SCHIZOPHRENIA

INFORMATION FOR FAMILIES

SUPPORT

INITIATIVE OF SUPPORT TO
PEOPLE DISABLED BY MENTAL ILLNESS

DIVISION OF MENTAL HEALTH
WORLD HEALTH ORGANIZATION
GENEVA
This publication aims to give information on schizophrenia in a simple way to families and the public at large. It presents useful and concrete information on how to set up self-help and mutual support groups for families with a relative affected by schizophrenia. It also includes up-to-date information on the nature and management of schizophrenia with emphasis on how to cope with it.

It is part of WHO's Initiative of Support to People Disabled by Mental Illness.

Key words: schizophrenia / family support groups / community support / self-help groups
In 1988 WHO launched its "Initiative of Support to People Disabled by Mental Illness". One of its major components deals with consumer involvement in planning, delivering and evaluating mental health services. We are now proud to present "Schizophrenia: information for families".

This booklet has been produced by family self-help groups around the world - from both developed and developing countries - put together by The World Schizophrenia Fellowship. It brings "the view from the other side" in a very cogent and germane way, and this view represents an invaluable contribution to the public health perspective. Some reviewers of earlier drafts remarked that (i) the overall tone of the text was a little bit too pessimistic and (ii) that the cover-age, both in extent and depth, was not as one would have wished.

In relation to the first point above, it was argued that the majority of people with schizophrenia have a noticeable degree of improvement/recovery over time which is true. What should not be forgotten is that some people do present little - if any - recovery and the information in this booklet is particularly useful for families with ill-recovering patients. Most of the authors are relatives - mothers, fathers, siblings - of real people with schizophrenia, with a long and lively experience of dealing with the illness. Instead of dismissing their views and experiences, we opted for bringing them into light in the hope that it will help in decreasing many people's sufferings.

As far as the coverage is concerned, although primarily written by consumers with direct experience, some outstanding professionals also contributed information. The disposition of this information was determined by families' experience and it certainly is different from a scientific journal publication.
The preparation of the text was coordinated by Mrs D. Froggatt, Executive Director of the World Schizophrenia Fellowship (Canada) and benefitted from contributions from many people, more particularly Dr M. V. Seeman (Canada), Prof. J. F. Wing (U.K.), Dr M. Leggatt (Australia), Mrs C. Rodney (Israel), Mr P. MacGibbon (Canada), Mrs C. Staniforth (New Zealand) and Dr R. Shankar (India), to whom we are grateful.

An important point, however, refers to the cultural background behind this text. Despite some contributions from people from developing countries it clearly reflects a specific socio-cultural and economic environment. Whether and how the ideas expressed here will work in regions or countries with quite distinct beliefs, social structures, health care systems and socio-economic models remains to be seen. It is anticipated that the basic ideas will remain valid even if some local adaptation may be needed. Rather than the final word on the subject this publication is intended to stimulate other organizations and groups to produce similar manuals or even translate this one into their language. Those wishing to do so are welcome to contact us at the address indicated below. Also welcome are comments on this publication as well as additional suggestions and experience reports.

This publication is now made available to all WHO Member States and NGOs. It is our hope it will be disseminated and made available directly to those most concerned and in greatest need.

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INTRODUCTION

The aim of this publication is to disseminate useful and up-to-date information about schizophrenia which will be of use to family support groups and to families interested in organizing such groups. It will discuss some of the methods used in establishing and maintaining support/self-help groups. It will also discuss the components of care for persons with schizophrenia, and give help and advice to those caring for a person with this illness. It is based on the experience in care-giving of family self-help groups around the world with the aid of their medical advisory panels; researchers; mental health professionals and many others.

The "Declaration of Luxor - Human Rights for the Mentally Ill" was adopted on 17 January, 1989, by the Nile Congress at Luxor, celebrating the fortieth anniversary of the World Federation for Mental Health. Important (particularly for those suffering from schizophrenia) among its eight articles are the following:

the right of mentally ill persons to dignified, humane and qualified treatment . . . freedom from medical neglect and abandonment, and concurrently the right to treatment including hospitalization (Article 1)

high priority must be given to research on the prevention of mental disease and ill health (Article 3)

Treatment for persons whose capacities for self-management have been impaired by illness should include psychosocial rehabilitation aimed at reinstating skills for living and should take account of their needs for housing,
employment, transportation, income, information and continuing care after hospital discharge (Article 4).

There is no cure for schizophrenia and treatment is palliative. Research efforts and new technologies are promising, but no substantially new treatments have evolved since the discovery of the benefits of the phenothiazine group of drugs in the 1950s.

In the past, care of those with chronic schizophrenia took place in psychiatric hospitals, where people often stayed for many years. The taking of anti-psychotic medications has allowed many people who might previously have been hospitalized to live in the community. Encouraged by this possibility since it appeared to provide a more humane life, many governments are committing their efforts to community based mental health services. It is unfortunate that many factors associated with the nature of schizophrenia make the design of care in the community very difficult. Thus the responsibility for care falls mainly to families who are often ill-prepared for the long term burden that schizophrenia places upon them. This book will act as a guide for those families and will aid them in forming networks of support in their communities.

An understanding of the nature of schizophrenia is crucial to reducing and eventually eliminating the misinformation prevalent today. Through education, people's attitudes can be changed and the stigma reduced. An enlightened public perception can do much to lighten the burdens of those who suffer from this disease and their families.
A. EXPLAINING SCHIZOPHRENIA

1. The Nature of the Illness

1.1 What is Schizophrenia?

Schizophrenia is a very common illness affecting one person in one hundred around the world. It affects people from all walks of life, and usually strikes young people (both men and women equally) between the ages of 15 and 30. Although an exact definition evades medical researchers, the evidence points more and more conclusively to a severe disturbance of the brain's functioning. Several types of brain malfunctioning have been proposed as a cause of schizophrenia, but so far no conclusive evidence has been found. There are billions of nerve cells in the brain. Each nerve cell has branches which 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 end of another. In the brain afflicted with schizophrenia, something goes wrong in this communication system. In *Schiz*o*phre*ni*a: Straight Talk for Family and Friends, using the analogy of a telephone exchange, Maryellen Walsh (1986) 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."
1.2 What are the Symptoms?

Schizophrenia may develop so gradually that no-one realizes 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. Schizophrenia may also develop suddenly with dramatic changes in behaviour occurring over a few weeks or even a few days. These sudden changes are called rapid or sudden onset schizophrenia. Sudden onset usually leads fairly quickly to an acute episode. Some people lead relatively normal lives between episodes, others find that they are rarely free of some of the symptoms.

The medical profession characterizes the symptoms of schizophrenia as "positive" or "negative". Symptoms brought on by the illness (e.g. hallucinations, delusions) are referred to as "positive". Qualities taken away by the illness (e.g. one’s drive and motivation are gone) are called "negative"; this may also be caused by medication itself.

