

Schizophrenia



Schizophrenia: A Handbook For Families

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Dedication

This handbook is dedicated to the families and to their loved ones who carry the burden of schizophrenia, a major psychiatric disorder.

Acknowledgements

Production of the handbook was made possible by a grant under the Health Promotion Contribution Program of Health and Welfare Canada. Its preparation was largely in the capable hands of Ms. Sharon Jennings, Communications Consultant, whose services were retained by the Schizophrenia Society of Canada (SSOC)* for that purpose. Overall supervision of the project was provided by Peter MacGibbon, Executive Director, SSOC, ably assisted by Karina Torrese, Executive Assistant, SSOC. Ms. Barbara Dubuc and her colleagues in the Mental Health Division of Health and Welfare Canada also gave valuable advice and suggestions. In

addition, Health and Welfare Canada provided funds to cover the cost of printing.

A wealth of practical information was derived from the real-life experiences of relatives as caregivers for a family member or members who have schizophrenia. Most of this input originated in three focus group meetings. The first of these, which included participants from Ontario Friends of Schizophrenics, was organized with help from Ms. June Beeby, Executive Director of that provincial association, and held in Toronto. The second meeting occurred in Montreal. It brought together representatives from member organizations of la Federation quebecoise des associations des familles et amis de la personne atteinte de maladie mentale. The arrangements for this meeting were made by the Federation's President, M. Paul-Emile Poirier. The final meeting comprised members from the Schizophrenia Society of Nova Scotia assembled under the direction of Ms. Barbara Bingham, President of that association. and took place in Halifax.

After the focus meetings, a draft of the handbook was given wide circulation to members of the SSOC provincial associations and to those of member organizations of la Federation quebecoise des associations des familles et amis de la personne atteinte de maladie mentale. Their comments and suggestions on the draft provided considerable additional material now incorporated in the handbook.

A great deal of assistance was received from health care professionals, mostly from the Clarke Institute of Psychiatry and the Queen Street Mental Health Centre in Toronto. Many helped, but I would particularly like to mention Dr. Mary Seeman, Chief in Psychiatry at Toronto's Mount Sinai Hospital, whose constructive criticism and comments on the contents of the handbook were especially valuable.

To all these people, and to Health and Welfare Canada who made the handbook possible, I express the gratitude and appreciation of the Board of Directors of the Schizophrenia Society of Canada.

Gordon Gwynne-Timothy
President
Schizophrenia Society of Canada
July 1990.

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* Formerly known as the **Canadian Friends of Schizophrenics**, the **Schizophrenia Society of Canada** adopted its new name after its Annual Meeting in July 1990. Several of the SSOC's provincial affiliates (Alberta, Manitoba and Nova Scotia) have also changed their names. These are respectively now called **Schizophrenia Society of Alberta**, **Manitoba Schizophrenia Society, Inc.**, and **Schizophrenia Society of Nova Scotia**. Whether or not the rest of the affiliates will follow the name change was not known during the final revision of the handbook.

Introduction

Family contributors to this handbook urged that its contents should help families who are new to the illness to deal with some of the fear, sorrow and bewilderment that the contributors themselves had endured when little information about schizophrenia was available. The handbook has been primarily developed, therefore, as a guide for families when early signs indicate that a relative may have schizophrenia, and as a resource for these families when a diagnosis of schizophrenia has been determined. To this end, it has been put together with help from many families with relatives who have schizophrenia. These people were willing to share their experiences

in order to offer others practical, common-sense advice on what to do.

They noted that when they discovered that a relative was ill, they were frequently frustrated because medical professionals could not provide them with clear-cut answers. They learned that with schizophrenia definite answers often do not come easily. Families now encountering the illness should know that they have not failed their relative: that a considerable amount of trial and error may be necessary to learn the best way of handling the situations that arise from the illness.

Looking back on their own experiences, contributors to this book expressed a number of wishes:

"I Wish I Had

- had more information about the disease
- known that it is not a preventable disease
- understood that it is not simply a matter of confused or troubled thinking, that my relative was not just passing through a difficult phase
- had someone, relative or friend, who would tell me that my family member was not behaving normally
- sought help sooner
- asked more questions
- had more patience
- known that all my horrible feelings of guilt and shame were normal
- known that in real life all families aren't perfect like the Waltons on television, and
- known that I had the right to ask questions and seek help from the health care professions."

In keeping with the preceding list, the families have endeavoured throughout this handbook to provide you with a range of ideas. They caution that not all of these ideas will work for your relative, or be appropriate for your ethnic background and family traditions. And, of course, there are many areas that cannot be covered within the scope of this publication. Therefore, when asked what one piece of advice they would pass on to you, families stressed the importance of belonging to a chapter of the Schizophrenia Society of Canada (SSOC), or to a group associated with la Federation quebecoise des associations des familles et amis de la personne atteinte de maladie mentale in Quebec or to any other self-help group organized by and for families of people with schizophrenia. It is at support group meetings that you will receive information, advice, and understanding. Moreover, families found that as members of SSOC or similar organizations they could deal more effectively with their community and provincial health care systems. They have their own knowledge and experience of the illness, they know their rights, and they are better able to get help for their relatives. One woman stated, "Becoming a member of a support group is a crucial step in coming quickly to knowledge, understanding, and acceptance. The most important factor in coping is feeling that you are not alone, and that the situation is not hopeless."

The health care professionals consulted agreed that there is a lack of practical advice. They felt that they, too, would benefit from the common-sense knowledge now available from the experiences of families. They also agreed about the importance of joining a family support group. As one health care worker stated, "Under current circumstances, people with schizophrenia have very little voice. The nature of the illness makes it difficult for many to join together and lobby for their rights. The support of families and friends, as advocates, is needed to call attention to the issues."

What Is Schizophrenia?

Although an exact definition of schizophrenia still evades medical researchers, the evidence indicates more and more strongly that schizophrenia is a severe disturbance of the brain's functioning. In *The Broken Brain: The Biological Revolution in Psychiatry*, Dr. Nancy Andreasen states "The current evidence concerning the causes of schizophrenia is a mosaic. It is quite clear that multiple factors are involved. These include changes in the chemistry of the brain, changes in the structure of the brain, and genetic factors. Viral infections and head injuries may also play a role....finally, schizophrenia is probably a group of related diseases, some of which are caused by one factor and some by another." (p. 222).

There are billions of nerve cells in the brain. Each nerve cell has branches that transmit and receive messages from other nerve cells. The branches release chemicals, called **neurotransmitters**, which carry the messages from the end of one nerve branch to the cell body of another. In the brain afflicted with schizophrenia, something goes wrong in this communication system.

Many families of people with schizophrenia have found comparing the brain to a telephone switchboard very helpful in understanding the disease. In *Schizophrenia: Straight Talk for Family and Friends* (p. 41), Maryellen Walsh states "In most people the brain's switching system works well. Incoming perceptions are sent along appropriate signal paths, the switching process goes off without a hitch, and appropriate feelings, thoughts, and actions go back out again to the world....in the brain afflicted with schizophrenia...perceptions come in but get routed along the wrong path or get jammed or end up at the wrong destination."

Schizophrenia may develop so gradually that the family and even the person with the disease may not realize that anything is wrong for a long period of time. This slow deterioration is referred to as **gradual-onset** or **insidious schizophrenia**. A gradual build-up of symptoms may or may not lead to an **acute or crisis episode** of schizophrenia. An acute episode is short and intense, and involves hallucinations, delusions, thought disorder, and an altered sense of self.

Sometimes schizophrenia has a **rapid or sudden onset**. Very dramatic changes in behaviour occur over a few weeks or even a few days. Sudden onset usually leads fairly quickly to an acute episode. Some people have very few such attacks in a lifetime; others have more. Some people lead relatively normal lives between episodes. Others find that they are very listless, depressed, and unable to function well.

In some, the illness may develop into what is known as **chronic schizophrenia**. This is a severe, long-lasting disability characterized by social withdrawal, lack of motivation, depression, and blunted feelings. In addition, moderate versions of acute symptoms such as delusions and thought disorder may be present in the chronic disorder.

Psychiatrists divide the symptoms of schizophrenia into "**positive**" and "**negative**" categories. This can be confusing. Dr. E. Fuller Torrey explains that the adjective "positive" "...denotes those symptoms which are present and should be absent..."; "negative" those "...that are absent but should be present...." (Torrey, *Surviving Schizophrenia: A Family Manual*, revised edition, p. 79). This classification system is believed to be helpful for research purposes. It may suggest more promising forms of treatment and may help predict the outcome of the illness.

Positive Symptoms

Hallucinations are thought to be a result of over-sharpening of the senses and of the brain's inability to interpret and respond appropriately to incoming messages. A person with schizophrenia may hear voices or see visions that are not there, or experience unusual sensations on or in his or her body. Auditory hallucinations, the most

common form, involve hearing voices that are perceived to be inside or outside of the person's body. Sometimes the voices are complimentary, reassuring, neutral. Sometimes they are threatening, punitive, frightening, and may command the individual to do things that may be harmful.

Delusions are strange and steadfast beliefs that are held only by the observer and that remain despite obvious evidence to the contrary. For example, red and green traffic signals may be interpreted by someone with schizophrenia as instructions from space aliens. Many people with schizophrenia who suffer from persecution delusions are termed "paranoid." They believe that they are being watched, spied upon, or plotted against. A common delusion is that one's thoughts are being broadcast over the radio or television, or that other people are controlling the ill person's thoughts. Delusions are resistant to reason. It is of no use to argue that the delusion is not "real."

Thought disorder refers to problems in the way that a person with schizophrenia processes and organizes thoughts. For example, the person may be unable to connect thoughts into logical sequences. "Racing thoughts" come and go so rapidly that it is not possible to "catch them." Because thinking is disorganized and fragmented, the ill person's speech is often incoherent and illogical. Thought disorder is frequently accompanied by inappropriate emotional responses: words and mood do not appear in tune with each other. The result may be something like laughing when speaking of sombre or frightening events.

Altered sense of self is a term describing a blurring of the ill person's feeling of who he or she is. It may be a sensation of being bodiless, or non-existent as a person. The ill individual may not be able to tell where his or her body stops and the rest of the world begins. It may be as if the body is separated from the person.

Negative Symptoms

Lack of motivation or **apathy** is a lack of energy or interest in life that is often confused with laziness. Because the ill person has very little energy, he or she may not be able to do much more than sleep and pick at meals. Life for the person with schizophrenia can be experienced as devoid of interest.

Blunted feelings or **blunted affect** refers to a flattening of the emotions. Because facial expressions and hand gestures may be limited or nonexistent, the ill individual seems unable to feel or show any emotion at all. This does not mean that the individual does not feel emotions and is not receptive to kindness and consideration. He or she may be feeling very emotional but cannot express it outwardly. Blunted affect may become a stronger symptom as the disease progresses.

Depression involves feelings of helplessness and hopelessness, and may stem in part from realizing that schizophrenia has changed one's life, from realizing that the "special feeling" experienced in the psychotic state is an illusion and that the future looks bleak. Often the person believes that he or she has behaved badly, has destroyed relationships, and is unlovable. Depressed feelings are very painful and may lead to talk of, or attempts at, suicide. Biological changes in the brain may also contribute to depression.

Social withdrawal may occur as a result of depression, as a result of a feeling of relative safety in being alone, or as a result of being so caught up in one's own feelings and fearing that one cannot manage the company of others. People with schizophrenia frequently lack the resources needed to show interest in socializing.

It is most common for schizophrenia to attack young people for the first time between 15 and 30 years of age, but the illness may develop as late as age 40. It occurs in all races, in all cultures, in all social classes, and in both sexes. The risk for anyone in the population becoming schizophrenic is generally accepted as one percent. This means that about 250,000 Canadians will suffer from this illness at some point in their lives.

Schizophrenia is not now curable, but through the use of anti-psychotic medication and psychotherapy, the

positive symptoms of schizophrenia can usually be controlled. Full recovery may occur, but it cannot be predicted. In some cases people get better on their own. Remission usually comes within the first two years and is rare after having the disease for five years. With advancing age, particularly after 40, life for the person with schizophrenia often becomes less difficult: positive symptoms tend to diminish and medication can often be taken at a low dose or less frequently.

An Illness Not Understood: The Stigma Of Schizophrenia

The stigma of schizophrenia is a barrier to those trying to rehabilitate themselves. It is also a very real problem for their families. Therefore, those involved with schizophrenia are concerned about the dozens of misconceptions about the illness. Schizophrenia is a disease that is not well understood and is greatly feared. Most of what people think they know about schizophrenia is wrong. People confuse schizophrenia with split personality or multiple personality. They believe that people with schizophrenia are violent and dangerous. A limited number are, of course, but media publicity about particularly frightening and bizarre crimes of violence committed by people with mental disorders has left the public with the impression that most persons with schizophrenia are violent. This is not true. The majority are not. However, wide differences in the effect that schizophrenia has on different people and the difficulty in understanding the actions of someone in a deeply psychotic state, whose thinking is thoroughly confused, reinforce the public's concern. Some believe that people with schizophrenia have weak personalities and have "chosen" their madness. Many believe that schizophrenia is the result of bad parenting and childhood trauma.

One parent stated that he was often accused of abandoning his daughter when he took her to the hospital. Another parent said that clerks in stores ignored her son when he asked for help or tried to make a purchase. Some religious groups hold the view that the illness is one of God's punishments.

The families consulted believe that it is important to understand how the stigma surrounding schizophrenia developed. The term "schizophrenia" was introduced in 1911 by a Swiss psychiatrist, Eugen Bleuler. The word comes from the Greek schizo meaning "split" and phrenia meaning "mind." Bleuler wanted to convey the split between what is perceived, what is believed, and what is objectively real. He did not mean that the person with schizophrenia is split into two personalities, but that there is a splitting away of the personality from reality. The concept of "split," however, has led to schizophrenia being confused with multiple personality, a less common and very different psychiatric disorder, much publicized through such stories as *Dr. Jekyll and Mr. Hyde*, *The Three Faces of Eve*, and *Sybil*. Today, many health care professionals regret the existence of the term "schizophrenia" because of the confusion and misunderstanding that surround it.

Added to this basic confusion is a history of blame. Families agree that blame is a major stumbling block to seeking and receiving support.

In the late 1800s and the early part of this century, three competing views about the nature of mental illness gained acceptance in the psychiatric profession.

Biological psychiatry grew from the research of Dr. Emil Kraepelin in Germany; psychoanalysis from the findings of Dr. Sigmund Freud and his colleagues in their studies on neuroses in Austria; and behaviourism from the work of Dr. John B. Watson in the United States. Kraepelin's views predominated the thinking of psychiatrists in Europe, while both psychoanalysis and behaviourism (see Glossary) flourished in North America (Andreasen, *The Broken Brain*, pp. 11-20).

In the 1950s, many North American psychiatrists began to believe that schizophrenia resulted from a form of psychic trauma inflicted on the individual early in life, typically by parents. Mothers of those with schizophrenia were believed to be over-anxious, obsessive, and domineering. These women were labelled "schizophrenogenic." One mother said she almost understood this. "When you are pushing to get help for your child, it is easy for some to 'put the cart before the horse' and point to this pushiness and tension as the cause of your child's problem, rather than the result of it." Gradually, blame was placed on the family as a unit. Theorists noticed poor family functioning where there was someone with schizophrenia, and confused the effect of the illness with its cause.

Two other theories contributed to the mythology surrounding schizophrenia. The American psychoanalyst Thomas Szasz pronounced that schizophrenia, like all other mental illnesses, is a set of behaviours, not a disease. The late R.D. Laing, a British psychiatrist, suggested that it is really a "healthy" response to an insane world. People burdened with terrible stress act "crazy" in an effort to adapt.

