schizophrenia
The National Alliance on Mental Illness (NAMI) is the nation's largest grassroots mental health organization dedicated to building better lives for the millions of Americans affected by mental illness. NAMI has more than 1,100 State Organizations and Affiliates across the country that engage in advocacy, research, support and education. Members are families, friends and people living with mental illnesses such as major depression, schizophrenia, bipolar disorder, obsessive compulsive disorder (OCD), panic disorder, posttraumatic stress disorder (PTSD) and borderline personality disorder.

Written by Ken Duckworth, M.D. with additional input by Irving Gottesman, Ph.D., and Charles Schulz, M.D. Copyright 2011 by the National Alliance on Mental Illness. Copies of this publication can be purchased at www.nami.org/store.

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Introduction

Schizophrenia is a serious mental illness that affects more than 2 million adult American men and women. While the condition is rare in childhood, it can begin onset in the mid- to late teen years. Reading this brochure is an important first step to answering your questions and understanding recovery for people living with schizophrenia.

People living with schizophrenia have talents, goals and feelings just like anyone else. But, if left untreated, their illness can have a profoundly negative effect on their own lives, their families and their communities. Because the illness may cause unusual, inappropriate and sometimes unpredictable and disorganized behavior, people who are not effectively treated are often shunned and can become the targets of social prejudice. People living with schizophrenia may also face poverty, homelessness and high risk for suicide.

Lack of services has left many people living with schizophrenia inappropriately placed in jails and prisons. Medication, rehabilitation and other community-based supports can often help people living with schizophrenia lead meaningful, satisfying lives.

This brochure will explain the symptoms, discuss treatment options and explore the latest in schizophrenia research. You’ll also find information on where you can turn for medical care and find the support needed to manage this persistent illness. Stay up-to-date on emerging research and treatments at www.nami.org/research.
Schizophrenia Defined

Dispelling Myths
There have been so many misconceptions about schizophrenia throughout history that it’s best to begin by looking at what schizophrenia isn’t.

● **MYTH:** Schizophrenia is the same as “split” or “multiple personality.”

  **FACT.** The origins of the word schizophrenia have contributed to this confusion. In an effort to describe the mismatch he observed between the feelings and thoughts of people experiencing this medical condition, Eugen Bleuler, a Swiss psychiatrist at the turn of the twentieth century, proposed the terms schizo (split) and phrenic (mind) to capture this juxtaposition. Many people have confused this term with so-called “split” or “multiple” personality (now called dissociative identity disorder), but there is no relation between the two conditions.

● **MYTH:** Schizophrenia is caused by bad parenting or personal weakness.

  **FACT.** Schizophrenia is a medical illness caused by a variety of factors including genetics, stress, substance use and trauma, among others.

● **MYTH:** People living with schizophrenia are violent.

  **FACT.** Almost all people living with schizophrenia are not dangerous when they are engaged in treatment, although the behavior of a person living with schizophrenia can be unsettling or unusual. Violence is a noteworthy risk for some people living with schizophrenia who are not in treatment and who also have co-occurring alcohol or drug use problems.

What Is Schizophrenia?
Schizophrenia is a mental illness that interferes with a person’s ability to think clearly, manage emotions, make decisions and relate to others. Many people living with schizophrenia have hallucinations and delusions, meaning they hear or see things that aren’t there and believe things that are not real or true. Organizing one’s thinking, performing complex memory tasks and keeping several ideas in mind at one time may be difficult for people who live with the illness. About one-half of people living with schizophrenia do not have awareness that their symptoms are part of an illness process. This neurological component to schizophrenia often complicates care efforts.
Research has linked schizophrenia to changes in brain chemistry and structure. Some of these changes may be present very early in life. Like diabetes, schizophrenia is a complex, long-term medical illness that affects everybody differently. The course of the illness is unique for each person.

**Diagnosing Schizophrenia**

There is no single laboratory or brain imaging test for schizophrenia. Treatment professionals must rule out multiple factors such as brain tumors and other medical conditions (as well as other psychiatric diagnoses such as bipolar disorder). At the same time, they must identify different kinds of symptoms that manifest in specific ways over certain periods of time. To make matters more complicated, the person they are treating may be in such distress that they have a hard time communicating. NAMI knows from the results of its report, *Schizophrenia: Public Attitudes, Personal Needs*, that it often takes a decade for people to be properly diagnosed with schizophrenia. A health care provider who evaluates the symptoms and the course of a person’s illness over six months or more can help ensure a correct diagnosis.

