achieve equality and participation through development co-operation and partnerships between persons with disabilities in Sweden and elsewhere.*

Voluntary Health Association of India (VHAI)

B-40, Qutab Institutional Area, South of IIT
New Delhi 110016, India
Tel: (91-112)651-8071-72
Email: vhai@vsnl.com
Web: www.vhai.org

*Health education materials in English and local Indian languages. Also publishes **Health for the Millions**, a journal on low-cost health care.*

Whirlwind Wheelchair International (WWI)

San Francisco State University
1600 Holloway Avenue - SCI. 251
San Francisco, California 94132, USA
Tel: (1-415)338-6277; Fax: (1-415)338-1290
Email: info@whirlwindwheelchair.org
Web: www.whirlwindwheelchair.org

***WWI** developed the Whirlwind wheelchair, a lightweight, low-cost, sturdy wheelchair designed for rough urban and rural conditions in developing countries. **WWI** works with an international network of wheelchair workshops to continually update its designs.*

World Blind Union

Enrique Pérez, Secretary General
C/Almansa 66, 28039 Madrid, Spain
Tel: (34)914-365-366; Fax: (34)915-894-749
Email: umc@once.es
Web: www.worldblindunion.org

*The **World Blind Union (WBU)** unites people with visual disabilities in member organizations around the world. They work to promote equal opportunities for the blind; to raise the status of blind women, DeafBlind persons, blind people with multiple disabilities; and to prevent blindness worldwide.*

World Federation of the Deaf (WFD)

Postal Address: P.O. Box 65, FIN-00401
Helsinki, Finland
Physical address: Light House, Ilkantie 4 Haaga,
Helsinki, Finland
Fax: (358-9)580-3572
Email: info@wfdeaf.org
Web: www.wfdeaf.org

***WFD** is an organization of national associations of deaf people. They work to improve the status of national sign languages and education for deaf people, improve access to information and services, improving human rights for deaf people, and promote the establishment of deaf organizations.*

World Health Organisation (WHO)

Rehabilitation Section
20 Avenue Appia
1211 Geneva 27 Switzerland
Tel: (41-22)791-2111; Fax: (41-22)791-3111
Email: info@who.int
Web: www.who.int

***WHO** provides advice and financial support to health-related programs.*

BOOKS AND OTHER PRINTED MATERIALS

A Woman's Guide to Coping with Disability
Esther Boylan (ed.)
Resources for Rehabilitation
33 Bedford Street, Suite 19A
Lexington, MA 02420, USA

Written by women with disabilities; personal accounts and experiences cover the stigma of disability, its challenges, and prevention. Includes general information and further resources on specific disabilities: arthritis, multiple sclerosis, osteoporosis, and spinal cord injury.

AgeWays **and** ***Aging and Development***
HealthAge International
67-74 Saffron Hill, London EC1R OBE, England
Tel: (44-207)278-777
Fax: (44-207)713-7993, (44-171)447-203
Email: helpage@gn.apc.org
Web: www.helpage.org

These free journals are printed 2 times a year. ***HelpAge*** *has a network of over 50 organizations worldwide, working to achieve a lasting improvement in the quality of life for older persons.*

Breast Awareness:
Taking Care of Our Breasts (booklet)
Women's Health Information & Support Centre
120 Bold Street, Liverpool, L1 4JA. England
Tel: (44-0151)707-1826; Fax: (44-0151)709-2566
Email: women@whisc.org.uk
Web: www.whisc.org.uk

Easy-to-read, heavily-illustrated booklet on how to give a breast exam. Written by and for women with learning troubles, but useful for all.

Women's Health Information & Support Centre *has also published:* ***Having a Mammogram: X-ray of the Breasts****,* ***Going to the Breast Assessment Clinic at the Breast Unit****, and* ***Having a Smear Test****.*

Building an Inclusive Development Community: A Manual on Including People with Disabilities in International Development Programs
Karen Heinicke-Motsch and Susan Sygall (eds)
Mobility International USA
P.O. Box 10767, Eugene, Oregon 97440, USA
Web: www.miusa.org

Strategies for including persons with disabilities in a wide range of development programs, including health care.

Also available from ***Mobility International USA****:*

Loud, Proud and Passionate:
Including Women with Disabilities in International Development Programs
C. Lewis and S. Sygall (eds.)

A great resource for starting a group to empower women with disabilities and train them in leadership skills. Includes profiles of individual women as well as groups, their strategies, successes and failures.