Scientific research and factual data have discredited these theories. Unfortunately, they were all popular enough at one time to have gained public attention. You may still run into health care professionals who will suggest that you "caused" your relative's illness, and that a continuing family relationship may hinder recovery.

Aside from the history of blame, the symptoms of the illness itself can often add to the stigma of schizophrenia. The odd and unpredictable behaviour, poor functioning, or lack of good health habits can be disturbing to others. News coverage on acts of violence or suicides committed by people reported as having schizophrenia serve to add to the stigma, even if unintentionally.

Families often find the stigma difficult to handle. Some try to hide the illness in the family. Others, however, prefer to speak openly about it. They say this gives peace of mind and allows them to join with others to try to remove the stigma.

Recognizing That Something Isn't Right

Family members commonly reported that they knew at an early stage that something wasn't right with their relative. They sensed that their son or daughter, brother or sister, husband or wife was not merely going through a phase, was not in a temporary bad mood, was not reacting to the overuse of drugs or alcohol. Some, however, said they were taken completely by surprise. They assumed that whatever unusual behaviour they had observed was due either to normal adjustment or to some degree of delinquency. All urge that people reading this Handbook trust their instincts and seek help immediately if they become concerned. Remember that you know your relative best.

Early Warning Signs - a list compiled from the focus group discussions

- inability to sleep, unusual waking hours, day and night mixed up
- social withdrawal, isolation, indifference
- deterioration in social relationships
- hyperactivity, or inactivity, or periods of alternation between the two
- inability to concentrate, noticeable difficulty in making decisions
- unusual preoccupation with religion or the occult
- hostility, suspicion, fearfulness
- over-reaction to peer or family disapproval

- deterioration in personal hygiene
- frequent hitch-hiking trips for unclear reasons
- excessive writing or childlike printing without clear meaning
- unusual emotional reactions
- flat, expressionless gaze
- staring, not blinking, or blinking incessantly
- unusual sensitivity to stimuli (noise, light)
- smelling and tasting things differently
- peculiar use of words or language structure
- bizarre behaviour: refusal to touch people, constant wearing of gloves, shaving head or body hair, cutting oneself, threats of self-mutilation

None of these signs by themselves indicate the presence of mental illness. Few of those who helped compile this list said that they had acted on these early warning signs. With the knowledge of hindsight, these family members urge you to seek medical advice if several of the behaviours listed above are present, or constitute a marked change from previous behaviour and persist over a few weeks.

Many families noticed that there was no logical flow of ideas during conversation. Others noticed that their relative began speaking out loud to no one, and did not seem to hear other people speaking to him or her. One young man began researching all religions and cults. Another young man began turning off all radios because he believed that he was receiving messages through this medium. In some families, their relative destroyed his or her bank book, birth certificate, and photographs. Signs of paranoia became apparent in many cases. A relative would begin talking about plots against him or her and had "evidence" that he or she was being poisoned. One man said that his wife assumed that whenever she saw people talking, they were talking about her.

Eventually, families reached a point where they could not tolerate the differences in behaviour any longer. Many commented that there was much confusion in the home, with some resentment and anger toward the person behaving strangely. Siblings often felt that their brother or sister was merely lazy and shirking responsibilities; children were embarrassed and confused by their parent acting so differently; parents disagreed on how to handle their child's problems; the stability of the marriage frequently suffered. All contributors stressed that you should not wait for tensions to reach such extreme levels. You should seek outside help from your family physician or some other appropriate source.

Where To Get Help: Seeking Medical Advice

When you have decided to make a doctor's appointment, there are several things you can do to help make the situation a little easier for everyone. First, be aware that your relative may not want to go to a doctor. He or she may be genuinely unaware of the abnormality of the symptoms. Lack of insight about the illness may cause your relative to deny that anything is wrong. Or, if aware that something is wrong, he or she has probably spent weeks or months in a state of confusion and fear, trying to understand the problem on his or her own. Your relative may have put a lot of energy, talent, and intelligence into creating an act designed to convince everyone that things are "normal." When you suggest the need to see a doctor, you are not offering comfort: you may be confirming strong, unspoken fears. Hostile or patronizing suggestions such as "You've been really weird lately," or "Why are you acting like this? You're being silly and lazy," will alienate this person further. It is also unwise

to say anything that could suggest that you have been discussing his or her behaviour behind the person's back: "We've all discussed your strange behaviour, and we agree that you need to see a doctor." Nor will it help to focus on the feelings and concerns of others: "Your behaviour is upsetting your mother," or "Your father is very angry with you."

It may be useful to focus on a particular symptom such as the inability to sleep, a lack of energy, or sadness and crying. You can then say something like: "I know you haven't been sleeping well at night, and you are so tired during the day. Why don't we make an appointment to see the doctor?" The doctor then can be perceived as someone who might be able to help rather than as a judge who will be critical.

If your relative agrees to see a doctor, ask the receptionist for a double booking - most appointments are only 10 or 15 minutes long - so that you will not feel rushed. Then, after you have arranged the appointment, send the doctor a letter outlining your concerns as clearly as possible. In addition to assisting the doctor, this will help you be clear about what has been happening. The following is a **sample letter**.

Dear Dr. Smith,

I have made an appointment for my daughter, Jane, to see you on Monday, May 8, at 10:00 a.m. Three months ago, Jane began acting in an unusual manner. The following are some of the behaviours that our family has noticed. She cannot sleep at night, has dropped out of her favourite clubs, refuses to see any friends, cries two to three hours a day, and will not allow anyone to touch her.

I have enclosed copies of her last two school reports, and a list of comments made by her friends. I believe that a medical assessment is necessary, and I am anxious to hear your opinion.

Sincerely

If your relative refuses to see a doctor, however, you should still make an appointment and go on your own. Again, seek a double booking, and send a variation of the above letter. After you have spoken to the doctor, you may be able, as a team, to get your relative in for an appointment.

If you have succeeded in convincing your relative to go to the doctor, you need to be aware that this first visit may not solve anything or answer any questions. Families who have been through this admitted that they had hoped this doctor's visit would be the "cure-all," and were frustrated when nothing seemed to happen.

During a doctor's appointment, your relative will rarely exhibit the behaviour that you have seen. Some people find talking to a doctor very stressful, and many people with schizophrenia have said that they found themselves going blank during the visit.

However, many people with schizophrenia said that their fear of going to see a doctor was somewhat alleviated when the doctor was able to ask the right questions; that is, because of the letter received in advance, the doctor was able to focus on the symptoms that were bothering the patient, and the patient found that he or she was more willing to open up to the doctor. For example, people found it comforting if the doctor said something like: "I understand you've been crying a lot lately. You must feel very confused about this."

Keeping Record

Now that you have begun the process of getting help for your relative, families advise that you begin keeping a record that documents your relative's behaviour, and the steps taken by you and others in the course of the illness. This may involve a good deal of effort, but the value was emphasized again and again by focus group participants and others. Your record will help you when a doctor is taking a history, or when you change doctors. It will also keep your mind clear about the course of the illness and the treatment that has been tried.

The record should be clear and precise and in point form. Avoid vague words and rambling descriptions. Medical practitioners stress the importance of listing behaviours that can be observed and measured. For example, you are noting a behaviour if you say that Joe refuses to wash, and wears the same clothes every day. This is more useful than saying that Joe looks terrible. Another example: you are noting a behaviour if you say that Susan cries every night for at least one hour. Again, this is much more useful to the doctor than, "Susan seems so sad." Write down the details of the noted behaviour, and include the day, time and duration, if applicable. Keep a record of your appointments with your doctor, and keep copies of all correspondence.

It is essential that you treat your record as a confidential document, one that should be used with great discretion. Moreover, if your relative has paranoid tendencies, knowledge of your record may only convince him or her that you are spying. On the other hand, some families have found that it is helpful to have their relative's involvement in the record keeping. If you feel it is appropriate, encourage your relative to jot down his or her thoughts and feelings.

Diagnosing Schizophrenia

There is, as yet, no simple lab test to make a diagnosis. Therefore, the diagnosis is based on the symptoms - what the person says and what the doctor observes.

To reach a diagnosis of schizophrenia, other possible causes such as drug abuse, epilepsy, brain tumour, thyroid or other metabolic disturbances, as well as other physical illnesses that have symptoms like schizophrenia, such as hypoglycemia and Wilson's disease, must be ruled out. The condition must also be clearly differentiated from bipolar (manic-depressive) disorder (see Glossary). Some patients show the symptoms of both schizophrenia and manic depression. This condition is termed "schizoaffective" disorder. Its relation to schizophrenia is unclear at present.

A diagnostic system for mental illness widely used in North America was developed by a task force of the American Psychiatric Association. The results of its work was published in a handbook called *The Diagnostic and Statistical Manual of Mental Disorders* (DSM). Andreasen noted in her book, *The Broken Brain: The Biological Revolution in Psychiatry*, that the third version of the Manual, commonly known as DSM-III, squarely placed the emphasis in diagnosis on "the careful study of objective symptoms" (p. 154). She went on to say that "the most important implication (of DSM-III) is a shift from the more psychoanalytic to a more medical approach" (p. 158).

Since DSM-III was published in 1980, further refinements have taken place. The current edition of the Manual is DSM-III-R (revised, 1987).

No matter what happens during the first visit to the doctor, the diagnosis of schizophrenia usually takes a long time. This is because it can be a very difficult diagnosis to make: the symptoms necessary for diagnosis either go unrecognized, or do not show themselves fully, until the illness is advanced. There are also many differences among individuals in the way in which symptoms present themselves. Most doctors, well aware of the stigma that still surrounds this illness, don't like to voice their suspicions until they are sure that this diagnosis is correct.

If your doctor does diagnose schizophrenia, do not assume that he or she has ruled out the possibility of another illness. Do not hesitate to ask about other illnesses and ask on what grounds the doctor has determined that schizophrenia is the problem. Where an illness as confusing and variable as schizophrenia is concerned, you should ask for a second medical opinion and a psychiatric referral, whether or not you are satisfied with your

doctor's response. A request of this nature is perfectly acceptable. Do not feel that the doctor will take it as a personal criticism.

Confidentiality

Sooner or later families run up against the legal and ethical issue of confidentiality. It is a basic principle in the practice of medicine. Information about a patient cannot usually be released, except to members of the treatment team, **unless** that patient has given written consent. The exceptions are when a patient is under age or is deemed to be mentally incompetent. Under the law in some jurisdictions, a priority list of those who may act on his or her behalf has been established for anyone judged to be mentally incompetent. It often comes as a surprise to parents, for example, that they are not first on such lists. In the case of a spouse in Ontario, if the person who is ill has appointed someone else when mentally competent, that person ranks before the spouse.

It is natural for care-giving family members to want to know as much as they can about their relative's situation to be able to help as much as possible. Health care professionals recognize this, but their hands may be tied because no patient's consent has been given. Ideally, written authorization for the doctor to talk to the family should be obtained when the patient is well. However, if the patient is unwilling to give consent, try asking the physician whether there is anything that you can do to help obtain it. Remember, also, a physician **can** speak if there is a risk of physical violence.

Legal requirements on disclosure vary among provinces and territories. You may also ask a health care professional what is needed in your particular province or territory. It may be worth seeing if it is possible to attend some of the health care team meetings or consultations with the patient. The patient may be more willing to accept this than to sign a consent form for the release of information.

A physician (and other health care professionals) will normally look to family members to supply information about the patient. At the doctor's discretion, your information may be passed on to the patient. Indeed, it is probably wise to assume this. You may wish to consider, therefore, the effects of telling your relative directly about any information that you have given to a member of the care team. Care-providers often find that this enhances their care-giving relationship with the patient.

What To Do In A Crisis

Most families reported that a crisis or psychotic episode - that is, a severe break with reality - occurred a few months to a year after they began to notice unusual behaviour. Some said, however, that the crisis occurred with little or no warning.

During a crisis episode, your relative will exhibit some or all of the following symptoms: hallucinations, delusions, thought disorder, and disturbances in behaviour and emotions. Families who have been through these psychotic episodes warn that no amount of preparation can fully protect you from the shock, panic, and sickening dread you will feel when your relative enters this stage of schizophrenia. Understand also that your relative may be as terrified as you are by what is happening: "voices" may be giving life-threatening commands; snakes may be crawling on the window; poisonous fumes may be filling the room. You must get medical help for your relative as quickly as possible, and this could mean hospitalization. If your relative has been receiving medical help, phone the doctor or psychiatrist immediately. Ask which hospital you should go to and for advice about what to do.

Guidelines that May Help You In Crisis

DO'S - Try to remain as calm as possible. Decrease other distractions; turn off the television, radio, etc. If other people are present, ask them to leave the room. Talk one at a time. Try saying, "let's sit down and talk," or "let's sit down and be quiet." Speak slowly and clearly in a normal voice. Make statements about the behaviour you are observing: "You are afraid/angry/confused. Please tell me what is making you afraid, etc." Avoid patronizing, authoritative statements such as "you are acting like a child," or "you'll do as I say, young lady." Repeat questions or statements when necessary, using the same words each time. Don't rephrase the question in the hope that this will make it clearer. Allow your relative to have personal "space" in the room. Don't stand over him or her or get too close. Understand that too much emotion on your part can upset your relative further.

DON'TS - Don't shout. If your relative appears not to be listening to you, it may be because other "voices" are louder. Don't criticize. Your relative cannot be reasoned with at this point. Don't challenge your relative into acting out. Avoid continuous eye contact. Don't block the doorway. Don't argue with other people about what to do.

It is far better, if possible, to have your relative go to the hospital voluntarily. If you do not think your relative will listen to you, see if a friend can talk the person into doing so. Some have found that presenting their relative with a choice seemed to work. "Will you go to the hospital with me, or would you prefer that John take you?" Such an approach may serve to reduce the person's feeling of helplessness. Offering choice, no matter how small, provides some sense of being in control of the horrible situation in which they find themselves.

Families warn that sometimes a psychotic episode will involve violence. In such situations, there will be no time to talk calmly to your relative, or to phone the doctor or psychiatrist to ask for advice. Because your relative is in an altered state of reality, he or she may try to act out the hallucination - for example, shatter a window. Your relative may threaten to harm him or herself, to hurt you, or to damage property. One mother said that her son kept yelling that God was ordering him to kill her. In such situations, you must do whatever is necessary to protect yourself and others (including the ill person) from physical harm. It may be that the wisest course is to leave the premises. The alternative might be to secure your relative in a room while you phone or go for help. Such an action, however, would be advisable only under extreme circumstances. In such charged situations, probably your only choice is to phone the police. It may be unwise to drive your relative to the hospital by yourself: do so only if someone else can go with you.

Police Involvement

Families who have been through this agreed that they were hesitant to call the police. They felt that they were treating their relative as a criminal, and that they were giving up and abandoning the person, however, in some situations they had no other choice. Many families discovered that the statement, "I am calling the police," calmed their relative. It let the person know that his or her behaviour would not be tolerated. One father said that the sight of the police uniform helped to defuse the situation. But another father, disagreeing with this tactic, warned that because his daughter was paranoid, seeing a police officer in her home was like waving a red flag and infuriated her further. Remember to trust your instincts: you know your relative better than anyone else and have a better chance of judging how he or she may respond to different tactics.

When you phone the police, explain that your relative is in urgent need of medical help, and that he or she has been diagnosed as having schizophrenia (if this is the case). Briefly describe what your relative is doing - making threats, damaging property - and state that you need police assistance to get your relative to a hospital. Make sure that the police know whether your relative is armed, and whether or not there are accessible weapons in the home.

