

## Chapter 1

# Understanding Schizophrenia: The Big Picture

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### *In This Chapter*

- ▶ Understanding what schizophrenia is, who gets it, and what the symptoms are
  - ▶ Looking at how schizophrenia is treated
  - ▶ Getting the support you need
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**S**chizophrenia. If someone you know has been recently diagnosed with schizophrenia, the very word may evoke a cascade of intense feelings: sadness, fear, confusion, shame, and hopelessness. You may ask yourself, how did this happen? Why did it happen to my loved one? It's natural to have these emotions. But take a deep breath. You need to know that the diagnosis isn't as catastrophic as it first appears to be.

Most people know very little about schizophrenia until it hits home, and what they do know is likely to be based on old myths and misperceptions. They need to find out as much accurate information as they can about this complex and misunderstood disease. Knowledge is power — and knowing what schizophrenia is (and isn't) is the first step toward moving beyond your worst fears.

In this chapter, we give you an overview of the brain disorder known as schizophrenia: what it is, who gets it, and what treatments are available. We dispel some common myths about the disorder and tell you how schizophrenia differs from other mental illnesses. Finally, we tell you the good news about the disorder and why you and your loved one have every reason to remain hopeful that recovery is possible.

Schizophrenia is a serious, long-term, life-altering illness, so it's natural to be stunned upon hearing the diagnosis. You may even feel paralyzed, not knowing what to do next. But the first step is clear: You need to gather all the information you can to make sure your loved one is getting the best possible treatment and supports available to him.

## Defining Schizophrenia

You're reading this book, which means you probably have a personal interest in schizophrenia — either you or someone close to you has been diagnosed with the disease or you're worried about someone showing signs or symptoms. In this section, we fill you in on what's currently known about schizophrenia and the way the disorder affects the people who have it, as well as their loved ones.

### *What schizophrenia is*

Schizophrenia is a brain disorder characterized by a variety of different symptoms, many of which can dramatically affect an individual's way of thinking and ability to function. Most scientists think that the disorder is due to one or more problems in the development of the brain that results in neurochemical imbalances, although no one fully understands why schizophrenia develops.

People with schizophrenia have trouble distinguishing what's real from what's not. They are not able to fully control their emotions or think logically, and they usually have trouble relating to other people. They often suffer from hallucinations; much of their bizarre behavior is usually due to individuals acting in response to something they *think* is real but is only in their minds.

Unfortunately, because of the way schizophrenia has been inaccurately portrayed in the media over many decades, the illness is one of the most feared and misunderstood of all the physical and mental disorders.

Schizophrenia is a long-term relapsing disorder because it has symptoms that wax and wane, worsen and get better, over time. Similar to many physical illnesses (such as diabetes, asthma, and arthritis), schizophrenia is highly treatable — although it isn't yet considered curable.

But the long-term outcomes of schizophrenia aren't as grim as was once believed. Although the disorder can have a course that results in long-term disability, one in five persons recovers completely. Some people have only one psychotic episode, others have repeated episodes with normal periods of functioning in between, and others have continuing problems from which they never fully recover.

### *Who gets schizophrenia*

No group is risk-free when it comes to schizophrenia, but some people are more likely than others to develop the disorder. The following statistics may surprise you:

REMEMBER



- ✔ **Schizophrenia is more common than you might think.** About 1 out of 100 people develop schizophrenia over the course of their lifetime. Schizophrenia is twice as common as Alzheimer's disease or HIV/AIDS, five times as common as multiple sclerosis, and six times as common as Type 1 (insulin-dependent) diabetes.

Although new cases of schizophrenia are somewhat rare, the number of individuals with the disorder remains relatively high because schizophrenia is a chronic disorder that often lasts for an extended period of time.

