

Section 1

Understanding the signs and symptoms of schizophrenia

Overview

Schizophrenia is one of the most challenging forms of mental illness. This fact is often felt keenly by the family members and other caregivers of the one per cent of the population who develop the illness. Though the signs can appear early on, the full illness usually appears relatively suddenly—likely in late teens for men and in middle to late 20s for women. It has so many different faces, outcomes and interpretations that even experts in the field have difficulty agreeing on how it should be defined and understood.

Regardless, it is a sad, stressful and life-altering circumstance for the family and friends of people who develop the illness.

There are, however, many advancements being made in schizophrenia research and its treatment. Research has revealed a more optimistic picture than we have held in the past, with increasing recognition that most people with schizophrenia can lead rewarding lives and contribute to their communities over the long term. Treatments have advanced as well, though they are not without shortcomings. We do not yet have a vaccine or a cure for schizophrenia. And while medications can help reduce symptoms, they often have negative side-effects. Additionally, while medications help with some symptoms, such as hallucinations, they are much less helpful with others, such as the impact schizophrenia has on attention and memory—and its “negative symptoms,” which we will describe in more detail on page 3. (For general information about schizophrenia, see a list of online resources in Appendix 1.)

Before discussing strategies to help manage the effects of schizophrenia, it is important to understand key aspects of the illness. You might already know a lot, but sometimes a refresher doesn't hurt!

Schizophrenia 101

Schizophrenia is a severe psychiatric illness characterized by positive symptoms, negative symptoms and cognitive problems.

Positive symptoms

Positive symptoms refers to hallucinations and delusions.

Hallucinations are experiences in any of the five senses that are often not linked to something happening in the person's environment. For example, someone may hear voices commenting on his or her behaviour. Or they may think that an angel or demon is speaking to them, and that the voices are coming from someone or something outside of themselves. Not only are these voices distracting (imagine someone yelling in your ear while you are trying to do a job interview), they can also be terrifying: imagine firmly believing that a demon is screaming at you.

Delusions are beliefs that are not true. For example, someone may believe that people are sending messages to them telepathically. Someone else might think that they are being stalked and watched by a religious group. Generally, these are beliefs that something (often something very upsetting) is happening in the world, despite evidence to the contrary.

When positive symptoms are severe, they may interfere with a person's ability to perform activities necessary in daily life, such as cooking or talking with others. Family members are often unaware of the extent of positive symptoms. Some people with schizophrenia have learned not to discuss these problems because it makes family members uncomfortable. Even though it can be difficult for the person to talk about, having you know how intense and frequent the voices are and what they say, or telling you how scary it is to believe that you are being followed, can help people with the illness to feel understood.

Arguing with your family member about the truth of symptoms like these is not helpful. Neither is saying that you agree with a delusion (e.g., agreeing that the person is being followed by cult members). Usually the best thing to do is simply to express understanding that the person is experiencing these voices and beliefs and to empathize with the stress that these symptoms are causing.

Hallucinations and delusions are not the focus of environmental support strategies, though they might have an impact on the strategies you choose and the pace at which you go in your plan.

Negative symptoms

Negative symptoms, the second major group of schizophrenia symptoms, are a range of challenges such as:

- showing little emotion
- having problems with motivation
- slowed movements
- withdrawing from others.

Sometimes people with schizophrenia use few gestures when speaking, tend to maintain the same facial expression no matter what they are talking about, and speak in a monotone. People may walk, dress and speak very slowly, or spend much of their time sitting or lying down. They may lack the motivation to set goals or make plans, even for performing everyday activities (e.g., showering, socializing, answering the telephone or taking out the trash). Some people with the illness keep to themselves even when others are in the room.

Clearly these problems interfere significantly with daily functioning. Many tasks may be left undone or only partially done, and the person may remain inactive much of the time. Health care workers, family members and even people with schizophrenia themselves may misinterpret negative signs as laziness or unco-operativeness. They may not realize this group of behaviours results from the illness itself.

Problems in motivation, movement, speech and socialization are often the signs of schizophrenia that family members are most concerned about and notice the most. Unfortunately, if this kind of withdrawal goes on too long, they may lose interest in things around them, have trouble identifying goals, lose opportunities for experiencing joy, and begin to have trouble with skills that were once easy for them.

These negative symptoms can be very persistent. While medication and other treatments might make gains in other aspects of the illness, negative symptoms frequently remain unchanged. Indeed, people for whom negative symptoms are the largest component of the illness often have the greatest struggles and need the most support. With this manual, you will learn many strategies to help the person you are supporting gradually move out from under the weight of this part of the illness.

Cognitive problems

Thinking or cognitive problems represent the third major challenge faced by people with schizophrenia. People with this illness often have trouble focusing their attention on an activity when distracting things are going on around them. For example, they may have trouble filling out a form while people are talking nearby. They may also have difficulty staying focused, sometimes for as little as a few minutes. Memory difficulties are also common. Remembering everything, from verbal and written instructions to completing routine day-to-day tasks, can present a tremendous challenge.

Finally, people with schizophrenia often have problems in what we call “executive” functions. This term refers to complex thinking processes such as making plans, starting an activity, carrying out the steps of a complicated task, and completing a task in the face of distractions. Like the executive of a company, our executive functioning in many ways directs our lives.

So often we hear people with schizophrenia and their families expressing frustration that while medications have reduced the impact of hallucinations and delusions, these cognitive problems remain, and greatly hamper their ability to get on with their lives—to pursue work, education, hobbies, and even to form friendships and romantic relationships.

How environmental supports can help with these challenges

This manual will help you and your relative formulate a plan to work around the cognitive problems and negative symptoms they experience in everyday life. The supports we recommend are based on rearranging the environment and teaching skills to help the person get around their cognitive problems and negative symptoms. Through being helped to bypass cognitive problems and find sources of motivation, people with schizophrenia can manage their lives better—professionally and otherwise—and with less support. Applying environmental supports is about collaborating on effective ways of overcoming some of the major barriers that schizophrenia can present, and getting on with a fulfilling life. It can be done. With the right supports and strategies, people can make tremendous strides.

Please see Appendix 1 for some of the many online resources available to people who want to expand their understanding of schizophrenia.