Symptoms of schizophrenia may include the following:

** DISORDERED OR JUMBLED THINKING - People with schizophrenia may have trouble getting their thoughts straight. They may also find it hard to remember things or to concentrate. These difficulties often mean that a person says things which don’t make sense to others.
FALSE BELIEFS WHICH CAN'T BE SHAKEN - The person may believe that others are trying to harm him¹ [paranoia: false beliefs of persecution], that he has strange powers, that others can hear his thoughts or that the TV or radio is sending him special messages.

 Hallucinations - The person may hear imaginary voices talking to him. He may also see or smell imaginary things or think that food tastes strange.

 Denial - The person may not accept that he is ill. He may refuse to seek or cooperate with professional treatment or help from others.

 Altered Sense of Self - The person has a sensation of being bodiless, non-existent as a person. He finds it difficult to distinguish between where his body stops and the rest of the world begins. He may feel his arms and legs do not belong to him.

 Changes in Emotions - Emotions may be dulled or flat, or out of control and over-excited. Flattened emotions may result in a lack of facial expression and an appearance of disregarding what is going on. Emotions may also be out of place, for example, crying at something funny.

¹For ease of expression this text will use the masculine pronouns: he, his, him, to represent both sexes. The editors recognise that men and women can be equally affected by schizophrenia.
** SOCIAL WITHDRAWAL - The person may retreat to a world of his own and avoid the company of others.

** LOSS OF PURPOSE - The person may feel drained of energy and drive. He may lose interest in life. The illness may also cause him to neglect his health and personal hygiene.

** DEPRESSION - Feelings of helplessness and hopelessness may stem from the realization that schizophrenia will change one's life. Often the person may feel he has behaved badly, has destroyed relationships and is unlovable. Such feelings may lead to talk of suicide.

Most people with schizophrenia do not have all these symptoms. Some are more severely affected by them than others. At their worst, the symptoms make it too difficult to lead a normal life. The world becomes a confusing and often frightening place.

1.3 The cause/causes

No-one knows yet what causes schizophrenia, but it is thought that the label probably includes a group of related illnesses, each having a different, specific cause. Vulnerability to schizophrenia may be partly inherited. Schizophrenia is more likely to occur in those with a schizophrenic first degree relative than in the general population. Nevertheless, the majority of individuals with a close blood relative with schizophrenia do not develop the illness themselves. And schizophrenia commonly occurs in families where no-one is known to have had the illness before. At present we do not know what the complex pathways are that lead from genetic vulnerability to outbreak
of illness. For more information about possible causes see: The Present State of Research, Section A.3, page 16.

Dopamine is the name of one of many chemicals found in the brain. In the brains of those with schizophrenia it is thought that too much dopamine is produced. Too much dopamine is thought to result in hallucinations, delusions and disordered thoughts.

This may be thought of as a break down in filtering whereby too many messages or stimuli get through. Imagine being in a room with 6 people all giving you directions at the same time. How would you know to whom to listen, how to respond, or even what the messages were? This is often what the world of schizophrenia is like day in day out. Today's medication tones down this bombardment of messages.

1.4 Recognizing that something is wrong

Most families, when experiencing the slow onset of schizophrenia, realize that their relative is going through something more than a troubled phase. The behaviour cannot be put down to such things as alcohol, drugs or adolescence. Below are some of the most common early warning signs.

- Inability to sleep; day/night reversal
- social withdrawal, isolation, fear and suspicion
- skipping classes/not going to work; avoiding going out
- inability to concentrate; staring, vagueness
- drug or alcohol abuse; repetitive actions; food fads
- deterioration in personal hygiene; eccentric dress
- frequent moves or trips or long walks leading nowhere
- unusual sensitivity to stimuli (noise, light); low tolerance to irritation
- undue preoccupation with spiritual or religious matters
- bizarre behaviour
- conversation that does not make sense - very abstract, seemingly deep but not logical or coherent; obsessed with one idea.

Medical advice should be sought if a number of these behaviours are present without any logical explanations. In the case of the last two, it would be apparent immediately that something is wrong. Families who have experienced the gradual onset of schizophrenia agree that it is difficult to pinpoint where normal ends and illness begins. Eventually, however, the abnormal behaviour becomes more obvious and is too distressing to tolerate without help.

1.5 Seeking Medical Advice

Quite often the person with the symptoms will not wish to admit that anything is wrong. He is probably very perplexed and frightened about what is happening. It is important that the subject be broached with caution and empathy. In many cases when seeking a doctor's advice is suggested, the person is relieved and glad to unburden himself of the knowledge of his problems. In other cases the person may deny that he is ill and needs to be persuaded to go the doctor. When suggesting an appointment, focus on a symptom such as the inability to sleep, a lack of energy or emotional changes. This may be an area of dysfunction that is easily acknowledged, acceptable and non-threatening. No-one wants to accept that he is mentally ill. It may be useful to write a letter or speak on the telephone to your doctor before your appointment and outline your concerns. This will help make it easier for your relative and yourself during the appointment. A letter should be short and to the point, listing the behaviour witnessed by the family and giving the doctor an idea of how long the problem has existed. If the person refuses to go to the
doctor, make an appointment and go yourself. The doctor may be able to help you get your relative to an appointment. In some communities, he may be willing to make a house-call.

1.6 A diagnosis of schizophrenia

It is wise to be aware that the first visit to a physician may not solve anything nor answer all the questions. There is no diagnosis that positively defines schizophrenia. There is no laboratory test that can be done, nor any physical signs to look for and measure. Diagnosis is based on symptoms and signs - that is, on what the person says and what the doctor observes.

In diagnosing the illness as schizophrenia, the doctor must rule out other alternatives [drug abuse, epilepsy, brain tumour, metabolic disturbances, and other physical illnesses that have symptoms like schizophrenia]. The disease must be clearly differentiated from bipolar (manic-depressive) disorder. The diagnosis of schizophrenia is difficult and is often made over a period of time. There are considerable differences between the symptoms of different individuals. Most doctors are reluctant to voice their suspicions until absolutely certain that the diagnosis of schizophrenia is correct.

2. Management of Schizophrenia

The management of schizophrenia requires medical treatment and psychosocial rehabilitation. Medication can help control some of the symptoms and in some cases at least a short stay in hospital may be necessary. Some people recover well and are able to lead normal lives. But more often others have continuing trouble with the symptoms, and will need to stay on medication for a long time, perhaps for the rest of their lives.
Medical treatments are important, but they do not 'cure' the illness. As with other medical conditions, people with schizophrenia also need support and understanding to help them towards better health and improved functioning. Individual and social programmes for re-learning old skills and developing new ones as well as learning to cope with the illness can be helpful to those whose symptoms have been controlled by medication. It is generally thought that people with schizophrenia need to avoid situations which cause them to feel stressed. Stress on its own does not cause schizophrenia. However, many people with schizophrenia have a low tolerance of stress and find it difficult to cope with the ordinary pressures of life. Too much stress can make the medication less effective in controlling the symptoms which may reappear. Family members, friends, colleagues and others can all help by keeping stress to a minimum (see Coping with Schizophrenia, Section B.). Many publications are available which educate care-givers on how to approach the whole problem of looking after and living with someone with schizophrenia. (See Book List, Appendix 2.).