- ✔ **Schizophrenia affects both sexes equally and is found among people of all races, cultures, and socioeconomic groups around the world.**
- ✔ **Although schizophrenia is more likely to affect people between the ages of 17 and 35 (the onset tends to be earlier in men than in women), it can begin in children as young as age 5 or have a late onset in a person's 50s, 60s, or 70s.**

WARNING!



Childhood-onset schizophrenia is extremely rare, affecting about 1 in 40,000 children. Only 1 in 100 adults now diagnosed with the disorder had symptoms before the age of 13. Because the disorder tends to surface more gradually in children, it often goes unnoticed. Chapter 2 lists some of the early red flags to watch for if you suspect that something may be wrong.

An earlier onset is often indicative of poorer outcomes because the disorder can interfere with education, development, and social functioning. On the other hand, early recognition can help improve outcomes and minimize disability.

## Famous people with schizophrenia

Many accomplished and successful people are reported to have had schizophrenia. Here's a short list:

- ✔ **Lionel Aldridge** (1941–1998), professional football player on the Green Bay Packers in the 1960s
- ✔ **Syd Barrett** (1946–2006), founding member of the band Pink Floyd
- ✔ **Jim Gordon** (1945–), drummer and member of Derek and the Dominoes
- ✔ **Peter Green** (1946–), guitarist and founder of the band Fleetwood Mac
- ✔ **Tom Harrell** (1946–), jazz musician
- ✔ **Jack Kerouac** (1922–1969), author of *On the Road*
- ✔ **Mary Todd Lincoln** (1818–1882), first lady of the United States, wife of Abraham Lincoln
- ✔ **John Nash** (1928–), mathematician, Nobel Prize winner, subject of the film *A Beautiful Mind*
- ✔ **Vaslav Nijinsky** (1889–1950), ballet dancer
- ✔ **Brian Wilson** (1942–), bass player and singer in the band The Beach Boys



## Comparing the schizophrenic brain to the normal one

New imaging techniques — like magnetic resonance imaging (MRI) and positron emission tomography (PET) — have opened virtual windows into the brain. Scientists have been able to visualize the living brain and discern some of the differences in the structure and function of the brains of people with schizophrenia and the brains of their normal peers.

Some of the differences observed in the brains of people with schizophrenia are

- ✓ **Enlarged ventricles:** Fluid-filled cavities within the brain
- ✓ **A loss of gray matter:** Brain tissue that is comprised of nerve cells
- ✓ **Abnormalities in white matter:** Myelin-covered nerve fibers that serve as “wiring” connecting different parts of the brain

In the rare cases where schizophrenia first appears in early childhood, differences have been found in the *cortex* of the developing brain. The cortex forms the surface of the brain.

*Functional magnetic imaging studies* have enabled scientists to observe the brain while it’s performing various tasks. These studies have found that the brains of people with schizophrenia work differently — either harder or less efficiently — than those of people without the disorder.

All these variations are meaningful, but when it comes to diagnosing a particular individual, science is not yet at the point where a diagnosis can be made based on imaging data.

## What causes schizophrenia

Schizophrenia is a no-fault, equal-opportunity illness most likely caused by a number of factors, both genetic and environmental. Most scientists now accept a *two-hit theory* for the cause of schizophrenia, which suggests that the genetic susceptibility is compounded by one or more environmental factors:

- ✓ **Genetic susceptibility:** Based on family genetic history, some people are more vulnerable to the disorder than other people are.
- ✓ **Environmental factors:** In someone genetically predisposed, certain environment factors may come into play, such as:
  - Physical trauma that occurs to the fetus during childbirth
  - Oxygen-deprivation or some psychological or physical problem that occurs to the mother during pregnancy and affects the developing fetus
  - Emotional stress, such as the loss of a parent or loved one during young adulthood



Although schizophrenia is genetically *influenced*, more than genetics is involved in its development. Studies of identical twins show that, if one twin develops schizophrenia, the other twin has only a 40 percent to 50 percent chance of also developing the illness. There's also an increased risk among fraternal twins when one develops schizophrenia, the other has between a 10 percent and 17 percent chance, far less than that of identical twins. Having a parent with schizophrenia also increases a person's risk of developing the disease, to about 10 percent. And if you have a sibling with the disorder — not your twin — you have a 6 percent to 9 percent chance of developing the disorder yourself.

