

Myths, Half-truths, and Common Misconceptions about Schizophrenia and Severe and Persistent Mental Illness (SPMI)

SOURCE: Adapted from the Center for Excellence in Community Mental Health is part of the Department of Psychiatry in the School of Medicine at the University of North Carolina at Chapel Hill.

It couldn't happen to me or anyone I love.

About 1 of every 100 people develops schizophrenia; 1 of every 50 develops some other psychotic illness.

It's a genetic illness. If you have a relative with schizophrenia, you or your children are likely to develop it too.

About 1 of every 100 people develops schizophrenia; 1 of every 50 develops some other psychotic illness. People with relatives who have schizophrenia have a slightly greater risk than others: the closer the relative, the greater the risk. You are at highest risk if you have an identical twin who has it. However, not all twins who have identical genes share this illness, so that proves that genes may play a role, but they are not the only factor responsible for the illness. If it were just a matter of genes, then if one identical twin got schizophrenia, the other always would too; in reality, this only happens in about half the cases.

Other factors that may play a role in who gets or doesn't get the illness are changes in the development of the brain in utero due to exposure to viruses, toxins, or lack of nutrients at critical periods. Stressors in early adulthood can play a role, too.

We still don't completely understand what causes schizophrenia. Many researchers think it may actually be different illnesses, with different origins, lumped together under one diagnostic label. Until we understand all this better, it will continue to be very hard to determine the likelihood that any given individual will get the illness.

It's a chemical imbalance/brain disorder that you can test for.

Although we think schizophrenia is a neurodevelopmental brain disorder that may involve chemical imbalances and possibly structural differences in the brain, we can't test for it at present. Researchers are exploring use of the human genome (map of genes both at the individual and larger group level), neuroimaging (highly detailed pictures of the brain), and electrophysiology (study of the brain's activity), to try to find indicators of illness. They are learning a great deal, but to date no markers that could be used as a test have emerged. (Source: OASIS Early Psychosis Toolkit)

I've never met anyone with a mental illness.

Chances are you have met someone with a mental illness, as one in five adults - experience a mental illness. Also consider that many people choose not to share information about their illness with others for fear of judgment or discrimination (stigma).

People snap and become psychotic with no warning or trigger.

For about half the people diagnosed with schizophrenia, their symptoms develop gradually, over the course of months or years. For the other half, it occurs more quickly, over the course of days or weeks. (Source: Textbook of Schizophrenia, p. 354)

The prodrome is a period of time during which the person's behaviors are markedly different from before and their ability to function overall declines, but they have not yet developed full psychosis. The prodrome period lasts on average from 2 to 5 years. (Source: Textbook of Schizophrenia, pp. 341-342)

Clinically, we have observed psychosis to be a stress-sensitive illness, as are many illnesses. Although sometimes it seems like symptoms just appear, we believe they are usually triggered by some perceived stress or stimulus (job loss, change in a relationship, etc.). Additionally, stressful events can trigger a relapse. As one of our doctors aptly puts it, "Anything that wigs you out can cause a relapse." Relapse planning or crisis planning is a process used by individuals and clinicians to identify triggers and to reduce their impact.

Schizophrenia is a severe and disabling illness that is downward-spiraling; people who have it will always be sick and will get sicker and sicker until they die.

Most individuals who develop a schizophrenic psychotic disorder will have a chronic illness. The severity of positive, negative, cognitive, and mood symptoms is highly variable, as is the severity of social and vocational disability. Long-term outcome varies from sustained recovery, to recurrent episodes with recovery between episodes, to varying severity of chronic, disabling, residual symptoms." (Source: Textbook of Schizophrenia, p. 290)

In our experience, a small group of people recovers almost fully with ongoing treatment, achieving satisfying work and social lives. A small proportion of people on the other end of the spectrum are severely disabled, unable to live independently or to care for themselves. The majority of people with schizophrenia fall somewhere in between. They live with some functional impairments and periodic crises, but also with skills, meaningful relationships, and engagement with their communities during significant periods of stability.

