Expert Consensus Treatment Guidelines for Schizophrenia: A Guide for Patients and Families

If you or someone you care about has been diagnosed with schizophrenia, you may feel like you are the only person facing this illness. But you are not alone—schizophrenia affects almost 3 million Americans. Although widely misunderstood and unfairly stigmatized, schizophrenia is actually a highly treatable brain disease. The treatment for schizophrenia is in many ways similar to that for other medical conditions such as diabetes or epilepsy. The good news is that new discoveries are greatly improving the chances of recovery and making it possible for people with schizophrenia to lead much more independent and productive lives.

This guide is designed to answer the most frequently asked questions about schizophrenia and how it is treated. Many of the recommendations are based on a recent survey of over 100 experts on schizophrenia who were asked about the best ways to treat this illness.

WHAT IS SCHIZOPHRENIA?

What are the symptoms?

The symptoms of schizophrenia are divided into three categories: positive symptoms, disorganized symptoms, and negative symptoms.

Positive or psychotic symptoms

- *Delusions, unusual thoughts, and suspiciousness.* People with schizophrenia may have ideas that are strange, false, and out of touch with reality. They may believe that people are reading their thoughts or plotting against them, that others are secretly monitoring and threatening them, or that they can control other people's minds or be controlled by them.
- *Hallucinations.* People with schizophrenia may hear voices talking to them or about them, usually saying negative, critical, or frightening things. Less commonly, the person may see objects that don't exist.
- *Distorted perceptions.* People with schizophrenia may have a hard time making sense of everyday sights, sounds, smells, tastes, and bodily sensations—so that ordinary things appear frightening. They may be extra-sensitive to background noises, lights, colors, and distractions.

Negative symptoms.

- *Flat or blunted emotions.* Schizophrenia can make it difficult for people to experience feelings, know what they are feeling, clearly express their emotions, or empathize with other people's feelings. It can be hard for people with such symptoms to relate to others. This can lead to periods of intense withdrawal and profound isolation.
- *Lack of motivation or energy.* People with schizophrenia usually have trouble starting projects or finishing things they've started. In extreme cases, they may have to be reminded to do simple things like taking a bath or changing clothes.
- *Lack of pleasure or interest in things.* To people with schizophrenia, the world seems flat, uninteresting, and cardboard. It feels like it is not worth the effort to get out and do things.
- *Limited speech.* People with schizophrenia often won't say much and may not speak unless spoken to.

Disorganized symptoms

- *Confused thinking and disorganized speech.* People with schizophrenia may have trouble thinking clearly and understanding what other people say. It may be difficult for them to carry on a conversation, plan ahead, and solve problems.
- *Disorganized behavior.* Schizophrenia can cause people to do things that don't make sense, repeat rhythmic gestures, or make ritualistic movements. Sometimes the illness can cause people to completely stop speaking or moving or to hold a fixed position for long periods of time.

When does schizophrenia begin?

Schizophrenia can affect anyone at any age, but it usually starts between adolescence and the age of 40. Children can also be affected by schizophrenia, but this is rare.

The person who is having a first episode of schizophrenia may have been ill for a long time before getting help. Usually he or she comes to treatment because delusions or hallucinations have triggered disturbing behavior. At this point, the person often denies having a mental illness and does not want treatment. With treatment, however, delusions and hallucinations are likely to get much better. Most people make a good recovery from a first episode of schizophrenia, although this can take several months.

What is the usual course of schizophrenia?

The severity of the course varies a lot and often depends on whether the person keeps taking medicine. Patients can be divided into three groups based on how severe their symptoms are and how often they relapse.

The patient who has a mild course of illness and is usually stable

- Takes medication as prescribed all the time
- Has had only one or two major relapses by age 45
- Has only a few mild symptoms

This Guide was prepared by Peter J. Weiden, M.D., Patricia L. Scheifler, M.S.W., Joseph P. McEvoy, M.D., Allen Frances, M.D., and Ruth Ross, M.A. The guide includes recommendations contained in the 1999 *Expert Consensus Treatment Guidelines for Schizophrenia*. The Editors gratefully acknowledge Laurie Flynn and the National Alliance for the Mentally Ill for their generous help and permission to adapt their written materials. Eli Lilly, Janssen Pharmaceutica, Novartis Pharmaceuticals, Ortho-McNeil Pharmaceutical, Pfizer Inc, and Zeneca Pharmaceuticals provided unrestricted educational grants in support of this project.

Reprinted from J Clin Psychiatry 1999:60 (suppl 11).