Scientists still don't know the precise causes of schizophrenia for any particular individual, yet family members and patients themselves tend to dwell on (or even obsess about) finding a “reason” or a “cause” for the illness. Although this instinct is a natural one, finding the precise cause or explanation is impossible, not to mention counterproductive — finding a reason doesn't help treatment, and it often creates unnecessary and misplaced guilt, with one family member blaming another.

See Chapter 2 for a full discussion of the possible causes of schizophrenia.

## The Symptoms of Schizophrenia

There are almost 300 named psychiatric disorders, and schizophrenia is one of them. Although many mental illnesses have symptoms that overlap, schizophrenia has a distinct pattern of symptoms. No two cases of schizophrenia look exactly the same, but most people with schizophrenia display three types of symptoms:

✓ **Positive symptoms:** The term *positive symptoms* is confusing, because positive symptoms (as the term might suggest) aren't “good” symptoms at all. They're symptoms that *add* to reality, and not in a good way. People with schizophrenia hear things that don't exist or see things that aren't there (in what are known as *hallucinations*). The voices they hear can accuse them of terrible things and can be very jarring (for example, causing them to think that they've hurt someone or have been responsible for some cataclysmic world event).

People with schizophrenia can also have *delusions* (false beliefs that defy logic or any culturally specific explanation and that cannot be changed by logic or reason). For example, an individual may believe that there is a conspiracy of people driving red cars that follows his every movement. He will use the fact that there are red cars everywhere he goes as evidence that the conspiracy is real.



- ✔ **Negative symptoms:** These symptoms are a *lack* of something that should be present; behaviors that would be considered normal are either absent or diminished. For example, people with schizophrenia often lack motivation and appear lazy. They may be much slower to respond than most other people, have little to say when they do speak, and appear as if they have no emotions, or exhibit emotions that are inappropriate to the situation. They may also be unable to get pleasure from the things that most people enjoy or from activities that once brought pleasure to them. Families often get frustrated when a relative with schizophrenia does nothing but sleep or watch TV — they wrongly attribute this behavior to the patient not being willing to assume responsibility or “pull himself up by his bootstraps.”

Negative symptoms are part and parcel of the illness for at least 25 percent of people with schizophrenia.

- ✔ **Cognitive symptoms:** Most people with the disorder suffer from impairments in memory, learning, concentration, and their ability to make sound decisions. These so-called *cognitive symptoms* interfere with an individual’s ability to learn new things, remember things they once knew, and use skills they once had. Cognitive symptoms can make it hard for a person to continue working at a job, going to school, or participating in activities she may have enjoyed at one time.

In addition to the symptoms mentioned above, people with schizophrenia may also have sleep problems, mood swings, and anxiety. They may experience difficulties forming and maintaining social relationships with other people. They may look different enough that other people notice that something is very odd or strange about them and that they don’t quite look “normal.” They may have unusual ways of doing things, have peculiar habits, dress inappropriately (such as wearing a heavy coat or multiple layers of clothes in the summer), and/or be poorly groomed, which can discourage other people from getting involved with them.

See Chapter 3 for more about the differences in these types of symptoms.

## *Dispelling the Myths Associated with Schizophrenia*

People wrongly associate the symptoms of schizophrenia with split or multiple personalities (like Dr. Jekyll and Mr. Hyde), antisocial behavior (similar to what we see in serial killers), and developmental disabilities. Others believe that schizophrenia is a character defect and that the individual could behave normally if he really wanted to.