When the police arrive, those families who have been through this experience warn that you must be prepared

for a variety of responses. Some police forces have specially trained officers who know how to handle psychiatric emergencies. Some police officers have little knowledge of, or experience in dealing with, this sort of crisis. Some officers may be extremely sympathetic, while others may be quite unhelpful. You might be asked by the police to lay a charge. You should think very carefully of the implications of doing so. Know too that your own attitude or emotional state may be a factor in conditioning police reaction. In your record, document everything that happens when you phone the police: note how long it took for someone to respond to your call; note the officers' names and badge numbers; note briefly how they treated you and how they handled the situation.

Once in your home, the police will try to assess the situation and decide what should be done. While the police are present, you may have the chance to phone your relative's doctor or psychiatrist to ask for advice. Inform the police if you have been advised by the doctor to take your relative to a particular hospital.

After the police have the information they need, they may take your relative to a hospital emergency department. It is the responsibility of the police to report all relevant information to the doctor. They are usually required by law to stay with your relative until an assessment is carried out. If you have not been able to go with the police to the hospital - although you should go if at all possible - ask the police to phone you back and let you know what has happened. We recommend that you speak directly to the doctor; the emergency head nurse should be able to help you get in touch. You will want to find out if your relative has been admitted to the hospital, and whether or not treatment is being given. Find out the name of the admitting physician. Record all of this information.

Hospital Admission and Mental Health Legislation

Admissions in all provinces and territories are governed by the mental health legislation in effect in each area. Although there are significant variations between the different Acts, all make a distinction between voluntary and involuntary admission (in Quebec called "*cure fermee*" or "closed treatment"). Voluntary admission is usually based upon a request from the prospective patient together with a recommendation from his or her physician. Involuntary admission is one that occurs **without** the patient's consent. Such a decision rests on an assessment of the seriousness of the patient's condition.

In many jurisdictions, although the language used may differ, involuntary admission is the result of a conclusion that the person is suffering from a mental disorder and is a danger to him or herself, or to others. Some jurisdictions allow involuntary admission without evidence of dangerousness, if it is established that substantial deterioration in the person's health will occur if the person is not treated immediately. In some, the application for such an admission must be supported by examinations by two physicians. In others, the certificate of admission must be signed by a physician other than the one signing the application.

An explanation of the legal situation may be provided to you by a health care professional. If not, ask for one. Other possible sources of information are a local SSOC chapter or another family self-help group in your area. Useful brochures on mental health legislation may be available from your provincial or territorial health department, or you might consider obtaining a copy of the relevant legislation from the publications office of the province or territory.

In crisis situations, you might normally expect your ill relative to be admitted, if not voluntarily, then involuntarily. However, this may not be the case. Your relative may refuse to be admitted, and the medical examination may not result in an assessment that would support involuntary admission. If you are not able to be at the hospital, it is possible that your relative may be allowed to leave before you are notified. If your relative is not admitted, families who have been through the experience recommend strongly that you consider other possible courses of action, including, in some circumstances, leaving your relative on his or her own. Without

the alternative of returning home, the hospital may appear to be a safe haven to the ill individual.

Emergency Planning

Contributing families recommend strongly that you have an **emergency plan** ready for crisis episodes.

1. Have handy a list of phone numbers for: the police, the doctor, the psychiatrist, and an emergency centre for psychiatric admissions.
 2. Ask your relative's doctor or psychiatrist ahead of time which hospital to go to in case of an emergency.
 3. Know which family members and friends your relative may trust more than others in an emergency.
 4. Find out whom you can phone for support at any time of the day or night.
 5. If applicable, decide who will take care of other children.
 6. Consider explaining the situation ahead of time to your local police department to get advice about what to do.
 7. Know that the crisis situation may be less frightening to your relative if the emergency procedure has been explained and is anticipated.
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Hospitalization

Your relative's doctor or psychiatrist may have recommended hospitalization for diagnosis early on in the assessment. If not, hospitalization will usually occur during or after a psychotic episode.

The availability of a bed may determine where your relative is hospitalized. In communities where there is a psychiatric hospital, your relative could be admitted there or sent to the psychiatric ward of a general hospital. The former usually offers the patient a wider range of supportive therapy and counselling programs. However, should he or she have another medical condition in addition to schizophrenia, a general hospital could be preferable. In addition, the patient might find a smaller setting easier to cope with, at least in the early stages of treatment. Normally, transfers can be arranged to meet any special need of the patient.

Families and health care professionals emphasized the importance of hospitalization for accurate diagnosis. The hospital setting allows intensive observation and testing, which will help to build up a picture of your relative's condition. When admitted to a hospital, a patient's valuables and money will normally be locked up for safekeeping until discharge. Some families suggest that it is worth making a list of these and any items of clothing and other personal effects that your relative takes to the hospital. This can be helpful to hospital staff and is a safeguard against subsequent misunderstandings.

When admitted, your relative will receive a thorough psychiatric examination and should also be given a complete physical check-up. The psychiatric examination is an interview process used to understand how your relative is thinking and feeling at that moment and to obtain a clearer idea of his or her situation.

If you are at the hospital with your relative, you will probably be interviewed. If not, you may request an interview. The purpose of the testing and interviewing is to achieve a diagnosis (if one has not already been made by your relative's doctor or psychiatrist), to determine appropriate treatment, and to decide if your relative should be treated further as an in-patient, or if out-patient psychiatric appointments are recommended.

The assessment also allows a decision to be made as to whether the patient is mentally competent, should this be an issue. If the person is deemed to be mentally incompetent, there is a need for a substitute decision-maker. Provisions regarding this vary across Canada. Mental health legislation in some jurisdictions, such as Ontario,

has established a precise list of substitute decision-makers, ranked in the order in which they must be approached. In others, the rules are more general.

Ontario legislation also formally defines the test to be used by physicians to determine mental competency. The patient is mentally competent if he or she "has the ability to understand the nature of the illness for which treatment is proposed and the treatment recommended and is able to appreciate the consequences of giving or withholding consent." (Section 1. Ontario Mental Health Act, as amended, Pocket Criminal Code 1990, incorporating 1985 Revised Statutes of Canada and Subsequent Amendments, eds, Gary P. Rodriguez, Jean Oyellet. Incourt, Ontario: Carswell Company Limited, 1989.)

In cases where the patient has an estate, the question of mental competence may also arise. All jurisdictions have legislation that provides for the appointment of a trustee to make financial decisions for someone deemed to be mentally incompetent.

At the present time, the concept of "mental competence" is receiving considerable attention, and there may well be significant changes in mental health legislation in this area.

Relations with Hospital Staff

When asked what advice they would give to people at this point, contributing families noted that the main goal during this period of hospitalization should be to establish effective communications with hospital staff. Most relatives arrive at the hospital in a state of panic and shock, and want to know what is going on and what will happen next. They do not understand the complicated hospital procedures. "Experienced" families state that it is important now that you **remember your objective** - to get help for your relative. They suggested a number of things you can do that will assist you in your efforts.

1. Keep a record of everything while you still remember. List the questions you ask, the responses you're given, the names and phone numbers of the staff attending your relative. Keep a record of the treatment given, including dates and times. Keep copies of anything you mail, and all notices and letters you receive from the hospital.
2. Recognize that hospital staff (and other health care professionals) are there to help your relative. Make it clear that you understand that this is their prime responsibility and that you are ready to do all you can to help them. See if you can establish a "partnership" relationship between the psychiatrist, your relative and yourself.
3. Find out the names of the assigned psychiatrist, psychiatric nurse, and social worker. These are the people responsible for the treatment of your relative. You should be able to phone and speak with them if you have any questions and concerns. Remember that the amount of information you are given may be limited by the constraints of confidentiality.
4. Be polite and assertive when talking to hospital staff. Use sentences such as, "Please help me," "Please tell me where I can get information about...."
5. Ask for a meeting with the assigned psychiatrist and social worker. Try to get to know them at the first meeting. At later meetings come prepared with a list of questions written down. Let them know of your willingness to provide them with information about the patient.
6. Keep all conversations to the point. Ask for specific information. Some sample questions: What are the specific symptoms you are most concerned about? What do these indicate? How do you monitor them? What is the medication being given? How often? How much? Have there been side effects? What is being done about them?
7. Ask for clarification of all answers. Do not settle for jargon and vague information.
8. If the psychiatrist is too busy to talk to you, write out what you want to ask or say (in point form), and

deliver the letter to his or her office.

9. If you phone to speak to someone who is not available, leave your name, your relative's name, and your number. Then stay home and keep your phone line as clear as you can so that the staff member can return your call.
10. Consider having a friend or relative who is less directly involved come with you to meetings at the hospital. This person can be a calm and reasonable presence should you be overwhelmed by emotion and frustration.
11. Write letters of appreciation or criticism, and send them to the head of the hospital and the ward of the unit. Consider sending copies to the College of Physicians, Nursing, etc., if you think it appropriate. Be specific and brief in your letters.
12. Be a member of SSOC. When all else fails, help from the chapter or group may possibly allow you to cut through hospital "red tape" and get answers.

Families who have had relatives hospitalized warn that you should avoid some actions. They will not be helpful to your relative.

1. Do not be rude. Do not let your fears and anxieties turn into anger. Do not approach the situation with a "chip on your shoulder". The illness is the enemy, not the staff.
2. Do not bother the staff with unnecessary special requests and excessive demands.
3. Do not make long, detail-filled telephone calls to staff.
4. Do not allow yourself to be intimidated. Do not try to intimidate the staff.
5. Do not come late to appointments. If your appointments are cancelled repeatedly, put your concerns in a letter.

Families make the following suggestions about what you can do to help your relative in the hospital.

1. Familiarize yourself with the routines of the ward.
2. Discuss what is happening with your relative. Tell him or her about anything you have done to try to get better help.
3. Respect your relative's wishes. If, for example, he or she seems upset by long family visits, make your visits brief and share them with other relatives and friends.
4. Do not undercut staff or criticize specific staff members.
5. Do not criticize training or activity programs.
6. Consider your relative's complaints realistically. Act on those complaints that appear to be real rather than imagined.
7. Do all you can to make it clear to your relative that this period of hospitalization is important.
8. If you should feel that your relative is being badly treated or is not receiving adequate care, and if polite approaches to the immediate caregivers fail to resolve your concerns, you may wish to raise the matter with the head of patient care.

Treatment

Treatment for schizophrenia involves both medication and supportive counselling. Depending upon the severity of the symptoms, someone with schizophrenia may be treated as an out-patient or, sometimes, as an in-patient at a hospital. Families stress that it is important for both you and your relative to understand what is involved in

treatment and to take an active role in planning the most suitable course.

Medication

In the 1950s a new group of drugs was developed. These **neuroleptics** or **anti-psychotic drugs** are highly effective in dealing with the positive symptoms of schizophrenia. Some of these symptoms can normally be brought under control in a matter of days; others in weeks. Usually, a period of months is required to achieve a fully stabilized condition. For people with recurrent schizophrenia, neuroleptics are used to try to prevent a relapse into acute symptoms. Unfortunately, the negative symptoms of more chronic schizophrenia, such as depression and apathy, do not respond as well to medications.

Neuroleptics block receptors for the brain chemical, dopamine, on dopamine-transmitting nerve cells.

Dopamine is one of the brain's neurotransmitters and carries messages from certain specific nerve cells to other specific cells in the brain. Evidence is accumulating that some people with schizophrenia may either have too many dopamine receptors, or else have receptors that are overly sensitive to dopamine. Because of this, the brain of a person who has schizophrenia may receive too many messages along these pathways. These extra messages may compete in some way with signals transmitted through other chemical pathways, and may result in the production of psychotic symptoms.

In North America, there are about 30 varieties of neuroleptics in common use. Each drug has several names: the generic or official name, and the brand names given to the drug by each of the pharmaceutical companies that manufacture it (see Appendix I).

Although all currently used neuroleptics interfere with dopamine, each drug differs in how it affects other brain chemicals. For this reason, individuals respond somewhat differently to the different neuroleptics. In addition, because of differences in sensitivity, individuals also respond differently to a given dosage. Some of the physical differences responsible for differing responses are sex, weight, metabolic rate, physical health, and severity of symptoms. Finding the right neuroleptic and the right dosage is usually a matter of trial and error. For some, it may take months, even years, before the right combination is found. It is important to remember that drug dosages need to be regularly monitored.

For almost everyone, the dosage of medication is lowered as time goes on. The **maintenance dosage** is the lowest dosage at which the patient's condition is stable. An increase from this level may be prescribed by the physician if a relapse occurs, if signs indicate that a relapse may be imminent, or if the patient is undergoing stress.

Neuroleptics are given in either tablet or liquid form, or as an intramuscular injection. Most patients are treated initially with oral medications, which provide a steady, low level of the medication in the system. People who are experiencing an acute attack of schizophrenia are often given a short-acting injection, which acts more rapidly than oral medications, to decrease the most frightening symptoms. As an out-patient, an individual may be treated with tablets or with a long-acting injection.

Other than a lack of insight about the illness, the most common reason for an individual to refuse to take medication is the complaint of **side effects**. Side effects cause different levels of discomfort and vary from person to person. The most common side effects are **acute dystonia** (a stiffening of muscles in the neck and jaw, which usually appears shortly after starting medication and is easily treated), drowsiness, faintness, lethargy, dry mouth, blurred vision, sensitivity to the sun, weight gain, and constipation. These problems are usually cleared up with a change of neuroleptic, a change in dosage, or the addition of another medication to control the side effects. **Tardive dyskinesia** is a side effect that may appear after a long period of medication. It consists of involuntary facial movements - spasms of the tongue and mouth. Sometimes it is accompanied by movements of limbs or other muscular systems. When the dosage of medication is reduced - there will be a

temporary worsening of the symptoms before there is an improvement. For some people, there is a risk that tardive dyskinesia may become permanent. This risk increases with age, but occasionally there are young patients who are disabled by tardive dyskinesia.

Families warn that some individuals are bothered more than others by side effects. They may feel embarrassed by involuntary movements, or frustrated by a lack of energy. These individuals may quite easily decide to stop their medication. In such a situation, families and health care professionals say that it may be preferable to lower the dosage of medication, even though some minor symptoms persist. This should be fully explained and discussed with your relative.

Families state that it is important that you understand as much as possible about side effects. This knowledge will prevent many misunderstandings - for example, you will not mistake lethargy for laziness, or become frightened by tremors and you will be able to provide valuable information to your relative's doctor. Families suggest that you think of yourself as the "nurse on the ward" and document all you can about how your relative is responding to the prescribed medication. For more information about side effects, you can speak to a pharmacist.

Supportive Therapy

In *Surviving Schizophrenia*, Torrey describes the role of psychotherapy. Supportive therapy "may provide a patient with friendship, encouragement, practical advice such as access to community resources or how to develop a more active social life, vocational counselling, suggestions for minimizing friction with family members, and, above all, hope that the person's life may be improved. Discussions focus on the here-and-now, not the past, and on problems of living encountered by the patient as he or she tries to meet the exigencies of life, despite a handicapping brain disease." (p. 259).

Torrey also distinguishes between supportive psychotherapy and "insight-oriented psychotherapy" -the uncovering and exploration of unconscious conflicts. He notes that "insight-oriented psychotherapy is of no value for schizophrenia" (p. 220), which does not mean that the person with schizophrenia, as any other person, cannot benefit from understanding himself or herself better.

Depending upon the severity of the symptoms, supportive therapy may begin with a healthcare professional helping the individual to recall the events and emotions that occurred before the acute episode, so that he or she may be able to watch for and recognize approaching signs of trouble.