The patient who has a moderate course of illness and is often stable

- Takes medication as prescribed most of the time
- Has had several major relapses by age 45, plus periods of increased symptoms during times of stress
- Has some persistent symptoms between relapses

The patient who has a severe and unstable course of illness

- Often doesn't take medication as prescribed and may drop out of treatment
- Relapses frequently and is stable only for short periods of time between relapses
- Has a lot of bothersome symptoms
- Needs help with activities of daily living (e.g., finding a place to live, managing money, cooking, laundry)
- Is likely to have other problems that make it harder to recover (e.g., medical problems, substance abuse, or a mood disorder)

What are the stages of recovery?

- ***Acute episode*:** this is a period of very intense psychotic symptoms. It may start suddenly or begin slowly over several months.
- ***Stabilization after an acute episode***: After the intense psychotic symptoms are controlled by medication, there is usually a period of troublesome, but much less severe, symptoms.
- ***Maintenance phase or between acute episodes***: This is the longer term recovery phase of the illness. The most intense symptoms of the illness are controlled by medication, but there may be some milder persistent symptoms. Many people continue to improve during this phase, but at a slower pace.

Why is it important to diagnose and treat schizophrenia as early as possible?

Early diagnosis, proper treatment, and finding the right medications can help people in a number of important ways:

- ***Stabilize acute psychotic symptoms.*** The first priority is to eliminate or reduce the positive (psychotic) symptoms, especially when they are disruptive. Most people's psychotic symptoms can be stabilized within 6 weeks from the time they start medication. Antipsychotic medications allow patients to be discharged from the hospital much earlier.
- ***Reduce likelihood of relapse and rehospitalization.*** The more relapses a person has, the harder it is to recover from them. Proper treatment can prevent or delay relapse and break the "revolving door" cycle.
- ***Ensure appropriate treatment.*** Sometimes a person is misdiagnosed as having another disorder instead of schizophrenia. This can be a serious problem because the person may end up taking the wrong medications.
- ***Decrease alcohol/substance abuse.*** More than 50% of people with schizophrenia have problems with alcohol or street drugs at some point during their illness, and this makes matters much worse. Prompt recognition and treatment of this "dual diagnosis" problem is essential for recovery.
- ***Decrease risk of suicide.*** The overall lifetime rate of suicide is over 10%. The risk is highest in the early years of the illness. Fortunately, suicidal behavior is treatable, and the suicide risk eventually decreases over time. Therefore, it is very important to get professional help to avoid this tragic outcome.
- ***Minimize problems in relationships and life disruption.*** Early diagnosis and treatment decrease the risk that the illness will get in the way of relationships and life goals.
- ***Reduce stress and burden on families.*** Schizophrenia places a tremendous burden on families and loved ones. Programs that involve families early in the treatment process reduce relapse and decrease stress and disruption in the family.
- ***Begin rehabilitation.*** Early treatment allows the recovery process to begin before long periods of disability have occurred.

Is schizophrenia inherited?

The answer is yes, but only to a degree. If no one in your family has schizophrenia, the chances are only 1 in 100 that you will have it. If one of your parents or a brother or a sister has it, the chances go up, but only to about 10%. If both your parents have schizophrenia, there is a 40% chance that you will have it. If you have a family member with schizophrenia and you have no signs of the illness by your 30s, it is extremely unlikely that you will get this illness. If you have a parent or brother or sister with schizophrenia, the chances of your children getting schizophrenia are only slightly increased (only to about 3%) and most genetic counselors do not consider this to be a large enough difference to change one's family planning.

Researchers have identified a number of genes that may be linked to the disorder. This suggests that different kinds of biochemical problems may lead to schizophrenia in different people (just as there are different kinds of arthritis). However, many other factors besides genetics are also involved. Research is currently underway to identify these factors and learn how they affect chances of developing the illness. We do know that schizophrenia is ***not*** caused by bad parenting, trauma, abuse, or personal weakness.

MEDICATION TREATMENT

The medications used to treat schizophrenia are called antipsychotics because they help control the hallucinations, delusions, and thinking problems associated with the illness. Patients may need to try several different antipsychotic medications before they find the medicine, or combination of medicines, that works best for them. When the first antipsychotic medication was introduced 50 years ago, this represented the first effective treatment for schizophrenia. Three categories of antipsychotics are now available, and the wide choice of treatment options has greatly improved patients' chances for recovery.

Conventional antipsychotics

The antipsychotics in longest use are called *conventional antipsychotics*. Although very effective, they often cause serious or troublesome movement side effects. Examples are:

Haldol (haloperidol)	Stelazine (trifluoperazine)
Mellaril (thioridazine)	Thorazine (chlorpromazine)
Navane (thiothixene)	Trilafon (perphenazine)
Prolixin (fluphenazine)	

Conventional antipsychotics are becoming obsolete. Because of side effects, experts usually recommend using a newer atypical antipsychotic rather than a conventional.