Here are a few of the most common misconceptions about schizophrenia:

✔ **Schizophrenia is the same as a split or multiple personality.**

Schizophrenia is *not* the same as multiple personality, which is an exceedingly rare, totally different disorder that is now more commonly called a *dissociative identity disorder*. (Under stress, people with this disorder often assume different identities, each with different names, voices, characteristics, and personal histories.)

✔ **People with schizophrenia are violent.** People with schizophrenia are more likely to be victims rather than perpetrators of crimes. Many people believe that most people with schizophrenia have a propensity for violence, but the reality is that most people with schizophrenia don't commit violent crimes, and most violent criminals don't have schizophrenia.

For example, *serial killers* (people who commit three or more subsequent murders) usually aren't *psychotic* (out of touch with reality); they're likely to be diagnosed with an *antisocial personality disorder* (a disorder in which people disregard commonly accepted social rules and norms, display impulsive behavior, and are indifferent to the rights and feelings of others).

However, people with untreated schizophrenia, who refuse to take medication and whose thinking is out of touch with reality are at increased risk of aggressive behavior and self-neglect. The risk of violence also increases if someone with schizophrenia is actively abusing alcohol or illicit drugs. For better or worse, the aggressive behavior is usually directed toward family or friends rather than toward strangers.

✔ **Poor parenting causes schizophrenia.** For many years, clinicians were taught and actually believed that schizophrenia was caused by parents who were either too permissive or too controlling. The term *schizophrenogenic mother* was once used to describe such parents — the blame usually fell heavily on mothers because they tended to spend the most time with their offspring. Another outdated theory is the *double-bind theory*, which suggested that schizophrenia is due to inconsistent parenting, with conflicting messages.

These ideas were not based on controlled studies, and these theories no longer have credibility today.

Schizophrenia is a no-fault disorder of the brain.

✔ **People with schizophrenia are mentally retarded.** Some people think that schizophrenia is synonymous with mental retardation (now called *developmental disabilities*). No. Like the general public, people with schizophrenia have a wide range of intellectual abilities. They may *appear* less intelligent because of the impaired social skills, odd behaviors, and cognitive impairments that are characteristic of schizophrenia. However, they're not lacking in intelligence, and schizophrenia is distinct from *developmental disabilities* (physical and mental deficits that are chronic and severe and that generally begin in childhood).





- ✔ **Schizophrenia is a defect of character.** Negative symptoms of schizophrenia give people the mistaken impression that those with the disorder are lazy and could act “normally” if they wanted to. This idea is no more realistic than suggesting that someone could prevent his epileptic seizures if he really wanted to or that someone could “decide” not to have cancer if he ate the right foods. What often appears as character defects are symptoms of schizophrenia.

When the negative symptoms of schizophrenia are persistent and primarily caused by schizophrenia, they’re referred to as *deficit syndrome*.

- ✔ **There’s no hope for people diagnosed with schizophrenia.** Sixty years ago when people were diagnosed with schizophrenia, they were either kept at home behind closed doors by embarrassed and forlorn families who saw no other alternative, or consigned to long-term stays in distant state hospitals for care that was largely *custodial* (they weren’t treated — they were just taken care of). Other than using highly sedating drugs, doctors had few tools available to them to relieve the agitation and torment of their patients or to help restore their functioning.

In contrast to how things were in the past, schizophrenia is now considered highly treatable. Several generations of new medications and the emergence of new forms of therapies have enabled doctors to treat the symptoms of the large majority of patients with schizophrenia enabling them to live meaningful, productive lives in their communities.

For more myths about schizophrenia, check out Chapter 16.

## ***Finding Out Whether Your Loved One Has Schizophrenia***

Schizophrenia doesn’t always make its appearance in the same way. Sometimes its symptoms come on suddenly, seemingly out of the blue, and this can be very confusing or even shocking. A very common scenario is that a young person, previously described as an excellent student, standout athlete, or all-around great kid, goes off for college and suddenly calls home after a month or two to report that he’s being followed or has been targeted by an alien group. When the individual has had no prior history of a serious mental disorder, the onset of this disorder is called a *first break* or an *acute psychotic break*.