2.1 The Role of Antipsychotic Drugs

In the 1950's the phenothiazine group of drugs was developed and was something of a break-through in the treatment of schizophrenia. Since then a number of other drugs with similar effects have been introduced. These drugs are known as antipsychotic, neuroleptics, psychotropics or major tranquilizers. They are not a cure, but they are usually quite successful in controlling the acute symptoms of schizophrenia fairly quickly and in preventing those with chronic schizophrenia from relapsing into acute symptoms.

These medications are not addictive. To get maximum benefit, it is important that the drug schedule prescribed by the doctor be
maintained. This may present a problem, since many people with schizophrenia do not recognize they need medication, or forget to take medication on a regular basis. The doctor should be told if this is a problem as it may be more effective to take the medication by intramuscular injection. Taking an injection every week or at longer intervals helps reduce the problems that arise from taking tablets daily. If pills are preferred, a seven-day pill box helps the person keep track of medication. Also these medications present some side effects that may call for other types of medication.

At present, all antipsychotic medications work by blocking the transmission of dopamine from one nerve cell to another. In the future, it is hoped that drugs blocking other transmitters, such as the chemical serotonin, may also be helpful.

Statistics advise that there is a high risk of relapse in the first post-breakdown year, associated with stopping medication. Even for those who take medication regularly the risk of relapse during the first year is around 20%.

It is important to know that some of the symptoms of schizophrenia are often not improved by anti-psychotic medicines. These are most often the symptoms which are called "negative" [see section A: What are the symptoms? for explanation]. They include lethargy, apathy, poverty of thought, lack of motivation and flattening of the emotions.

Although all current anti-psychotics act by the same dopamine-blocking mechanism, they actually belong to different chemical families. Further details are given in Appendix 1. Different people react differently to different chemical structures. Therefore the correct medication and the correct dosage may be quite different from one
person to another. It may therefore take some time to find the right amount to stabilize your relative. You may wish to keep a record of the medications and dosages which your relative has tried, and those which have proved effective. This will help you if your relative changes his physician, moves away or has to re-start his medication after failing to take it for a while.

After a very long time on medication some people may develop tardive dyskinesia, which is most often characterized by involuntary jaw and tongue movements. This condition may be irreversible in some instances. Doctors are very much aware of this potentially permanent and very unpleasant side-effect and must monitor the person carefully for signs of it so that the medications may be adjusted. Reduction of the dose may be sufficient, or the addition of another medicine may help. Sometimes, paradoxically, raising the dose of the antipsychotic is the strategy considered best by the physician. Ask the doctor why he has made the decision.

2.2 The Needs of People with Schizophrenia

I want people to understand that I am just like everyone else. I am an individual, and should be treated as such by society. I should not be stuck away in a box labelled schizophrenia.

Jane

The needs of someone suffering from schizophrenia are similar to the needs of the general population. The difference is that people with schizophrenia are often not able to satisfy these needs because of their illness. The major needs can be said to be the following:

- control of the illness
- a clean, safe, comfortable place to live
- something to do that is worthwhile, enjoyable, non-stressful
- relationships that are accepting and non-judgmental

2.3 Services for People with Schizophrenia

While those with schizophrenia may be hospitalized for several weeks or even months, the aim of hospital treatment is to stabilize a person so that he may return to the community. In general people released from hospital are not cured, but are under control if they are supported upon discharge. They need special services suited to their abilities and functions in order to maintain the level of health achieved at the time of discharge from hospital. Below are areas of need which have been pinpointed as necessary adjuncts to hospital treatment in various studies and reports.

1. Medical care

available in the community: family doctor; psychiatrist; clinic; hospital. Here is also included physical care, such as oral and ophthalmological.

2. Supportive Housing

place to live where burden of responsibility has been removed or lightened; group home with in-house programmes; supervised, supportive boarding home; club-house model.

3. Love and friendship

accepting family and friends
4. Social Support

drop-in [social] centres, clubs, recreational therapy, social skills training, physical recreation, training in use of leisure time

5. Vocational support

assessment, education, skills training, work adjustment; supported employment; sheltered employment [for some, competitive employment will never be feasible]; transitional employment, job placement; special training programmes; employer bank [employers willing to employ ex-psychiatric patients]; self-help programmes.

6. Crisis Centres

attached to hospitals or clinics for 24 hour accessibility; mobile units.

7. Resource person

trained mental health worker or team assigned to patient on a long-term basis, maintaining liaison among all care givers

8. Community Outreach

provided by and in the community for those who do not seek services

9. Transportation

to and from treatment centre, employment, recreation, etc.
10. Asylum (in the sense of being safe from harm)

safety from the extreme difficulties experienced because
of the continuing symptoms of the disease. A place of
shelter and relief for those severely disabled with schizo-
phrenia who have gained only minimal benefit from medi-
cal treatment and for whom "rehabilitation" is unattainable.

11. Income

In some places, government disability pension and/or
supported employment, depending on the local socioeconomic
characteristics.

A well organized system which provides all of the above services
is at present hard to find, but is a goal of many communities. It is
most likely that it will fall upon the family to provide most of the needs
and services listed above.

It is generally agreed that people with schizophrenia respond
best to a structured environment. If your relative is living at home, try
to create a routine that will match the abilities of the person. This
system may begin with personal hygiene, eating regularly, dressing
appropriately, etc. and progress to special tasks for the household,
such as gardening, light grocery shopping, looking after the family pet
and more. All these things must be engineered with the utmost
patience, tact and respect for someone who is experiencing a very
difficult illness. To accomplish the above, family members have to be
in harmony. They need to accept that it is the illness that is creating
the symptoms. They need to understand that creating the above
environment takes time and that the frustrations they will feel are
shared by all families in a similar situation.
Many families who have looked after their relative at home for a number of years find that such care takes its toll. They also realize that the person will eventually have to survive without their help. For this reason families consider finding alternative housing. It is easier for a person to adjust to living outside the family home while the family is still available to give support, encouragement and help. Supported housing, where it is available, will help the person feel more independent, enable the family to use their energies more productively and relieve the person of any guilt he feels.

3. The Present State of Research

"The current evidence concerning the causes of schizophrenia is a mosaic. It is quite clear that multiple factors are involved. Factors proposed as causes of schizophrenia 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. Some of these may be predisposing factors rather than actual causes. Some may be actual causes but will not produce disease unless helped along by predisposing factors ... Finally, schizophrenia is probably a heterogeneous group of diseases, some of which are caused by one factor and some by another (Andreasen, 1984)."