There are two exceptions. For those individuals who are already doing well on a conventional antipsychotic without troublesome side effects, the experts recommend continuing it. The other exception is when the person has had trouble taking pills regularly. Two of the conventional antipsychotics, Prolixin and Haldol, can be given in long-acting shots (called "depot formulations") at 2- to 4-week intervals. With depot formulations, medication is stored in the body and slowly released. No such depot preparations are yet available for the newer antipsychotics.

Newer atypical antipsychotics

The treatment of schizophrenia has been revolutionized in recent years by the introduction of several *newer atypical antipsychotics*. These medications are called atypical because they work in a different way than the conventional antipsychotics and are much less likely to cause the distressing movement side effects that can be so troubling with the conventional antipsychotics. The following newer atypical antipsychotics are currently available:

- Risperdal (risperidone)
- Seroquel (quetiapine)
- Zyprexa (olanzapine)

Other atypical antipsychotics, such as Zeldox (ziprasidone), may be available in the near future.

The experts recommend the newer atypical medications as the treatment of choice for most patients with schizophrenia.

Clozaril (clozapine)

Clozaril, introduced in 1990, was the first *atypical antipsychotic*. Clozaril can help 25%–50% of patients who have not responded to conventional antipsychotics. Unfortunately, Clozaril has a rare but potentially very serious side effect. In fewer than 1% of those taking it, Clozaril can decrease the number of white blood cells necessary to fight infection. This means that patients receiving Clozaril must have their blood checked regularly. The experts recommend that Clozaril be used only after at least two other safer antipsychotics have not worked.

Selecting medication for a first episode

The experts recommend the newer atypical antipsychotics as the treatment of choice for a patient having a first episode of schizophrenia. This reflects their better side effect profile and lower risk of tardive dyskinesia. Clozapine is not recommended for a first episode because of its side effects.

How long does it take antipsychotics to work?

Usually the antipsychotic medications take a while to begin working. Before giving up on a medicine and switching to another one, the experts recommend trying it for about 6 weeks (and perhaps twice as long for Clozaril).

Selecting medication for relapses

If a person has a relapse because of not taking the medication as prescribed, it is important to find out why he or she stopped taking it. Sometimes people stop taking medication because of troubling side effects. If this happens, the doctor may lower the dose, add a side effect medication, or switch to a medication with fewer side effects (usually an atypical antipsychotic). If the person was not taking the medication for other reasons, the doctor may suggest switching to a long-acting injection given every 2–4 weeks, which makes it simpler to stay on the medication.

Sometimes a person will relapse *despite* taking the medication as prescribed. This is generally a good reason to switch to another medication—usually one of the newer atypical antipsychotics if the person was taking a conventional antipsychotic, or a different newer atypical antipsychotic if the person had already tried an atypical antipsychotic. Fortunately, even if someone has not responded well to a number of other antipsychotics, clozapine is available as a backup and may work when other things have failed.

Medication during the recovery period

We now know that schizophrenia is a highly treatable disease. Like diabetes, a cure has not yet been found, but the symptoms can be controlled with medication in most people. Prospects for the future are constantly brighter through the pioneering explorations in brain research and the development of many new medications. To achieve good results, however, you must stick to your treatment and avoid substance abuse.

It is very important that patients stay in treatment even after recovery. Four out of five patients who stop taking their medications after a first episode of schizophrenia will have a relapse. The experts recommend that first episode patients stay on an antipsychotic medication for 12–24 months before even trying to reduce the dose. Patients who have had more than one episode of schizophrenia or have not recovered fully from a first episode will need treatment for a longer time, maybe even indefinitely. Remember—stopping medication is the most frequent cause of relapse and a more severe and unstable course of illness.

Be sure to take your medicine as directed. Even if you have felt better for a long time, you can still have a relapse if you go off your medication.

What are the possible side effects of antipsychotics?

Because people with schizophrenia have to take their medications for a very long time, it is important to avoid and manage unpleasant side effects.

Perhaps the biggest problem with the conventional antipsychotics is that they often cause muscle movements or rigidity called extrapyramidal side effects (EPS). People may feel slowed down and stiff. Or they may be so restless that they have to walk around all the time and feel like they're jumping out of their skin. The medicine can also cause tremors, especially in the hands and feet. Sometimes the doctor will give a medication called an anticholinergic (usually benztropine [Cogentin]) along with the antipsychotic to prevent or treat EPS. The atypical antipsychotics are much less likely to cause EPS than the conventional antipsychotics.