Since scientific knowledge is changing all the time, the diagnostic criteria may change as well. Schizophrenia has been categorized in several subtypes such as paranoid, catatonic, disorganized and undifferentiated, but these divisions may be phased out in favor of a syndrome model that includes multiple dimensions.

The *Diagnostic and Statistical Manual of Mental Disorders (DSM)*, the book health care professionals use to diagnose mental illness, provides a set of common standards. The DSM often gets revised as new research develops, and a fifth edition is due out in 2013. Find out more about the DSM at www.dsm5.org.

The current *DSM IV* lists the following as schizophrenia classification guidelines in patients if two or more occur persistently. However, delusions or hallucinations alone can often be enough to lead to a diagnosis of schizophrenia.

- Delusions
- Hallucinations
Disorganized speech
Disorganized or catatonic behavior
Negative symptoms (see page 5)

Health care providers also look for social/occupational dysfunction in one or more areas:
• Work or school
• Interpersonal relations
• Self care

Health care providers look for duration of these symptoms in this pattern:
• Persist for at least six months
• Include symptoms from the symptoms above for at least one month
  - May include periods of prodromal (early signs) or residual symptoms or only symptoms from the social bullet section or two or more symptoms from the first section of bullets, with less intensity

Health care providers make sure the following are not present:
• Sustained mood disorder symptoms during the episode*
• The direct effects of substance use
• An underlying medical condition
• A pervasive developmental disorder (such as autism)
  unless prominent delusions or hallucinations are present

According to current research, it is extremely important to identify schizophrenia as early as possible. Studies show that catching schizophrenia early can increase the chances of managing the illness and recovery. If identified and treated early on, schizophrenia can be managed fairly well and the chances of subsequent psychotic episodes are greatly reduced. The DSM 5 manual of the American Psychiatric Association is at this time considering whether to include a diagnosis for early onset of symptoms consistent with this line of thinking.

The Symptoms of Schizophrenia
As you can see from the DSM criteria, no single symptom positively identifies schizophrenia. On top of that, an individual’s symptoms can change over time. The symptoms of schizophrenia are generally divided into three categories: positive, negative and cognitive symptoms.

*Note: Schizoaffective disorder is characterized by a combination of the symptoms of schizophrenia and an affective (mood) disorder. Most clinicians and researchers agree that it is primarily a form of schizophrenia. Learn more about schizoaffective disorder at www.nami.org/schizoaffective.
Positive symptoms are also known as “psychotic” symptoms because the person has lost touch with reality in certain ways. The term “positive symptoms” refers to mental experiences that are “added on” to a person’s usual experience—typically these are hallucinations and delusions.

- **Hallucinations** cause a person to hear voices inside or outside their heads or, less commonly, see things that do not exist.
- **Delusions** occur when someone believes ideas that are clearly false, such as that people are reading their thoughts or that they can control other people’s minds.

Negative symptoms do not refer to negative thinking, but rather reflect symptoms that indicate reduction of a capacity, such as motivation. Negative symptoms often include emotional flatness or lack of expressiveness, an inability to start and follow through with activities, speech that is brief and lacks content and a lack of pleasure or interest in life. Difficulties with social cues and relationships are common. These symptoms challenge rehabilitation efforts, as work and school goals require motivation as well as social function. Negative symptoms can also be confused with clinical depression.

Cognitive symptoms pertain to thinking processes. People living with schizophrenia often struggle with executive functioning (prioritizing tasks), memory and organizing thoughts. Cognitive function is involved in many tasks of daily living—especially in work or school settings. A common cognitive deficit associated with this condition is anosognosia or “lack of insight”—when someone is not aware of having an illness. This difficulty in understanding is based in the brain—it is not a choice or psychological denial—and can make treating or working with people who live with schizophrenia much more challenging. I Am
Not Sick, I Don’t Need Help, a book by Xavier Amador, Ph.D., is a great resource for dealing with this challenge.

Medications are crucial to symptom control, and other psychological strategies are also gaining acceptance to augment their impact. For example, a treatment called Cognitive Behavioral Therapy (CBT) is well-established as a useful strategy to help people actively manage their hallucinations. See page 13 for more on CBT.