3.1 Why research is needed

Research into schizophrenia is needed for three reasons:

1) to discover causes and underlying mechanisms in order to prevent and reverse disease process;
2) to compare and evaluate treatments and methods of rehabilitation and coping;

3) to assess and evaluate models of service delivery that will most effectively and acceptably identify and meet the needs of people afflicted by schizophrenia and their families:

3.2 Discovering the causes

Is schizophrenia one or more diseases?

It is possible that there are several conditions, each with its own cause, which express themselves in similar symptoms. All may share a central predisposition. Studies by the World Health Organization suggest that a core disorder, defined by delusions and hallucinations of a particular type, occurs at approximately the same frequency in most parts of the world. That suggests a cause which is universal.

On the other hand, schizophrenia, which includes "negative" symptoms such as slowness and lack of motivation, may be less common in developing than in developed countries. This suggests another syndrome with a different cause.

3.3 What differences in distribution exist?

The rate of newly diagnosed schizophrenia varies substantially among different districts of the same country, probably because socially isolated pre-schizophrenics tend to congregate in certain areas. It has been suggested that immigration is associated with high rates of schizophrenia. Perhaps individuals in the early stages of illness are restless and leave their country of origin. On the other
hand, since certain immigrants may also be susceptible to poverty, poor nutrition, infection and poor obstetrical care, they may be at special risk. Social factors such as discrimination and inferior education, child abuse or family violence may contribute to differential rates of illness.

Different areas seem also to show different rates of schizophrenic illness. It seems, for instance, that the rate of new cases in England, Scotland, and Denmark is decreasing, though some researchers point to differences in diagnostic techniques to explain this.

3.4 Genetics

There is little doubt that genetic factors (i.e. those due to hereditary and the make up of one's genes) are involved, either producing a vulnerability to environmental factors such as those mentioned above, or causing symptoms directly through the production of "abnormal gene products". However, no clear genetic pattern has been found for schizophrenia. Clearly, if one or more abnormal genes were found responsible for a substantial proportion of cases, the ultimate benefits for prevention and treatment could be substantial. Searching for responsible genes in an illness with no clear genetic pattern and with no current possibility of identifying subjects-at-risk is a difficult research strategy. Controversies about what syndromes belong together (i.e. are caused by the same gene) complicate the problem. Nevertheless, family linkage studies are under way throughout the world.

In order to elucidate these matters, it is essential to be able to describe the symptoms and signs accurately and to develop testable theories of how "hearing voices", for example, might be linked to brain mechanisms and pathology. Increased social and other stimulation
seems to exacerbate the "positive" symptoms and under-stimulation seems to exacerbate the "negative" symptoms. Therefore, further work on linking the symptoms and course of the illness to the brain systems underlying arousal and attention is likely to lead to useful results. Increasingly sophisticated methods of seeing into the brain (brain imaging) will make tests of such theories feasible.

3.5 Research into treatments

Whether the causation is genetic or environmental or a combination of both, there will probably be accompanying changes in the anatomy, physiology or biochemistry of the brain. Changes have been reported in the frontal and temporal regions but they are seen only in some individuals and it is not yet clear how specific they are to schizophrenia. Further clues to abnormal brain functioning are derived from studies of the effects of medication. The ability of all effective drugs to block certain dopamine receptors has implicated this system as a final common pathway. Much attention is focused on the interaction between different kinds of dopamine receptors and on drugs that differentially block one or the other. New drugs are also being developed that may be more effective with the "negative" symptoms and have fewer side effects.

Other treatment research concerns the possibly preventive effects of early treatment, with low dose medication regimes, and identification of the early symptoms of increasing illness. So far, there is some indication that early treatment may help prevent later disability in some spheres. This work has been less encouraging but research is continuing. Lowering the emotional tension around people with schizophrenia and increasing the ability of those afflicted and their families to cope with persisting symptoms has been demonstrated to reduce the rates of hospital readmission.
3.6 Evaluating services for people with schizophrenia and their families

In many parts of the developed world, where the pattern of hospital care has been dominated by large psychiatric hospitals erected during the latter part of the nineteenth century, there has been a more or less determined move towards a different service delivery pattern, i.e. "community care". Research into methods of rehabilitation, protection and security which help to diminish impairment and to provide a decent quality of life for those who remain chronically disabled, was only started half a century ago. Lessons learned have not always been widely applied. Further research is urgently needed to determine what constitutes optimal care for the individual patient.
B. COPING WITH SCHIZOPHRENIA

1. Some Guidelines

When a person is diagnosed with schizophrenia, he may be admitted to hospital for treatment (see Section A). During his stay relatives play an important role in reassuring the person that he is still a loved and valuable member of his family by visiting on a regular basis.

Schizophrenia is a disease that imposes its symptoms upon the existing personality: the relative’s abilities will depend a great deal on what he was like before becoming ill. The age of onset may also be a factor in how the relative copes. People who had well developed work and social skills may function better than those who had not developed these prior to onset.

On the person’s discharge from hospital he usually returns to the family home. There are a number of things that can be attempted to help the person continue recuperation, though these efforts involve much trial and error. [It must be remembered that some people with schizophrenia can only achieve a limited recovery. For the most part the strategies suggested are based on overcoming the difficulties the person experiences as a result of his symptoms].

- recognise that any long term illness requires a period of adjustment
- speak slowly, quietly and clearly; when giving instructions or asking questions, give them one at a time. Several may be confusing.
- avoid emotional scenes and stressful situations
- do not ignore the person even when he appears not to be listening to what is going on
- show the person you love him in a calm reassuring manner
- attempting to dissuade a person from false beliefs is generally of no avail and often results in even more distress for the person
- use a positive approach to encourage personal hygiene
- try to build self-respect by encouraging the person in his achievements, no matter how small
- provide daily routine and structure
- provide both an opportunity for social interaction and the availability of privacy when needed
- try to ensure your relative takes his medications
- avoid unnecessary criticism
- conversations can be difficult. Sometimes talking about childhood memories, before the onset of illness, create a pleasant atmosphere for all parties.

2. **What to Do in a Crisis**

   Crises are usually brought about by the recurrence of the acute symptoms of the illness. They usually happen when someone is not on medication, but can happen at other times. Thus, the person may be experiencing powerful hallucinations, delusions, thought disorder and/or disturbances of behaviour and emotions. He may be as terrified about this situation as the person looking on. The "voices" may be giving life threatening commands that are completely real to the person, or he may feel something threatening is happening in the environment around him.

   The person may need to get to hospital and be treated. To create an atmosphere in which acceptance of this fact will be realized it is useful to follow guidelines below:
- remember that you cannot reason with acute psychosis
- do not express irritation or anger; keep your emotions under control
- decrease other distractions immediately - turn off the TV, radio
- calmly ask anyone present (guests, friends, etc.) to leave
- speak quietly, firmly and with simplicity
- express understanding for what your relative is experiencing

Should the psychotic episode involve violence there may be no time for the above strategies. Do not hesitate to call the police. Explain what you are experiencing and that you need their help to obtain medical treatment and to control the violent behaviour. After the police have been called it is wise to telephone the psychiatrist who has been involved in the treatment and ask for his advice. Because it is rarely possible to foresee a crisis, a plan should be made, before it happens. All the relevant names and telephone numbers of those who can help in any way should be put together for easy access.

