

The background is a textured yellow surface with several abstract, layered shapes in dark grey and orange. In the top left, there's a dark grey shape with a yellow dot and a red dot. A dark grey circle is in the top right. A dark grey shape with an orange semi-circle is on the right side. A dark grey shape with an orange semi-circle is at the bottom right. A small orange square and a vertical black line are near the bottom center.

Schizophrenia

The *Schizophrenia Bulletin* features art done by current and former mental hospital patients. The painting that appears on the cover of this brochure was done by Philip Kurz. The artist has provided us with the following description of his artwork:

I believed that everything within me and around me was passing through my blank mind and my arm onto the paper. I felt that keeping a blank mind was important to the success of the painting and this was relatively easy to do since it approximated by normal state. This feeling all seems outlandish now.

Schizophrenia is a chronic, severe, and disabling brain disease. Approximately 1 percent of the population develops schizophrenia during their lifetime –

more than 2 million Americans suffer from the illness in a given year. Although schizophrenia affects men and women with equal frequency, the disorder often appears earlier in men, usually in the late teens or early twenties, than in women, who are generally affected in the twenties to early thirties. People with schizophrenia often suffer terrifying symptoms such as hearing internal voices not heard by others, or believing that other people are reading their minds, controlling their thoughts, or plotting to harm them. These symptoms may leave them fearful and withdrawn. Their speech and behavior can be so disorganized that they may be incomprehensible or frightening to others. Available treatments can relieve many symptoms, but

most people with schizophrenia continue to suffer some symptoms throughout their lives; it has been estimated that no more than one in five individuals recovers completely.

This is a time of hope for people with schizophrenia and their families. **Research** is gradually leading to new and safer medications and unraveling the complex causes of the disease. Scientists are using many approaches from the study of molecular genetics to the study of populations to learn about schizophrenia. Methods of imaging the brain's structure and function hold the promise of new insights into the disorder.

Schizophrenia As An Illness

Schizophrenia is found all over the world. The severity of the symptoms and long-lasting, chronic pattern of schizophrenia often cause a high degree of disability. Medications and other treatments for schizophrenia, when used regularly and as prescribed, can help reduce and control the distressing symptoms of the illness. However, some people are not greatly helped by available treatments or may prematurely discontinue treatment because of unpleasant side effects or other reasons. Even when treatment is effective, persisting consequences of the illness – lost opportunities, stigma, residual symptoms, and medication side effects – may be very troubling.

The first signs of schizophrenia often appear as confusing, or even shocking, changes in behavior. Coping with the symptoms of schizophrenia can be especially difficult for family members who remember how involved or vivacious a person was before they became ill. The sudden onset of severe psychotic symptoms is referred to as an “acute” phase of schizophrenia. “Psychosis,” a

common condition in schizophrenia, is a state of mental impairment marked by hallucinations, which are disturbances of sensory perception, and/or delusions, which are false yet strongly held personal beliefs that result from an inability to separate real from unreal experiences. Less obvious symptoms, such as social isolation or withdrawal, or unusual speech, thinking, or behavior, may precede, be seen along with, or follow the psychotic symptoms.

Some people have only one such psychotic episode; others have many episodes during a lifetime, but lead relatively normal lives during the interim periods. However, the individual with “chronic” schizophrenia, or a continuous or recurring pattern of illness, often does not fully recover normal functioning and typically requires long-term treatment, generally including medication, to control the symptoms.

Making A Diagnosis

It is important to rule out other illnesses, as sometimes people suffer severe mental symptoms or even psychosis due to undetected underlying medical conditions. For this reason, a medical history should be taken and a physical examination and laboratory tests should be done to rule out other possible causes of the symptoms before concluding that a person has schizophrenia. In addition, since commonly abused drugs may cause symptoms resembling schizophrenia, blood or urine samples from the person can be tested at hospitals or physicians’ offices for the presence of these drugs.

At times, it is difficult to tell one mental disorder from another. For instance, some people with symptoms of schizophrenia exhibit prolonged extremes of elated or depressed mood, and it is important to determine whether such a patient has schizophrenia or

actually has a manic-depressive (or bipolar) disorder or major depressive disorder. Persons whose symptoms cannot be clearly categorized are sometimes diagnosed as having a “schizoaffective disorder.”

Can Children Have Schizophrenia?