When people take antipsychotic medications for a long time, they sometimes develop a side effect called *tardive dyskinesia*—uncontrolled movements of the mouth, a protruding tongue, or facial grimaces. Hands and feet may move in a slow rhythmical pattern without the person wishing this to happen and sometimes even without the person being aware of it. The chances of developing this side effect can be reduced by using the lowest possible effective dose of antipsychotic medication. If someone taking a conventional antipsychotic develops tardive dyskinesia, the experts recommend switching to an atypical antipsychotic.

Medications for schizophrenia can cause problems with sexual functioning that may make patients stop taking them. The doctor will usually treat these problems by lowering the dose of antipsychotic to the smallest effective dose or switching to a newer atypical antipsychotic.

Weight gain can be a problem with all the antipsychotics, but it is more common with the atypical antipsychotics than the conventional antipsychotics. Diet and exercise can help.

A rare side effect of antipsychotic medications is neuroleptic malignant syndrome, which involves very severe stiffness and tremor that can lead to fever and other severe complications. Such symptoms require the doctor's immediate attention.

Tell your doctor right away about any side effects you have

Different people have different side effects, and some people may have no problems at all with side effects. Also, what is a troublesome side effect for one person (for example, sedation in someone who already feels lethargic because of the illness) may be a helpful effect for someone else (sedation in someone who has trouble sleeping).

It can also be very hard to tell if a problem is part of the illness or is a side effect of the medication. For example, conventional antipsychotics can make you feel slowed down and tired—but so can the lack of energy that is a negative symptom of schizophrenia.

If you develop any new problem while taking an antipsychotic, tell your doctor right away so that he can decide if it is a side effect of your medication. If side effects are a problem for you, you and your doctor can try a number of things to help:

- *Waiting a while to see if the side effect goes away on its own*
- *Reducing the amount of medicine*
- *Adding another medication to treat the side effect*
- *Trying a different medicine (especially an atypical antipsychotic) to see if there are fewer or less bothersome side effects*

Remember: Changing medicine is a complicated decision. It is dangerous to make changes in your medicine on your own! Changes in medication should also be made slowly.

PSYCHOSOCIAL TREATMENT AND REHABILITATION

Although medication is almost always necessary in the treatment of schizophrenia, it is not usually enough by itself. People with schizophrenia also need services and support to overcome the illness and to deal with the fear, isolation, and stigma often associated with it. In the following sections, we present the experts' recommendations for the kinds of psychosocial treatment, rehabilitation services, and living arrangements that may be helpful at various stages of recovery. These recommendations are intended to be guidelines, not rules. Each patient is unique, and special circumstances may affect the choice of which services are best for a specific patient at a particular time during recovery. Also, some communities have a lot of different services to choose from, while others unfortunately have only a few. It is important for you to find out what services are available to you in your community (and when necessary to advocate for more).

Key components of psychosocial treatment

Patient and family education. Patient, family, and other key people in the patient's life need to learn as much as possible about what schizophrenia is and how it is treated, and to develop the knowledge and skills needed to avoid relapse and work toward recovery. Patient and family education is an ongoing process that is recommended throughout all phases of the illness.

Collaborative decision making. It is extremely important for patient, family, and clinician to make decisions *together* about treatments and goals to work toward. Joint decision making is recommended at every stage of the illness. As patients recover, they can take an increasingly active part in making decisions about the management of their own illness.

Medication and symptom monitoring. Careful monitoring can help ensure that patients take medication as prescribed and identify early signs of relapse so that preventive steps can be taken. A checklist of symptoms and side effects can be used to see how well the medication is working, to check for signs of relapse, and to figure out if efforts to decrease side effects are successful. Medication can be monitored by helping the person fill a weekly pill box or by providing supervision at medication times.

Assistance with obtaining medication. Paying for treatment is often difficult. Health insurance coverage for psychiatric illnesses, when available, may have high deductibles and copayments, limited visits, or other restrictions that are not equal to the benefits for other medical disorders. Public programs such as Medicaid and Medicare may be available to finance treatment. The newer medications that can be so helpful for most patients are unfortunately more expensive than the older ones. The treatment team, patient, and family should explore available ways to get access to the best medication by working through public or private insurance, copayment waivers, indigent drug programs, or drug company compassionate need programs.

Assistance with obtaining services and resources. Patients often need help obtaining services (such as psychiatric, medical, and dental care) and help in applying for programs like disability income and food stamps. Such assistance is especially important for people having their first episode and for those who are more severely ill.