Causes
Researchers still don’t know exactly what causes schizophrenia, but they do know that the brains of people living with schizophrenia are different, as a group, from the brains of those who don’t live with the illness.

Research strongly suggests that schizophrenia has something to do with problems involving brain chemistry and brain structure and, like many other medical illnesses, is thought to be caused by a combination of problems, some inherited and others occurring during a person’s development. For example, some researchers think that schizophrenia may be triggered by a viral infection affecting the brain very early in life or by mild brain damage from complications during birth. Drug use can trigger underlying genetic vulnerability in a person. It is still premature to label schizophrenia as either a neurodevelopmental (impairment of the growth and development of the brain) or a neurodegenerative (progressive loss of structure or function of neurons) disorder, as both seem to be in play over the course of the illness. Scientists are working to understand if changes in the brain are present early in life and how much those changes worsen over time.

People can develop schizophrenia at any age. About 1 percent of the world’s population develops schizophrenia, meaning that out of all the people born today, one in 100 will develop the disorder by the time they reach age 55. About 75 percent of people living with the illness develop it between the ages of 16-40; women typically have a later onset than men. Children can also be diagnosed with schizophrenia, though this is quite rare before the age of 12. New cases are uncommon after age 40.

Extensive and intensive molecular genetic research programs continue to generate hope that specific combinations of genes will provide an answer to the riddle of what causes schizophrenia and other psychoses. Just like in the early stages of cancer and diabetes research, more time and innovative research are needed to learn more about this complex disorder.
The Genetics of Schizophrenia

Doctor and family historians have long noticed that mental illnesses like schizophrenia seemed to occur more often in certain families, but scientists are only beginning to unravel the complex genetic components that underlie these conditions.

Unlike genetic conditions like Huntington’s Disease or cystic fibrosis, which are related to differences on a single gene, mental illnesses like schizophrenia and bipolar disorder have a more complex pattern of inheritance and depend on both genetic and environmental factors. Whereas we know someone with a single-gene trait has a predictable chance of passing on the condition to their children (one in two or one in four), it is difficult to determine the exact probability of an affected parent passing a genetic risk for schizophrenia along to a child, and even harder to predict if that child will go on to develop the illness.

Studies of identical twins (who share the same genetic information) have found that if one is living with schizophrenia, the other has roughly a 50 percent chance of developing the condition, which is about three times that of fraternal twins and nearly 50 times that of the general population. This genetic component appears to extend beyond family environment. For example, children with one parent living with schizophrenia who were put up for early adoption still develop schizophrenia at a higher rate than the rest of the population. Yet genetics are not the whole story, which strongly suggests that there are other environmental factors involved in possibly developing the illness.

Many people living with schizophrenia, their family members and even their distant relatives may have questions about the role of genetics in developing schizophrenia. Genetic counselors may provide useful information for anyone who is interested in the way their diagnosis of schizophrenia or that of a relative relates to the rest of the family. It is important to point out that the advances in gene-finding, when they occur, cannot be used to discriminate against patients or their family members in the realm of health insurance; the Genetic Information Nondiscrimination Act (GINA) signed into law in 2008 was designed to benefit both genetic research and to protect the privacy of those families affected.

The National Institute of Mental Health website, www.nimh.gov, is a good place to start when searching for updates on the developing field of genetics and mental illness.
Treatment and Recovery

The treatment of schizophrenia requires an all-encompassing approach, and it is important to develop a plan of care that is tailored to each person’s needs. Mental health care providers and the individual should work together to craft this plan.

Finding the right medication is one important aspect of symptom management, but other services are also needed in order to promote recovery. Rehabilitation strategies involving work, school and relationship goals are also essential and need to be addressed in creating a plan of care. Peer support—learning from someone who has “been there”—is a growing area of the field and can also provide employment opportunities for people living with mental illness. See the resources section for peer support group information.

The fact that schizophrenia occurs in all cultures means that treatment options should account for these differences in cultural context. See “The Social Aspects of Mental Illness” on page 14 for more information about culture and treatment.
Most people living with schizophrenia can manage their conditions with the interventions listed in this section. Long-term research demonstrates that, over time, individuals living with schizophrenia often do better in terms of coping with their symptoms, maximizing their functioning while minimizing their relapses. Recovery is possible for most, though it is important to remember that some people have more trouble when it comes to managing their symptoms. Although many effective treatments exist, more research is needed to promote greater understanding, more effective treatments and a potential cure for schizophrenia and other mental illnesses.