Most people whose psychosis is untreated have a period of up to five years when they experience a series of psychotic episodes, with decreased functioning after each episode. After that initial period, functioning tends to plateau, and remain at a similar level, despite crises. This new baseline may be very different from their level of functioning before they got sick (called

"premorbid"). It is our belief that with earlier treatment to prevent or delay some of those early episodes, a person's long-term level of functioning may be higher.

Early intervention won't help.

Early intervention can make a huge difference. "The onset of illness in the late teens to 20s for most affected individuals is a crucial time for psychosocial development. Emerging psychosis often derails normal development and early intervention may minimize functional losses." (Source: Textbook of Schizophrenia, p. 355) In addition, early intervention may prevent problematic or dangerous behaviors. The shorter the duration of untreated psychosis, the greater the chance that a person's baseline functioning will be better.

There's no point in getting help until the illness is really bad, full-blown, or someone gets hurt.

Treatment early in the process, even in the "at risk" or prodromal phases before full psychosis has developed, can pre-empt scary, risky behaviors and may prevent the development of full-blown psychosis altogether for some people. Those interventions can include individual and family therapy, education about the illness (psychoeducation), and close monitoring of symptoms. This allows the treatment team, including the individual and family, to build critical relationships, knowledge, and supports; to develop communication, problem-solving, coping, and stress reduction skills; and to catch emerging psychosis as early as possible.

People with schizophrenia are violent; and most violent crimes are committed by people with mental illness.

The media, whether through movies or sensationalized reportage of individual acts, would have us believe that people with schizophrenia are likely to commit extremely violent acts. On the contrary, research shows that individuals with schizophrenia who are in treatment are no more dangerous than the general population.

Individuals who are not in treatment do have increased risk for violence. It is not unusual for the first-episode patient to have done bizarre or aggressive acts. In fact, about a third of patients commit a violent act prior to first treatment contact that proves to be embarrassing to the patient, or affects their relationships, especially if the target of the aggression was a family member, employer, teacher, or friend. (Source: OASIS Early Psychosis Toolkit)

Individuals with schizophrenia who are the most dangerous are those who are not receiving treatment and are also abusing substances. Research also shows that most individuals with a serious mental illness who commit violence, hurt people they know and see on a regular basis, usually family caretakers. Studies have shown that between 50 and 60 percent of the victims are family members.

Schizophrenia means having multiple personalities. People with schizophrenia believe two opposing views of something at the same time (ex. "I am schizophrenic on that issue.").

Despite the meaning of the Greek words from which the name was derived that translate as "split mind," schizophrenia is not a case of multiple personalities (dissociative identify disorder), nor is it the state of thinking two opposite things at once. The key features of the illness were originally thought to be the split from reality people experience when they believe their delusions or perceive hallucinations.

Schizophrenia is just a bad case of the nerves, a nervous breakdown; the person just needs some rest.

The idea that schizophrenia is a bad case of the nerves is closer to reality than some of the other myths because many people with this illness suffer from terrible anxiety, either as a primary symptom, or secondary to the other perceptual events they are experiencing (hearing voices, paranoia, etc.). Unfortunately, rest at a lovely spa somewhere will not cure this complex illness.

Schizophrenia is caused by bad parenting.

In the 1950s, some therapists working with families thought that schizophrenia was caused by bad parenting, and coined the term "schizophrenogenic," (causing schizophrenia), which was usually applied to mothers. While fun to say, this term was neither helpful nor accurate, putting unwarranted blame on families already struggling to come to terms with the burdens of a chronic illness.

It is true that high-stress family situations may exacerbate the illness when families fail to recognize problems, to initiate early treatment, or to provide good communication, problem-solving, boundaries, and support; but these things do not cause schizophrenia

Street drugs can make people feel better, make symptoms go away. If a psychotic break is triggered by substance abuse, it will go away once the substance use stops.

Substance use can cause psychosis that will resolve when the substance is cleared from the user's system, particularly stimulants, cocaine, and cannabis. It can also trigger an underlying psychotic disorder that hasn't manifested yet, that subsequently may never go away. That's a big risk. Marijuana in particular may be an environmental risk factor for psychosis in some biologically predisposed individuals.