Arrange for supervision of financial resources. Some patients may need at least temporary help managing their finances—especially those with a severe and unstable course of illness. If so, a responsible person can be named as the patient's "representative payee." Disability checks are then sent to the representative payee who helps the patient pay bills, gives advice about spending, and helps the patient avoid running out of money before the next check comes.

Training and assistance with activities of daily living. Most people who are recovering from schizophrenia want to become more independent. Some people may need assistance learning how to better manage everyday things like shopping, budgeting, cooking, laundry, personal hygiene, and social/leisure activities.

Supportive Therapy involves providing emotional support and reassurance, reinforcing health-promoting behavior, and helping the person accept and adjust to the illness and make the most of his or her capabilities. Psychotherapy by itself is not effective in treating schizophrenia. However, individual and group therapy can provide important support, skill building, and friendship for patients during the stabilization phase after an acute episode and during the maintenance phase.

Peer support/self-help group. Almost all mutual support groups are run by peers rather than professionals. Many of these groups meet 1–4 times a month, depending on the needs and interest of the members. Guest speakers are sometimes invited to add education to the fellowship, caring, sharing, discussion, peer advice, and mutual support that are vital parts of most consumer support groups. Peer support/self-help groups can play a very important role in the recovery process, especially when patients are stabilizing after an acute episode and during long-term maintenance.

Types of services most often needed

Doctor and therapist appointments for medication management and supportive therapy. It is very important to keep appointments with your doctor and therapist during every phase of the illness. These appointments are a necessary part of treatment regardless of where you are in the recovery process—during an acute episode, stabilizing after an acute episode, and during long-term recovery and maintenance. It may be tempting to skip appointments when your symptoms are under control, but continued treatment during *all* phases of recovery is extremely important in preventing relapse. Many people with schizophrenia also need one or more of the services described below to make the best recovery possible.

Assertive community treatment (ACT). Instead of patients going to a mental health center, the ACT multidisciplinary team works with them at home and in the community. ACT teams are staffed to provide intensive services, so they can visit often—even every day if needed. ACT teams help people with a lot of different things like medication, money management, living arrangements, problem solving, shopping, jobs, and school. ACT is a long-term program that can continue to follow the person through all phases of the illness. The experts strongly recommend ACT programs, especially for patients who have a severe and unstable course of illness.

Rehabilitation. Three types of rehabilitation programs may help patients during the long-term recovery and maintenance phase of the illness. Rehabilitation may be especially important for patients who need to improve their job skills, want to work, have worked in the past, and have few remaining symptoms.

- *Psychosocial rehabilitation*: a clubhouse program to help people improve work skills with the goal of getting and keeping a job. Fountain House and Thresholds are two well-known examples.
- *Psychiatric rehabilitation*: a program teaching skills that will allow people to define and achieve personal goals regarding work, education, socialization, and living arrangements.
- *Vocational rehabilitation*: a work assessment and training program that is usually part of Vocational Rehabilitation Services (VRS). This type of rehabilitation helps people prepare for full-time competitive employment.

Intensive partial hospitalization. Patients in Partial Hospitalization Programs (PHPs) typically attend structured groups for 4 to 6 hours a day, 3 to 5 days a week. These education, therapy, and skill building groups are designed to help people avoid hospitalization or get out of the hospital sooner, get symptoms under control, and avoid a relapse. A PHP is usually recommended for patients during acute episodes and while stabilizing after an acute episode.

Aftercare day treatment. Day Treatment Programs (DTPs) typically provide a place to go, a sense of belonging and friendship, fun things to do, and a chance to learn and practice skills. They also provide long-term support and an improved quality of life. DTPs can help patients while they are stabilizing after an acute episode and during long-term recovery and maintenance.

Case management. Case managers usually go out to see people in their homes instead of making appointments at an office or clinic. They can help people get the basic things they need such as food, clothes, disability income, a place to live, and medical treatment. They can also check to be sure patients are taking their medication, help them manage money, take them grocery shopping, and teach them skills so they can be more independent. Having a case manager is helpful for many people with schizophrenia.

Types of living arrangements

Treatment won't work well if the person does not have a good and stable place to live. A number of residential options have been developed for patients with schizophrenia—unfortunately, they are not all available in every community.

***Brief respite/crisis home*:** an intensive residential program with on-site nursing/clinical staff who provide 24-hour supervision, structure, and treatment. This level of care can often help prevent hospitalization for patients who are relapsing. Brief respite/crisis homes can be a good choice for patients during acute episodes and sometimes during the stabilization phase after an acute episode.