Children over the age of five can develop schizophrenia, but it is very rare before adolescence. Although some people who later develop schizophrenia may have seemed different from other children at an early age, the psychotic symptoms of schizophrenia – hallucinations and delusions – are extremely uncommon before adolescence.

The World of People With Schizophrenia

Distorted Perceptions of Reality

People with schizophrenia may have perceptions of reality that are strikingly different from the reality seen and shared by others around them. Living in a world distorted by hallucinations and delusions, individuals with schizophrenia may feel frightened, anxious, and confused.

In part because of the unusual realities they experience, people with schizophrenia may behave very differently at various times. Sometimes they may seem distant, detached, or preoccupied and may even sit as rigidly as a stone, not moving for hours or

uttering a sound. Other times they may move about constantly – always occupied, appearing wide-awake, vigilant, and alert.

Hallucinations and Illusions

Hallucinations and illusions are disturbances of perception that are common in people suffering from schizophrenia. Hallucinations are perceptions that occur without connection to an appropriate source. Although hallucinations can occur in any sensory form – auditory (sound), visual (sight), tactile (touch), gustatory (taste), and olfactory (smell) – hearing voices that other people do not hear is the most common type of hallucination in schizophrenia. Voices may describe the patient's activities, carry on a conversation, warn of impending dangers, or even issue orders to the individual. Illusions, on the other hand, occur when a sensory stimulus is present but is incorrectly interpreted by the individual.

Delusions

Delusions are false personal beliefs that are not subject to reason or contradictory evidence and are not explained by a person's usual cultural concepts. Delusions may take on different themes. For example, patients suffering from paranoid-type symptoms – roughly one-third of people with schizophrenia – often have delusions of persecution, or false and irrational beliefs that they are being cheated, harassed, poisoned, or conspired against. These patients may believe that they, or a member of the family or someone close to them, are the focus of this persecution. In addition, delusions of grandeur, in which a person may believe he or she is a famous or important figure, may occur in schizophrenia. Sometimes the delusions experienced by people with schizophrenia are quite bizarre; for instance, believing that a neighbor is controlling their

behavior with magnetic waves; that people on television are directing special messages to them; or that their thoughts are being broadcast aloud to others.

Disordered Thinking

Schizophrenia often affects a person's ability to "think straight." Thoughts may come and go rapidly; the person may not be able to concentrate on one thought for very long and may be easily distracted, unable to focus attention.

People with schizophrenia may not be able to sort out what is relevant and what is not relevant to a situation. The person may be unable to connect thoughts into logical sequences, with thoughts becoming disorganized and fragmented. This lack of logical continuity of thought, termed "thought disorder," can make conversation very difficult and may contribute to social isolation. If people cannot make sense of what an individual is saying, they are likely to become uncomfortable and tend to leave that person alone.

Emotional Expression

People with schizophrenia often show "blunted" or "flat" affect. This refers to a severe reduction in emotional expressiveness. A person with schizophrenia may not show the signs of normal emotion, perhaps may speak in a monotonous voice, have diminished facial expressions, and appear extremely apathetic. The person may withdraw socially, avoiding contact with others; and when forced to interact, he or she may have nothing to say, reflecting "impoverished thought." Motivation can be greatly decreased, as can interest in or enjoyment of life. In some severe cases, a person can spend entire days doing nothing at all, even neglecting basic hygiene. These problems with emotional

expression and motivation, which may be extremely troubling to family members and friends, are symptoms of schizophrenia – not character flaws or personal weaknesses.

Normal Versus Abnormal

At times, normal individuals may feel, think, or act in ways that resemble schizophrenia. Normal people may sometimes be unable to “think straight.” They may become extremely anxious, for example, when speaking in front of groups and may feel confused, be unable to pull their thoughts together, and forget what they had intended to say. This is not schizophrenia. At the same time, people with schizophrenia do not always act abnormally. Indeed, some people with the illness can appear completely normal and be perfectly responsible, even while they experience hallucinations or delusions. An individual’s behavior may change over time, becoming bizarre if medication is stopped and returning closer to normal when receiving appropriate treatment.

Are People With Schizophrenia Likely To Be Violent?