“There were three essential elements to my journey of recovery. One: getting out of my bedroom and socializing. Two: getting on the right medication. Three: Using my dad to help with my faulty perception of reality. It is very important for someone with my illness to find a person they can trust—and believe—to give them a reality check.

I tell you today that there is hope. With new medications, with therapy, with the will to recover and the ever-present support of my family, I am reclaiming my life. It hasn’t been easy and there is still a long bumpy road ahead, but I am determined to completely beat this thing. I take my medication every day. I am certainly not healed, and my life is not perfect, but I run the illness, the illness does not run me.”

-Pat Quinn on living with schizophrenia

Medication

A cure for schizophrenia has not yet been found, but most people’s symptoms can be improved with medication. The primary medications for schizophrenia, called antipsychotics or neuroleptics, help relieve the hallucinations, delusions and, to a lesser extent, the thinking problems people can experience. These medications are thought to work by correcting an imbalance in the chemicals that help brain cells communicate with each other.
The first-generation of antipsychotic medications were introduced in the 1950s. These earlier medications, now called conventional, or typical, antipsychotics, often have side effects of restless motion (called akathisia), Parkinson-like symptoms (e.g., stiffness, dry mouth, sedation) and can cause a disabling, embarrassing and untreatable movement disorder called tardive dyskinesia.

<table>
<thead>
<tr>
<th>First-generation Antipsychotics</th>
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<tbody>
<tr>
<td><strong>Generic Name</strong></td>
<td><strong>Brand Name</strong></td>
</tr>
<tr>
<td>Chlorpromazine</td>
<td>Thorazine</td>
</tr>
<tr>
<td>Fluphenazine*</td>
<td>Prolixin</td>
</tr>
<tr>
<td>Haldolperidol*</td>
<td>Haldol</td>
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<tr>
<td>Loxapine</td>
<td>Loxtane</td>
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<tr>
<td>Perphenazine</td>
<td>Trilafon</td>
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<tr>
<td>Thoridazine</td>
<td>Mellaril</td>
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<tr>
<td>Thiothixene</td>
<td>Navane</td>
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<tr>
<td>Trifluoperazine</td>
<td>Stelazine</td>
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</table>

There is a second-generation of antipsychotic (SGA) drugs called atypical antipsychotics, so called because they do not cause most of the movement problems noted above. SGAs appear to have a relatively lower risk of causing tardive dyskinesia, the movement disorder that is the most troubling problem with conventional antipsychotic medications. In some cases, switching to clozapine may provide some relief for tardive dyskinesia. If movement disorders are a concern, individuals should speak with a health care provider.

<table>
<thead>
<tr>
<th>Second-generation Antipsychotics</th>
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<tbody>
<tr>
<td><strong>Generic Name</strong></td>
<td><strong>Brand Name</strong></td>
</tr>
<tr>
<td>Aripiprazole</td>
<td>Abilify</td>
</tr>
<tr>
<td>Asenapine</td>
<td>Saphris</td>
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<tr>
<td>Clozapine</td>
<td>Clozaril</td>
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<tr>
<td>Iloperidone</td>
<td>Fanapt</td>
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<tr>
<td>Lurasidone</td>
<td>Latuda</td>
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<tr>
<td>Olanzapine</td>
<td>Zyprexa*</td>
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<tr>
<td>Paliperidone</td>
<td>Invega*</td>
</tr>
<tr>
<td>Quetiapine</td>
<td>Seroquel*</td>
</tr>
<tr>
<td>Risperidone</td>
<td>Risperdal</td>
</tr>
<tr>
<td>Ziprasidone</td>
<td>Geodon</td>
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* Also available in long-acting injectable at time of publication, 3/2011.
Clozapine (Clozaril) was the first atypical antipsychotic in the United States and it has demonstrated a clear advantage over the other medications for difficult-to-treat symptoms. Clozapine is often a very effective medication, particularly for people who have not responded well to at least two other antipsychotic medication trials (a trial requires adequate dose and duration). A drawback is that it requires blood monitoring to check for—and prevent—a very rare adverse effect: a decrease in white blood cells which increases the risk for infection. Clozapine appears to reduce the symptoms of schizophrenia in some people, but it is hard on the body and may lead to weight gain, diabetes and other medical conditions. Clozapine has also been shown to reduce suicide risks for individuals living with schizophrenia. Clozapine has complex risks and benefits.