3. **Refusing to take medication**

Almost anyone who has had experience with schizophrenia will agree that one of the most frustrating things about the illness is the all too common fact that patients frequently refuse to take medication. There are several reasons for this. They may deny that they are ill (see section A.1), or they may claim that they have recovered. Medication often causes side effects that are not pleasant. [Among the most common are dry mouth and blurred vision]. Some people find the continuous taking of medicine hard to accept. This may be made easier by quoting other illnesses that require daily medications, e.g. diabetes.
Refusal to take medication may result in the return of the "positive" symptoms [hallucinations, etc. see section A.2] and an acute episode. Persuading someone to take medication is not an easy task. The realization that medication will probably prevent relapse may not come until after a person has had schizophrenia for some time and obtained some insight into his disease. There are no easy answers to this, except to say that again the family must use patience and calmness in their attempts to persuade their relative.

4. **Families and professionals - the view from the other side**

Because schizophrenia is an illness of unknown cause, attribution, i.e. "this person or this event is to blame", is impossible. It would be a relief to all concerned, patients, families, and mental health professionals if they were able to lay the responsibility for illness at someone’s door. They try. Some patients blame themselves for being "weak", "not going to church", "not listening to mother". Families may blame themselves for being "bad parents", "too harsh", "not attentive enough". Professionals blame themselves, too. They may feel guilty about being slow to diagnose, inadequate in treating, inept at keeping the illness at bay. Not surprisingly, guilt and self-blame do not endure unadulterated for very long. They repeatedly and inevitably turn to anger. The patient becomes enraged at psychiatrists who "push pills". Families lose patience with sons, daughters or parents who "sit around doing nothing". Professionals dream up theories of families who make the patient ill. Culprits seem to be necessary and a common enemy often brings people closer. So patients ally with parents against doctors. Or doctors and parents find fault with patient, or patient and therapist malign the family.

These shifting loyalties occur almost invariably and should not unduly interfere with treatment, if properly understood. Ideally, the
search for attribution is eventually overcome. Schizophrenia is best seen as a challenge, multi-faceted and eminently improvable. Doctors can improve certain symptoms with medications. Social workers can advise parents how best to respond to specific behaviour. Psychologists can teach families to enhance their own lives. Nurses can educate families about medications. Occupational therapists can devise programmes of gradual rehabilitation. Many professionals cross discipline boundaries and become "schizophrenia specialists", knowledgeable and helpful in many areas.

Families need to understand that other professionals, not only psychiatrists, are available for guidance. The psychiatrist may - but may not - be the person to call in an emergency. Some psychiatric timetables do not permit unanticipated drop-ins or visits. Dropping off notes may be more effective than phone calls because notes can be read and responded to at leisure. Concerns for confidentiality, however, may severely inhibit professionals from talking freely to relatives. Moreover, decisions about patients are often made by a multi-disciplinary team so that recommendations cannot be made to family members until the team has met.

If your relative is in a programme [e.g. hospital out-patient day care], find out when the team meets and ask to be notified at that point of any changes in treatment plans. If unhappy about the direction or magnitude of therapeutic change, do not hesitate to ask for a second opinion. A new look at a difficult challenge can only help. Importantly, professionals need to know that you are entrusting them with your close relative whose well-being is of foremost importance to you. They need to know that you care even during the periods - which may occur - when you and your relative are not on speaking terms. Professionals need to know - but may forget to ask - what the person with schizophrenia is like at home - how does he
sleep, when does he get up, what can he do with respect to self-care, what are his interests, who are his friends, what are his ambitions?

The more professionals can know your relative as a person, and not only as a patient, the better their treatment is likely to become. That works the other way as well. The more you see the professional treating your relative as a person, with skills and limitations, with knowledge and gaps in knowledge, with imperfect judgment, with generally good motives but with the usual quirks of human nature, the more productive your partnership will be. Doctors, like everyone else, get tired, hungry, exasperated, impatient, slipshod. They may respond badly to being attacked, undermined, overruled. Much as you would like the professional to whom you have entrusted your relative to be perfect, it is unlikely for that to happen. Realism works best. The professional has some real knowledge to impart but has to be asked. He or she does not know your concerns instinctively.

Support from professionals is essential for you but professionals may need to be educated about what families need. Try to put yourself in the other person’s shoes and give him the information that's necessary so that he, in turn, can step into your shoes and view schizophrenia from the family perspective. Multiple views can only enrich the professional - family partnership and improve the situation for the patient.

5. **After We’re Gone - Every Parent’s concern**

Of high priority on the list of parent concerns is how to provide for the person with schizophrenia after the parents’ death. This is a very serious concern for those whose relative has been sick for several years and whose condition now appears to be chronic. It is most important to make a will. Provision may be made for the relative
by putting money in trust for him. In many countries, people with schizophrenia receive disability benefits from their governments. One concern parents have is that these benefits will be withdrawn if the person receives a legacy. The legacy will soon be used up without anyone to guide the spending of the money. A discretionary trust, sometimes called a supplementary trust can help. It works by giving money to the person at the discretion of the trustees, for supplementary needs (examples might be a winter overcoat, or items for there person’s comfort). It is wise for one of the trustees to be familiar with the person (probably a sibling) so that sensitive and practical decisions may be made on his behalf.

In some parts of the world governments recognize moneys from discretionary trusts as supplementary income and continue to pay the person disability benefits. A lawyer versed in these matters will help to create the most practical future for your relative.

6. The Law as it Relates to Schizophrenia

In the course of living with schizophrenia, families and their relative may very probably come into contact with the mental health laws in their jurisdiction. It is wise to become familiar with the statutes which may affect a person’s care and treatment.¹

6.1 The Right to Treatment and Rehabilitation

Around the world jurisdictions are re-examining their mental health laws in the light of the recent focus on civil rights. The advent

¹The United Nations’ General Assembly has approved the “Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care” that clarifies what is acceptable practice for the treatment of mental illness.
of patients' rights movements and the fact that individual freedom is becoming a priority in many societies makes the creation of good mental health laws very complex. Since schizophrenia rarely goes away without treatment [anti-psychotic medications with rehabilitative care] families are concerned that their relative's right to treatment be recognized in law. This is all the more important given that the patient is often not aware that he is in need of medical care and rehabilitation.