News and entertainment media tend to link mental illness and criminal violence; however, studies indicate that except for those persons with a record of criminal violence before becoming ill, and those with substance abuse or alcohol problems, people with

Substance Abuse

Substance abuse is a common concern of the family and friends of people with schizophrenia. Since some people who abuse drugs may show symptoms similar to those of schizophrenia, people with schizophrenia may be mistaken for people “high on drugs.” While most researchers do not believe that substance abuse causes schizophrenia, people who have schizophrenia often abuse alcohol and/or drugs, and may have particularly bad reactions to certain drugs.

Substance abuse can reduce the effectiveness of treatment for schizophrenia. Stimulants (such as amphetamines or cocaine) may cause major problems for patients with schizophrenia, as may PCP or marijuana. In fact, some people experience a worsening of their schizophrenic symptoms when they are taking such drugs. Substance abuse also reduces the likelihood that patients will follow the treatment plans recommended by their doctors.

Schizophrenia and Nicotine

The most common form of substance use disorder in people with schizophrenia is nicotine dependence due to smoking. While the prevalence of smoking in the U.S. population is about 25 to 30 percent, the prevalence among people with schizophrenia is approximately three times as high. Research has shown that the relationship between smoking and schizophrenia is complex. Although people with schizophrenia may smoke to self-medicate their symptoms, smoking has been found to interfere with the response to antipsychotic drugs. Several studies have found that schizophrenia patients who smoke need higher doses of antipsychotic medication. Quitting smoking may be especially difficult for people with schizophrenia, because the symptoms of nicotine withdrawal may cause a temporary worsening of schizophrenia symptoms. However, smoking cessation strategies that include nicotine replacement methods may be effective. Doctors should carefully monitor medication dosage and response when patients with schizophrenia either start or stop smoking.

schizophrenia are not especially prone to violence. Most individuals with schizophrenia are not violent; more typically, they are withdrawn and prefer to be left alone. Most violent crimes are not committed by persons with schizophrenia, and most persons with schizophrenia do not commit violent crimes. Substance abuse significantly raises the rate of violence in people with schizophrenia but also in people who do not have any mental illness. People with paranoid and psychotic symptoms, which can become worse if medications are discontinued, may also be at higher risk for violent behavior. When violence does occur, it is most frequently targeted at family members and friends, and more often takes place at home.

What About Suicide?

Suicide is a serious danger in people who have schizophrenia. If an individual tries to commit suicide or threatens to do so, professional help should be sought immediately. People with schizophrenia have a higher rate of suicide than the general population. Approximately 10 percent of people with schizophrenia (especially younger adult males) commit suicide. Unfortunately, the prediction of suicide in people with schizophrenia can be especially difficult.

WHAT CAUSES SCHIZOPHRENIA?

There is no known single cause of schizophrenia. Many diseases, such as heart disease, result from an interplay of genetic, behavioral, and other factors; and this may be the case for

schizophrenia as well. Scientists do not yet understand all of the factors necessary to produce schizophrenia, but all the tools of modern biomedical research are being used to search for genes, critical moments in brain development, and other factors that may lead to the illness.

Is Schizophrenia Inherited?

It has long been known that schizophrenia runs in families. People who have a close relative with schizophrenia are more likely to develop the disorder than are people who have no relatives with the illness. For example, a monozygotic (identical) twin of a person with schizophrenia has the highest risk – 40 to 50 percent – of developing the illness. A child whose parent has schizophrenia has about a 10 percent chance. By comparison, the risk of schizophrenia in the general population is about 1 percent.

Scientists are studying genetic factors in schizophrenia. It appears likely that multiple genes are involved in creating a predisposition to develop the disorder. In addition, factors such as prenatal difficulties like intrauterine starvation or viral infections, perinatal complications, and various nonspecific stressors, seem to influence the development of schizophrenia. However, it is not yet understood how the genetic predisposition is transmitted, and it cannot yet be accurately predicted whether a given person will or will not develop the disorder.

Several regions of the human genome are being investigated to identify genes that may confer susceptibility for schizophrenia. The strongest evidence to date leads to chromosomes 13 and 6 but remains unconfirmed. Identification of specific genes involved in

the development of schizophrenia will provide important clues into what goes wrong in the brain to produce and sustain the illness and will guide the development of new and better treatments.

Is Schizophrenia Associated With A Chemical Defect In The Brain?

