DISCOVERING SOMEONE CLOSE TO YOU HAS SCHIZOPHRENIA

"I couldn't believe our sensible, studious daughter. She had changed into a person I hardly recognized. She refused to change her clothes and said she heard voices telling her she was evil and deserved to die."

Many family members say that the greatest challenge in their lives has been learning to cope after someone close to them develops schizophrenia. For the first few months, especially in the active phase, people with schizophrenia, their families, and people in their social network may be troubled by their worry, disappointment and grief. The danger of families and relationships splitting apart under the stress of facing a serious illness can be all too real.

It is important for family members, partners and friends to talk to each other openly about their concerns and to find ways to support each other during this difficult time. Professional counselling can help alleviate tension and distress.

In spite of the many difficulties, most family members usually manage to rally together, to learn about the illness, to come to terms with their concerns for the future and their sense of loss, and to work toward the rehabilitation of the person with schizophrenia.

Some people recover from their first active phase of schizophrenia and stay well; others are not so fortunate. Whatever happens, people with the illness and their families need to find ways to live their lives as fully as possible.

Family concerns about schizophrenia

As a family member or friend of a person with schizophrenia, you may find the illness distressing, especially during the active phase. The first episode can be particularly upsetting if you do not know what is wrong or how to help. Most hospitals have trained staff who will talk about what is happening and who can offer some guidance.

Schizophrenia is not caused by family pressure or parental errors. When people with schizophrenia are ill, they may become so absorbed in their strange, sometimes frightening, inner word that they lose interest in their work or studies. In some cases, they may turn away from partners or family members or become hostile. In other cases, they may cling to family members and not want to let them out of their sight.

You may feel intense pity, compassion, love, fear, anger, resentment, guilt, even hatred toward the person with schizophrenia. Such feelings are common and understandable. It is useful to talk about these feelings with people you trust. You need the comfort and support of other family members and friends during this time.

Finding treatment

If people are experiencing some of the symptoms described earlier in this guide, they should seek psychiatric help as soon as possible. They may not understand the need for treatment, but as a family member, partner or friend you should urge them to go to a doctor, community psychiatrist, or the emergency department of the nearest psychiatric or general hospital. Depending on the severity of symptoms, treatment may be recommended on an outpatient basis or in hospital.

Most people with schizophrenia want treatment and can be persuaded to accept it. Others, whose judgment is seriously impaired, may not recognize that they are ill. This makes it difficult for them, if they refuse to accept the help they need, and for their family members, who recognize the need for treatment.

If people with schizophrenia refuse psychiatric help, family doctors, the local psychiatric hospitals or public health departments can give you information and advice about how to handle the situation. If there is a risk of self-harm or harm to other, you can phone the police or go to a Justice of the Peace. In most communities, the police are authorized to take ill people to hospital for an examination if they observe dangerous behaviour, or if they have either a doctor's certificate or a judicial warrant from a Justice of the Peace.

What to do when a relative is in hospital?

"I was initially kept in the dark and didn't know what they were doing to my son in the hospital. I was terribly worried and felt much better after the initial interviews were over. The sooner the interviews take place, the better."

- a mother

"His doctor wouldn't speak to us and we didn't find out why until later. The reason for confidentiality should be explained by hospital staff."

- a wife and a son

During the first hospitalization, you may learn for the first time that your relative has schizophrenia. It is important to realize that schizophrenia is an illness that can be treated. You may be extremely upset about the diagnosis, and need to talk about your feelings and concerns. Most hospitals have social workers or other professionals on staff that is available to talk with families.

Visits are usually encouraged, but to begin with, hospital staff often recommends that they be brief. To avoid frustration, you and other family members may want to take turns visiting. Each hospital ward has its own visiting hours. You can help by learning ward routines. You can also help by reassuring the ill person that hospitalization is needed for proper assessment and treatment.

Family members are often asked for information, because people with schizophrenia are often too frightened or disturbed to give an accurate picture of the development of their illness. Some people may refuse to allow hospital staff to contact their families. If this happens, hospital staffs, like family doctors, have no alternative but to abide by their clients' wishes. However, families are able to contact hospital staff and voice their concerns.

Family involvement

In recent years hospital staffs have become increasingly aware that families are important partners in treatment. People with schizophrenia, their families and mental health professionals need to work together toward recovery. It is also important that family members feel they are listened to and understood because they have major and sometimes difficult adjustments to make as a result of the illness.

You will probably have questions and concerns about various aspects of the illness and its treatment. It is important for you and the ill person to know what is happening. You should not hesitate to ask for

information from hospital staff. It also helps people with schizophrenia when they hear their illness openly discussed the ill relative will probably be included in family counselling sessions as soon as the active phase is over.

Medication and side-effects

When the ill person starts taking medication, you may be distressed to see side-effects such as drowsiness or restlessness. What seems most difficult for many families to deal with is the stiff, zombie-like" look that people taking medication sometimes develop. Medication changes can be made. The initial dose can be lowered or another drug can be prescribed to take away the stiffness. In spite of the side-effects, it is important that medication be taken so that symptoms clear.

Leaving hospital too soon

Sometimes ill people want to leave hospital before their treatment is completed. This can have serious repercussions, because the illness can worsen and they will need to return to hospital. You should strongly urge them to stay in hospital until hospital staffs agree it is time for discharge. However, if ill people are not suicidal, nor threatening others, or if they are able to care for themselves, they cannot be forced to remain in hospital, even if their decision is contrary to medical advice.

Relating to an acutely ill person

You may not know what to say to the acutely ill person. In the active phase of schizophrenia, people may feel their minds are being bombarded from all directions by ideas, questions and commands. They may feel too overwhelmed to sort out even minor problems. Generally speaking, you should try to be as supportive and understanding as possible, and to peak in a calm, clear and straightforward manner. When necessary, you can help to reduce stress by relieving the ill person's responsibilities.

People with schizophrenia may use words that sound like nonsense to others. If they cannot be understood, you should try to communicate your interest and concern in other ways. You can listen to music, paint, watch television or sit quietly together. You will soon learn what works best by noticing the person's responses to what you do together. Never talk as if the ill person is not there. People with schizophrenia are usually aware of what is going on around them, even if they appear not be listening.

Living arrangements

As a person with schizophrenia improves, hospital staff, especially social workers, may talk to family members about living arrangements. Some people return home, some go to group homes and still others find rooms and apartments or their own. Each family must make its own decision. It is not unusual to try one living plan and then another. It is often helpful to discuss what kind of accommodation is available and what could be most helpful to the ill person at different stages of recovery.

Where people do best

People with schizophrenia seem to do best in well-organized home environments with regular routines that include meals, sleep, work and recreation. They also do best when living with people (either family members, friends or group home employees) who are calm, matter-of-fact and warm without getting too close. Sometimes they can tolerate only limited emotional involvement with family members, even those with whom they have previously been close.

Some concerned families are naturally low-key in the way they express themselves; others are excitable and over-anxious. Family members and friends need to learn how to visit or live with a person with schizophrenia. Even if your family is naturally calm and supportive, you will need information and guidance when dealing with the illness for the first time.