6.2 Involuntary Hospitalization

Before the advent of medications which alleviated the symptoms of schizophrenia, many patients were hospitalized involuntarily (against their will) and voluntarily (willingly) for long periods of time. The purpose was to give them shelter and safety from harm, but rarely was any treatment successful. Now, the focus of involuntary hospitalization has changed. Treatments are available which may substantially reduce symptoms. If a patient is admitted involuntarily it is in the hope that a period of treatment will reduce the acute symptoms. There may come a time when your relative becomes very ill, yet does not realize that he needs treatment. When he cannot be convinced of this, families may be able to turn to Mental Health Laws to help them get treatment through involuntary admission to hospital. In some places it is only necessary for one or two physicians to recognize a patient's need, in order for involuntary hospitalization to take place. In others, the patient must exhibit signs of dangerous behaviour in order to be admitted involuntarily. In some jurisdictions the mental health laws allow differences of interpretation which create problems for patients, their relatives and their doctors. It is important to stress here that when a person is admitted involuntarily to a reputable psychiatric facility, it is for the purpose of undergoing recognized treatments for schizophrenia.
6.3 The Civil Rights of Those with Schizophrenia

There has been growing concern over the past decade over the treatment of the mentally ill both in and out of hospital. Many of the most severely ill are those who do not respond to medications. They may remain for long periods in psychiatric hospitals. Governments, urged on by an increasing lobby of vocal relatives and ex-patients, are turning their attention to the rights of patients residing in government and private institutions. In some developing countries even minimum standards of care have yet to be established. In others, the patient’s right to treatment may be complicated when there is no legislation to control the quality of medications or their availability.

6.4 Criminal Law

If a person with schizophrenia is charged with a crime, he is dealt with by the same criminal justice system as everyone else. For the most part crimes committed by people with acute episodes of schizophrenia have been influenced by psychosis or paranoia (false beliefs of persecution) or other illness related manifestations. It is important that the person who is charged has a lawyer who understands the nature of schizophrenia, and its improvement with continued medications, so that he may be better able to plead for a medical assessment and treatment.
C. SUPPORT FOR FAMILIES

1. The need - Coming to terms with schizophrenia

I didn’t believe that this had happened to me. Mental illness was the fate of poor, disadvantaged people, not me. Then I went to a support group meeting - I was amazed - there were families from all walks of life, many of them in circumstances similar to my own.

Inge, a mother

Being able to accept that a relative has schizophrenia takes time. People who have not experienced mental illness up close are embarrassed and fearful, just as the person with schizophrenia and his family are when it happens to them. They find it difficult to speak about the illness, because of their own emotions and because they are afraid of how people will react. They may also be the victims of their own prejudices about mental illness. Forced to examine their own feelings, they must take a critical look at their own values. Historically mental illness has been a reason for shame. Now that we know that schizophrenia is described as a chemical, sometimes genetic, disorder of the brain by the medical profession (see sections A.1 & A.3), there should be no reason for shame. Schizophrenia is an illness in the same way as is multiple sclerosis or cancer. Nevertheless, old perceptions die hard, and the family may have a great deal of difficulty admitting to themselves as well as to others that they have been affected by major mental illness. Until they can do this, the burden will be even greater.
2. Emotional and Practical Support

People involved with schizophrenia note that the family, most often the primary care giver, is under enormous stress every day:

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 depended - 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." (Smith, 1988)

Families and health care professionals caution that the strain of having a relative with schizophrenia can begin in the very early days, when the person’s behaviour starts to deteriorate. Even before a diagnosis is made, families undergo unusual pressures coping with someone whose behaviour is becoming increasingly abnormal. After the illness is diagnosed it is entirely normal to have feelings of guilt, resentment, fear, anger, bitterness, shame and grief. The important thing is to learn to deal with these feelings. Meeting with other families that share a similar experience has proven invaluable in easing the burden. There are support groups for families in many communities which were begun by and for families in need of help, and by professionals who recognise this need. They have been able to give each other great strength in dealing with their problems. Many groups have become more sophisticated and offer a wide range of services and programmes to their members.
3. The Many Roles of Family Self-Help Groups

Family members around the world have joined to create support for both themselves and their relatives. Through the sharing of experiences, most groups provide information and emotional support. These functions enable care-givers to seek help more confidently for their relatives with schizophrenia. As family groups grow and strengthen, they develop new objectives in advocacy and education.

Self-help groups for families coping with a relative with schizophrenia are somewhat unique. They help themselves while at the same time promoting the well-being of others who cannot help themselves - their loved ones. The focus of such a group must retain a balance between these two objectives.

Goals for family support groups may include the following:

* to identify the needs of families affected by schizophrenia and respond to those needs by providing emotional support, problem-solving and coping skills, information and practical help whenever possible.

* to clarify the relationship between families and professional health care providers and provide the necessary support to achieve a partnership which can move towards the goal of informed, concerned and compassionate care for individuals suffering from schizophrenia.

* to provide individuals with a clear understanding of the current status of schizophrenia in society, the current treatment programmes, and the choices available at various stages of the illness.
* to provide family members with education on schizophrenia

* to advocate for improved mental health laws

* to advocate more funding of research to find the cause, better treatments, and eventually a cure for schizophrenia

* to reduce the stigma associated with mental illness by educating and informing the public

* to advocate for better services for the diverse needs of people with schizophrenia in all areas, including direct health care (acute and long term), housing, occupational therapy, recreational programmes, employment programmes, etc., and to encourage and support innovative ideas in these areas

* to provide facilities such as drop-in centres, housing and recreational programmes

* to provide respite care for families, exhausted from the task of care-giving

* to provide grief counselling for families where the severity of the illness has robbed them of their loved one as a consequence of suicide

4. **Beginning and maintaining a support group**

   Family Support Groups have remained the backbone of many of the self-help organizations which have grown out of them. They
are an invaluable means of self-help which can augment services provided by professional care givers. The groups provide participants with four broad opportunities:

1) unique support, understanding and strength given by people who are experienced in caring for a person with schizophrenia

2) a chance to learn from the combined wisdom of others experienced in coping with day to day problems

3) an occasion to make new friends after years of being a care giver has left people isolated

4) encouragement and support to work towards improving the lot of both people with schizophrenia and their families

A support group may be set up by a professional in the field, who has patients whose relatives are interested in meeting other relatives. It may also be set up by a group of several relatives on their own. To begin with, a group may be completely informal. A professional may lead the group to ensure that information provided is correct and to offer the advice of experience, until the membership is able to take over. Support of professionals will continue to be important - for special advice, material resources and for referrals to the group.

4.1 Holding Meetings

Obtain a central location (local community centre, service club premises, or church hall), which is easily accessible. Some groups prefer not to attend meetings in hospitals or clinics. Others feel that
meeting in a hospital adds credibility to the meeting, or it may be that the group leader is a professional at the hospital.

See that the room is pleasant with comfortable seating and privacy. An additional asset would be the possibility of serving refreshments (for instance, electricity or fire for the coffee/tea pot). Arrange regular meetings to be held on the same day each session (e.g. each Tuesday; the first and third Thursday of each month). People should be made welcome and the set-up of seats should invite communication (a circle is ideal).