Basic knowledge about brain chemistry and its link to schizophrenia is expanding rapidly. Neurotransmitters, substances that allow communication between nerve cells, have long been thought to be involved in the development of schizophrenia. It is likely, although not yet certain, that the disorder is associated with some imbalance of the complex, interrelated chemical systems of the brain, perhaps involving the neurotransmitters dopamine and glutamate. This area of research is promising.

Is Schizophrenia Caused By A Physical Abnormality In The Brain?

There have been dramatic advances in neuroimaging technology that permit scientists to study brain structure and function in living individuals. Many studies of people with schizophrenia have found

abnormalities in brain structure (for example, enlargement of the fluid-filled cavities, called the ventricles, in the interior of the brain, and decreased size of certain brain regions) or function (for example, decreased metabolic activity in certain brain regions). It should be emphasized that these abnormalities are quite subtle and are not characteristic of all people with schizophrenia, nor do they occur only in individuals with this illness. Microscopic studies of brain tissue after death have also shown small changes in distribution or number of brain cells in people with schizophrenia. It appears that many (but probably not all) of these changes are present before an individual becomes ill, and schizophrenia may be, in part, a disorder in development of the brain.

Developmental neurobiologists funded by the National Institute of Mental Health (NIMH) have found that schizophrenia may be a developmental disorder resulting when neurons form inappropriate connections during fetal development. These errors may lie dormant until puberty, when changes in the brain that occur normally during this critical stage of maturation interact adversely with the faulty connections. This research has spurred efforts to identify prenatal factors that may have some bearing on the apparent developmental abnormality.

In other studies, investigators using brain-imaging techniques have found evidence of early biochemical changes that may precede the onset of disease symptoms, prompting examination of the neural circuits that are most likely to be involved in producing those symptoms. Meanwhile, scientists working at the molecular level are exploring the genetic basis for abnormalities in brain development and in the neurotransmitter systems regulating brain function.

HOW IS IT TREATED?

Since schizophrenia may not be a single condition and its causes are not yet known, current treatment methods are based on both clinical research and experience. These approaches are chosen on the basis of their ability to reduce the symptoms of schizophrenia and to lessen the chances that symptoms will return.

What About Medications?

Antipsychotic medications have been available since the mid-1950s. They have greatly improved the outlook for individual patients. These medications reduce the psychotic symptoms of schizophrenia and usually allow the patient to function more effectively and appropriately. Antipsychotic drugs are the best treatment now available, but they do not “cure” schizophrenia or ensure that there will be no further psychotic episodes. The choice and dosage of medication can be made only by a qualified physician who is well trained in the medical treatment of mental disorders. The dosage of medication is individualized for each patient, since people may vary a great deal in the amount of drug needed to reduce symptoms without producing troublesome side effects.

The large majority of people with schizophrenia show substantial improvement when treated with antipsychotic drugs. Some patients, however, are not helped very much by the medications and a few do not seem to need them. It is difficult to predict which patients will fall into these two groups and to distinguish them from the large majority of patients who do benefit from treatment with antipsychotic drugs.

A number of new antipsychotic drugs (the so-called “atypical antipsychotics”) have been introduced since 1990. The first of these, clozapine (Clozaril(r)), has been shown to be more effective than other antipsychotics, although the possibility of severe side effects – in particular, a condition called agranulocytosis (loss of the white blood cells that fight infection) – requires that patients be monitored with blood tests every one or two weeks. Even newer antipsychotic drugs, such as risperidone (Risperdal(r)) and olanzapine (Zyprexa(r)), are safer than the older drugs or clozapine, and they also may be better tolerated. They may or may not treat the illness as well as clozapine, however. Several additional antipsychotics are currently under development.

Antipsychotic drugs are often very effective in treating certain symptoms of schizophrenia, particularly hallucinations and delusions; unfortunately, the drugs may not be as helpful with other symptoms, such as reduced motivation and emotional expressiveness. Indeed, the older antipsychotics (which also went by the name of “neuroleptics”), medicines like haloperidol (Haldol®) or chlorpromazine (Thorazine®), may even produce side effects that resemble the more difficult to treat symptoms. Often, lowering the dose or switching to a different medicine may reduce these side effects; the newer medicines, including olanzapine (Zyprexa®), quetiapine (Seroquel®), and risperidone (Risperdal®), appear less likely to have this problem. Sometimes when people with schizophrenia become depressed, other symptoms can appear to worsen. The symptoms may improve with the addition of an antidepressant medication.