Transitional group home: an intensive, structured program that often includes in-house daily training in living skills and 24-hour awake coverage by paraprofessionals. Treatment may be provided in-house or the resident may attend a treatment or rehabilitation program during the day. Transitional homes can help patients while they are stabilizing after an acute episode and can often serve as the next step after hospitalization or a brief respite/crisis home. They can also be helpful during an acute relapse if a brief respite/crisis home is not available.

Foster or boarding homes: supportive group living situation owned and operated by lay people. Staff usually provide some supervision and assistance during the day and a staff member typically sleeps in the home at night. Foster homes and boarding homes are recommended for patients during long-term recovery and maintenance, especially if other options (living with family,

a supervised/supported apartment, or independent living) are not available or do not fit patient/family needs and preferences.

Supervised or supported apartments: a building with several one- or two-bedroom apartments, with needed support, assistance, and supervision provided by a specially trained residential manager who lives in one of the apartments or by periodic visits from a mental health provider and/or family members. These types of apartments are recommended for patients during long-term recovery and maintenance.

Living with family: For some people, living with family may be the best long-term arrangement. For others, this may be needed only during acute episodes, especially if other types of residence are not available or the patient and family prefer to live together.

Independent living: This type of living arrangement is strongly recommended during long-term recovery and maintenance, but may not be possible during acute episodes of the illness and for patients with a more severe course of illness who may find it hard to live independently.

OTHER TREATMENT ISSUES

Hospitalization

Patients who are acutely ill with schizophrenia may occasionally require hospitalization to treat serious suicidal inclinations, severe delusions, hallucinations, or disorganization and to prevent injury to self or others. Hospitalizations usually last 1 to 2 weeks. However, longer hospitalization may be needed for first episodes or if the person is slow to respond to treatment or has other complications.

It is important for family members to be in touch with the hospital staff so they can tell them what medications the person has received in the past and what worked best. It is useful for the family to be proactive in working with the staff to make living and financial arrangements for the patient after discharge. Family should ask the staff to give them information about the patient's illness and discuss ways to help the patient stick with outpatient treatment.

After discharge

Patients are usually not fully recovered when they are discharged from inpatient care. This can be a difficult time with increased risks for relapse, substance abuse, and suicide. It is important to be sure that a follow-up outpatient appointment has been scheduled, ideally within a week after discharge, and that the inpatient staff has provided the patient with enough medication to last until that appointment. Ask the staff for an around-the-clock phone number to call if there is a problem. It is a good idea for someone to call the patient shortly before the first appointment as a reminder. If the patient fails to show up, everyone should work to make another appointment and to get the person there for it. Good follow-up care is the best way to avoid a severe course with repeated revolving-door hospitalizations.

Involuntary outpatient commitment

Involuntary outpatient commitment and "conditional release" use a court order to require people to take medication and stay in treatment in the community. While not a first line treatment, resorting to legal pressure to require compliance with treatment may sometimes be helpful for patients who deny their illness and relapse frequently.

Postpsychotic depression

Depression is not uncommon during the maintenance phase of treatment after the active psychotic symptoms have resolved. It is important for patients and family members to alert the treatment team if a patient who has been improving develops depressive symptoms, since this can interfere with the person's recovery and increase the risk of suicide. The doctor may suggest an antidepressant medication, which can help relieve the depression. A psychiatric rehabilitation program may benefit patients experiencing postpsychotic depression who see little hope for the future. Family and patient education can help everyone understand that postpsychotic depression is just a part of the recovery process and can be treated successfully. Peer self-help groups may also provide valuable support for patients who have postpsychotic depression.

Medical problems associated with schizophrenia

Patients with schizophrenia often get very inadequate care for their medical illnesses. This is particularly unfortunate because they are at increased risk for the complications of smoking, obesity, hypertension, substance abuse, diabetes, and cardiovascular problems. The experts therefore recommend regular monitoring for medical illness and close collaboration between the mental health clinicians and the primary care doctor.

WHAT CAN I DO TO HELP MY DISORDER?

You and your family should learn as much as possible about the disorder and its treatments. There are also a number of other things you can do to help cope with the illness and prevent relapses.

Avoid alcohol or illicit drugs

The use of these substances provides a short-term lift but they have a devastating effect on the long-term course of the illness. Programs to help control substance problems include dual diagnosis treatment programs, group therapy, education, or counseling. If you can't stop using alcohol or substances, you should still take your antipsychotic medication. Although mixing the two is not a great idea, stopping the antipsychotic medication is a much worse one.

Become familiar with early warning signs of a relapse

Each individual tends to have some "signature" signs that warn of a coming episode. Some individuals may become increasingly suspicious, worry that other people are talking about them, have altered perceptions, become more irritable or withdrawn, have trouble interacting with others or expressing themselves clearly, or express bizarre ideas. Learn to identify your own warning signals. When these signs appear, speak to your doctor as soon as possible so that your medications can be adjusted. Family members may also be able to help you identify early warning signs of relapse.