Other times, schizophrenia comes on gradually, or its symptoms are so subtle that the person simply hasn’t been diagnosed earlier. Often, it’s difficult for the individual and people around her to notice that anything is wrong (because they’ve come to accept what they view as the person’s quirky personality) until things further deteriorate and can no longer be ignored.



Families say that their relative never seemed “quite right”; the person may have had problems at school or work, problems relating to peers, and a history of odd or unusual behaviors. Then she suddenly exhibits delusions, hallucinations, or other signs indicating that she’s out of touch with reality. After that, the possibility of schizophrenia can no longer be ignored.

No matter how the scenario unfolds, the key is getting a diagnosis for your loved one and ruling out other possible causes for the symptoms you’re noticing. In the section below, we tell you how to do both.

## *Getting a diagnosis*

If you have any suspicion that your loved one may have schizophrenia, it’s vitally important that he be seen by a mental-health professional as soon as possible. If the clinician is not a psychiatrist — maybe he’s a psychologist or social worker — he’ll likely suggest that your loved one be seen by an internist or general practitioner to make sure that the symptoms are not due to any underlying physical disorder (such as a brain tumor, epilepsy, or drug intoxication) and to rule out other medical explanations.

Unlike some physical illnesses, there’s no simple blood test or X-ray that can establish the diagnosis of schizophrenia. So the mental-health professional will interview your loved one and take a thorough history to help arrive at an accurate diagnosis. Often they will interview family members to round out their understanding of the patient’s history and functioning at home, and to solicit their assistance in filling in details that the patient may have forgotten or be hesitant to talk about.



When mental-health professionals make diagnoses of schizophrenia, they sometimes identify various subtypes of the disorder based on their characteristic symptoms. These subtypes include paranoid schizophrenia, catatonic schizophrenia, and undifferentiated schizophrenia (see Chapter 4 for more information on all these). These subtypes no longer hold the same diagnostic or *prognostic* (ability to predict the future) importance that they once did. Today, more emphasis is placed on designing treatment strategies that address positive, negative, and cognitive symptoms.



Early diagnosis is important — it leads to better outcomes. Even having a name for the disturbing symptoms people experience enables patients and those around them to better understand and cope with their situation.

## *Ruling out other explanations*

After medical causes are ruled out and schizophrenia is suspected, your next step is for your loved one to see a psychiatrist — specifically, someone who is experienced in diagnosing and treating schizophrenia.

Finding a psychiatrist experienced in diagnosing and treating schizophrenia isn't always easy. Two of the best sources of referrals are academic medical centers and family support groups. (For more on finding a psychiatrist for your loved one, check out Chapter 4.)

One of the reasons that diagnosing schizophrenia can be challenging is that its symptoms sometimes overlap with other mental disorders. Mental-health professionals determine whether a person has schizophrenia or some other psychiatric condition with similar or overlapping symptoms by doing what's called a *differential diagnosis*. For example, to diagnose schizophrenia, some of the conditions psychiatrists rule out include

- ✔ **Mood disorders:** People with schizophrenia can have mood swings, become depressed, or exhibit *hypomanic* (persistently elated or irritable) moods or behaviors. People with *bipolar disorder* or *severe depression* can have psychotic thoughts (such as delusions or hallucinations) that resemble those found in schizophrenia. But in schizophrenia, the thought disorder predominates over mood symptoms.
- ✔ **Schizoaffective disorder:** Schizoaffective disorder, despite the name, isn't a type of schizophrenia — instead, it's a different diagnosis with a combination of thought and mood symptoms. The diagnosis is sometimes used when the symptoms of the disorder can't be clearly categorized as either schizophrenia or a mood disorder.
- ✔ **Substance use and abuse:** The symptoms associated with acute schizophrenia can be caused by drug-induced intoxication, especially from hallucinogenic drugs (like LSD), cocaine, or amphetamines. A significant proportion of people with schizophrenia use alcohol and/or other drugs to mask their symptoms and/or ease their anxiety about their symptoms and have co-occurring mental-health and substance-use disorders.