Patients and families sometimes become worried about the antipsychotic medications used to treat schizophrenia. In addition to concern about side effects, they may worry that such drugs could

lead to addiction. However, antipsychotic medications do not produce a “high” (euphoria) or addictive behavior in people who take them.

Another misconception about antipsychotic drugs is that they act as a kind of mind control, or a “chemical straitjacket.” Antipsychotic drugs used at the appropriate dosage do not “knock out” people or take away their free will. While these medications can be sedating, and while this effect can be useful when treatment is initiated particularly if an individual is quite agitated, the utility of the drugs is not due to sedation but to their ability to diminish the hallucinations, agitation, confusion, and delusions of a psychotic episode. Thus, antipsychotic medications should eventually help an individual with schizophrenia to deal with the world more rationally.

How Long Should People With Schizophrenia Take Antipsychotic Drugs?

Antipsychotic medications reduce the risk of future psychotic episodes in patients who have recovered from an acute episode. Even with continued drug treatment, some people who have recovered will suffer relapses. Far higher relapse rates are seen when medication is discontinued. In most cases, it would not be accurate to say that continued drug treatment “prevents” relapses; rather, it reduces their intensity and frequency. The treatment of severe psychotic symptoms generally requires higher dosages than

those used for maintenance treatment. If symptoms reappear on a lower dosage, a temporary increase in dosage may prevent a full-blown relapse.

Because relapse of illness is more likely when antipsychotic medications are discontinued or taken irregularly, it is very important that people with schizophrenia work with their doctors and family members to adhere to their treatment plan. Adherence to treatment refers to the degree to which patients follow the treatment plans recommended by their doctors. Good adherence involves taking prescribed medication at the correct dose and proper times each day, attending clinic appointments, and/or carefully following other treatment procedures. Treatment adherence is often difficult for people with schizophrenia, but it can be made easier with the help of several strategies and can lead to improved quality of life.

There are a variety of reasons why people with schizophrenia may not adhere to treatment. Patients may not believe they are ill and may deny the need for medication, or they may have such disorganized thinking that they cannot remember to take their daily doses. Family members or friends may not understand schizophrenia and may inappropriately advise the person with schizophrenia to stop treatment when he or she is feeling better. Physicians, who play an important role in helping their patients adhere to treatment, may neglect to ask patients how often they are taking their medications, or may be unwilling to accommodate a patient's request to change dosages or try a new treatment. Some patients report that side effects of the medications seem worse than the illness itself. Further, substance abuse can interfere with the effectiveness of treatment, leading patients to discontinue medications. When a complicated treatment plan is added to any of these factors, good adherence may become even more challenging.

Fortunately, there are many strategies that patients, doctors, and families can use to improve adherence and prevent worsening of the illness. Some antipsychotic medications, including haloperidol (Haldol®), fluphenazine (Prolixin®), perphenazine (Trilafon®) and others, are available in long-acting injectable forms that eliminate the need to take pills every day. A major goal of current research on treatments for schizophrenia is to develop a wider variety of long-acting antipsychotics, especially the newer agents with milder side effects, which can be delivered through injection. Medication calendars or pill boxes labeled with the days of the week can help patients and caregivers know when medications have or have not been taken. Using electronic timers that beep when medications should be taken, or pairing medication taking with routine daily events like meals, can help patients remember and adhere to their dosing schedule. Engaging family members in observing oral medication taking by patients can help ensure adherence. In addition, through a variety of other methods of adherence monitoring, doctors can identify when pill taking is a problem for their patients and can work with them to make adherence easier. It is important to help motivate patients to continue taking their medications properly.

In addition to any of these adherence strategies, patient and family education about schizophrenia, its symptoms, and the medications being prescribed to treat the disease is an important part of the treatment process and helps support the rationale for good adherence.

What About Side Effects?

Antipsychotic drugs, like virtually all medications, have unwanted effects along with their beneficial effects. During the early phases of drug treatment, patients may be troubled by side effects such as drowsiness, restlessness, muscle spasms, tremor, dry mouth, or blurring of vision. Most of these can be corrected by lowering the dosage or can be controlled by other medications. Different patients have different treatment responses and side effects to various antipsychotic drugs. A patient may do better with one drug than another.