Don't quit your treatment

It is normal to have occasional doubts and discomfort with treatment. Be sure to discuss your concerns and discomforts with your doctor, therapist, and family. If you feel a medication is not working or you are having trouble with side effects, tell your doctor—don't stop or adjust your medication on your own. Symptoms that come back after stopping medication are sometimes much harder to treat. Likewise, if you are not satisfied with the program you are in, talk to your therapist about what other services are available. With all the new treatment options, you, your doctor, and your therapist can work together to find the best and most comfortable program for you.

WHAT CAN FAMILIES AND FRIENDS DO TO HELP?

Once you find out that someone close to you has schizophrenia, expect that it will have a profound impact on your life and that you will need help in dealing with it. Because so many people are afraid and uninformed about the disease, many families try to hide it from friends and deal with it on their own. If someone in your family has schizophrenia, you need understanding, love, and support from others. No one causes schizophrenia, just as no one causes diabetes, cancer, or heart disease. You are not to blame—and you are not alone.

Help the person find appropriate treatment and the means to pay for it

The most important thing you can do is to help the person find effective treatment and encourage him or her to stick with it. To find a good doctor or clinic, contact your local mental health center, ask your own physician for a referral, or contact the psychiatry department of a university medical school or the American Psychiatric Association. You can contact the National Alliance for the Mentally Ill (NAMI) to consult with others who have a family member with schizophrenia or who have the disorder themselves.

It is also important to help the person find a way to pay for the medications he or she needs. Social workers or case managers may be able to help you through the difficult red tape, but you may also have to contact your local Social Security or social services office directly to find out what benefits are available in your area and how to apply for them. Finding the way through the maze of application processes is difficult even for those who are not ill. A person with schizophrenia will certainly need your help to obtain adequate benefits.

Learn about the disorder

If you are a family member or friend of someone with schizophrenia, learn all you can about the illness and its treatment. Don't be shy about asking the doctor and therapist questions. Read books and go to National Alliance for the Mentally Ill (NAMI) meetings.

Encourage the person to stick with treatment

The most important factors in keeping patients out of the hospital are for them to take their medications regularly and avoid alcohol and street drugs. Work with your loved one to help him or her remember to take the medicine. Long-acting injectable forms of medication can help patients who find it hard to take a pill every day.

Handling symptoms

Try your best to understand what your loved one is going through and how the illness causes upsetting or difficult behavior. When people are hallucinating or delusional, it's important to realize that the voices they hear and the images they see are very real to them and difficult to ignore. You should not argue with them, make fun of or criticize them, or act alarmed.

After the acute episode has ended, it is a good time for the patient, the family, and the healthcare provider to review what has been learned about the person's illness in a low-key and non-blaming way. Everyone can work together to develop plans for minimizing the problems and distress that future episodes may cause. For example, the family members can ask the person with schizophrenia to agree that, if they notice warning signs of a relapse, it will be OK for them to contact the doctor so that the medication can be adjusted to try to prevent the relapse.

Learn the warning signs of suicide

Take any threats the person makes *very seriously*. Seek help from the patient's doctor and other family members and friends. Call 911 or a hospital emergency room if the situation becomes desperate. Encourage the person to realize that suicidal thinking is a symptom of the illness and will pass in time as the treatment takes effect. Always stress that the person's life is important to you and to others and that his or her suicide would be a tremendous loss and burden to you, not a relief.

Learn to recognize warning signs of relapse

Learn the warning signs of a relapse. Stay calm, acknowledge how the person is feeling, indicate that it is a sign of a return of the illness, suggest the importance of getting medical help, and do what you can to help him or her feel safe and more in control.

Don't expect too fast a recovery

When people are recovering from an acute psychotic episode, they need to approach life at their own pace. Don't push too hard. At the same time, don't be too overprotective. Do things *with* them, rather than *for* them, so they can regain their sense of self-confidence. Help the person prioritize recovery goals.

People with schizophrenia may have many health problems. They often smoke a lot and may have poor nutrition and excessive weight gain. Although you can encourage the patient to try to control these problems, it is important not to put a lot of pressure on him or her. Focus first on the most important issues: medication adherence and avoiding alcohol and drug use. Your top priority should be to help the patient avoid relapse and maintain stability.

Handling crises

In some cases, behavior caused by schizophrenia can be bizarre and threatening. If you are confronted with such behavior, do your best to stay calm and nonjudgmental, be concise and direct in whatever you say, clarify the reality of the situation, and be clear about the limits of acceptable behavior. Don't feel that you have to handle the situation alone. Get

medical help. Your safety and the safety of the ill person should always come first. When necessary, call the police or 911.