In all situations, supportive therapy involves the teaching of such life skills as managing medication, learning to socialize, handling finances, and getting a job. Ideally, in-patient programs should be linked as much as possible with appropriate community-based programs, to provide a continuing pattern of care.

Other Forms of Treatment

Electro-Convulsive Therapy (ECT)

Over the years, a considerable amount of controversy has surrounded ECT. Since its introduction in 1938, this form of treatment has undergone many refinements. Today, the patient is put to sleep and given a muscular relaxant. A small amount of electric current is then applied to the patient's temples. This produces a seizure. (Andreasen, *The Broken Brain*, p. 264).

ECT has proven highly beneficial in the treatment of depression. It is also sometimes used with patients in depressive episodes of bipolar illness (manic depression). Although it does not appear to be especially helpful with schizophrenia, it is occasionally given to patients who present serious safety risks and do not respond to medication. In 1985, the report of the Electro-Convulsive Therapy Committee, an interdisciplinary committee

appointed under the Ministry of Health Act in Ontario, recommended that this form of treatment continue to be available for those who freely choose it, but that its use should be surrounded by special safeguards.

Nutritional Treatment

This form of treatment has arisen out of an early theory put forward by Drs. H. Osmond and A. Hoffer that a lack of Vitamin B could be the cause of schizophrenia. The theory they developed became known as the megavitamin theory, and treatment consisted of massive doses of niacin (Vitamin B3). Several attempts were made by other physicians to achieve the results that Osmond and Hoffer claimed (notably one by Dr. E. Heinz Lehmann at Montreal 's Douglas Hospital) but all failed. Nonetheless, this school of thought continues to persist and has evolved into a school of orthomolecular psychiatry. (Torrey, *Surviving Schizophrenia*, revised edition, pp. 148-149).

This form of treatment, where it is practised, usually includes the use of neuroleptic medication together with other vitamins and niacin. There are other nutritional theories about the cause of schizophrenia, but these have not been scientifically proven. However, adequate nutrition, fitness programs, relaxation programs, massage, art and dance therapy and skill acquisition can all contribute to general well-being and indirectly, to improvement.

Planning For Discharge

When your relative is in the hospital, make sure the staff are aware that you would welcome assistance in planning for what should happen when your relative is released from the hospital. Families suggest that a letter to the appropriate hospital personnel is better than telephoning (letters don't go away). An example is:

Thank you for the care you are giving my son, _____. (If you can, give a specific example of help that has been particularly important to him.) Now that his discharge is approaching, I'd like to meet with you to learn about and discuss the options available for him

Families also suggest that you have a note put on your relative's file to remind staff to alert you about approaching discharge. Hospitals are busy places, and staff can forget to keep you informed. Some families have said that they arrived at the hospital and were told, "Oh, by the way, your son is being discharged tomorrow."

In most provinces or territories, a social worker will have been assigned to your relative during the hospital stay. This person can advise you and your relative about the social services and community programs available upon discharge. He or she can also help to decide whether it is best for your relative to return home, or if alternative housing should be sought. Families also suggest it could be important to involve family members, including brothers or sisters

The Housing Issue

One of the most important issues facing families at the time of discharge is the question of **housing**. If your relative does not return home with you (and unless your relative is under-age, no-one has the right to insist on this), there are a number of options, such as a group home, a boarding house, an apartment, a room, or shared accommodations. Group homes may vary considerably in the degree of support they offer. Supervision may range from 24 hours a day to one person dropping in periodically. There may or may not be some in-house counselling or life skills training. Rules and policy may vary considerably. It is obviously necessary to know precisely what is offered before you and your relative can make a decision whether a particular group home is "right" for him or her. Boarding houses and shared accommodation typically offer little supervision, and housing in the form of an apartment or flat would require an ability on the part of your relative to function well

in an independent situation. Initially, a considerable degree of family support would be advisable.

Because there are usually waiting lists for supportive housing such as group homes, you should place your relative's name on a list as soon as possible, once a decision satisfactory to him or her has been reached.

The decision about housing can often be emotional. Contributing families have offered several guidelines to help make a choice.

In general, **at-home arrangements seem to work best** under the following circumstances:

- your relative functions at a fairly high level, has friendships, and is involved in activities outside the house;
- if there are young children, their lives are not negatively affected;
- the interaction among family members is relaxed, and
- your relative intends to take advantage of available support services.

In general, **at-home arrangements are not appropriate** in the following circumstances:

- the main support person is single, ill, or elderly;
- the person with schizophrenia is so seriously ill that there is little or no chance to lead a normal family life;
- children become frightened and resentful, and feel as if they were living in a hospital;
- marital relationships deteriorate;
- most family events and concerns revolve around the person with schizophrenia, and
- no support services are used, or services are not available. (Walsh, *Schizophrenia*, pp. 109-110).

If you and your relative decide that he or she will live at home, the family as a group should have interviews with the therapist to clarify treatment issues. You should keep a record of how the situation works and how other family members are affected. This will give you valuable back-up material should you and your relative decide that a different housing environment is needed.

Families often feel very guilty if they have made the decision **not** to have their relative live at home; this appears to be especially true for women. If this is your experience, consider what one woman had to say: "A break should be made at some point, and often it is easier for your relative to adjust to the transition to a group home, boarding home, or whatever, while you are still available to give support and to encourage the use of community resources. Otherwise, your relative may have to make this adjustment without your help." (For more information on housing, please see *Returning Home: The Goal of Independent Living*, below).

Out-patient Programs

At discharge time, many hospitals will release their patients to a **day program** (where available). Such programs may include psychotherapy sessions, skills training, family education, physical activities and occupational therapy. In choosing any program, the wishes and preferences of the patient are vital to successful participation. The family's role should be one of support rather than direction. Such programs give the ill individual a routine to follow, and the doctor a chance to monitor progress. Help should also be available from the hospital with respect to government welfare and disability insurance programs.

Families warn that follow-up programs are very inconsistent across the country and non-existent in some regions. You should be able to obtain a list of support services, rehabilitation programs and self-help groups from the hospital, or by contacting your nearest chapter of SSOC or the Canadian Mental Health Association.

Returning Home: The Goal Of Independent Living

Family members have a number of concerns about what will happen when a relative with schizophrenia returns home after discharge from the hospital. They need to know how to behave toward their relative, what to say, or what expectations are realistic. Families who contributed to this handbook recommend that you should aim at helping your relative to become as independent as possible, consistent with the extent of the disability. Your relative's ability to do so will depend a great deal upon what he or she was like before becoming ill. The age of onset of the illness may also be a factor in how your relative copes now. Normally, the more skills and social development acquired before the illness, the greater the person's ability to function.

The process of helping your relative move toward greater independence really starts upon discharge from the hospital. Recognize that it will involve much trial and error. Families who have been through this experience urge you to keep the process in perspective in schizophrenia as with any other major illness - heart disease, cancer, diabetes - where the ill individual and the family must learn to cope with new and demanding circumstances. For the discharged person, diet, exercise, work and social obligations will represent a considerable challenge. Taking medication regularly and attending therapy sessions may need to become part of the person's lifestyle for the first time. Other family members will need to learn the most effective ways of speaking to and behaving toward your relatives.

One of the first things you should do before your relative comes home is to think about safety precautions. Although you may be hopeful of a permanent or long-term remission, this is not the experience of the majority of patients. If your relative is disoriented, depressed, or begins to talk of suicide, you need to be aware of the potential dangers of matches, drugs, poisons, sharp objects and so on. Many patients are heavy smokers. You should also decide ahead of time what sort of "house" rules you will need with regard to smoking. If a relative has shown signs of aggression or violence, it may be wise to consider putting locks on some doors. You may want to leave your car locked with the keys in a safe place. Explain the risks involved of driving when tired or sleepy from medication.

At an early stage of your relative's return home, it is advisable to discuss frankly the risks of drugs and alcohol and the question of sex. The approach you take should be consistent with the degree of your relative's maturity. You may wish to consult your relative's therapist about the best way to do this.

People with schizophrenia may be highly vulnerable to the temptations of the street. They need to be made fully aware that the use of drugs or alcohol can impair the effectiveness of their neuroleptic medication. Taken in excess, they may create difficult treatment problems for the attending physician. Heavy consumption of street drugs or alcohol may create symptoms of psychosis difficult to distinguish from those of a psychotic episode caused by schizophrenia. Street drugs taken by injection add an extra danger due to the possibility of infection by the virus that causes AIDS (Acquired Immunodeficiency Syndrome).

Sexual activity may also develop into a problem area for your relative. Although the medication tends to lower the sex drive, this can usually be dealt with by reducing dosages. The vulnerability of young people, because of loneliness, their need for social acceptance, their willingness to trust strangers too easily, and pressure from peers, makes them easy targets for sexual victimization. They are often not aware of the risks they are running. This is doubly so for the young person with schizophrenia. Starved for friendship, they may be driven by desperation into relationships and situations in which they are exposed to infection by AIDS or other sexually transmitted diseases. For women, there is the added risk of an unwanted pregnancy.

Patients of both sexes should be instructed in the use of condoms and birth control methods should they decide to participate in sexual intercourse. Condoms can be obtained without prescription. For women who are on the

pill and who think this is enough protection, the risks of such possible infection as gonorrhea or AIDS should be clearly explained.

If possible, families suggest that an ill member should be encouraged to bring friends home. If your daughter is beginning to become friendly with a man, you might tell her that you would like to meet him and would she ask him to come for a meal. You could also advise her to meet her new friend only in public places until she gets to know him well. Explain the problems that could arise from going to a man's house alone.

Persons with schizophrenia are often more at ease with children than with adults. Although this does not indicate a sexual interest, it can, especially with men and children, lead to potential concerns. It is behaviour that should be carefully monitored. Young girls with schizophrenia are vulnerable to sexual advances from adults. For men in the younger age groups, homosexual approaches may occur and may be experienced as frightening. In large cities, such approaches are not uncommon, and reassurance is needed that nothing in your relative's behaviour or appearance has triggered the approach.

Negligence in dress may be a problem. Open trousers may look like exposure, but it is not necessarily intended. It may simply be the result of unconscious carelessness. Some persons with schizophrenia may masturbate in public (see *Embarrassing Behaviour*, p. 39).

It is important to discuss sexual matters with your relative in a way that takes account of today's standards and the concerns of the younger generation. Although sexual morality may loom large for some families, safety issues need to be a first priority. Those with schizophrenia need protection from violence, assault, unwanted pregnancy, unwanted attention, unlawful behaviour, transmission of disease, undue naivete and heartbreak.

Suggestions for Coping

The following **suggestions** may help you cope during this early stage.

1. Speak with a slow-paced and low-toned voice. Use short, simple sentences to avoid confusion. If necessary, repeat statements and questions using the same words.
2. Explain clearly what you are doing, and why you are doing it. For example, "I am putting your clean clothes in your closet. You can choose which clothes you want to wear today."
3. Establish a structured and regular daily routine. Be predictable. Be consistent. Do not say you will do something and then change your mind.
4. Offer praise continually. If your relative combs his or her hair after three days of not doing so, comment on how attractive he or she looks.
5. Avoid over-stimulation. Reduce stress and tension. For example, eating meals with the family may be too overwhelming at first.
6. Persuade, but never force, your relative to take his or her medication and to keep all medical appointments.

With time, your relative may show signs of being able to handle more responsibility. Although you should always keep in mind the above ideas for reducing stress, families have compiled **other suggestions for the time after the initial period of adjustment**.

1. Discuss with your relative how he or she feels about doing more things.
2. Begin with mastery of self-care tasks - personal hygiene, getting dressed, eating scheduled meals.
3. Assign household responsibilities that are within your relative's abilities. Watch to see if your relative prefers to work alone or with others. For example, he or she may like to wash dishes, but may not be able to handle the "help" of someone else drying.

4. Encourage, but never push, your relative to be part of social gatherings if appropriate. One or two relatives or friends over for dinner may be manageable, whereas an all-day gathering of the clan - for example, a wedding - may cause frustration.
5. Discuss plans with your relative for an outing once a week. A drive and a walk in the country may be fun, whereas a trip to the city may be too noisy and tension filled. If your relative enjoys coffee and doughnuts, plan a break around going to the donut shop, rather than a restaurant where there may be a more formal atmosphere.
6. Do not be too inquisitive. Do not always ask your relative, "What are you thinking about? Why are you doing that?" Talk simply about outside events: "Did you hear about the new movie starring...."
7. Understand that although it may be very difficult for your relative to have a conversation with you, he or she may be able to enjoy your company in other ways. Consider watching television, listening to music, or playing cards. Talk about childhood events. Your relative may appreciate being read to.
8. Avoid constant, petty criticism. Identify the major behaviours and learn to deal with them in an honest, direct manner. For example, in many families, the lack of personal hygiene is a source of great irritation. But saying things like, "Why can't you wash?" or "You smell awful," does not seem to have much effect in solving the problem. It is better to present the problem as your own. "I do not like the way you smell. I have a problem with the fact that you do not shower regularly. How can we work out an agreement that you will shower daily?"
9. Be forgetful. Say something like, "I forgot the milk. Can you get it please'?"
10. Encourage your relative to take responsibility. For example, leave instructions about starting dinner in case you are late getting home that night. And then be late.
11. Teach your relative how to deal with stress in a socially acceptable manner. For example, if he or she is in a public place and begins to feel panicky, he or she can go to a washroom until the feeling has passed.
12. Remember that family members are often the only friends your relative has. So try to be a friend; talk as a friend would. "I'd really like to see this movie. Would you come with me tonight?"
13. If you are a member of a church, encourage someone from the congregation to befriend your relative. (Look for someone your relative's age.)
14. Always try to put yourself in your relative's place. Respect his or her feelings. Saying "Don't be silly. There's nothing to be afraid of," will get you nowhere. Allow your relative to feel frightened by saying something like, "It's all right if you feel afraid. Just sit here by me for awhile."
15. Respect your relative's concerns about the illness. Often, those who have schizophrenia ask their families not to "go public" - that is, not to become a public speaker or to give interviews on behalf of their support group. Although some families feel that they have a lot to offer in terms of helping others, they have decided for now to abide by their relatives' wishes. Others, although fully sympathetic with their relative, have decided otherwise.

With time, your relative will begin to feel more confident and secure about the ability to do things. Some health care professionals have noted that it is around this period that new problems can emerge, particularly if the family isn't prepared to grow with their relative. In other words, the family may have developed a routine of treating the relative like a sick person or like a child, and it is the family that begins to fall behind in the recovery process. Your relative may begin to have reasonable expectations about what he or she can do, things like socializing, returning to school or becoming employed. This can cause friction in families if they do not constantly monitor the progress of the person's schizophrenia and re-evaluate goals. If a social work service is available, do all that you can to ensure that your relative is visited by a social worker. Work with this person, your doctor and your support group, so that you can help your relative make informed and realistic choices about the future.

In many cases, the most important goal for a person with schizophrenia, particularly a son or a daughter, is to become sufficiently independent to move out of the family home, although the importance of this goal may vary because of ethnic backgrounds and family traditions. Those families who believe that it is a critical issue give four reasons for their point of view. First, the person with schizophrenia may be able to fulfill his or her potential better by leaving home. Second, as the supportive member or members age, become ill, or die, the relative may be left alone with few survival skills. Third, living with someone with schizophrenia can be very demanding, and other family members may have put their own lives "on hold" to support their relative. Fourth, both you and your relative may have too much "emotional baggage," such as childhood dreams and expectations, transferred blame and resented authority, for the person to be anything but tense and frustrated living at home.