To determine whether psychotic symptoms are induced by drugs or a symptom of schizophrenia, a clinician may need to see the patient over time and observe the patient when she is not using drugs or alcohol.

- ✔ **Borderline personality disorder:** People with borderline personality disorder often have moods that change on a dime, have conflicts with other people, act out inappropriately, or have impaired judgment. They may also behave in ways that hurt themselves (for example, deliberating cutting or burning themselves). However, it's not common for people with borderline personalities to have hallucinations or cognitive impairments.

Sometimes an individual's psychiatric diagnosis changes over time based on whichever symptoms appear to be most prominent at the time the person is seen. It doesn't necessarily mean that the previous diagnosis was wrong.

## Normal teenage behaviors and the diagnosis of schizophrenia

Not surprisingly, the teenage years have been called the “roller-coaster years” because of the ups and downs caused by surging hormones, and because adolescents are prone to engage in strange and risky behaviors. Many young people have mood swings, use and/or abuse alcohol, or maintain unusual sleep schedules (reversing day and night, or sleeping too little or too much).

Because the onset of schizophrenia usually coincides with the late teenage years, schizophrenia is often missed and its symptoms are dismissed as behaviors of normal adolescence. It takes an experienced clinician to confirm or rule out a diagnosis of schizophrenia in teens, but some warning signs include the following:

- ✔ **A dramatic decline in school performance:** For example, excessive absences or failing subjects at which she once excelled.
- ✔ **Having thoughts that often don’t make sense:** For example, a teenager with schizophrenia may think his thoughts are being monitored by electronic equipment in the house or that his food is being poisoned.
- ✔ **Being suspicious or paranoid:** Lots of teenagers are “paranoid” that their parents are going through their things or spying on them, but that’s not what we’re talking about here. The suspiciousness or paranoia in a teenager with schizophrenia might lead him to believe that his room is bugged by the FBI.
- ✔ **Staying isolated or not having friends:** Not every teen is captain of the football team or homecoming queen — we’re not talking about popularity here. We mean having absolutely no friends — not even one — and never socializing with other kids or participating in school activities.
- ✔ **Use of drugs and/or alcohol:** Teenagers frequently experiment with drugs or alcohol, so if you find out your teen is doing either of these, that doesn’t mean he has schizophrenia. But if you see drug and alcohol use in conjunction with the other symptoms in this list, that can be evidence that he may have schizophrenia. **Remember:** Drug and alcohol use in teens is a serious problem whether they have schizophrenia or not, so if you suspect your teen may be drinking or doing drugs, be sure to get him help. Contact the federal government’s Center for Substance Abuse Treatment (CSAT) toll-free help line at 800-662-4357 or go to [www.findtreatment.samhsa.gov](http://www.findtreatment.samhsa.gov) for tips on where to start.
- ✔ **Family history of mental illness:** Genetics alone doesn’t cause schizophrenia, but if you have a family history of mental illness, and you’re noticing other symptoms in this list, your teen may have schizophrenia.

## Improving the Lives of People with Schizophrenia

Since the 1950s, the mental-health profession has made marked advances in the treatment of schizophrenia. Now most people with schizophrenia are

treated in the community as opposed to remaining in hospitals for long-term care. When individuals *do* need to be hospitalized, it's usually for a brief period of time to stabilize their symptoms. In this section, we cover the range of treatments and supports that are essential to recovery.

## Medication

Today, medication is considered the mainstay of treatment for most individuals with schizophrenia. However, medication alone isn't enough — it's more successful when combined with psychosocial (see the following section) interventions.