Couples with Intellectual Disabilities Talk about Living and Loving
Karin Schwier Melberg, Woodbine House
5615 Fishers Lane, Rockville, MD 20852, USA
Tel: (1-301)897-3570
Tel in the US (toll-free): (800)843-7323
Fax: (1-301)897-5838
Web: www.woodbinehouse.com

Fifteen interviews with couples with disabilities reveal their personal stories on finding love, companionship, and happiness.

Disability Dialogue

56-64 Leonard Street, London, EC2A 4JX,
England
Tel: (44-207)549-0240; Fax: (44-207)549-0241
Email: info@healthlink.org.uk
Web: www.healthlink.org.uk

***Disability Dialogue** (formerly **CBR News**) newsletter exchanges information between disabled people and development, health and rehabilitation workers, and aims to promote disability equality, and good policy and practice. Practical information about community approaches and appropriate equipment, published in various language editions.*

Bangla:
Social Assistance for the Physically Vulnerable (SARPV)
3/8, Block-F, Lalmatia, Dhaka 1207, Bangladesh
Email: shaque@bd.drik.net
Web: www.sarpv.org

***English for Africa and Portuguese** (planned):*
Southern Africa Federation
of the Disabled (SAFOD)

PO Box 2247, 19 Lobengula Street
Bulawayo, Zimbabwe

Tel: (263-9)69356; Fax: (263-9)74398
Email: safod@netconnect.co.zw
Web: www.safod.org

***English for India and Hindi** (Akshamata Samvad):*
Amar Jyoti Rehabilitation and Research Centre

Kakardooma, Vikas Marg, Delhi 110 092, India
Email: amarjoti@del2.vsnl.net.in

French:
Mauritium, 5 Avenue Buswell
Quatre Bonnes, Mauritius

Gujarati:
Centre for Health Education Training and Nutrition Awareness (CHETNA)

Lilavatiben Lalbhai's Bungalow
Civil Camp Road, Shahibaugh, Ahmedabad
Gujarat 380 004, India
Tel: (91-079)286-696; Fax: (91-079)286-6513
Email: chetna@icenet.net
Web: www.chetnaindia.org

***Nepali** (Apangata Kurakani)*:
Partners for Rehabilitation
International Nepal Fellowship
PO Box 28, Pokhara, Nepal
Email: kurakani@bigfoot.com

***Tamil** (Oonam Seithi)*:
Rural Unit for Health and Social Affairs (RUHSA)
Christian Medical College and Hospital RUHSA
Campus Post Office, Vellore District Tamil Nadu
632 209, India
Email: abel-rajaratnam @hotmail.com

*Audio-cassette (International edition) **Action on Disability and Development (ADD)**, UK-distributed by **Healthlink Worldwide** at the address above*

English braille
and *Indian language audio-cassette:*
Blind People's Association of India

Dr Vikram Sarabhai Rd Vastrapur, Ahmedabad
380 015, India
Tel: (91-079)2630-5082; Fax: (91-079)2630-0106
Email: blinab@sancharnet.in

Disability, Inclusion and Development: Key Information Resources (directory)

Source, c/o Healthlink Worldwide
50-64 Leonard Street, London EC2A 4JX, England
Tel: (44-207)549-0240; Fax: (44-207)549-0241
Web: www.asksource.info/res_library/disability.htm

Directory of over 300 information resources with abstracts and details of distributors and linked to the full resource online. For people with limited access to the Internet, the directory is available in print with a CD-ROM, which holds the fully searchable and browseable text of many resources.

Our Bodies Ourselves

Boston Women's Health Book Collective, OBOS
34 Plympton Street, Boston, MA 02118
Tel: (1-617)451-3666; Fax: (1-617)451-3664
Email: office@bwhbc.org
Web: www.ourbodiesourselves.org

Includes a chapter on Sex and Disabilities, including the effects of the disability on sexuality, and helpful hints and special implications.

Multiplying Choices:
Improving Access to Reproductive Health Services for Women with Disabilities
Barbara Waxman Fiduccia
Berkeley Planning Associates
Oakland, CA 94610, USA
Tel: (1-510)465-7884; Fax: (1-510)465-7885
Email: info@bpacal.com
Web: www.berkeleypolicyassociates.com

Excellent book compiled by disabled women describes their concerns regarding health services, offers suggestions to meet the reproductive health needs of women with disabilities. Has information on the Americans with Disabilities Act, and offers lists of books and articles about sexual and reproductive health for women with disabilities.

Reproductive Issues
for Persons with Physical Disabilities
F. Haseltine, S. Cole, and D. Gray (eds.)
Paul H. Brooks Publishing Co.
P.O. Box 10624
Baltimore, Maryland, 21285-0624, USA
Tel: (1-410)337-9580; Fax: (1-410)337-8539
Email: custserv@brookespublishing.com
Web: www.brookespublishing.com

Written for professionals, caregivers, researchers and individuals with disabilities, it provides research findings and personal stories exposing myths surrounding disability and reproductive issues.