Other atypical medications do not require blood monitoring. However, they all can cause important, yet largely preventable, side effects: weight gain and metabolic syndrome, which is increased triglycerides and risk of diabetes or cardiac disease. Clozapine and olanzapine have the highest risk of these problems; ziprazidone and aripiprazole have the lowest. Learn more about preventing these medical risks at the NAMI Hearts & Minds website at www.nami.org/heartsminds.

Two SGAs—risperidone (Risperdal) and aripiprazole (Abilify)—are approved by the FDA for use in teenagers aged 13-17. The FDA periodically approves medications. For a current list, visit www.fda.gov.

Choosing an Antipsychotic
The Clinical Antipsychotic Trials of Intervention Effectiveness (CATIE) study, funded by the National Institute of Mental Health, released in 2006, looks at medication adherence in individuals with chronic schizophrenia. The study, which raises more questions than it answers, confirms that the differences in side effects in and between these newer and older medications are substantial, which further emphasizes the need to individually tailor the treatment to the individual. Another noteworthy aspect is that among severely ill individuals who did not respond to other treatments, most subjects in the study did not continue their treatments. This is another argument for letting the individual and the doctor choose the best medicine.
Psychosocial Rehabilitation
Like all people, individuals living with schizophrenia typically have important goals for themselves in the areas of relationships, work and living. Psychiatric rehabilitation strategies are designed to enable people to compensate for, or eliminate, the environmental and interpersonal barriers as well as the functional deficits created by this illness. The field of psychosocial rehabilitation helps people successfully live in independent housing, pursue education, find jobs and improve social interaction. Learn more about psychosocial treatment such as Cognitive Behavioral Therapy and supported employment in "The Social Aspects of Mental Illness" on page 14.

ACT, or PACT, known as Assertive Community Treatment, is an evidence-based, service-delivery model that provides comprehensive, locally based treatment to people living with serious mental illness such as schizophrenia. Available 24 hours a day, seven days a week, ACT professionals meet people where they live, providing at-home and in-community support at whatever level is needed. Professionals work with individuals living with mental illness to address problems proactively, helping to make sure that crises do not happen, ensure medications are being properly taken and assist in helping individuals meet the routine challenges of daily life. Visit www.nami.org or see the link in the resources section of this brochure for more about ACT.

Medical Care and Wellness
People living with schizophrenia are subject to many medical risks and typically receive poor medical care. High rates of smoking (which may have positive impacts on memory for some but very bad health effects overall) and co-occurring alcohol and drug problems can endanger an individual’s health. Risks of obesity and diabetes related to some of the medications noted above are also of significant concern. Research shows that monitoring is often not adequate for these metabolic side effects. Learning how to better manage your own health—becoming a self advocate—is very important.

Better and more integrated care is essential for people living with schizophrenia. Diet, exercise and other supplements play a big role in managing health. There is interest in the potential of omega-3 fatty acids (found in fish oil) to improve brain health and outcomes for individuals living with mental illness. Ask your doctor about the latest research on this evolving area of the field. On the NAMI Hearts & Minds website, there are tools and information on health, wellness, self-care and support.
Schizophrenia and Co-occurring Disorders

When someone is living with schizophrenia and another medical or psychiatric condition (known as a co-occurring disorder), it is important that all aspects of care are coordinated, especially medications. It is not uncommon for people living with schizophrenia to experience depression, although it may be difficult to distinguish depression (low mood) from the negative symptoms that affect someone’s ability to display emotion. Symptoms of depression in addition to the existing symptoms of schizophrenia may significantly add to a person’s distress and increase the likelihood of suicide. It is important to discuss any possible symptoms of depression with a health professional and examine antidepressants, such as Selective Serotonin Reuptake Inhibitors (SSRIs) that may be safely added to the current treatment.