Antipsychotic medications — like medications used to treat many other chronic illnesses (such as diabetes, epilepsy, heart disease, and asthma) — control symptoms. They don't provide a cure.

Good *psychopharmacologists* (psychiatrists who have training and experience in prescribing medications that are used to treat psychiatric illnesses) now are more likely to work along with individuals and families to find a medication regimen that will help keep positive symptoms under control. Also, today doctors are more likely to listen to patients who complain of adverse side effects and to modify doses or the type of medication accordingly, to encourage compliance. Finally, the availability of *practice guidelines* (summaries of best practices based on research evidence or professional consensus), developed by many professional organizations, have improved the overall state of the art of medication management.



Collaboration between a patient and doctor is less possible when a person with schizophrenia is acutely ill and unable to understand or remember what's being discussed. The approach to medication management is a long-term one.

We cover medication options in Chapter 8.

## Psychosocial treatments

Psychosocial treatments include psychological treatments, social approaches, and combined approaches that are especially helpful in restoring confidence and self-esteem, as well as in helping people with schizophrenia develop the skills they never acquired or lost as a result of their illness (which often curtails or interrupts an individual's education or work).

Psychosocial treatments include social skills training, vocational counseling and job training, *cognitive remediation* (compensatory learning strategies that improve neuropsychological functions like memory, concentration,

planning and organizing), and assistance with the activities of daily living. Psychological treatments include supportive psychotherapy (talk therapy) and *cognitive behavioral therapy* (CBT), which is focused on changing negative thinking patterns. Self-help approaches and family psychoeducation are important elements of a comprehensive system of care.

Because cognitive problems and the complexity of the service system often make it hard for people with schizophrenia to arrange for their own care, in the past, families were usually thrust into the role of de facto case managers. Increasingly, professional *case managers* (mental-health workers who help people with chronic illnesses navigate the complex system of healthcare and social services) have become part of the landscape of mental-health treatment. Case managers coordinate services, help in the event of crises, and provide ongoing support to enable people live successfully with some degree of autonomy and independence. Assertive community treatment (ACT) programs, comprised of multidisciplinary treatment teams, reach out to the patient and can be particularly helpful to those with a more severe form of the illness.

We cover the variety of psychosocial approaches in detail in Chapter 9.

## ***Family psychoeducation***

Although families were once seen as part of the problem, they're now viewed as part of the solution and frequently essential to recovery. With the growth of groups like the National Alliance on Mental Illness (NAMI), family psychoeducation has flourished at national, state, and local levels.

Family psychoeducation groups provide a place for families to exchange information about the illness, learn what works and what doesn't (both in terms of treatment and coping strategies), identify ways to minimize the risk of relapse, and find out how to identify and access community resources. For example, the NAMI Family-to-Family educational program has given countless families the opportunity to learn the things they need to know to be effective caregivers and advocates for their loved ones.

More important, perhaps, family psychoeducation groups help family members recognize that they're not alone and that others are working hard to improve care — not only for their own loved ones, but for all individuals and families affected by serious mental disorders. At the same time, they help people to live their lives without letting them be defined solely by the illness. Families have been instrumental, in turn, in improving public understanding and awareness of the needs of people with schizophrenia.

You can find information on advocacy organizations for dealing with schizophrenia in Chapters 11 and 15.

## *Peer support and mutual self-help*

Another crucial element to recovery is providing people with schizophrenia the opportunity to talk to and exchange information with their peers. Having the chance to know other people facing the same challenges can help people with schizophrenia recover more quickly from acute episodes of the illness and can help them avoid relapse and hospitalization. Clubhouses, drop-in centers, and mutual support groups can play an important role in fostering recovery. For example, NAMI Peer-to-Peer programs offer a recovery curriculum for consumers.

For more on these support groups, turn to Chapter 9.