Marijuana is an interesting drug, because the different chemicals in it have different effects on the brain. THC causes hallucinations and negative symptoms, while cannabidiol can have anti-anxiety and anti-psychotic effects. This is why many people with psychosis claim marijuana helps them feel better, although simultaneously it may be making their symptoms worse.

(Source: OASIS Early Psychosis Toolkit)

If a person is intelligent, they will understand they are ill and shouldn't be bothered by hallucinations or delusions.

Part of the definition of hallucinations and delusions in people with schizophrenia is that regardless of their intelligence or rational evidence to the contrary, the person believes this idea, or this perceptual experience, to be true. The experiences feel very real, which can cause tremendous anxiety. This occurs across the range of intelligence.

Once a person is diagnosed, they understand their symptoms and aren't affected by them as much. You can talk someone with schizophrenia out of their delusions.

Pointing out a person's symptoms, or labeling them with a diagnosis, is rarely enough to make symptoms go away, whether you are talking about depression, mania, psychosis, or any other illness for that matter. Just telling a person it is a delusion, or a product of their mind rarely helps.

The idea of insight, having an understanding of the illness and its effects, is what many of the psychosocial treatments work to instill. Using the process of psychoeducation, a care provider teaches about the specific illness, how it affects people, and how treatments work. Cognitive-behavioral approaches help people evaluate their beliefs and how those affect their feelings and behaviors. Group interventions help break the isolation and allow peers to educate each other and practice skills together. Family psychoeducation and family groups help families understand these interactions and reinforce them outside of the session.

Over the course of an illness, individuals can achieve a great deal of insight and significant coping skills that will help them not only understand but manage their symptoms. That is often a gradual process achieved over time, and can be an important part of the recovery process.

Once the hallucinations or delusions are controlled by medications, the person should be able to return to normal and get on with his or her life.

To a degree this may be true, but for some people with schizophrenia, medications do not completely control the positive symptoms (hallucinations, delusions, and disorganized behavior), nor do they have much effect on the negative symptoms (brief or no replies in conversation, lack of motivation, inability to experience pleasure, blunted affect), or cognitive symptoms (impaired attention, memory, and executive functioning). Given that these other symptoms can affect a person's ability to function as much as or even more than the positive symptoms, it's clear that the medications we have currently are not always enough to return a person to full recovery. That's why we recommend a team approach to treatment that includes medications and psychosocial interventions.

Once a diagnosis is given, it will never change.

There are several reasons why diagnoses may change over time.

1. Sometimes a diagnosis designates a very specific timeframe for duration of symptoms. For example, more than one day but less than one month is called a brief psychotic disorder. More than one month but less than six months is called schizophreniform. If the person is given one of those diagnoses but symptoms continue, the diagnosis will need to be updated.
2. Sometimes the clinicians don't have the whole picture when they assign a diagnosis. For instance, they may meet a person with depression and diagnose major depressive disorder, but later the person experiences a manic episode, which would indicate bipolar disorder. A new diagnosis will need to be added.
3. Periodically the guidelines for diagnosis, the Diagnostic and Statistical Manual, are revised to reflect new information on mental illness. When that happens, symptoms may be categorized differently for scientific accuracy. Diagnoses may have new criteria, get new names, or may disappear into another category altogether.

If you have questions about diagnoses, talk with the clinicians who assigned them, or those with whom you are working now, to get clarification. Sometimes a wacky diagnosis may be the result of a clerical error, and those should definitely be corrected.

People with schizophrenia tend to live in institutions.

People with mental illness do tend to spend time in institutions during their lifetimes; not only hospitals, but also jails and prisons. Most stay for relatively brief periods.

People with SPMI also live independently, in supported housing, or in the community with family members. Between 40 to 80 percent live with family, depending on the sub-group. People with SPMI who are from sub-groups that have traditionally cared for their ill and elderly at home, such as African-Americans, tend to live with family at higher rates.

Long-term hospitalization is an option for treatment of schizophrenia.

For better or for worse, long-term hospitalization is a very scarce resource, largely due to cost. Those who stay longer stay for one primary reason: "Schizophrenic patients who remain in state psychiatric hospitals for a prolonged period often have an illness complicated by persistent violent behavior," (Textbook of Schizophrenia, p.399). We assume this applies to the mentally ill people in prison too.