If you and your son or daughter have agreed that moving away is desirable, this may be done best around the age that he or she normally would have left, that is, the early to mid-20s. Too many parents avoid the issue until they have to say, "I can't stand this anymore. You have to leave." The result is guilt and resentment at the changes the illness has brought upon the family.

The process of becoming independent is gradual. As well as the ideas listed above, families suggest that at an appropriate time, you begin to say something like, "If you decide to live on your own..." as often as possible. Gradually, change this to, "When you decide to live on your own...." For example: "If you decide to live on your own, you'll need to know how to do your own laundry." And then, "When you decide to live on your own, you'll be glad you learned how to use the laundromat."

Families suggest that at some point you and your relative make a commitment about when the move will occur. Work together (with the social worker, if there is one) to set a date that will give you both plenty of time to seek and approve accommodation. For example, you may come to an agreement that in six months, on May 1, John will be ready to live on his own, in whatever form of housing he and you have decided will be best.

Once the move has been completed, there may be some resentment on the part of your relative. It is very important to help him or her not to feel abandoned by the family. You will have to work hard over the first few weeks to reinforce the idea of the move as a positive step.

- Be a friend. Call your relative and make dates to go places and do things.
- Encourage self-esteem by offering praise and support.
- Respect your relative's wishes and concerns as much as possible.

As well as emotional support, you may have to be involved in such things as housework, shopping, cooking and management of finances. The amount of daily assistance your relative needs will, of course, depend on the condition of his or her illness. Families stress the importance of working with your relative as you do these tasks.

Allowing for your family's background and traditions, the relationship should become less intense over time. At first your relative may wish to come back every weekend. Contributing families agree that this is fine for the first few weeks or months. Then, however, you should begin to pick the occasional weekend when he or she may not return home. You should have a valid reason, such as "We'll be away that weekend." Gradually decrease visits to one or two weekends a month. You may also find that at first, your relative will phone home constantly, often three or four times a day. If this persists, the use of an answering machine may be advisable. You can then return calls as you deem appropriate. As time passes, your relative should become more confident of his or her capabilities and the number of phone calls will settle into a normal pattern.

Social And Vocational Rehabilitation

Opportunities to participate in rehabilitation programs vary a great deal across Canada. Ideally, in-patient and out-patient treatment should be linked together in one continuous process. In some situations, a caseworker is assigned who has the prime responsibility of following the patient's progress in the community and providing advice and assistance when needed.

Most provinces and territories now have their mental health services under review with the aim of achieving more effective treatment and greater control over rising costs. The underlying premise in such approaches is that many services can be provided more efficiently and effectively in the community than in the hospital.

Hopefully, prior to discharge from the hospital, your relative will already have taken part in a number of programs designed to ease the return to life in the community. These may have included social and vocational counselling and, dependent on individual needs, plans for some academic skills training or for social-recreational activity.

Patients returning to the community should be assessed to determine what stage they are at with respect to independent living and what supports they may need.

If this is done by a health care professional, families should seek to provide some input. Should professional help not be available, however, families should help their relative make this kind of assessment. Many elements may be involved, such as: what skills did the person have before hospitalization? Have these been strengthened by in-patient programs? Has he or she had previous employment experience? What opportunities are available? Are there sheltered workshop programs that would offer a useful intermediate step? Should he or she consider a volunteer job as a start? If the person is receiving welfare benefits, how will these be affected?

The most basic question is whether your relative is really ready for a job, even the simplest kind. Much will depend on his or her level of social skills and confidence. Parents should not push. Let the initiative come from the person, but be there to help and provide encouragement.

An excellent brochure, *Vocational Rehabilitation*, put out by the Clarke Institute of Psychiatry, looks at this issue and others for patients involved in looking for work. Authors Hana Scholz and Terry Krupa have written it specifically for "people recovering from psychiatric illness." Employment and Immigration Canada offers training programs and other employment-related programs that may be helpful to your relative. Your provincial or territorial government also provides vocational rehabilitation services.

Some communities have non-profit organizations modelled on the Fountain House Project in New York. This type of operation is called a "club-house program." It has been designed specifically for people with psychiatric disorders who may join "the club" for a modest fee. The club-house is the focus of services provided, such as meals at reasonable prices, social and recreational activities, and some sheltered employment. Most such organizations develop good working relations with local employers to arrange jobs for those able to function at this level. They may also provide some housing accommodation at different levels of support. Many families have found this approach excellent for a relative who is well enough to be able to participate.

Those who have gone through their relative's move out of the family home know that you will have many worries at this time. Keep in mind that a family support group can supply you with all sorts of ideas and advice about handling the practical concerns of day-to-day living that you and your relative will face.

What Do I Do About ...?

Many families said that when their relative was discharged from the hospital, they hoped the major problems were all behind them and that their relative was well on the road to recovery. They believed that with proper medication and therapy, their relative would just keep getting better and better until "cured." It came as a surprise to many that there were now new problems to face. Families who have struggled through these problem areas believe that it is best to be prepared.

Refusal to Take Medication

This is one of the most frustrating problems. It may be hard to understand why someone with schizophrenia would refuse to take medication when the necessity of doing so is so obvious to everyone else. Families have found that there are **five main reasons why someone might refuse medication**.

1. Your relative may lack insight about the illness. Not believing that he or she is ill, he or she sees no reason to take medication. Or, some think that it is the medication that causes the illness. If the illness involves paranoia, your relative may view the medication as part of a plot to prevent him or her from functioning.
2. Your relative may be suffering from unpleasant side effects as a result of the medication and believe that it causes more problems than it solves.
3. Your relative may be on a complicated medication scheme that involves taking several pills a day. He or she may find the regimen too confusing, and may resent the constant reminders of illness.
4. Your relative may feel so well that he or she either forgets to take the medication, or thinks that it is not necessary any more.
5. Your relative may welcome the return of certain symptoms such as voices that say nice things and make him or her feel special.

People with schizophrenia **need to take prescribed medication**, and the following is a list of ideas and guidelines to help you with this difficult problem

1. Know that the initial medication dose must be continuously monitored. Therefore, you should always listen to your relative's complaints about side effects. Do your best to empathize with any distress about medications.
2. Know that "bad" symptoms (usually the positive, see pp. 8-9) will not reappear immediately upon discontinuation of medication. Anti-psychotic drugs stay in the system for six weeks to three months. This "grace" period gives you some time to deal with the problem. After three months, however, getting back to a maintenance dosage may mean "starting over" at a higher than maintenance level.
3. Explain to your relative that he or she may end up back in the hospital if medication is not taken (this should not be a threat). Some will not accept warnings, and still others may not mind returning to the hospital.
4. If other people in your family are on medication, turn pill taking into a ritual. Everyone takes his or her medication at the same time (even if it is a vitamin pill).
5. It is easier to take one pill a day than six. Talk to the doctor about the form in which your relative is receiving medication.
6. For people who keep forgetting to take oral medication, the use of a weekly pill box can be an effective tool.
7. Never sneak pills into food. If paranoia exists, this will increase it. Trust will never be built up.

8. More people go off oral medication than injectable medication. With injectable, you are sure the person is getting it. He or she can't spit it out, hide it under the tongue, etc. Discuss the pros and cons of switching medications with the doctor. (Health care professionals note that there is a "down" side to injections: possible feelings of humiliation, loss of control, and the potential for build-up of medication over time.)
9. Injectable medication is given once a week or once every few weeks, depending on the type of neuroleptic. Consider arranging a "treat" built around going for the medication - seeing a movie, going for lunch, etc. Let your relative know that you are proud of the way in which he or she is handling the need for medication.
10. Do your best to be calm and reasonable about getting your relative to take medication. If you press too hard, you may make it more difficult for your relative to move to greater independence. A period of learning through experience may be necessary.

Signs of Relapse

With schizophrenia, relapse refers to a return of acute symptoms. As Jeffries, Plummer, Seeman and Thornton state, "Schizophrenia, for the most part, is a 'relapsing' condition, and so it makes sense to expect a return of symptoms and not to be caught off guard." (*Living and Working with Schizophrenia*, p. 72).

Families have noted that the behaviours that indicate a relapse are usually the same as those that occurred prior to the first episode. Some of the more common behaviours are - sleeplessness, increased social withdrawal, deterioration of personal hygiene, thought and speech disorder and signs of visual and auditory hallucinations (e.g. listening excessively to loud music, usually with headphones, perhaps in an attempt to drown out the voices): Should you become aware of any of these behaviours, call your relative's doctor immediately.

Relapse can occur for a number of reasons, as well as for no apparent reason. Sometimes the ill person has stopped taking medication for a long enough period of time for acute symptoms to reappear. Sometimes the dosage of medication is not high enough to prevent the return of acute symptoms. Perhaps the person afflicted is not receiving enough support, either at home or from community services. Perhaps the individual has recently experienced some severe mental stress - the death of a loved one, the loss of a job, the move to a new place to live. Sometimes the individual is simply physically exhausted, or is using alcohol or street drugs in an effort to feel "better" briefly. Sometimes the cause may be something that can be dealt with quite easily. For example, medication can be increased, a brief hospital stay can be arranged, more support can be found.

Health care professionals warn that relapse can occur during a period called "self-cure." (This also occurs in other illnesses, such as diabetes and arthritis.) Usually, such an attempt occurs three to five years after a diagnosis of schizophrenia has been made. It is a time when the ill individual, tired of the disease, decides to take matters into his or her own hands. He or she may stop taking prescribed medication, may join a cult, may try to "exorcise" the illness out of the body, may do strenuous exercise to get rid of it, may consume vast quantities of vitamins or herbal medicines, and so on.

A relapse is very disappointing, but as one mother said, "People with schizophrenia are not much different from people suffering any other disease, especially if you are dealing with young people. They won't follow proper health care or eat nutritiously; they forget medication; they skip medical appointments; they may have a 'who are you to tell me' attitude."

Many families have found that they can come to an agreement with their relative, when well, about what to do when facing the possibility of relapse. This is discussed with the individual and his or her doctor. For example, one family made it clear to their son, who had behaved extremely aggressively in the beginning, that if he ever threatened violence or damaged property again he would have to leave home. He could go to the hospital in a taxi, with the police, or with his parents, but he would not be permitted to remain at home any more. They told

him that because he was of age, they would even charge him with trespassing and call the police should he break his agreement.

Other families, dealing with someone with less aggressive tendencies, found that it was sufficient to tell the individual that he or she could continue to live at home as long as he or she agreed to get help, should relapse occur.

Once again, families stressed that they have found that knowing the course of the illness in their relative is most important in taking steps to avoid a relapse. Many of the people who have schizophrenia and who have come to terms with it have learned to watch for signs of relapse and to call their doctors. Some have even learned to phone the police when they feel themselves losing control. You may find it helpful to discuss the advantages of developing a "signs of relapse" list and a "strategies" list with your relative, as some do to help themselves get through the bad times.

Embarrassing Behaviour

Families suggest that embarrassing behaviour can be dealt with in two ways: clearly outline and reach an agreement with your relative about what behaviour will and will not be tolerated, and examine your own attitude about why you are allowing yourself to be embarrassed.

Families have found that coming to an agreement about behaviour is sometimes a lot easier than people think. One woman related the following story: "In monitoring my daughter's behaviour, I often tried to find just the 'right' way of dealing with it. I wanted to correct in a positive way so that her feelings wouldn't be hurt. As a result, sometimes I did nothing, because I couldn't figure out what to do. For example, one day my son told me that whenever he had friends over, his sister would join them and do embarrassing things. Could I please do something about it? I spent days trying to decide how to handle this situation wisely. Then my son told me he had handled it himself. He simply told his sister, 'When I have friends over, I want to be alone with them.' My son was direct and honest and no feelings were hurt."

Many families agree that the direct approach can sometimes work well. Saying something like "Stop that," or "Knock it off," or "That's inappropriate behaviour," changed the behaviour. This may have to be repeated. Families say that you have to realize that sometimes your relative is not aware of acting in an inappropriate manner, and therefore a simple statement from you will serve the purpose. For example: "Please don't smoke in here, Mrs. Jones suffers from asthma."

Families may find themselves "bargaining" for suitable behaviour, but they should weigh the risks carefully before doing so: "If you do this, or don't do that, then we'll go out for dinner, buy that new record, go for a drive," and so on. As always, your ability to achieve results will depend upon a realistic assessment and acceptance of the problem. Remember that some behaviours will take longer than others to correct. Much patience is needed.

Sometimes no amount of intervention works, and embarrassing behaviour will take place on the spur of the moment. This is when families stress that you need to examine your own attitude. Why are you allowing yourself to be embarrassed by someone you know is ill with a disease that interferes with brain functioning? The answer, of course, as with all embarrassing behaviour, is that we assume that everyone is looking at us, and thinking that there is something wrong with us, not with the person who is behaving inappropriately. This is true whether or not the person is a spouse who has had too much to drink at a party, a two-year-old throwing a tantrum, or a teenager with schizophrenia dancing naked on the lawn. The problem is that when we allow our self-esteem to suffer because of someone else's behaviour, we can no longer deal effectively with that behaviour. Mixed with this may be genuine concern that the person is losing the esteem of others - "There goes John's chance of making some friends."

Families who have worked through this problem of attitude feel that if necessary, they are now able to take a responsible role in assisting their relative - without taking blame for embarrassing behaviour that might occur. They have undergone a shift in outlook and realize that it is the "onlooker" who may have an attitude problem. Often, they now feel saddened, rather than embarrassed, as they watch their relative struggling to adapt to the world of "normal" behaviour. They suggest one keep in mind that if the family member who is suffering the most is **not** the person who is ill, something is wrong and you should seek professional help.

Here are some **suggestions for dealing with your relative's sudden or impulsive actions.**

1. Take immediate steps to stop or change the behaviour.
2. Be firm, sometimes angry, but never abusive with your relative.
3. Be polite to bystanders. Assume that they are understanding and tolerant.
4. If necessary, apologize and explain the situation to anyone involved in the incident.
5. If warranted, offer to pay for damages, clean up the mess, explain to whomever, and so on.
6. Keep your sense of humour.
7. Share the story with someone you know will see its "funny" side.

Disappearance

This can be a difficult problem for families. Frequently, persons with schizophrenia decide that somehow a new location will provide an answer to the problems that the illness has imposed on them -- or they may be directed by "voices" to leave. They simply take off. If their relative is a minor, the family should contact the Missing Persons Bureau of their local police department. Remember that if your relative is legally of age the police may have no authority to return your relative or inform you of his or her actions or whereabouts.

It may happen that your relative leaves the hospital before treatment has been completed. If he or she is an involuntary patient, the hospital is responsible for notifying the police to look for and return the patient to the hospital. In some jurisdictions, if the police have been unable to find a missing involuntary patient within a certain period, the hospital then has the right to discharge the person.

A voluntary patient of majority age has the right to discharge him or herself at any time. The attending physician (or physicians if two signatures are required) may decide to change the person's status from voluntary to involuntary, if the person is sufficiently ill to meet the requirements for doing so. The patient will not then be allowed voluntary discharge. This option is also open to the attending physician(s) if the person has simply walked away. The police can then be asked to look for the individual.

Often, relatives may simply have to wait until the patient surfaces. This may happen when the person has been picked up as a vagrant, has gone to a hostel, or has been taken to a hospital for help. Then, (unless the police have been involved) you may make arrangements for the person to return home or consider other options. For example, if the person is under treatment when located and this appears to be working well, consider leaving him or her until treatment has been completed.

What are the things one can do?

