

Team Solutions

Schizophrenia:

Coping with Symptoms and Side Effects

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Introduction

Sometimes it's hard to understand why you may be having certain symptoms. Or why you're still having symptoms from your illness even though you've been taking your medicine for several days or weeks.

In some cases, the problem you may be experiencing could be a symptom of your illness. In other cases, it may be a side effect of your medicine. The purpose of this booklet is to explain why you may be having these symptoms, what may be causing them, and how you can manage them.

Managing Symptoms and Side Effects

Sometimes it may not be clear if a problem you're having is a symptom of your illness or a side effect of your medicine. This booklet will help you identify what's causing the problem and suggest ways you may be able to manage the problem.

As you use this booklet, please keep these points in mind:

- Symptoms of an illness or side effects of a medicine may happen to some people and not to others—that's because everyone's system is different, and people react differently to medicines
- Not all of the side effects mentioned in this booklet may apply to the medicine you may be taking at this time
- This booklet discusses the most commonly observed side effects—if you are concerned about a problem you are having, speak with your doctor or other member of your treatment team
- In most cases, there's no need to stop your medicine if you are having a side effect from your medicine—many side effects can be managed as you continue your treatment
- Many of the side effects included in this booklet are annoying, but not serious. Serious side effects that occur rarely but require *immediate* attention include:
 - Overheating (hyperthermia)
 - Low white blood cell count (agranulocytosis)
 - Immobility and severe rigidity (neuroleptic malignant syndrome)
 - Seizures
 - Uncontrollable muscle spasms (dystonia)

If you are concerned about any symptom or side effect you may be having, speak with your doctor or other member of your treatment team. This booklet is intended to help you understand why you may be having certain symptoms—it does not take the place of good medical care.

How to Use This Booklet

This booklet lists symptoms, side effects, and other topics in alphabetical order. Below is a list of the topics covered in this booklet and the page where you can find each topic.

<i>Topic</i>	<i>Page Number</i>
Agranulocytosis (low white blood cell count)5
Akathisia (restlessness)5
Akinesia (feeling slowed down)5
Anger6
Anxiety (nervousness)6
Blurry vision7
Concentration difficulties7
Constipation8
Delusions9
Depression (sadness)10
Dizziness11
Drinking alcohol11
Drowsiness12
Dry mouth13
Dystonia (muscle spasms)13
Hallucinations14
Hyperthermia (overheating)15
Indifference15
Laboratory tests16
Loneliness16
Memory problems17
Milk leaking from breasts18
Missed menstrual periods18
Muscle stiffness18
Neuroleptic malignant syndrome18
Oversensitivity to sound and light19

Seizures	.19
Self-care	.19
Sexual difficulties	.20
Sleep problems	.20
Street drugs	.21
Suicidal thoughts	.21
Sunburn	.22
Tardive dyskinesia (involuntary muscle movements)	.22
Thirst or excessive urination	.23
Tremors	.23
Urinary retention	.23
Weight gain	.24
Weight loss	.24
National organizations that can provide information and support	.25

Agranulocytosis

A medical term that means “low white blood cell count.” White blood cells help fight infection—so if your white blood cell count gets too low, you may be less protected against infections such as pneumonia, thrush, and urinary tract infection.

Agranulocytosis is a serious side effect of certain medicines—ask your doctor if your medicine causes this side effect. If so, your doctor will probably want to check your blood count regularly. Even if you are taking a medicine that may cause agranulocytosis, this side effect rarely occurs. It’s important to keep your appointments for blood tests so that this problem can be avoided. Be sure to report high fevers and painful sore throats to your doctor as soon as possible.

Akathisia

You may feel like you have to keep moving—it’s hard to sit still. This feeling of restlessness is a possible side effect of antipsychotic medicines. If this side effect is bothering you, tell your doctor. Your doctor may want to adjust your medicine or control the akathisia with another medicine.

Akinesia

A medical term for feeling slowed down, or “feeling like a zombie.” Akinesia is a possible side effect of antipsychotic medicines.

If you don’t know why you’re feeling slowed down, speak with your doctor or other member of your treatment team—they’ll work with you to find out if this feeling is being caused by your illness, or if it’s a side effect of your medicine. If it’s a side effect of your medicine that’s causing the problem, your doctor may want to adjust your dosage. Do not make any changes on your own—work with your doctor to relieve this problem.

Anger

Everyone feels angry from time to time. So, anger under certain circumstances can be very normal. But feeling angry or irritable can also be a symptom of mental illness. Often, these feelings are triggered by fears or stress. Some people may find they become angry quickly or get very annoyed over small matters. Others have feelings of anger that last over long periods of time. Either way, anger can lead to a crisis situation if it is not managed properly. There are many things you can do to minimize and control feelings of anger:

- Take your medicine regularly—over time, your medicine may help you feel less irritable or angry
- Learn techniques to control anger, such as counting to 10
- Avoid things that may trigger anger

If you feel angry often, talk with your doctor. If you have thoughts about hurting yourself or someone else, contact your doctor or a member of your treatment team immediately.