The meeting will be the focal point of your group. It should be no longer than two hours. An informal ten minutes at the beginning during which the coordinator welcomes everyone at the door, helps create an atmosphere of trust and openness, and releases tension for newcomers who do not know what to expect. Members will then discuss their problems and offer advice to each other. A coffee break should occur after the support session so that members can mix and exchange information. During the break a collection may be made to share expenses.

At the first meetings an interim convener/chairperson and alternate should be selected, and members who wish to be further involved in the group may be appointed to open the premises, prepare the room, bring coffee, etc...

4.2 Objectives for the Meeting

* recognise an atmosphere of confidentiality

* render participants sufficiently at ease to talk about their worries and their relative without being fearful of criticism
* let members receive enough feedback, by word or gesture, to know they have really been understood. In this group experiences like theirs are common and their reactions normal.

* let participants be given recognition for the great achievements they have made already and realistic praise for how well they have coped rather than suggest what else might have been done.

* allow participants to simply listen and absorb or rest, if that is what they need.

* let participants experience feelings of hope - realistic hope, in that even if there is little change for the person with schizophrenia, the family as a whole can learn to cope and lead a relatively satisfying life.

* allow members to hear a variety of different solutions from ordinary people coping with similar situations; none being of a dogmatic nature.

* let participants realize their experience and suggestions are very important. Care givers learn a lot through practical experience that is invaluable in augmenting professional treatment.

* direct participants to a more appropriate group if this one is unable to help.
welcome new members and encourage them to speak, while first recognising that it is probably a particular problem that has brought them to the meeting

enable the participant to leave the meeting feeling substantially better than when he arrived, or at least, to make sure that there is an exchange of telephone numbers or an address to visit for follow-up

The self-help group relies on the experiences of members more than on the knowledge of experts. Consensus and cooperative effort are what are used to find workable solutions. People learn from each other, so that the behaviour of members, the group activity and the structure and setting of meetings will all have a bearing on the group's success. Compromise, humour and sensitivity to everyone will help develop an unwritten law of the group's conduct. Certain behaviours can disrupt the harmony. There can be: talking too much too often; dominating; not listening, criticising, etc... Identify these issues as they arise and resolve them. Sometimes it is only the anger, hopelessness and frustration of the person that brings forth this kind of behaviour.

The leadership style of the convener/coordinate affects the meeting. Balancing the discussion; summarizing and clarifying points; keeping the group on topic, i.e. the well-being of the care givers; and giving everyone a chance to speak, helps the meeting run smoothly and amicably. It also helps achieve the common goal of learning to cope and understand.
4.3 Building Membership

After the support group has been meeting for some time further objectives may emerge. These may be:

* to be better informed (about services, course of the illness, etc.)

* to inform others

While continuing the support meeting, a regular information meeting may be arranged, and speakers invited (research scientists, social workers, psychiatrists, lawyers, etc.). Members wishing to provide written information may strike a committee to accomplish this task. Always remember that many members have very onerous burdens. They should not be coerced into activities they cannot handle.

Be sure to use the resources in your community: the Mental Health Association; the Lions, Kiwanis, Rotary or other service club; University, high school or college students (volunteers - can deliver and post advertisements); churches; pharmaceutical manufacturers; local businesses; police department; local politicians, philanthropists, etc...

Whatever character the group evolves, it must be well organized. People will be discouraged if information about meetings proves incorrect, or someone fails to unlock the door at the meeting hall.

Formal groups with a board of directors are often better at complex tasks than at meeting emotional and personal needs of
members. Decisions about finances or the running of the group should be made separately from the support meeting. Some groups arrange "executive" meetings before or after the support meeting to reduce meeting nights to a minimum.

4.4 Forming an Executive

When the size of the group gets to about twelve people it should be formalized by creating an executive. Not all the positions listed below are necessary at first.

Coordinator - President - Chairperson: calls meetings; recruits volunteers; represents the group at outside functions; ensures group sets up regulations and goals. This person needs good interpersonal skills to work productively with others. The coordinator's function at a meeting is to act as the leader of a democratic group with one all-important overriding concern: he/she must be sensitive to a very vulnerable group of people who are more than normally stressed, often with few or no supports; many of whom have lost the confidence to press for their concerns to be met.

Vice-coordinator (Vice President, Vice Chairperson): chairs meetings in the coordinator's absence and therefore needs similar skills; represents the chapter at outside functions; prepares to take over coordinator's role at end of his term (this ensures continued leadership). Helps recruit members.

Secretary/Treasurer: handles and keeps accurate records of chapter funds. Prepares financial reports. Is a signing officer for bank accounts. Takes minutes of the chapter's annual meeting. Keeps organized record of correspondence, reports, etc.; orders chapter supplies. Keeps members well informed of chapter activities in liaison
with the coordinator. This job should be separated into two as the group grows.

**Medical Advisory Committee:** It is very important to have professionals on-side right from the start. Their support will add credibility and be invaluable in supplying medical knowledge. Enlist the support of at least two, preferably psychiatrists or psychiatric nurses, who have a particular interest in schizophrenia. They should agree with and champion the group’s goals and objectives. These professionals will form the basis of a medical advisory committee.

**Communications Officer:** organizes telephone committee which keeps members informed of all meetings, etc... Places ads with the media. Organizes a publications committee for the distribution of pamphlets, news sheets, etc...

**Fund Raising Officer:** this officer must feel comfortable contacting local businesses, etc. to obtain donations of supplies or funds for running expenses. Other duties may be small scale at first: bake sales, raffles, etc., and can only be done with the support and help of the members at large or a committee struck for the purpose.

4.5 A Telephone Line

At the beginning it is usually the convener and his/her alternate whose telephone number is given to members and which appears on any leaflet that is produced. This in turn generates more telephone calls until eventually it may overwhelm the person attending to it. A solution to this problem may be to install a telephone line and an answering machine so that calls may be attended to in time set aside for the purpose. Volunteers may take turns to return these calls. Alternatively, the group may find a location where member volunteers
on rotation may answer the telephone and/or receive families who have questions. The member volunteer force should not be over extended. Begin the service with only a few hours a week (e.g. Mondays and Wednesdays, 9:00 a.m. - 12:00 noon). It is not productive to have a telephone line that is inadequately manned, nor one where the volunteer is poorly informed.

4.6 A Volunteer Manual

As the experience of the group and its members grows, a store of information will evolve about local services. This information should be catalogued in a volunteer manual for easy reference, and the information noted by volunteers.

4.7 A Log Book

A confidential record of each telephone call or visit should be kept in a log book bought for the purpose. This ensures that names, addresses and telephone numbers are not mislaid and that volunteers are always informed of any problems that have arisen and what solutions were found.