The long-term side effects of antipsychotic drugs may pose a considerably more serious problem. Tardive dyskinesia (TD) is a disorder characterized by involuntary movements most often affecting the mouth, lips, and tongue, and sometimes the trunk or other parts of the body such as arms and legs. It occurs in about 15 to 20 percent of patients who have been receiving the older, “typical” antipsychotic drugs for many years, but TD can also develop in patients who have been treated with these drugs for shorter periods of time. In most cases, the symptoms of TD are mild, and the patient may be unaware of the movements.

Antipsychotic medications developed in recent years all appear to have a much lower risk of producing TD than the older, traditional antipsychotics. The risk is not zero, however, and they can produce side effects of their own such as weight gain. In addition, if given at too high of a dose, the newer medications may lead to problems such as social withdrawal and symptoms resembling Parkinson’s disease, a disorder that affects movement. Nevertheless, the newer antipsychotics are a significant advance in treatment, and their

optimal use in people with schizophrenia is a subject of much current research.

What About Psychosocial Treatments?

Antipsychotic drugs have proven to be crucial in relieving the psychotic symptoms of schizophrenia – hallucinations, delusions, and incoherence – but are not consistent in relieving the behavioral symptoms of the disorder. Even when patients with schizophrenia are relatively free of psychotic symptoms, many still have extraordinary difficulty with communication, motivation, self-care, and establishing and maintaining relationships with others. Moreover, because patients with schizophrenia frequently become ill during the critical career-forming years of life (e.g., ages 18 to 35), they are less likely to complete the training required for skilled work. As a result, many with schizophrenia not only suffer thinking and emotional difficulties, but lack social and work skills and experience as well.

It is with these psychological, social, and occupational problems that psychosocial treatments may help most. While psychosocial approaches have limited value for acutely psychotic patients (those who are out of touch with reality or have prominent hallucinations or delusions), they may be useful for patients with less severe symptoms or for patients whose psychotic symptoms are under control. Numerous forms of psychosocial therapy are available for people with schizophrenia, and most focus on improving the patient's social functioning – whether in the hospital or community, at home, or on the job. Some of these approaches

SCHIZOPHRENIA IS NOT “SPLIT PERSONALITY”

There is a common notion that schizophrenia is the same as “split personality” - a Dr. Jekyll-Mr. Hyde switch in character. This is not correct.

are described here. Unfortunately, the availability of different forms of treatment varies greatly from place to place.

Rehabilitation

Broadly defined, rehabilitation includes a wide array of non-medical interventions for those with schizophrenia. Rehabilitation programs emphasize social and vocational training to help patients and former patients overcome difficulties in these areas. Programs may include vocational counseling, job training, problem-solving and money management skills, use of public transportation, and social skills training. These approaches are important for the success of the community-centered treatment of schizophrenia, because they provide discharged patients with the skills necessary to lead productive lives outside the sheltered confines of a mental hospital.

Individual Psychotherapy

Individual psychotherapy involves regularly scheduled talks between the patient and a mental health professional such as a psychiatrist, psychologist, psychiatric social worker, or nurse. The sessions may focus on current or past problems, experiences, thoughts, feelings, or relationships. By sharing experiences with a trained empathic person – talking about their world with someone outside it – individuals with schizophrenia may gradually come to understand more about themselves and their problems. They can also learn to sort out the real from the unreal and distorted. Recent studies indicate that supportive, reality-oriented, individual psychotherapy, and cognitive-behavioral approaches that teach coping and problem-solving skills, can be beneficial for outpatients with schizophrenia. However, psychotherapy is not a substitute for antipsychotic

medication, and it is most helpful once drug treatment first has relieved a patient's psychotic symptoms.

Family Education

Very often, patients with schizophrenia are discharged from the hospital into the care of their family; so it is important that family members learn all they can about schizophrenia and understand the difficulties and problems associated with the illness. It is also helpful for family members to learn ways to minimize the patient's chance of relapse – for example, by using different treatment adherence strategies – and to be aware of the various kinds of outpatient and family services available in the period after hospitalization. Family “psychoeducation,” which includes teaching various coping strategies and problem-solving skills, may help families deal more effectively with their ill relative and may contribute to an improved outcome for the patient.

Self-Help Groups

Self-help groups for people and families dealing with schizophrenia are becoming increasingly common. Although not led by a professional therapist, these groups may be therapeutic because members provide continuing mutual support as well as comfort in knowing that they are not alone in the problems they face. Self-help groups may also serve other important functions. Families working together can more effectively serve as advocates for needed research and hospital and community treatment programs. Patients acting as a group rather than individually may be better able to dispel stigma and draw public attention to such abuses as discrimination against the mentally ill.