## *Basic support: Housing, financial aid, and healthcare*

Like everyone else, people with any mental illness need stable and affordable housing, entitlements when they can't support themselves financially, and access to quality healthcare, mental-health treatment, and medications. Often, mental illnesses are associated with poverty and a cascade of personal losses — including friendships, work opportunities, and a place to call home.

Because the resources needed to cope with any chronic disorder are generally beyond the reach of any one individual family, governmental and charitable organizations oversee and fund many of these services and supports, which are cost-saving in human and economic terms.

Chapters 7 and 13 discuss various financing and housing options for people with schizophrenia.



Family and close friends can play a vital role in fostering their loved one's recovery. They're the ones who best know their loved one, including his hopes and dreams. They also are likely to have the greatest stake in seeing him recover and succeed. One advocate we know once said, "No one has the same fire in his belly to make the system work for his loved one."

## *Recognizing the Challenges That Remain*

We'd be less than honest if we said that everything is perfect today for people dealing with schizophrenia — it's not. Here are a few of the problems that remain:

- ✔ **Many patients still are unable to find a medication that works for them.** Their persistent positive, negative, and cognitive symptoms are vexing to them, as well as to their families and clinicians. (See Chapter 8 for more about medications and schizophrenia.)
- ✔ **Doctors still don't know which drugs work best for which individuals.** The choice of medication still relies on a good deal of trial and error, which takes time and requires patience.
- ✔ **Families still have to learn that, despite their best efforts, they can't talk someone out of schizophrenia or wish it away with an abundance of love and caring.** (See Chapter 11 for ways to help everyone in the family live with schizophrenia.)
- ✔ **Most communities don't have the full breadth of services and supports to necessary to support recovery.** (See Chapters 12 and 13 for more information on community resources.)
- ✔ **The scarcity of appropriate low-cost housing, adequate health-insurance coverage, and competitive jobs undermine progress for many people with schizophrenia.**
- ✔ **Mental-health services still tend to be fragmented and insufficient in number, and finding psychiatrists who are experienced and willing to work with individuals with long-term mental illnesses is still difficult (particularly in rural areas).** (See Chapter 5 for information on choosing the right doctors.)

## *Holding On to Hope: The Good News about Schizophrenia*

It's easy to dwell on the negatives when dealing with schizophrenia, but the truth is, there are many reasons for hope:

- ✔ **We know, without question, that schizophrenia is a no-fault disorder of the brain and that with appropriate treatment and supports, the illness doesn't necessarily have to have a chronic, deteriorating course.** People do and can recover!
- ✔ **Early diagnosis and the availability of community-based treatment and social supports can restore an individual's dignity, improve her quality of life, and enable her to make meaningful contributions to her family and community.** Your loved one may find a different path than you or she anticipated, but it can still be a good one.
- ✔ **The ultimate goal of recovery is about more than relief of symptoms.** Recovery entails helping people get back to work or school, live with others, and make their own life decisions. Patients and families should accept no less.

- ✓ **The role of families and friends is critical to recovery.** They need to:
  - Support and anchor their loved ones during the acute phases of the illness
  - Help their loved ones find the tools they need to recover and avoid relapse
- ✓ Continue to educate themselves to better cope with the challenges they encounter, working individually and collectively to fight stigma and discrimination based on misunderstanding
- ✓ **Just as scientists now know that there are many different types of cancer, researchers may one day learn that schizophrenia is a family of similar disorders that are currently lumped under one term.** This discovery could pave the way for more targeted and personalized treatments. Because the precise causes of schizophrenia are still unknown for any particular individual, scientists are exploring a number of possibilities including genetic, viral, infectious, chemical, developmental, and environmental explanations. There has never been more research being conducted on the causes and cures for schizophrenia than there is today. (See Chapter 10 for the latest on research into schizophrenia.)



Never give up hope. Just around the corner are answers to questions that can't be answered today and solutions to problems that seem insurmountable.