5. Sharing with Other Self-Help Groups

As groups become stronger they wish to share the knowledge and the benefits of family self-help and support with others. From the beginning - when one group splits into two - grow local, provincial, national, and international bodies. Conferences to exchange information occur on a regular basis. Family organizations are listed in Appendix 4.
6. **Patient Self-Help Groups**

   Increasingly, patients and former patients have formed groups to help each other. Such groups may set up clubs, correspond through newsletters, lobby government, and otherwise support each other and educate the public.
D. FORMING GOVERNMENT POLICIES ON SCHIZOPHRENIA

There is increasing evidence of the high cost of schizophrenia in terms of human suffering; financial burden; hospital and community care; and lost employment [for both sufferers and burdened family]. Research is comparatively very poorly funded at present. Schizophrenia is one of the severest mental illnesses and because it afflicts people at a young age, in many instances it has a duration of fifty years or more. Research into cause, treatment and rehabilitation should therefore be of high priority.
APPENDIX 1

ANTI-PSYCHOTIC MEDICATIONS

Several different chemical families of antipsychotic drugs are used. Below are the families and the more common drugs in each family. Each drug has two names, one is the official name for that chemical compound, the generic name indicated below; the other is the brand name used by the pharmaceutical companies and it may vary from country to country. Ask your doctor to indicate to you the local brand name for the drugs your relative is using or has used. 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.

The asterisk preceding the name of some drugs indicates those included in WHO's Essential Drugs List (the use of essential drugs, Geneva, WHO, 1990).

<table>
<thead>
<tr>
<th>DRUG FAMILY</th>
<th>GENERIC NAME</th>
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<tbody>
<tr>
<td>Aliphatic phenothiazines</td>
<td>*chlorpromazine</td>
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<td></td>
<td>promazine</td>
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<tr>
<td></td>
<td>triflupromazine</td>
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<td>methotrymeprazine</td>
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<td>Piperazine phenothiazines</td>
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<td>fluphenazine</td>
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<td></td>
<td>prochlorperazine</td>
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<td>acetophenazine</td>
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by intramuscular injection: *fluphenazine decanoate
fluphenazine enanthate

Piperidine phenothiazines
thioridazine
mesoridazine
Pipotiazine Palmitate

Thioxanthenes
thiothixene
flupenthixol
diclofenac
zuclopenthixol
dihydrochloride
chlorprothixene
flupenthixol decanoate
zuclopenthixol decanoate

Butyrophenones (tablet) (Injection)
*haloperidol
haloperidol decanoate
pimozide
droperidol
fluspirilene
penfluridol

Dibenzoaxazepines
loxapine

Dihydroindolones
molindone
APPENDIX 2

SUGGESTED READINGS


Personal Accounts:


APPENDIX 3

SELF-HELP ORGANIZATIONS FOR FAMILIES

AUSTRALIA
Schizophrenia Australia Foundation, 223 McKean Street, North Fitzroy, 3068, Victoria, Australia. All the Australian State Fellowships may be contacted through this address.

AUSTRIA
Hilfe Fur Psychisch Erkrankte (HPE) Vereinigung der Angerhorigen und Freunde, Westbahnstrasse 1b, A-1070, Vienna.

BELGIUM
Federatie van Belgische Simileskringen, Groenwig 151, 3030 Heverlee.

BERMUDA
Bermuda Schizophrenia Society, P. O. Box DV 688, Devonshire, Bermuda, DUBX.

CANADA
Schizophrenia Society of Canada (formerly Canadian Friends of Schizophrenics), 75 The Donway W., Suite 814, Don Mills, Ontario, MEC 3E9. All Canadian Provincial Friends may be contacted through this address.

COLOMBIA
Dr Augustin Azuero, El Remanso, Carrera 53A No. 119a22, Bogota, D.E.
FRANCE
UNAFAM, 8 Rue de Montyon, 75009 Paris.

GERMANY
- Bundesverband Der Angehören Und Freunde, Thomas Mann Str. 48A, D-5300, Bonn 1, West Germany.

- Aktionsgemeinschaft Stuttgart der Angehörigen Psychisch Kranker e.V., Ernst-Lehmann-Str. 19, 7022 Leinfelden-Echterdingen, West Germany.

- Nachbarschaftshilfe e.V. Selbsthilfegruppe Angehörige Psychisch Kranker, Uerdinger Str. 26 4000 Dusseldorf 30, West Germany.

INDIA
AASHA (hope), Schizophrenia Research Foundation, No. c-46 13th Street, East Anna Nagar, Madras - 600.

IRELAND
Schizophrenia Association of Ireland, 4 Fitzwilliam Place, Dublin 2.

ISRAEL
ENOSH National Center, P. O. Box 1593, Ramat Hasharon, 47-113.

ITALY

JAPAN
Zenkaren, C/O Kawamura Building, 7-11-7 Ueno, Taito-ku.
MEXICO
La Asociacion Mexicana de Amigos del Paciente Esquizofrenico A.C.,
Nicolas Bravo #47, Lomas del Huizachal, Haugalpan Edo. de Mexico
CP 53840.

NEW ZEALAND
New Zealand Schizophrenia Fellowship, P. O. Box 593, Christchurch.

NETHERLANDS
Ypsilon, Grindweg 135, 3054VJ Rotterdam, 010 - 183050.

SOUTH AFRICA
Cape Support for Mental Health, 211 Monte Carlo Building,
Heerengracht, Foreshore, Cape Town 8001.

SPAIN
- A S A E N E S (Asociacion de Allegados de Enfermos
Esquizofrenicos), Alejandro Collantes, 85 - 1. 41005 Sevilla.

- Feracion Estatal de Asociaciones de Familiares Y Enfermos
Psiquicos, c/o Colomer 14, 28028 Madrid.

SWEDEN
Intresseforening for Schizofreni (IFS), Swedish Schizophrenia

SWITZERLAND
VASK (Vereinigung der Angehörigen Schizophreniekranken),
- Postfach 6161, 8023 Zurich
- Postfach 186, 4027 Basel
- Postfach 140, 3084 Wabern
- Postfach 1530, 9102 Herisau 2.
UNITED KINGDOM
The National Schizophrenia Fellowship, 28 Castle Street, Kingston-upon-Thames, KT1 1SS, Surrey, England [for all branches].

Schizophrenia Association of Great Britain, Bryn Hyfryd, The Crescent, Bangor, LL57 2AG, Wales, U.K.

NSF Scotland, 40 Shandwick Place, Edinburgh EH2 4RT, Scotland.

UNITED STATES
National Alliance for the Mental Ill, 2101 Wilson Blvd., #302, Arlington, Virginia. State organizations of the Alliance may be contacted through NAMI.

URUGUAY
- Pro Ayuda Enfermo Siquiatrico, Rafael, No. 4091, Montevideo.
- Ofelia S. de Caldeyro Barcia, Grupo La Esperanza, Mar del Plata 6829, Montevideo.

WORLD

The World Schizophrenia Fellowship, 238 Davenport Road, Suite 118, Toronto, Ontario, M54 IJ6, Canada.