1. If your relative says anything about places he or she is interested in or would like to see or visit sometime, jot it down. It could be a useful clue as to where to look should your relative disappear.
2. If your relative decides to travel, try to think of some effective way of staying in touch. For example, one father arranged with his son that he would keep his son's money for him. Then, whenever the son let him know he needed some funds, he would send him some-not too much. He found this to be an effective way

of maintaining contact.

3. If you have lost touch with your relative for a period of time, it is wise not to wait too long before you begin checking. Although the police may have no basis for active involvement, it is worth speaking to Missing Persons and telling them your story. They may be able to help by doing some checking, or with some practical advice.
4. If you have some idea where your relative may have gone, get in touch with your local SSOC chapter or the national office in Toronto. They may be able to help you through a provincial association or chapter in the area where you think your relative may be. If travel to the United States is a possibility, contact the National Alliance for the Mentally Ill (NAMI) directly or through SSOC.
5. Check with local voluntary agencies such as the Salvation Army. Sometimes a missing relative will show up in one of their hostels. Also your church may be able to help, particularly if your relative took a keen interest in religion.
6. If you decide to use the services of a firm of private investigators, determine if the firm you select has strong connections with the police. (They may be able to get help from this source which you wouldn't.) Discuss with the firm a reasonable limit on its expenses, including the fee, to undertake a realistic search on your behalf.

Risk of Suicide

With schizophrenia the possibility of suicide is an ever-present fear. The illness involves depression, delusions and sometimes command hallucinations that may tell the person to attempt suicide. There is a tendency to act impulsively. Torrey noted that an estimated 10 percent of all patients with schizophrenia kill themselves (*Surviving Schizophrenia*, revised edition, p. 123). As in the general population, men are more likely to complete suicide, while women attempt it more often. Suicide, when it happens, occurs most commonly during the first five years of illness. After this, the risk drops considerably. Torrey suggests that "Those at highest risk have a remitting and lapsing course, good insight (i.e., they know they are sick), have a poor response to medication, are socially isolated, hopeless about the future, and have a gross discrepancy between their earlier achievements and their current level of function." (*Surviving Schizophrenia*, revised edition, p. 124).

Sometimes a suicide is methodically planned and deliberately committed. At other times, a suicide may be accidental - that is, the victim is acting out a hallucination or delusion when in a psychotic state. Families caution that in either of the above situations, there are some preventive measures you can take, although you can never guard completely against the possibility of suicide.

Here is a list of **behaviours that may indicate suicide is being contemplated**.

- Your relative talks about suicide: what it would be like to die, how to go about it, comments such as "When I'm gone...", and so on.
- Your relative is concerned about having a will and about the distribution of possessions. He or she begins giving away treasured possessions.
- Your relative expresses feelings of worthlessness: "I'm no good to anybody."
- Your relative shows signs of hopelessness about the future: "What's the use?"
- Your relative is showing signs of hearing voices or seeing visions that may be instructing him or her to do something dangerous.

All talk of suicide or self-harm must be taken seriously. It is not true that someone who talks about suicide rarely does it. If your relative begins to talk about suicide, or inflict wounds - no matter how superficial - upon him or herself, it is vital that you reach your relative's therapist immediately. If this isn't possible, take your

relative to the hospital where he or she was previously admitted, or to the nearest emergency department. In many communities, there is a suicide phone "hotline" available.

If suicide is attempted, and you are the one who discovers your relative:

1. Phone 911 immediately. (If this service is not available in your area, call the emergency number of the nearest hospital.)
2. If appropriate, and if you are familiar with it, perform CPR (cardiopulmonary resuscitation).
3. Phone someone to come and be with you, whether it is at the hospital as you wait for news, or at home to take care of you. Although it is perhaps not likely, be prepared for the possibility that the hospital may not admit your relative, even after a suicide attempt.
4. Get in contact with your local support group, if there is one, and let them know what has happened.
5. Do not try to handle the crisis alone.
6. Do not hesitate to contact other support groups that deal specifically with grief and bereavement

Often, when someone commits suicide, the family members, if they belong, stop coming to support group meetings. The relatives of suicide victims may believe that their presence is too depressing for other members of the group. Families in support groups urge these people to keep attending meetings. As one father stated, "When a relative develops schizophrenia, the support group becomes your family, because so often you lose family and friends. Now, when you've lost your relative, you need your new family more than ever."

Trouble with the Law

Unfortunately, a significant number of people with schizophrenia find themselves in trouble with the law. Offences may range from shoplifting, mischief, assault or ordering a meal at a restaurant and refusing to pay for it to much more serious charges such as aggravated assault, arson or murder.

Should your relative be charged, try to secure the services of a lawyer who is familiar with the problems of schizophrenia. You should be able to determine this by questioning the lawyer about his or her knowledge of schizophrenia and its impact on the individual. In the course of their law practices, most criminal lawyers have defended clients with psychiatric disabilities and therefore have some knowledge of schizophrenia. As well, most criminal lawyers do accept clients supported by legal aid.

Families often think that the legal defence for someone with schizophrenia charged with an indictable offence should be based on a plea of "not guilty by reason of insanity." This requires that the person be assessed under subsection 16 (2) of the Criminal Code as having "disease of the mind to the extent that renders the person incapable of appreciating the nature and quality of an act or omission or of knowing if an act or omission is wrong." This test is a legal one designed to determine the degree to which the individual is to blame. This is **not** an assessment of the degree to which the person may be mentally ill.

If the plea is upheld, the result will take the form of a Lieutenant Governor's Warrant under which the person will be held indefinitely in the forensic unit of a psychiatric centre or discharged "either absolutely or subject to such conditions as he (the Lieutenant Governor) prescribes" in accordance with the provisions of section 614 of the Criminal Code.

The Criminal Code provides for the establishment of an Advisory Review Board in each province. These Boards are required to make annual reviews of all those held under Lieutenant Governors' Warrants in their respective provinces.

A criminal lawyer will always counsel against such a plea in cases where the charge is minor, because a finding of "not guilty by reason of insanity" is a potential life sentence.

The defence lawyer and the lawyer for the prosecution may sometimes agree on a joint submission as to disposition of the case and explain the circumstances of the person on charge and the illness to the judge. The judge may then choose to give a suspended sentence, with probation, and require that the person receive treatment and take any prescribed medication.

A major concern with Lieutenant Governors' Warrants is the potential for a lifetime of confinement. Those held in custody may be released only by the Advisory Review Board, either absolutely or under such terms and conditions as the Board may establish. These provisions in the Criminal Code were designed to recognize the need to protect the public in situations where the past behaviour of the individual was extremely serious and future behaviour is unpredictable.

One father reported that the Lieutenant Governor's Warrant imposed on his son has at least had a positive effect in restraining his son's behaviour. The young man understands that if he does not conduct himself in a law-abiding manner, he runs the risk of being sent away again to the forensic unit of a psychiatric centre for an indefinite period. Make no mistake, however--it is still indefinite confinement. It should only be viewed as a last resort, where the individual's behaviors a serious and ongoing danger to others. It is by no means the answer to disruptive behaviour short of that level of seriousness.

Money Problems

Many people with schizophrenia have trouble in handling money matters. This can present families with some awkward situations. Some of these may be beyond an immediate or a ready solution.

Normally, where a patient is entitled, he or she will receive help at the hospital to complete arrangements for welfare benefits. In this situation, your relative will then receive a monthly income that is under his or her complete control. Most will need a good deal of help in learning how to budget properly to meet such basic items as rent or board, food and transportation. They need to know that their spending over and above regular monthly needs should not exceed what is left.

For many this is difficult, at least at the start. When a substantial sum is available (for example, on receipt of a welfare cheque), many tend to "blow" all or a large part on impulse spending, often foolishly, or to give their money away to friends -- even to strangers. Families find that they are then called upon to make up the amount needed to cover neglected basic living expenses. Behaviour of this sort, although not surprising for someone with few chances to enjoy life, is disconcerting for families and requires that they exercise a good deal of patience.

For the individual, managing money well is an important step toward the achievement of greater independence. In situations where families are providing money regularly to a relative with schizophrenia, Torrey suggests that one approach is "...to link autonomy in money management to other behaviour indicating independence ... the successful performance of chores is another way that schizophrenic patients can demonstrate that they are ready for greater financial responsibility." (*Surviving Schizophrenia*, revised edition, p. 291). This strategy provides an incentive to the person to learn how to deal better with money matters, and is also a way for families to avoid getting into the habit of only doling out money in small amounts, when this is no longer necessary.

Support For The Family

People involved with schizophrenia note that the family, most often the primary caregiver, is under a great deal of stress every day. One woman states: "Personal stress is something that often goes unacknowledged. The sick person becomes a priority, and we forget our own needs. The day-to-day tasks involved in caring for a dependent - sudden crises, worry, financial problems, searching for community services, coping with bureaucracy, becoming an advocate, squeezing out precious moments for our other family members - depletes and robs us of our energy. Eventually we end up with stress exhaustion, and this can lead to depression, anxiety, burnout, and psychosomatic illnesses." (Elenor Smith, editor, *Alberta Friends of Schizophrenics Newsletter*, Nov. 1988).

Families and health care professionals caution that the strain of having a relative with schizophrenia can begin in the very early days, when that person first behaves unusually. Normally, when we see someone who is visibly handicapped - for example, using a wheelchair or white cane - we are inclined to offer that person our support. With mental illness, however, often the only way one realizes that something is wrong is to actually see someone exhibit "weird" behaviour. It is natural to be disturbed by such behaviour, and we tend to withdraw from them. When "weird" behaviour occurs within a family, the reaction is not much different, and may even be hostile. In the early days, family members may be bewildered and resentful, and often blame and criticize the ill individual. Members may blame other members of the family as their fear and frustration grow.

Families drew up the following **list of negative responses that they found very common, both in the early days and in reaction to a diagnosis of schizophrenia:**

- denial of the illness entirely: "This can't happen in our family."
- denial of the severity of the illness: "She's just going through a phase."
- refusal to discuss one's fears
- withdrawal from usual social functions
- shame and guilt: "Where did we go wrong?"
- feelings of isolation: "Nobody knows what I'm going through."
- bitterness: "It isn't fair. Why us?"
- blame: "You should have stayed home with the kids."
- preoccupation with moving away: "Maybe if we left the city, lived in the country."
- excessive searching for possible explanations: "Maybe we punished her too much."
- inability to think or talk about anything but the illness
- extreme ambivalence toward the ill person
- marital dissension; eventual divorce
- sibling rivalry and refusal to talk to or be with the afflicted sibling
- increased drinking or dependence upon tranquilizers
- depression
- insomnia, weight loss, anxiety.

Families caution that one of the most important things to watch for is resentment in siblings. When you are spending all of your time and energy supporting and seeking help for your ill child, it is very easy to neglect other children. Families warn that you may also have to accept that a sibling may never have any feeling of affection for the ill relative. As one woman said, "My brother was several years older than me. I never had a relationship with him when he wasn't ill. When he first got sick, I was very young, and his behaviour scared me.

Then, as I got older, the things he did embarrassed me. It's very hard for my parents to accept, but I don't feel any connection to this ill man." Many parents cannot understand this lack of empathy, and find that they resent their other children for not feeling the same way they do about the ill individual.

Some families believe that one way to prevent resentment is to include siblings in family discussions about the ill relative, and to ask for their support in caregiving. Parents often try to protect children by keeping the truth from them, but ignorance can be very frightening. Children should be given as much information as is appropriate for their age. One woman, whose parents always included her in the support of her brother, stated, "My brother is only one year older than me. I don't remember a time when he wasn't there. I love him dearly, and I am the only person he can really talk to about what is happening to him." One father said that now that his ill daughter is on medication and doing well, his other three daughters are willing to be supportive. In the past, they had been afraid of and embarrassed by their sister. But now the four daughters go out once a week and have created strong family ties.

Because the different relationships within a family can show signs of strain during the very early days, families of those with schizophrenia stress again the importance of joining a support group as soon as the diagnosis has been determined. Listening to others who have been through the experience will help you to acknowledge your feelings of anger, confusion, guilt, shame, and so on, and to realize that these feelings are all normal. Normal as these feelings are, however, they are painful and will grow when the family members are uninformed and unsupported. The sooner a family comes to an understanding of the illness and finds appropriate ways of relating to the ill individual, the greater chance a family has of remaining a healthy, functioning unit.

Burnout

The other reason for joining a support group early is to find ways of avoiding the **burnout** that so often comes with the burden of caring for someone with schizophrenia. Feelings of chronic fatigue and utter exhaustion, a lack of interest in life, a lack of self-esteem, and a loss of empathy for the person with schizophrenia are common to people who have been coping alone for a number of years. These people are the "walking wounded", and may suffer from headaches, insomnia, drug and alcohol abuse, depression, and stress-related illnesses.

Families offer the following **ideas for avoiding burnout**:

1. Be aware of your health on a day-to-day basis. Eat nutritiously. Join an exercise club. Go for walks as often as possible. Get enough sleep. Visit your own doctor for regular check-ups. Let him or her know that you are the caregiver of a relative with schizophrenia.
2. Learn about relaxation techniques.
3. Schedule a break for yourself every day.
4. Take regular vacations if you can afford to. Try to get a day or a night to yourself every now and then: will a friend stay overnight while you go to a hotel? (Some families, who are able to be flexible about vacations, go on holiday when a bed is available at a local group home. This sort of respite care is becoming more readily available.)
5. Avoid self-blame and destructive self-criticism.
6. Take a school course - give yourself a few hours when you have to concentrate on something else.
7. If your relative lives away from home, don't visit more than three times a week after the initial transition. Limit phone calls.
8. Try not to neglect the other relationships in your family.
9. Share your grief and problems with supportive people. Be careful from whom you seek advice. (For

example, misinformed people may suggest that schizophrenia is something you caused.)

10. Aim for teamwork in your family.
11. Recognize that successful treatment and workable after-care programs require the co-ordinated and shared efforts of several groups of caregivers.
12. Realize that life must go on for you and for others in the family. This attitude may benefit your relative. He or she may be strengthened by the realization that life goes on.
13. Keep on top of developments in your relative's illness that may indicate that a change of lifestyle is necessary. For example, many families have found that although their relative lived at home successfully for a number of years, at some point a change occurred that lowered the quality of life for everyone. Do not insist on keeping your relative at home if different housing is now indicated.
14. Keep your religious beliefs. This may be important to your relative.
15. Keep a sense of humour.
16. Never lose hope.

Burnout may also be caused by a lack of acceptance on the family's part. Some people are unable to recognize the illness for what it is. The realization that your relative may never be the same again, may never get "cured," is too unbearable to contemplate. Many of these people attend support group meetings on a regular basis, insisting all the while that their wife will get better, that their son will be cured. One mother said that she devoted all of her time to her son the first year he became ill. Then it was pointed out to her that because she was a social worker, she felt that she ought to be able to help him. This mother now strongly cautions others not to impoverish themselves emotionally or financially by chasing "will-o'-the-wisp" cures that have not been scientifically substantiated.

There are those who push themselves to the limit. They never let go. They never get on with their own lives. They wear themselves out. Those with experience advise that once you let go, once you say "This is it," life becomes simpler. One father stated, "You work through fear, anger, grief, and finally come to acceptance. Acceptance is like adopting someone new - the other person is no longer there." Acceptance means that you have learned to look at your relative as he or she is now. Then there is room for hope, and you can begin to work for those things that will really make a difference in your relative's life.

Research: The Hope For Tomorrow

Less research is done on schizophrenia than on any other major disease, given both the human and the financial burden that this illness imposes.

