

RETURNING HOME – FAMILY CONCERNS...about schizophrenia

What families say they need and want?

Upon return from hospital, people with schizophrenia and their families face many challenges. Below is list of things various families have said were most helpful when their ill relatives returned to the community:

- Journals and books about schizophrenia
- Talking to the ill relative to learn about the illness
- Support from people in their social network
- Case management support
- A support group, such as the Schizophrenia Society
- A job for the ill person to go to
- Contact with hospital staff and family doctor
- A good sense of humour
- Police support

Stressors after discharge

When people are discharged from hospital after the active phase of schizophrenia, some symptoms may remain. They may be withdrawn and prefer to spend time alone. They may be preoccupied with their own thoughts and fantasies, leading to problems with concentration. Personal grooming may slip. They may sleep during the day and be up at night. Interest and energy for activities they previously enjoyed may disappear. They may resent being reminded of daily routines.

You may find these behaviours and attitudes very stressful. As a result, it is important to find ways for your ill relative to carry out his or her responsibilities. It is helpful to set reasonable expectations and to work out a structured approach to accomplishing tasks.

Social contacts

It is common for people with schizophrenia to feel uncomfortable in the presence of others, especially as they recover from the effects of an active phase. Interpersonal contact can be very difficult for a number of reasons, including fear of people, lack of confidence, and feelings of inadequacy or being different from others. You need to understand these problems, but at the same time you need to emphasize the importance of social contact to the person's health. Encouraging them to "do their best" and helping to set up structured interactions can benefit people with schizophrenia. Just carrying on with regular family activities helps build up tolerance for interaction with others.

Finding the right pace

It will take time for you and your ill relative to establish a pace that supports recovery. Often you may be "out of sync" with each other, with one or the other moving too quickly or too slowly. To get "in sync" it may be helpful for everyone to negotiate a daily routine that includes element of self-responsibility, activity and social contact.

You can help by being open and supportive to the ill relative's efforts to reconstruct his or her life. Recognizing that people do things differently will prevent needless arguments over the "right way" to perform a task.

Suggestions regarding inappropriate behaviour will be heard more easily if they are delivered in a low-key manner. It helps to emphasize the positive. You may need to provide more input and perform more tasks in the early stages of recovery. As the ill person progresses, you will need to do less.

Family relationships

Coping with schizophrenia may raise a variety of issues and needs for different family members depending on their relationship to the person with schizophrenia. For example, children of a parent with schizophrenia are likely to be confused and upset by their parent's changed behaviour. They may be afraid, hurt or ashamed when schizophrenia affects children, parents will often feel guilty and burdened.

The needs of siblings are sometimes overlooked. Like parents, siblings may feel self-blame and guilt. It is also common for siblings to be afraid of becoming ill themselves. Support family counselling can help all family members to address their needs and concerns.

Couples

Support is critical to the well-being of ill people. It is important that couples in which one partner has schizophrenia find ways of maintaining and expressing their affection for each other. Task sharing is an important element of primary relationships. If couples can agree on what tasks ill partners perform as they recover, it will be easier to move forward. If the ill person cannot act as a confidante, his or her partner should seek an alternative source of support, possibly through a relative's group. If a couple experience ongoing difficulty in their relationship, couple counselling should be considered.

The needs of the family

You need the support of relatives and friends to cope effectively. Keep in mind that all family members are important and have their own needs. You need to find a balance – which will vary according to the changing circumstances of your lives. If you don't take time for yourself, you risk becoming exhausted or "burned out." Other people, such as friends, therapists and the clergy, may be willing to help and should be called upon when the need arises.

Disagreements

At times you and your ill relative will disagree. The best way to handle disagreements is to make sure that the ill person's point of view is made clear. This will avoid any misunderstanding in perspectives. By stating thoughts and feelings calmly and matter-of-factly, it is more likely that you will resolve your differences of opinion constructively. It will not help to give in to unreasonable demands out of sympathy or fear.

Aggressive behaviour

Most people with schizophrenia would never harm anyone. In fact, they tend to be timid. However, a person with schizophrenia may make threats or strike out in response to hallucinations and delusions. This

can be surprising and frightening to those around him or her. Aggressive behaviour toward others often results when people with schizophrenia think others are hostile, or when they feel crowded or trapped.

If they are upset, do not trivialize their feelings. Do not tease or insult or nag them. Do not get too close either emotionally or physically. If violent threats are made, remain calm and take steps to ensure your safety. Help from friends, neighbours or the police may be necessary. Therapists should be informed, and can give you ideas to prevent or deal with similar episodes in the future.

You and the person with schizophrenia can learn to deal with anger and conflict in a constructive manner. You may meet with therapists to talk about how to prevent violent episodes in the future. Some hospitals and outpatient clinics offer family education programs to help relative learn coping and communication strategies.

Depression and suicide attempts

Some people with schizophrenia feel depressed, unlovable and hopeless. Occasionally, they may be in serious danger of taking their own lives. This is most common in young men during the first 5 years of their illness. Suicidal thoughts may also be a sign of relapse. People considering suicide often talk about it.

If your relative expresses such thoughts or ideas, they should be taken seriously and discussed with the person's therapist. If the therapist cannot be reached, take the person to the emergency department of the hospital where treatment was previously provided, or to the nearest general or psychiatric hospital. The risk of suicide may make family members overly cautious. Conversely, some families underestimate the risk. Encourage the ill person to share any feelings of depression as possible warning signs. If you can recognize suicidal thinking, you will be more prepared to act quickly and competently in times of crisis.

Organizations for families and friends

Many families and friends join support or self-help organizations where they can meet others who are struggling with the same problems. Members learn from and support each other at all stages of care. See Appendix 2 for names and addresses of support groups.