About 25 percent of people living with schizophrenia also have a substance abuse disorder, frequently called a dual diagnosis. While it may seem like a way to escape from the distressing experiences associated with the illness, substance abuse can make treatment for schizophrenia less effective or make people less likely to follow their treatment plan. Drugs like marijuana and stimulants such as amphetamines or cocaine may make symptoms worse. Marijuana use, in particular, is thought to have a correlation with the onset of schizophrenia, perhaps triggering the illness in those with a genetic predisposition. Traditional 12-step programs, such as Narcotics Anonymous and Alcoholics Anonymous, can be effective for some people living with schizophrenia, while others do better with treatment specialized for the needs of individuals living with a dual-diagnosis.

Therapy and Cognitive Aspects

Medication is an important way to reduce symptoms, but some studies have shown that people living with schizophrenia can also benefit from changing their approach to symptom management. In particular, Cognitive Behavioral Therapy (CBT) has been shown to be an effective part of a treatment plan for some people living with schizophrenia, and it is widely used in the United Kingdom. CBT, which is becoming more widely available in the U.S., engages the individual in developing proactive coping strategies for persistent symptoms.

Many people report that it is beneficial to have someone to discuss their experiences with. Talk therapy is a helpful tool in learning how to better manage mental illness.
Peer support groups like NAMI Peer-to-Peer and WRAP (Wellness Recovery Action Plan) encourage involvement in recovery by working on social skills with others. The Illness Management Recovery (IMR) model is an evidence-based approach that emphasizes setting goals and acquiring skills to meet those goals. The clubhouse recovery model promoted by the International Center for Clubhouse Development (ICCD) helps individuals move towards recovery by providing a safe place to socialize and work. See the resources section for more information.

Complimentary and Alternative Medicine (CAM) refers to practices that are not part of standard care and do not carry scientific evidence. However, respecting a person's culture and personal choice in managing his or her illness should be a top priority. Meditation, acupuncture or other alternative approaches can be beneficial when it comes to managing personal well-being.

In the beginning, schizophrenia may completely alter a person's way of life, affecting daily functional tasks from personal hygiene to eating well and following medical treatment. Although new and better treatments allow many people to return to more active lives, many people living with schizophrenia may need help over the long term with their basic needs, such as money, housing, food and clothing. One goal of recovery is to promote as much independence as possible.

Recovery is not a linear process. Setbacks and relapses can occur; progress should be evaluated on each level separately. Perhaps someone is not making as rapid progress towards full-time employment as he or she would like, but he or she has improved social skills by involvement with a church or overall health by keeping a regular exercise routine. A holistic view of wellness does not end with taking medication regularly. It’s about taking medicine to help get closer to other life goals.

The Social Aspects of Mental Illness
Living with mental illness means living within a society and all its specific cultural, economic and political factors. In addition to competent mental health care, people living with schizophrenia need strong social supports. Individuals and families should work together to create the best environment to management recovery. For more on how to make a difference in the mental health care community, see Becoming an Advocate on page 19.
Culture
While schizophrenia occurs in approximately 1 percent of any society’s population, some groups are more likely to be diagnosed with schizophrenia in the United States. African Americans and Latinos are more prone to misdiagnosis, likely due to differing cultural or religious beliefs or language barriers. For anyone who has received a diagnosis of schizophrenia, it is important to look for a health care professional who understands a person’s cultural background and shares the same expectations for treatment.

Socializing and Bias
Social difficulties are one of the hallmarks of schizophrenia. Negative symptoms can make picking up on social cues challenging, which, further complicated by competing stimuli from positive symptoms, can make conversations more difficult, particularly with people who don’t know much about schizophrenia. In addition, some people feel isolated because they are aware that others do not share their hallucinations or delusions.

There is bias around mental illness, and as many as 96 percent of individuals living with schizophrenia experience discrimination—other people expecting negative things of them, or nothing at all, because of their illness. Prejudice can come from the outside and the inside of a person. A person might have negative experiences with potential employers rejecting their job applications, or they might be hindered by anxiety about these possible transactions.

Social skills training can be useful laboratory for finding appropriate ways to interpret and respond to social cues. This training can occur formally (in classes or therapy) or informally (within peer groups or a clubhouse setting). Volunteer opportunities or any other venue where an individual already has something in common with the other participants can offer a less risky environment for socializing.