Most research conducted until the end of the Second World War was biological, after which there was an interlude of 10 to 15 years when psychiatry based its attempts to understand and to treat mental illness on the study of human behaviour. This approach led to the development of psychoanalytic techniques. This treatment, as noted earlier, is not effective for patients with schizophrenia.

Modern research into the biological causes of the disease began with the introduction of the neuroleptic drugs in the 1950s. This brought about a change in the direction of research on schizophrenia and its possible causes from the behavioural to the neurochemical. It is now largely accepted that the symptoms of the disease arise from a failure of the chemical processes in the brain to function properly. Today, the primary thrust in research on schizophrenia is to discover the reasons for this.

Research expenditures on schizophrenia still lag far behind those on other serious illnesses. Research interest in

this mental disorder has, however, increased greatly throughout the world in recent years. Scientists now perceive a much wider range of opportunity in the search for answers about schizophrenia and other neurological illnesses (diseases affecting the nervous systems) than before. Torrey has noted that "we are in the midst of an explosion of knowledge in the neurosciences and its effects are spilling over to schizophrenia." (*Surviving Schizophrenia*, p. 129).

New Resources

Brain Tissue Banks

Brain tissue banks have been established to provide researchers with brain tissue for the study of neurological diseases, including schizophrenia. The Canadian Brain Tissue Bank is located in Toronto and is managed by the Canadian Neurological Coalition. (See Appendix II for a description of the work of the Brain Tissue Bank and how brains may be donated for research.)

Imaging Facilities

Research in the fields of neurology and biochemistry is greatly benefiting from the development of new brain imaging techniques that allow researchers to observe brains in living human beings directly. Brain investigations are no longer limited to the use of brain tissue from the deceased. (Appendix III gives a brief description of the different types of imaging.)

Basic Science Laboratories

The way in which neuroleptic medication affects dopamine receptors in the brain and reduces their ability to receive messages from the neurotransmitter dopamine, as explained earlier in the handbook, has led to a growing body of research on the dopamine system. Dr. Philip Seeman of the University of Toronto has been in the forefront of research in this area. Through his efforts and those of others, a picture of how neuroreceptors interact is gradually being clarified.

Among other benefits, this work promises significant improvement in the kinds of medication available for the treatment of schizophrenia in the near future.

One such medication, known as **Clozaril (Clozapine)**, was introduced in 1989 in the United States, and is currently awaiting approval for its widespread use in Canada by the Health Protection Branch of the Department of National Health and Welfare. Known to be effective in treating cases that are resistant to other types of anti-psychotic medications, Clozaril also appears useful in the treatment of the negative symptoms of schizophrenia and the lowering of many side effects commonly caused by neuroleptics, such as stiffness and strong spasms of the eyes, neck and back. Because Clozaril has been linked with the reduction of white blood cells necessary to combat disease, careful consideration is required before the drug is accepted as a standard neuroleptic.

Genetic Laboratories

In the field of genetics it has long been known that members of families who have a history of schizophrenia have a greater likelihood of becoming ill with this disease. The closer the family relationship to someone with schizophrenia the higher the degree of risk. A great deal of attention is now being given to the role that our genes play in neurological illnesses. In many diseases, scientists have undertaken major work to find the faulty gene or genes responsible for such illnesses. Success has been achieved in a number of diseases. A recent example is the discovery of the defective gene responsible for cystic fibrosis at The Hospital for Sick Children in Toronto.

Well-publicized observations by Drs. Bassett and Jones at the University of British Columbia led to the identification of a chromosome 5 abnormality in an uncle and his nephew. Both suffer from schizophrenia and both have several identical physical abnormalities. Based on the Bassett and Jones findings, research has been

conducted on a number of British and Icelandic families with a history of schizophrenia in several generations. Drs. Gurling and Sherrington of the University of London found that the chromosome 5 segment identified by Bassett and Jones seemed to be crucial to inheritance of schizophrenia in these families. Other groups, studying other families with a history of schizophrenia, have not found this linkage.

Social Science Programs

Research in the social sciences is also offering some encouraging results. Commenting on recent work in the United States and in Canada at Laval and McMaster Universities, Dr. Heather Munroe-Blum, Dean of Social Work at the University of Toronto noted that "of the few studies of psychosocial interventions (combined with drug therapy) most have demonstrated a significant reduction in relapse rates when compared with the drug therapy alone." (*The Medical Post*, March 13, 1990).

Co-ordination Effort

Starting a few years ago, the National Institute of Mental Health in the United States began a determined research attack on schizophrenia. This resulted in the development of "A National Plan for Schizophrenia Research." The plan covers all forms of research activity and is being supported by rapidly increasing annual amounts of public funds.

In Canada, a workshop on "Multicentre Study of Schizophrenia" sponsored by Health and Welfare Canada, was held in Ottawa in October 1989. This brought together leading researchers from across the country, and representatives from patient groups, voluntary family organizations, service agencies and the federal government.

The need for a national research strategy was clearly recognized in the proceedings. As a first step toward this objective, an interim group has been formed, with Dr. Barry Jones as Chairman. According to the report from the workshop, this group now has the task of telling the public and its political representatives about current schizophrenia research needs and their importance. The report also notes that a record of resources and people who could be usefully involved in research initiatives is needed. It concluded that a co-ordinating body is required to assist in moving ahead toward these goals.

Better Outlook for Research

Schizophrenia research opportunities now promise better understanding of the illness and eventually full knowledge of its cause or causes. Better treatment for patients and more effective support services in the community are now within reach. In the longer term, there is the hope of a cure. The challenge to both private and public sectors is to provide sufficient funding to make these possibilities a reality.

Research Findings of Interest

A higher percentage of people born in winter and early spring develop schizophrenia than during the remainder of the year. This may suggest viral infection.

More people with schizophrenia suffer birth complications than do the general population. This implies that early brain damage may play a role.

As mentioned earlier, schizophrenia runs in families. This suggests genetic inheritance.

Schizophrenia and manic-depressive psychosis may run in the same families. What is inherited may be a vulnerability to psychosis.

More people with schizophrenia have enlarged cisterns or ventricles in the brain than do the general population.

This enlargement could be produced by infection or trauma in early life, perhaps prenatal life.

A large percentage of those with schizophrenia have discontinuous eye movements. This eye-tracking disorder seems to be inherited.

The course of schizophrenia is different for males and females, for example, the age of onset is typically earlier for males. This may be a clue to a hormonal connection.

Some schizophrenics have a greater density of dopamine type 2 receptors than the regular population. This may be inherited.

Some with schizophrenia seem to have a deficiency of frontal lobe (front of the brain) functioning. This may help to explain "negative" symptoms in particular.

Some schizophrenics have abnormalities of left or right brain functioning. The left brain seems to be most affected.

Some with schizophrenia have memory system, arousal system and attention system abnormalities. A common neurotransmitter system may be implicated.

The outcome in schizophrenia is better in the long term than in the short term. Aging seems to reduce the symptoms. This may be an effect of brain cell loss.

Glossary

Asthma

A respiratory disease marked by intermittent fits of difficult breathing that has a wheezing sound, and is accompanied by chest constriction, coughing, and discharge of phlegm.

Behaviourism

An approach to psychology in which only observable, measurable behaviour is studied. Unconscious processes, such as dreams, have no relevance.

Biochemistry

Chemistry that deals with the chemical make-up of living organisms and their life processes.

Biological Psychiatry

A school of psychiatric thought that emphasizes physical, chemical and neurologic causes of psychiatric illness and treatment approaches.

Bipolar (Manic-Depressive) Disorder

A mental illness characterized by two opposite and extreme types of moods: episodes of mania (hyperactivity, excessive cheerfulness and excitement, decreased need of sleep, flight of ideas, etc.) and depression (marked by poor appetite and poor self-esteem, sleep disturbances [insomnia or oversleeping], hopelessness, loss of energy, suicidal ideas, etc.). An ill individual may experience a series of manic or depressive episodes, or both.

Cardiopulmonary Resuscitation (CPR)

The re-establishment of heart and lung action for cardiac arrest (sudden and often unexpected stoppage of effective heart action) using a well-defined, specialized procedure. This may include the clearance of air passages to the lungs, heart massage, and use of drugs.

Chromosome

Any one of the threadlike structures in the nucleus of a cell that function in the transmission of genetic information.

Cystic Fibrosis (CF)

An inherited disorder of the exocrine glands. There is no known cure yet.

Epilepsy

A disorder characterized by disturbances of the central nervous system and usually illustrated by convulsive attacks or seizures that often leave the individual unconscious.

Forensic Unit

A hospital team that makes assessments to provide information for use in legal proceedings.

Gene

Located on a chromosome, a gene regulates a particular body function.

Genetics

The science that studies the principles and mechanics of heredity, particularly with respect to the processes by which traits are passed from parents to offspring, as well as the causes of the similarities and differences.

Hypoglycemia

A condition marked by an abnormally low level of sugar in the blood. Symptoms may include sweating, trembling hands, and heart palpitations.

Indictable Offence

An action by an individual for which he or she can be charged under the law and punished if found guilty.

Insight

With respect to mental illness, this is a person's awareness of the presence and meaning of symptoms and their origin and role in producing the illness. Although insight alone may not "cure" the illness, emotional acceptance of one's illness is often required before meaningful changes can occur and for the symptoms to diminish.

Kraepelin, Dr. Emil (1856-1926)

A German psychiatrist well known for his extensive classification of mental illnesses. He was one of the first to describe the concept of dementia praecox, the name formerly given to schizophrenia.

Long-Acting (Depot) Injection

This type of injection into a muscle slowly releases the medication into the bloodstream. It is usually used for patients who have difficulty taking neuroleptics orally as an out-patient, or who refuse to do so.

Maintenance Dosage

A dosage that, taken at set intervals, helps to control symptoms.

Metabolism

The physical and chemical processes in a living organism concerned with the absorption of nutrients into the blood after digestion. This involves the conversion of nutrients into energy in order to build up and maintain the organism.

Multiple or Split Personality

A generally rare disorder characterized by the appearance of two or more distinct and separate personalities in one person.

Neurosis

An emotional disturbance in which the patient's behaviour and thinking are poorly adapted and cause suffering. The patient does not exhibit psychotic symptoms and behaviour usually remains within socially acceptable limits.

Occupational Therapy

Therapy in which the patient is involved in a variety of creative tasks and activities related to daily living. This may include the making of handicrafts (carpentry, pottery, painting, etc.) and expressive activities such as participation in dramatic role playing, music or poetry reading.

Out-patient

An individual who comes to the hospital for medical or surgical care but does not need to be admitted as an in-patient.

Psychiatric Nurse

A nurse with specialized training and experience in dealing with psychiatric patients.

Psychiatrist

A licensed physician who specializes in psychiatry. Training involves a medical degree and four years or more of postgraduate training. Compare to Psychologist.

Psychiatry

The medical science that deals with the origin, diagnosis, prevention and treatment of mental and emotional disorders.

Psychoanalysis

A talking therapy introduced by Dr. Sigmund Freud which involves the analysis of dreams, childhood experiences, etc.. to overcome present problems. It is founded on the belief that unconscious, repressed instinctual drives and negative early childhood experiences are mainly responsible for an individual's problems.

Psychologist

A person who holds a degree in psychology from an accredited program. Psychologists involved with patient care are called clinical psychologists. They may provide psychotherapy but are not authorized to prescribe medication. Compare to Psychiatrist.

Psychology

An academic discipline, a profession, and a science dealing with the study of mental processes and behaviour of people and animals.

Psychosis

A major mental disorder in which a person's ability to think, respond emotionally, remember, communicate, interpret reality and behave appropriately is impaired to a degree that greatly interferes with the person's capacity to meet the ordinary demands of life.

Psychosomatic Illness

A disorder with physical symptoms that may be produced in part by stress or other supposedly psychological, non-physical factors.

Psychotherapy

The treatment of a patient's mental and emotional problems through verbal communication between patient and therapist. There are many types of psychotherapy, varying in aims, intensity, duration, and theoretical bases. Supportive therapy is a form of psychotherapy.

Receptor

Special places on nerve endings capable of responding to a chemical or physical stimulus from within the body or in the environment. Some drugs are known to increase or decrease sensitivity of a receptor.

Rehabilitation

The restoration of an individual to normal functioning after a disabling disease, injury, addiction, or imprisonment. Rehabilitation programs are designed to help the patient to sustain an independent existence.

Remission

The subsiding of symptoms. In schizophrenia this may take the form of the partial or complete decline of symptoms.

Schizophrenogenic

This term refers to the tendency to cause schizophrenia. Used in combination with the false and outdated belief that mothers of those ill with schizophrenia were to blame for the appearance of this disease in their offspring.

Self-help Group

A group of people who meet to improve their situation through discussion and special activities. Unlike group psychotherapy, they are not usually led by a therapist.

Sheltered Workshop

An example of an employment or vocational program involving a simulated work situation. Contracts are received from local businesses and the mentally ill individual is trained and supervised to do the work. Job types vary, depending on the institution. Common jobs are unskilled manual labour (such as factory work) and clerical work. Although the main benefits of the program are to provide basic work skills, individuals receive modest payment for their efforts.

Short-acting Injection

The use of a needle to administer neuroleptics in a muscle during an emergency situation such as an acute attack, when a quick effect is needed. The effect wears off in 12 to 24 hours maximum.

Social Worker

A person with specialized training to help individuals with their social adjustment. With regard to mental illness this may involve the counselling of individuals and their families in dealing with various social or emotional issues that are a result of the illness.

Stigma

A term indicating an individual's noticeable features--either physical or behavioural--that lead to societal rejection. In the context of mental illness, stigma refers to society's negative assessment of mentally ill people in general, often reflected in the public's negative treatment of such persons.

Vocational Counselling

Counselling involving a client's search and training for a job.

Watson, John B. (1878-1958)

An American psychologist who led the development of the behaviourist school of thought.

Wilson's Disease

A rare hereditary disorder involving the body's inability to metabolize copper. The condition causes cirrhosis of the liver and severe mental disorder.

Principal Sources And Recommended Readings

Books

Andreasen, Nancy C.

The Broken Brain: The Biological Revolution in Psychiatry; published in 1984 by Harper & Row, Publishers, Inc., 10 East 53rd St., New York, N.Y., U.S.A., 10022

Dr. Andreasen has provided a clearly written outline of the structure and function of the brain in terms understandable to the lay person. In addition to schizophrenia, her book covers other forms of mental illness such as manic depression and anxiety disorders.

Bernheim, Kayla F., Lewine, Richard R.J., Beale, Caroline T.

The Caring Family; Living with Chronic Mental Illness; published in 1982, available in Canada at Beaverbooks Ltd., 195 Allstate Parkway, Valleywood Business Park, Markham, Ont. L3R 4T8

The information provided in this book is supported by extensive use of case history descriptions which, while increasing the reader's interest, add credibility to the advice and suggestions proffered.

Jeffries, Joel J., Plummer, Elizabeth, Seeman, Mary V., Thornton, John F.

Living and Working with Schizophrenia; second edition, published in 1990, University of Toronto Press, 5201 Dufferin St., Toronto, Ont. M3H 5T8

This publication provides a wealth of basic information. French and German versions are also available. It was written as a practical reference for those with schizophrenia and their families and relatives. It may be obtained through the Schizophrenia Society of Canada provincial association offices or from the Clarke Institute of Psychiatry, 250 College St., Toronto, Ont. M5T 1R8

Fuller, Torrey, E.