South African Women's Health Book
Order through: Heinemann Publishers
Grayston Office Park, 128 Peter Road
PO Box 781940 Sandown
Johannesburg, South Africa 2146
Tel: (27-11)322-8660
Fax: (27-11)322-8715 or -8716
Email: cust_services@heinemann.co.za

Comprehensive information on women's health in South Africa including stories from women in local communities. Includes chapters on gender, culture, healthy living, violence, work, sexuality, and reproductive health.

The Disabled Woman's Guide
to Pregnancy and Birth
Judith Rogers, Demos Medical Publishing
386 Park Avenue South, Suite 301
New York, NY 10016, USA
Tel: (1-212)683-0072
Tel from US (toll free): (1-800)532-8663
Fax: (1-212) 683-0118
Email: orderdept@demosmedpub.com
Web: www.demosmedpub.com/default.aspx?page_id=0

Pregnancy and childbirth information for women with disabilities. Revised and re-titled version of ***Mother To Be: A Guide to Pregnancy and Birth for Women with Disabilities.*** *Based on the experiences of 90 women with disabilities who chose to have children.*

The Kenyan's Deaf Peer Education Manual
Sahaya International, USA
c/o Koen Van Rompay
2949 Portage Bay Avenue, Apartment #195
Davis, CA 95616, USA
Tel:(1-530)756-9074
Email: kkvanrompay@ucdavis.edu
Web: www.sahaya.org

A training manual with activities for basic understanding of sexual health, HIV and AIDS.

Welner's Guide to the Care
of Women with Disabilities
Sandra L. Welner and F. Haseltine
Lippincott Williams & Wilkins
530 Walnut Street, Philadelphia, PA 19106, USA

Guide for caregivers focusing on management of pain, osteoporosis, anesthesia, incontinence, infertility, depression and psychotropics, substance abuse, and hormonal management. Also addresses more fundamental issues such as nutrition, sexuality, exercise, physical examination, etc.

Internet-based resources

The World-Wide Web is an incredible resource for those who have access to it. Besides the very useful websites listed for the organizations and print materials on the previous pages, here we list just a few of the websites we use most frequently when we look for disability and health information.

Contact

www. wcc-coe.org/wcc/news/contact.html

***Contact**, published in French, Spanish, English and Portuguese by **World Council of Churches**, focuses on issues of health and healing.*

Disability Knowledge and Research

www.disabilitykar.net/learningpublication/references.html

*The **Disability Knowledge and Research** program, an effort of **Healthlink Worldwide** and the **Overseas Development Group** of East Anglia University, aims for better health and quality of life for people in developing countries. This website presents their papers, research, etc., including:*

Mainstreaming disability in development: lessons from gender mainstreaming

Carol Miller and Bill Albert (March 2005)

Explains mainstreaming, as a strategy of feminist advocacy in the context of development, and draws comparisons with the history of the disability movement. Includes recommendations for mainstreaming disability, and compares these with 'good practices' in gender mainstreaming.

Mainstreaming disability in development: India country report

Philippa Thomas (June 2005)

Examines disability in relation to poverty and social exclusion. The report also highlights ways to integrate disability into development.

Disability, poverty and the 'new' development agenda

David Seddon and Rebecca Yeo (July 2005)

Looks at changes that have taken place in recent years around poverty, disability and the relationship between the two.

Disability World

www.disabilityworld.org

This is a great site that is an internationally focused news web magazine covering disability issues. The site is useful in sorting out relevant information and is in both English and Spanish. Internet users with slower connections can load the site as text only.

Source International Information Support Centre

www.asksource.info

***Source**, is an international information support centre designed to strengthen the management, use and impact of information on health and disability.*

***Source** now has over 25,000 information resources on a range of subjects including HIV and AIDS, disability and inclusion, mother and child health, information and communication technology and participatory communication. Resources are available online, by CD-ROM and as printed materials.*

Table Manners and Beyond: The Gynecological Exam for Women with Developmental Disabilities and Other Functional Limitations.

www.bhawd.org/sitefiles/TblMrs/cover.html

An excellent guide, edited by Katherine M Simpson and Kathleen Lankasky, for both women with disabilities and health care workers of how to do pelvic and breast exams for women with a wide range of disabilities.

World Enable

www.worldenable.net/women/

A project of several disability organizations with a great list of resources and a page specifically on women with disabilities.