Coping with schizophrenia

Many people find that joining a family support group is a turning point for them in their struggle to understand the illness and get help for their relative and themselves. More than 1,000 such groups affiliated with the National Alliance for the Mentally Ill (NAMI) are now active in local communities in all 50 states. Members of these groups share information and strategies for everything from coping with symptoms to finding financial, medical, and other resources.

Families who deal most successfully with a relative who has schizophrenia are those who come to accept the illness and its difficult consequences, develop realistic expectations for the ill person and for themselves, accept all the help and support they can get, and also keep a philosophical perspective and a sense of humor. It takes times to develop these attitudes, but the understanding support of others can be a great help.

Schizophrenia poses undeniable hardships for everyone in the family. To deal with it in the best possible way, it's particularly important for you to take care of yourself, do things you enjoy, and not allow the illness to consume your life. Experts on schizophrenia believe that recently introduced new treatments are already a big improvement and that new research discoveries will bring a better understanding of schizophrenia that will result in even more effective treatments. In the meantime, help the patient live the best life he or she can *today*, and do the same for yourself.

SUPPORT GROUPS

NAMI

The National Alliance for the Mentally Ill (NAMI) is the national umbrella organization for more than 1,140 local support and advocacy groups for families and individuals affected by serious mental illnesses. To learn more about NAMI or locate your state's NAMI affiliate or office, contact:

NAMI
200 N. Glebe Rd., Suite 1015
Arlington, VA 22203-3754
NAMI Helpline at 800-950-NAMI (800-950-6264).

Several other organizations can also help you locate support groups and information:

National Depressive and Manic-Depressive Association
730 N. Franklin St., Suite 501
Chicago IL, 60610-3526
800-82-NDMDA (800-826-3632)

National Mental Health Association (NMHA)
National Mental Health Information Center
1021 Prince Street
Alexandria, VA 22314-2971
800-969-6642

The National Mental Health Consumer Self Help Clearinghouse
1211 Chestnut St., 11th Floor
Philadelphia, PA 19107
800-688-4226

FOR MORE INFORMATION

The following materials provide more information on schizophrenia. Most are available through NAMI. To order or to obtain a complete publications list, write NAMI or call 703-524-7600.

Books

Adamec C. How to Live with a Mentally Ill Person: A Handbook of Day-to-Day Strategies. Wiley & Sons, 1996.

Backlar P. The Family Face of Schizophrenia. J P Tarcher, 1994.

Bouricius JK. Psychoactive Drugs and Their Effects on Mentally Ill Persons. NAMI, 1996.

Carter R, Golant SK. Helping Someone with Mental Illness. Times Books, 1998.

Gorman JM. The New Psychiatry: The Essential Guide to State-of-the-Art Therapy, Medication, and Emotional Health. St. Martins, 1996.

Hall L, Mark T. The Efficacy of Schizophrenia Treatment. NAMI, 1995.

Hatfield A, Lefley HP. Surviving Mental Illness: Stress, Coping, and Adaptation. Guilford, 1993.

Lefley HP. Family Caregiving in Mental Illness. Sage, 1996.

Mueser KT, Gingerich S. Coping with Schizophrenia: A Guide for Families. Harbinger Press, 1994.

Torrey EF. Surviving Schizophrenia: For Families, Consumers, and Providers (Third Edition). Harper & Row, 1995.

Weiden PJ. TeamCare Solutions. Eli Lilly, 1997 (to order, call 888-997-7392).

Weiden PJ, Diamond RJ, Scheifler PL, Ross R. Breakthroughs in Antipsychotic Medications: A Guide for Consumers, Families, and Clinicians. Norton, 1999.

Woolis R. When Someone You Love Has Mental Illness: A Handbook for Family, Friends, and Caregivers. Tarcher/Perigee, 1992.

Wyden P. Conquering Schizophrenia. Knopf, 1998.

Videos

The following videos may be ordered from: Division of Social and Community Psychiatry, Box 3173, Duke University Medical Center, Durham, NC 27710.

Burns BJ, Swartz MS, Executive Producers. Harron B, Producer and Director. Hospital without Walls. Department of Psychiatry, Duke University, 1993.

Swartz MS, Executive Producer. Harron B, Producer and Director. Uncertain Journey: Families Coping with Serious Mental Illness. Department of Psychiatry, Duke University, 1996.

To request more copies of this handout, please contact NAMI at 800-950-6264. You can also download the text of this handout on the Internet at www.psychguides.com.