Employment
Research suggests that as many as 70 percent of people living with schizophrenia would like to be engaged in competitive employment, but fewer than 15 percent are actually employed. People living with schizophrenia can find a sense of
accomplishment and independence from working. In addition, it improves social skills rather than isolating an individual, which tends to exacerbate negative symptoms. Research demonstrates that a supported employment model has better outcomes for a more safe and successful route to finding and keeping a job. Supported employment opportunities are scarce, however, which is an advocacy concern for NAMI. A good place to begin is your local Office of Vocational Rehabilitation (OVR). Some clubhouses or hospitals also offer supported employment opportunities or referrals.

People receiving Social Security benefits used to run the risk of losing their eligibility if they began to work, but the new Ticket to Work program gives people more freedom to pursue employment. See www.ssa.gov/work for more information.

Families and Social Factors
For people living with schizophrenia, spirituality can be a source of comfort and strength. The most supportive congregations will be those that are aware of the medical nature and treatments for mental illness or are open to learning about them. In NAMI’s report, Schizophrenia, Public Attitudes, Personal Needs, respondents living with schizophrenia indicated that faith-based support was a top need and benefit in managing recovery. It is important to include prayer in recovery management for people of faith.

Families who are educated about schizophrenia can offer strong support to their loved one and help reduce the likelihood of relapse. The key is to be in tune with what the person is open to at any given time. For example, arguing with an individual about delusions creates distance and is usually ineffective. Empathizing with someone’s distress or success is more likely to foster more positive outcomes.

One of the challenges of a caregiver is to find ways to support and protect their loved one while allowing room for self-reliance. Every family is different, but family structures tend to vary from culture to culture, with certain groups like Latinos tending to benefit from treatment solutions that involve the entire family.
Over time and without support, some family caregivers can begin to experience anxiety or depression. Families can experience “caregiver burnout” and a sense that their challenges are not valued as much as those faced by caregivers of people with other illnesses. Families should also become educated about health privacy rules and the legal aspects of providing care for an adult living with schizophrenia who is too ill to understand the need for treatment. The Treatment Advocacy Center has state-by-state information on treatment laws at www.treatmentadvocacycenter.org. Psychiatric advance directives, which allow individuals to designate treatment and contact persons in case they are unable to make their own decisions, can be another tool. The National Resource Center on Psychiatric Advance Directives offers state-by-state information on its website at www.nrc-pad.org.

Because of all of these levels on which the fight to regain well-being is fought, family members often find it helpful to keep a journal of all medications, medical visits, treatments and legal actions they have undertaken. Having this information handy can be helpful when switching providers or dealing with a crisis.
For all of these reasons, family members should seek education and support for their own needs from groups specially designed for families, such as NAMI’s evidence-based practice Family-to-Family educational group. It is taught by families who have first-hand experience and provides education and support to thousands of families nationwide. There are Family-to-Family groups in most states, available through many NAMI affiliates and provided in multiple languages.

See the chart below for challenges and solutions for different stages of the illness.

<table>
<thead>
<tr>
<th>Stage in illness</th>
<th>Individuals’ needs</th>
<th>Tools</th>
<th>Family goals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute</td>
<td>Support, safety, cessation of crisis symptoms</td>
<td>Medical work up, medication, family support</td>
<td>Protect well-being of entire family, gather information and support</td>
</tr>
<tr>
<td>Stabilization</td>
<td>Person-centered input on treatment, fine-tuning short-term goals</td>
<td>Support system—NAMI support group, clubhouse, church, ACT team, etc.</td>
<td>Creating support system to facilitate longer-term goals, keeping relationships strong</td>
</tr>
<tr>
<td>Stable</td>
<td>Pursuing goals and recovery</td>
<td>Peer support groups, supported employment, supported housing, mental health professionals</td>
<td>Facilitate individual independence for individual, advocacy for better care</td>
</tr>
</tbody>
</table>
Becoming an Advocate

Becoming an advocate means working to change the world, starting with oneself. Advocates change what they can, beginning with small, everyday problems but dreaming big.

There are numerous social issues that are related to schizophrenia.

- Funding for treatment, including new treatments and disparities
- Homelessness
- Funding for research
- Supported employment
- State health care budgets
- Criminalization of people living with mental illness

Learn about these issues and how to encourage policy makers to take action on them in NAMI’s Legislative Action Center at www.nami.org/advocacy/policy.

For years in this county, mental health care services have fallen short when it comes to the support and treatment of individuals living with mental illness. It is very important to make sure competent care is available in your state. NAMI’s 2009 Grading The States report reviews the care systems in every state and provides advocacy points as well as outlining strengths and urgent needs for each state. The report is available at www.nami.org/grades.