Family and peer support and advocacy groups are very active and provide useful information and assistance for patients and families of patients with schizophrenia and other mental disorders. A list of some of these organizations is included at the end of this document.

HOW CAN OTHER PEOPLE HELP?

A patient's support system may come from several sources, including the family, a professional residential or day program provider, shelter operators, friends or roommates, professional case managers, churches and synagogues, and others. Because many patients live with their families, the following discussion frequently uses the term "family." However, this should not be taken to imply that families ought to be the primary support system.

There are numerous situations in which patients with schizophrenia may need help from people in their family or community. Often, a person with schizophrenia will resist treatment, believing that delusions or hallucinations are real and that psychiatric help is not required. At times, family or friends may need to take an active role in having them seen and evaluated by a professional. The issue of civil rights enters into any attempts to provide treatment. Laws protecting patients from involuntary commitment have become very strict, and families and community organizations may be frustrated in their efforts to see that a severely mentally ill individual gets needed help. These laws vary from State to State; but generally, when people are dangerous to themselves or others due to a mental disorder, the police can assist in getting them an emergency psychiatric evaluation and, if necessary,

hospitalization. In some places, staff from a local community mental health center can evaluate an individual's illness at home if he or she will not voluntarily go in for treatment.

Sometimes only the family or others close to the person with schizophrenia will be aware of strange behavior or ideas that the person has expressed. Since patients may not volunteer such information during an examination, family members or friends should ask to speak with the person evaluating the patient so that all relevant information can be taken into account.

Ensuring that a person with schizophrenia continues to get treatment after hospitalization is also important. A patient may discontinue medications or stop going for follow-up treatment, often leading to a return of psychotic symptoms. Encouraging the patient to continue treatment and assisting him or her in the treatment process can positively influence recovery. Without treatment, some people with schizophrenia become so psychotic and disorganized that they cannot care for their basic needs, such as food, clothing, and shelter. All too often, people with severe mental illnesses such as schizophrenia end up on the streets or in jails, where they rarely receive the kinds of treatment they need.

Those close to people with schizophrenia are often unsure of how to respond when patients make statements that seem strange or are clearly false. For the individual with schizophrenia, the bizarre beliefs or hallucinations seem quite real – they are not just “imaginary fantasies.” Instead of “going along with” a person’s delusions, family members or friends can tell the person that they do not see things the same way or do not agree with his or her conclusions, while acknowledging that things may appear otherwise to the patient.

It may also be useful for those who know the person with schizophrenia well to keep a record of what types of symptoms have appeared, what medications (including dosage) have been taken, and what effects various treatments have had. By knowing what symptoms have been present before, family members may know better what to look for in the future. Families may even be able to identify some “early warning signs” of potential relapses, such as increased withdrawal or changes in sleep patterns, even better and earlier than the patients themselves. Thus, return of psychosis may be detected early and treatment may prevent a full-blown relapse. Also, by knowing which medications have helped and which have caused troublesome side effects in the past, the family can help those treating the patient to find the best treatment more quickly.

In addition to involvement in seeking help, family, friends, and peer groups can provide support and encourage the person with schizophrenia to regain his or her abilities. It is important that goals be attainable, since a patient who feels pressured and/or repeatedly criticized by others will probably experience stress that may lead to a worsening of symptoms. Like anyone else, people with schizophrenia need to know when they are doing things right. A positive approach may be helpful and perhaps more effective in the long run than criticism. This advice applies to everyone who interacts with the person.

WHAT IS THE OUTLOOK?

The outlook for people with schizophrenia has improved over the last 25 years. Although no totally effective therapy has yet been devised, it is important to remember that many people with the

illness improve enough to lead independent, satisfying lives. As we learn more about the causes and treatments of schizophrenia, we should be able to help more patients achieve successful outcomes.

Studies that have followed people with schizophrenia for long periods, from the first episode to old age, reveal that a wide range of outcomes is possible. When large groups of patients are studied, certain factors tend to be associated with a better outcome – for example, a pre-illness history of normal social, school, and work adjustment. However, the current state of knowledge, does not allow for a sufficiently accurate prediction of long-term outcome.