People pretend to be ill just to get disability and to get out of working.

Applying for disability is a fairly daunting bureaucratic process, and one that is often unsuccessful on the first try, even for people with a clear disability. Most people would agree that the amount they get (approximately \$750/month in Manitoba), is not enough to support more than a very meager existence.

People with mental illness would rather be homeless than do what it takes to maintain a place to live.

Many of our nation's people living without housing have severe mental illness. But it's anyone's guess how much of that is by choice rather than being due to illness-related factors or larger, system-wide issues. For example, many factors can play a role, including disorganization, cognitive deficits, poor impulse control, paranoia, burnout or alienation of family, deinstitutionalization, and lack of adequate low-income or supported housing, or residential treatment services. The link between homelessness and mental illness is well documented:

- 30-35 percent of the homeless in general, and up to 75 percent of homeless women specifically, have a mental illness.
- 20-25 percent of homeless people suffer from concurrent disorders (severe mental illness and addictions).
- People who have a severe mental illness are over-represented in the homeless population, as they were released from hospitals and jails without proper community supports in place for them.
- People with mental illness 'remain homeless for longer periods of time and have less contact with family and friends. They encounter more barriers to employment and tend to be in poorer health than other homeless people.' (Source: CMHA)

People stop taking the medication because they feel better, or because they're lazy and would rather be ill than have to work.

Research shows that at some point during the course of any illness, physical as well as mental, most people go off their medicines. There are many reasons a person may stop taking their medication, including: 1) The drug has stopped the symptoms. 2) They don't want to believe that they are chronically ill and need medicine. 3) The medicine has powerful, negative side effects such as sedation, agitation, constipation, weight-gain, and worse. 4) They can't afford a particular medication.

Physicians don't let patients have a say about which medications to take.

A good psychiatrist will seek input from the patient about his or her medication preferences, if options are available that don't compromise patient safety. This includes class of drug, side effect profiles, patient or family history with similar drugs, generic vs. name brands, and cost, among others.

People with schizophrenia push shopping carts and smell bad. People with schizophrenia can't make meaningful contributions to the world.

It is true that some people with schizophrenia store their belongings in shopping carts and may neglect their hygiene, like Nathaniel Ayers, depicted in Steve Lopez's book, *The Soloist*. But it's also true that some people with schizophrenia hold chaired professorships at world-class universities, like Elyn Saks, PhD, who shares her story in the book, *The Center Cannot Hold*. These books illustrate that both of these individuals have added to the beauty and mystery of the world by being in it. And while not everyone with schizophrenia will make publication-worthy contributions, they all have the potential to find important work and develop meaningful relationships with the people in their families and communities.

You can't have a conversation with a person who is psychotic.

Sure you can! The conversation may be a little different than your average conversation, but that doesn't mean you shouldn't undertake it.

Some people with schizophrenia may be distracted by positive symptoms, voices they are hearing, things they are seeing, or beliefs they are having. For instance, they may think that you can read their mind or are thinking horrible things about them. All those distracting thoughts make it harder for them to have a topical conversation. People with significant negative symptoms may show little interest in conversation, or little emotional response to conversation, but that doesn't necessarily mean they don't want to talk. People with significant cognitive impairments may not always make sense; they may use the wrong words, use new, made-up words, or drift away from the topic.

All of these examples represent the more severe end of the spectrum, some of which could be positively affected by medications. Symptoms may be better or worse depending on the day, and may vary in severity as people move in and out of crisis, or become stabilized. Someone who is hard to converse with at one point may be very different after a hospitalization, a medication change, or a little time. The bottom line is that most people with these illnesses can and will participate in and benefit from regular old conversation. And you will benefit too, if you engage with the person.

Therapy is useless with someone who has a psychotic disorder.

Therapy may not be the most appropriate intervention when a person is acutely psychotic, but individual, group, and family therapy may be very helpful at many stages of the recovery process. There is strong evidence that treating psychosis by using cognitive-behavioral therapy (CBT) or some of its offshoots, along with supportive interpersonal therapy, will enhance treatment adherence. A therapist's job is to build a healthy clinical relationship with the individual, and in doing so to learn what supports and interventions the individual will need to manage their illness and find their place in the world.