Surviving Schizophrenia: A Family Manual; revised, published in 1988 in the United States by Harper & Row Publishers, Inc.; in Canada by Fitzhenry & Whiteside Limited, 195 Allstate Parkway, Markham, Ont. L3R 4T8

A comprehensive examination of schizophrenia, how it affects those afflicted with this illness, the needs of the family, legal and ethical dilemmas and other matters. In the Preface to the first edition, Dr. Torrey reveals that he too has experienced schizophrenia through the illness of his sister. The manual, therefore, has been written with a special concern for the problems that confront families affected by the illness. Available from the Schizophrenia Society of Canada at a modest price, or through provincial and chapter associations.

Walsh, Maryellen.

Schizophrenia: Straight Talk for Families and Friends; published in 1985 by William Morrow and Company Inc., New York, N.Y. Available in soft cover from Warner Books Inc., 666 Fifth Avenue, New York, N.Y., U.S.A. 10103

Ms. Walsh learned about schizophrenia through her first-hand experiences with the illness in two people, one of whom was her son. As a professional writer as well as a parent, her book shows special sensitivity to the difficulties and problems that confront families with a member suffering from schizophrenia.

Pamphlets and Brochures

1. a) [*Schizophrenia: Symptoms and Management at Home*](#)
[*Schizophrenia: Returning Home*](#)
[*Schizophrenia: Rehabilitation*](#)
[*Schizophrenia: Courses and Outcome*](#)

La Schizophrenie: Symptomes et Traitement a Domicile
La Schizophrenie: Le Retour a la Maison
Readaptation du Schizophrene
La Schizophrenie: Evolutions et Issue

Mary V Seeman, John F. Thornton, Elizabeth Plummer

- b) [*Schizophrenia: The Medications*](#)

La Schizophrenie: Les Medicaments

Mary V. Seeman, John F. Thornton, Elizabeth Plummer, Joel J. Jeffries

Pamphlets in this series are available in English or in French, free of charge, from The Professional Services Department of Merrill Dow Pharmaceuticals (Canada) Inc., 380 Elgin Mills Road East, Richmond Hill, Ont. L4C 5H2

They may also be obtained through Schizophrenia Society of Canada provincial association offices and the Clarke Institute of Psychiatry

2. a) *A Guide for Patients and Families: Schizophrenia*

Ann Kerr, Ruth Thompson, Joel J. Jeffries

- b) *A Guide for Patients and Families: Depressive Illness*
A Guide for Patients and Families: Manic-Depressive Illness

Ruth Thompson, Harvey C. Stancer, Emmanuel Persad

- c) *A Guide for People Recovering from Psychiatric Illness: Vocational Rehabilitation*

Hana Scholz, Terry Krupa

Any of these pamphlets may be obtained at a modest price from the Social Work Department, Clarke Institute of Psychiatry, 250 College St, Toronto, Ont. M5T 1R8

3. *Palmerston North Teachers College, New Zealand, in collaboration with Schizophrenia Fellowship (NZ) Inc., Study Guides One to Four:*

One: Something is Not Quite Right
Two: Something is Definitely Wrong
Three: Adjusting to Diagnosis of Schizophrenia
Four: Living with Chronic Schizophrenic Disability

These excellent studies were prepared for courses in Caring Education administered by the Advanced Studies for Teachers Unit of the Palmerston North Teachers College. The courses have been designed to meet the needs of "families, and all who support families, caring for the seriously psychiatrically ill or disabled." The Guides contain a wealth of practical information about schizophrenia, and ways and means of coping with the problems that arise when a family member has been afflicted with the illness.

Other Material

As well as the books and brochures recommended, many other excellent publications about schizophrenia, its impact on those with this illness and their families are available. In addition, a number of high-quality videotapes have been produced. Most Schizophrenia Society of Canada member provincial associations and their chapters maintain libraries with a wide variety of material, which may usually be obtained upon request.

Livres et brochures recommandees en francais

Avec la gracieuse permission d'Yves Lamontagne, C.M., M.D., Hopital Louis-H. Lafontaine, Montreal, Quebec.

Livres

Seeman, M.V., Littmann, S.K., Plummer, E., Thornton, J.F. et Jelfries, J.J. *Vivre et Travailler avec la Schizophrenie*; traduit et adapte par Yves Lamontagne et Alain Lesage; Edisem, Montreal et Maloine, Paris, 175 pages, 1983.

Paquette, R., Delage, J. et Lalonde, P. *L'abime du Reve: la Tempete de la Schizophrenie*; Gaetan Morin Editeur, Montreal, 125 pages, 1990.

Lalonde, P. *La Schizophrenie Expliquee*; Gaetan Morin Editeur, Montreal, 1988.

Sidouin, P. et Lalonde, P. *Schizophrenie: Nouvelles Perspectives*; Edisem, Montreal et Maloine, Paris, 1988.

Fondation des Maladies Mentales: Le Schizophrene et sa Famille; Texte des conferences du symposium international sur le schizophrene et sa famille, Montreal, 1983.

Brochures

Fondation des Maladies Mentales: Les Maladies Mentales; 4 pages, 1985.

Fondation des Maladies Mentales: Medicaments contre les Maladies Mentale Craves; 4 pages, 1986.

Fondation des Maladies Mentales: La Schizophrenie; 4 pages, 1988.

Resources

Schizophrenia Society of Canada

Note: Please contact provincial offices for latest update on chapter locations.

National Office:

814-75 The Donway West, Don Mills, Ontario, M3C 2E9

Tel: (416) 445-8204, FAX: (416) 445-2270

Provincial Offices and Chapter Locations:

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North Shore

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Saint-Jerome

Shawinigan

Sherbrooke

Montreal Metropolitan

Dorval

Laval

Montreal (3)

Appendix I: Common Anti-Psychotic Medications

Five different chemical families of anti-psychotic drugs are used in most developed countries. Below are the families and the more common drugs in each family. You will note that each drug has two names: one is the official name for that chemical compound, the generic name; the other is the brand name used by the pharmaceutical companies. The correct dosage for your relative may be quite different from the amount another patient requires. That is why it may take some time to find the right amount to stabilize your relative.

Drug Family =====	Generic Name =====	Brand Name =====
ALIPHATIC PHENOTHIAZINES	CHLORPROMAZINE PROMAZINE TRIFLUPROMAZINE	LARGACTIL; THORAZINE SPARINE VESPRIN
PIPERAZINE PHENOTHIAZINES	TRIFLUOPERAZINE PERPHENAZINE FLUPHENAZINE PROCHLORPERAZINE ACETOPHENAZINE	STELAZINE FENTAZINE; TRILAFON PROLIXIN; PERMITIL COMPAZINE TINDAL
by intramuscular injection:	FLUPHENAZINE DECANOATE FLUPHENAXINE ENANTHATE	MODECATE MODITEN
PIPERIDINE PHENOTHIAZINES	THIORIDAZINE MESORIDAZINE	MELLARIL SERENTIL
THIOXANTHENES	THIOTHIXENE FLUPENTHIXOL ZUCLOPENTHIXOL DIHYDROCHLORIDE CHLORPROTHIXENE	NORVANE FLUANXOL CLOPIXOL TARACTAN
by intramuscular injection:	FLUPENTHIXOL DECANOATE ZUCLOPENTHIXOL DECANOATE	DEPIXOL CLOPIXOL
BUTYROPHENONES (tablet), (injection)	HALOPERIDOL HALOPERIDOL DECANOATE PIMOZIDE DROPERIDOL FLUSPIRILINE PENFLURIDOL	HALDOL HALDOL DECANOATE ORAP INAPSINE IMAP SEMAP
DIBENXOXAZEPINES	LOXAPINE	LOXITANE; DAXOL
DIHYDROINDOLONES	MOLINDONE	MOBAN

Courtesy of the World Schizophrenia Fellowship (July 1990)

**** Addendum To Appendix ****

Note: Clozapine to be available soon in Canada

It is expected that a new neuroleptic drug will be available for schizophrenia patients in Canada in the near future. Called clozapine, it belongs to the didemodiazepene chemical group. It will be marketed by Sandoz Canada Inc., a subsidiary of the giant Swiss drug company that developed it, under the trade name Clozaril.

This new anti-psychotic agent appears to cause fewer side effects (most importantly with respect to tardive dyskinesia) compared with other neuroleptics now available. It also gives better anti-psychotic results for some patients. There is, however, a greater risk of agranulocytosis for a small number. For these, this condition may lead to potentially fatal results, because it affects the immune system by limiting the body's ability to produce white blood cells. To guard against this, the drug's introduction will be accompanied by weekly blood testing for those who take it.

Appendix II: The Canadian Brain Tissue Bank

As advances continue to be made in research laboratories throughout the world, more and more people are beginning to appreciate the enormous potential of post-mortem human brain tissue research. What the public does not seem to realize, however, is that although promising results are being reported and our understanding of severe neurologic and psychiatric disorders is improving, more significant progress is actually being delayed because of a scarcity of brain tissue donations.

The Canadian Brain Tissue Bank was established in 1981 in order to support medical research through the collection, storage, and distribution of brain tissue to interested scientific investigators. Such research is concerned with the causes, treatments and eventual cures for the many psychiatric and neurological disorders affecting so many people today. These include schizophrenia, Alzheimer's disease, dystonia, epilepsy, among many others.

Research over the past decade has shown that the study of human brain tissue is essential to increasing our understanding of how the nervous system functions and consequently in preventing and alleviating these illnesses. Most recently, post-mortem human brain research played a significant role in the development of a genetic test for Huntington's disease and a treatment for Parkinson's disease. Additionally, human brain tissue is necessary because several serious neurologic and psychiatric conditions affect only humans and therefore, animal models are not relevant.

For comparative purposes, brain tissue is needed from healthy individuals, as well as from those who died with a neurologic or psychiatric illness. There is also a critical need for relatives of people with genetically inherited disorders to donate their brains after death. Samples of DNA are kept from all tissue to help in future genetic testing.

What You Should Know About Brain Donation

- Your next-of-kin must verify your intent to donate at the time of your death.
- Even if a decision to donate was not made prior to death, family members can arrange for the donation of brain tissue after death.
- In all cases, the identity of each donor and potential donor will remain strictly confidential.

- Because the brain is removed from an incision in the back of the skull, there is no disfigurement. Thus, brain donation does not interfere with an open casket or other traditional funeral arrangements.
- An autopsy is not necessary. Brain tissue removal will not change the appearance of the donor. Only the donor's brain will be sent to the Brain Bank.
- When appropriate, a diagnostic report will be sent to the family and health professionals involved with the case.
- There are four major circumstances where a brain generally becomes unsuitable for donation. These are: when a person dies while on a respirator; when a person dies from a highly contagious disease; when a person plans to make a whole body donation to a medical school; and when a person makes a donation of heart, eyes, etc., and is therefore maintained on life support systems.
- The Canadian Brain Bank is funded by government grants and private foundations. Usually, brain donation involves no cost to the family. Occasionally, however, charges may be incurred with the local hospital or funeral director.
- Because the majority of studies can be carried out on a very small amount of tissue, each donated brain provides a large number of samples for many researchers.
- Autopsies must be made promptly after death. One half of the brain is frozen immediately, for future biochemical studies. The other half is placed in a special solution called formalin for pathological studies and determination of the exact disease process.
- The Brain Bank should be contacted as soon as a potential donor dies. Delay could result in the loss of the donation.

How to Donate

Becoming a prospective tissue donor is easy. Call the Canadian Brain Tissue Bank at (416) 977-3398. If you prefer, you can obtain a copy of the pamphlet entitled *A Gift of Hope - Canadian Brain Tissue Bank* and fill out the attached donor card. But first, do the most important thing of all: inform your family that you would like your brain donated to the Brain Bank after death; they will have to do it for you and they must understand why you wish to donate.

Appendix III: Types of Brain Imaging Techniques

Note: The following techniques can also be used for other parts of the body.

Techniques that Measure Structure

These allow for the study of brain anatomy and possible structural abnormalities.

Computerized Tomography (CT)

Developed in the early 1970s, this is one of the earliest imaging techniques. Basically, CT emits a beam of X-rays that rotates around the patient. Detectors placed on the other side of the patient's body pick up the radiation. The computer aspect of CT then translates the pattern of radiation into images of detailed, cross-sectional slices.

CT has proven useful in spotting brain abnormalities that may be connected with different types of mental

illness, including schizophrenia, depression, and bipolar disorder. Additionally, it is a painless procedure that requires no special preparation.

One of the more consistent findings using CT is an indication that schizophrenia patients appear to have larger ventricular sections of the brain when compared to other individuals. The ventricles are cavities in the brain filled with fluid, and it is thought that an enlargement in this area occurs at the expense of other brain tissue.

Magnetic Resonance Imaging (MRI)

Also known as NMR (nuclear magnetic resonance), MRI is a relatively new technique that has become widely available over the last four years. Unlike CT, it can image brain regions in different directions and uses a magnetic field as opposed to radiation. It can also produce an accurate reconstruction of brain structures, thus leading to improved visualization, particularly of areas not easily picked up by CT. Because MRI does not use ionizing radiation, it poses a minimum risk for the patient.

Unfortunately, because of its newness, more research needs to be conducted on its potential range of applicability. Several studies done with MRI, however, appear to support the observation of several abnormalities in people with schizophrenia, including enlarged ventricles.

Techniques that Measure Function

These enable the study of the brain at work, through the measurement of metabolic activity and neurotransmitter systems.

Regional Cerebral Blood Flow (RCBF)

This method involves the measurement of the blood flow using what is known as tracers. A tracer is a substance that carries or emits electromagnetic radiation. The most common is the use of a safe radioactive gas called xenon 133 in which its rate of disappearance is measured after the patient has inhaled it. One study using this method has indicated that there is an abnormality in the blood flow of schizophrenic patients.

By having the individual perform various tests or "challenges," RCBF can be used to map patterns of metabolic activity in the brain. For example, one study has demonstrated that patients with schizophrenia appear to have a reduced ability to use the parts of the brain known as the frontal lobes. This finding is consistent with the general hypothesis or premise that schizophrenic individuals suffer from frontal lobe dysfunction. Additionally, there have been some abnormalities observed with the left hemisphere, that is the left half of the brain, of schizophrenic patients. This seems consistent with the language and auditory abnormalities noticed in schizophrenia.

Single Photo Emissions Computed Tomography (SPECT)

This scanning technique uses the method of both CT and MRI in combination with the detection of radioactive particles (photons), which are emitted through an externally administered tracer. Xenon can sometimes be used as a tracer but its low energy makes it impractical for detection. At present, tracers exist for dopamine receptors.

Tracers appropriate for imaging entire neurotransmitter systems are currently being developed, and may make it possible to use SPECT to monitor the effects of treatment and mechanisms of drug action. This method has already proven particularly fruitful in its application to Alzheimer's disease.

SPECT is less expensive to use than PET and although its resolution is not as good as that of PET, it may prove

useful in a variety of applications. For example, further development of this technique may make it feasible for use in smaller university centres and community hospitals. Additionally, for research purposes, both SPECT and PET have the advantage of being able to evaluate a large group of samples rapidly.

Positron Emission Tomography (PET)

Unlike RCBF and SPECT studies, which rely on the detection of single photons, PET detects two photons, thus allowing for better, clearer imaging.

Although PET is the most flexible and sensitive of all techniques, it unfortunately requires specialized equipment and considerable expertise to run it, thus making the purchase and operation of PET expensive.

PET research appears especially promising in the area of neurotransmitter systems in the brain. An example is the study of nerve receptors using the neurotransmitter dopamine, and in particular their relation with schizophrenia. Furthermore, with PET, one can examine the effects that various medications have on different receptors. This could have great significance for the understanding of side effects such as tardive dyskinesia, and could lead to the development of better effective treatments for schizophrenia.

Copies of this report can be obtained from:

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