Participation in research studies is another way to take an active part in improving options for people living with schizophrenia. Scientists need volunteers from all backgrounds to volunteer for studies. ClinicalTrials.gov is one resource for finding these opportunities and www.nami.org/research also lists research studies for schizophrenia.

Written by Ken Duckworth, M.D.
Additional input by Irving Gottesman, Ph.D. and Charles Schulz, M.D.
Resources
National Institute of Mental Health (NIMH):
www.nimh.nih.gov

Mental Health America
www.nmha.org

The National Association for Research on Schizophrenia and Depression (NARSAD)
www.narsad.org

Schizophrenia.com
www.schizophrenia.com
A nonprofit source of information, support and education.

Schizophrenia Research Forum
http://schizophreniaforum.org
A good summary of advances in the field of schizophrenia.

Schizophrenia and Related Disorders Alliance of America (SARDAA)
www.sardaa.org
Schizophrenia and related disorders.

www.nami.org/schizophreniasurvey

www.schizophreniadigest.com
A magazine dedicated to hope, dignity and support by providing information about schizophrenia for individuals, families, friends and others.

NAMI FaithNet
www.nami.org/faithnet

Treatment Advocacy Center
www.treatmentadvocacycenter.org

Wellness Recovery Action Program (WRAP) groups
www.illinoismentalhealthcollaborative.com/wrap/search.action

Meetup.com
Look for mental illness-friendly social groups in your area.

Coping with Schizophrenia
Longtime NAMI supporter Fred Frese is a psychologist who lives with schizophrenia.
www.mentalhealth.com/story/pS2-sc04.html

Assertive Community Treatment
www.nami.org/act

International Center for Clubhouse Development
www.iccd.org

www.nami.org Updated daily, NAMI’s website features the latest information on mental illnesses, medication and treatment and resources for support and advocacy. Other features include online discussion groups and fact sheets.

StrengthofUs.org, an online social community for teens and young adults living with mental illness, is a place where they can connect while learning about services, supports and handling the unique challenges and opportunities of transition-age years.
The NAMI Information HelpLine receives more than 4,000 requests each month from individuals needing support, referral and information. More than 60 fact sheets on a variety of topics are available along with referrals to NAMI's network of local affiliates in communities across the country.

www.nami.org/helpline • 1 (800) 950-NAMI (6264)

NAMI Hearts & Minds is an online, interactive wellness educational initiative intended to promote quality of life and recovery for individuals who live with mental illness. Focuses include exercise, nutrition and smoking cessation.

www.nami.org/heartsandminds

NAMI Peer-to-Peer is a free, nine-week education course on the topic of recovery for any person living with a serious mental illness. Led by mentors who themselves have achieved recovery, the course provides participants comprehensive information and teaches strategies for personal and interpersonal awareness, coping skills and self-care.

www.nami.org/peertopeer

NAMI Family-to-Family is a free, 12-week course for family caregivers of adults living with mental illness. An evidence-based practice taught by trained NAMI family members who have relatives living with mental illness, the course provides caregivers with communication and problem-solving techniques, coping mechanisms and the self-care skills needed to deal with their loved ones and the impact on the family. Also available in Spanish.

www.nami.org/familytofamily

NAMI In Our Own Voice is a public education presentation. It enriches the audiences’ understanding of how the more than 58 million Americans contending with mental illness cope while also reclaiming rich and meaningful lives. Presented by two trained speakers who themselves live with mental illness, the presentation includes a brief video and personal testimonials, last 60-90 minutes and is offered free of charge.

www.nami.org/ioov

NAMI Connection is a recovery support group for adults living with mental illness regardless of their diagnosis. Every group is offered free of charge and meets weekly for 90 minutes. NAMI Connection offers a casual and relaxed approach to sharing the challenges and successes of coping with mental illness. The groups are led by trained individuals who are in recovery—people who understand the challenges others living with mental illness face.

www.nami.org/connection

NAMI Basics is a free, educational program for parents and other primary caregivers of children and adolescents living with mental illness. The course is presented in six different classes, provides learning and practical insights for families and is taught by trained parents and caregivers who have lived similar experiences with their own children.

www.nami.org/basics