Elyn R. Saks writes very eloquently about the importance of therapy in her recovery process. "...what has allowed me to see the meaning in my struggles - to make sense of everything that happened before and during the course of my illness, and to mobilize what strengths I may possess into a rich and productive life - is talk therapy. People like me with a thought disorder are not supposed to benefit much from this kind of treatment, a talk therapy oriented toward

insight and based upon a relationship. But I have. There may be a substitute for the human connection - for two people sitting together in a room, one of them with the freedom to speak her mind, knowing the other is paying careful and thoughtful attention - but I don't know what that substitute might be." (Source: *The Center Cannot Hold*, p. 331.)

People with an illness like schizophrenia don't need social support or friends.

Due to their tendency toward isolation out of anxiety, paranoia, negative symptoms, or shame and fear of stigma, people with these illnesses need support as much or more than most people, particularly from family and friends. This can be hard, as there is often so much transition and loss in the manifestation of a mental illness, but there is much to be regained through the recovery process. The relationships may not be the same as before the illness, but they are extremely important.

People with schizophrenia can't be good parents, employees, or neighbors.

As with any severe or chronic illness, the patient's ability to fulfill social roles will depend on the degree to which they are able to achieve and maintain stable recovery from the effects of illness. If a person's illness is severely debilitating, they will not be able to fill these roles, or fill them well. But many people with schizophrenia and other SPMI's can and do make good neighbors, employees, and parents.

People with mental illness are talented artists, or highly creative people who always think outside of the box.

Although many people with mental illness are artists, musicians, writers, or otherwise gifted individuals (famous or not), they have those talents in spite of the illness, not because of it. Some people don't discover their talent, or have the time to develop it, until they become ill. But chances are they would have been creative even if they had not become ill. This doesn't mean their work is unaffected by their illness; because how prolific the work is, the themes it covers, or the media chosen may, in fact, be affected by the illness. But the myth that mental illness is the gateway to creativity doesn't hold up under scientific scrutiny.

Education, or being smart, can protect you from getting schizophrenia.

Education is not a protective factor against schizophrenia. However, because of the age at which the illness strikes, many people have their first psychotic episodes while away at college.

People with mental illness are mentally "retarded."

Schizophrenia and other SPMI's affect people across the cognitive spectrum, whether they have a high or low I.Q. A person can be diagnosed with a mental disability/challenge and also have psychosis or depression.

People with schizophrenia can't learn new things.

Schizophrenia can affect cognition, making it more difficult to pay attention, remember things, think abstractly, organize thoughts and behaviors, make decisions, learn new things, and communicate. Despite these challenges arising from thought disorders and cognitive impairments, people with schizophrenia do successfully go to school, hold jobs, and do things that require them to use their brains in multiple ways.

You can treat schizophrenia with herbal remedies and naturopathy.

The research is still unclear on this. Some symptoms of schizophrenia may be exacerbated by nutritional deficits, but to date no herbal remedies or naturopathy has proven to consistently address the illness. Check with your doctor first, to make sure any nutritional supplements you are considering are safe.

If a person is a true religious believer, they shouldn't have to take medicine; prayer and faith should be enough to heal them.

Prayer and participation in a faith community can be a very important part of a person's recovery process. Doing that in lieu of medication can be a recipe for relapse. The best solution is to do both, involving chosen members of the individual's faith community in the treatment process, and including important religious practices as part of the individual's health maintenance routine. Faith partners can be important in helping a person keep his or her recovery on track. And involvement in a faith community that is safe and supportive for people with mental illness can be an important community connection.

The media (TV, newspaper, radio, internet, commercials) are the best sources of information about mental illness.

Sometimes the media do a decent job; other times they spread misinformation and stigma.

Some of the best sources of good information are evidence-based practice centers, research groups or specialty clinics, mental health professionals (psychiatrists, social workers, etc.), and experienced family members and peers (people with the illness). Any time you come across a source of information, it is important to consider who it is, who they are affiliated with, and who is funding their work. And it never hurts to check other sources, cross-reference the information, or get a second opinion.