Given the complexity of schizophrenia, the major questions about this disorder – its cause or causes, prevention, and treatment – must be addressed with research. The public should beware of those offering “the cure” for (or “the cause” of) schizophrenia. Such claims can provoke unrealistic expectations that, when unfulfilled, lead to further disappointment. Although progress has been made toward better understanding and treatment of schizophrenia, continued investigation is urgently needed. As the lead Federal agency for research on mental disorders, NIMH conducts and supports a broad spectrum of mental illness research from molecular genetics to large-scale epidemiologic studies of populations. It is thought that this wide-ranging research effort, including basic studies on the brain, will continue to illuminate processes and principles important for understanding the causes of schizophrenia and for developing more effective treatments.

All material in this publication is free of copyright restrictions and may be copied, reproduced, or duplicated without permission from NIMH; citation of the source is appreciated.

This booklet was written by Melissa K. Speaking, M.H.S., of the Office of Communications and Public Liaison, NIMH. Scientific information and review were provided by NIMH staff members David Shore, M.D., and John K. Hsiao, M.D.

This booklet is also available on the NIMH Web site at <http://www.nimh.nih.gov/publicat/schizoph.htm>.

For more information on research into the brain, behavior, and mental disorders contact:

National Institute of Mental Health (NIMH)

Office of Communication and Public Liaison

Information Resources and Inquiries Branch

6001 Executive Boulevard, Rm. 8184, MSC 9663

Bethesda, MD 20892-9663

Phone: 301-443-4513

Fax: 301-443-4279

E-mail: nimhinfo@nih.gov

Fax back system: Mental Health FAX4U at 301-443-5158

Web site address: <http://www.nimh.nih.gov>

Information, support, and advocacy organizations:

The National Alliance for the Mentally Ill (NAMI)

Colonial Place Three
2107 Wilson Blvd., Suite 300
Arlington, VA 22201-3042
Phone: 1-800-950-NAMI (6264) or (703) 524-7600
Internet: <http://www.nami.org>

National Mental Health Association (NMHA)

1021 Prince Street
Alexandria, VA 22314-2971
Phone: 1-800-969-6942 or (703) 684-7722
Internet: <http://www.nmha.org>

National Mental Health Consumers' Self-Help Clearinghouse

1211 Chestnut Street, Suite 1000
Philadelphia, PA 19107
Phone: 1-800-553-4key (4539) or (215) 751-1810
Internet: <http://www.mhselfhelp.org/index2.html>

National Alliance for Research on Schizophrenia and Depression (NARSAD)

60 Cutter Mill Road, Suite 404
Great Neck, NY 11021
Phone: (516) 829-0091
Internet: <http://www.narsad.org>



This is the electronic version of a National Institute of Mental Health (NIMH) publication, available from <http://www.nimh.nih.gov/publicat/index.cfm>. To order a print copy, call the NIMH Information Center at 301-443-4513 or 1-866-615-6464 (toll-free). Visit the NIMH Web site (<http://www.nimh.nih.gov>) for information that supplements this publication.

To learn more about NIMH programs and publications, contact the following:

Web address:

<http://www.nimh.nih.gov>

E-mail:

nimhinfo@nih.gov

Phone numbers:

301-443-4513 (local)

1-866-615-6464 (toll-free)

301-443-3431 (TTY)

Fax numbers:

301-443-4279

301-443-5158 (FAX 4U)

Street address:

National Institute of Mental Health

Office of Communications

Room 8184, MSC 9663

6001 Executive Boulevard

Bethesda, Maryland 20892-9663 USA

This information is in the public domain and can be copied or reproduced without permission from NIMH. To reference this material, we suggest the following format:

National Institute of Mental Health. Title. Bethesda (MD): National Institute of Mental Health, National Institutes of Health, US Department of Health and Human Services; Year of Publication/Printing [Date of Update/Revision; Date of Citation]. Extent. (NIH Publication No XXX XXXX). Availability.

A specific example is:

National Institute of Mental Health. Childhood-Onset Schizophrenia: An Update from the National Institute of Mental Health. Bethesda (MD): National Institute of Mental Health, National Institutes of Health, US Department of Health and Human Services; 2003 [cited 2004 February 24]. (NIH Publication Number: NIH 5124). 4 pages. Available from: <http://www.nimh.nih.gov/publicat/schizkids.cfm>