Anxiety

At times, you may feel extremely nervous, worried, or afraid. Your heart might race and you may feel like you can't catch your breath. Your muscles may feel tense or you may have a headache. These are all feelings of anxiety.

Many people feel anxious when they're around other people or in new situations. If this is true for you, you may want to tell someone on your treatment team. They may suggest things you can do to help yourself relax during these situations.

Anxiety may also be related to symptoms of mental illness, and may improve as your other symptoms improve.

Your doctor may suggest using another medicine to help relieve anxiety. Work with your treatment team to find the best treatment to help you manage anxiety.

Blurry vision

You may have a hard time seeing at short distances, especially while you're reading. If you experience blurry vision soon after you start taking your medicine, it might be a side effect of your medicine. This side effect is usually temporary and will probably disappear as you continue your treatment. Some people find that reading glasses help them see more clearly. You can buy reading glasses from most pharmacies without a prescription.

If your vision doesn't improve or if this side effect is really bothering you, speak with your doctor. Your doctor may want to adjust your medicine or may recommend another medicine to control this side effect.

Concentration difficulties

At times, you may find it hard to complete a task or stay focused on something you're doing. It may also be difficult for you to concentrate on things like reading a book or watching TV. And you may have a hard time getting your thoughts together when speaking with other people.

Having trouble concentrating is a symptom of schizophrenia, bipolar disorder, and other mental illnesses. The good news is that for many people, concentration problems usually improve over time with treatment.

If you are having trouble completing a large project or task, you might want to break up the task into small parts. Work on only one part at a time and take frequent breaks. That way, you'll feel less stressed and more relaxed overall.

Constipation

If you are having fewer bowel movements than usual and have hard stools that are uncomfortable, the following suggestions may help relieve this problem:

- Drink adequate amounts of fluids daily
- Eat foods that are rich in fiber, such as bran cereals, fruits, vegetables, and whole grain breads
- Avoid large amounts of foods that may worsen constipation, such as rice or bananas
- Do light exercise or a physical activity every day

Although constipation is a common problem for many people, antipsychotic medicines can make it worse.

The suggestions above may help relieve constipation, but if you are feeling uncomfortable, speak with your doctor or pharmacist. There are different kinds of products you can buy over-the-counter to relieve constipation. Your doctor or pharmacist can help you choose the one that's best for you.

Delusions

A delusion is something you believe, that others say is not true. You might feel afraid of being followed, harmed, or killed, and not know why. You might feel suspicious that other people are talking about you or plotting against you. Or perhaps you believe that others can hear or read your thoughts. These beliefs are all symptoms of schizophrenia.

As you continue to take your medicine, you may notice these symptoms start to disappear. Once your symptoms have improved, keep taking your medicine to help prevent these symptoms from returning.

Delusions that have returned or gotten worse may be an early warning symptom—a signal that a relapse has started. One way you can keep delusions in control is to have your family and friends warn you when they notice changes in your mood or changes in your response to situations around you.

If your delusions get worse, be sure to tell your doctor or another member of your treatment team. You may need to have your treatment adjusted to offset these symptoms.

Depression

Everyone feels sad from time to time. But feeling sad for weeks at a time, or feeling helpless or hopeless, may mean that you are suffering from depression.

Sometimes depression can happen when symptoms of schizophrenia start to improve. This is called *postpsychotic depression*. This kind of depression can often be treated with medicine.

People who have postpsychotic depression sometimes need to take medicine for their depression as well as their schizophrenia. If you're being treated for postpsychotic depression, keep in mind the depression medicine takes time to work. You may not notice any benefits from the medicine right away, but you're likely to feel better within a few weeks.

You can also help yourself feel better by:

- Keeping stress at a comfortable level
- Talking to a friend, family member, your counselor, or someone else on your treatment team
- Getting the right amount of exercise and rest (Remember to talk to your doctor before beginning any new exercise program)
- Doing an activity you usually enjoy
- Having a routine you follow each day that is flexible

If you feel extremely discouraged and have suicidal thoughts, tell your doctor immediately. If you can't reach your doctor, tell someone else who can help you. It's important to get help so that you'll be able to manage these feelings.

Dizziness

You may feel dizzy or light-headed when you get up too quickly from sitting in a chair or lying on your bed or couch. Fainting can also happen if you get up too quickly.

Dizziness may occur when you first start taking your medicine. It's usually temporary, and tends to disappear as you continue your treatment.

To prevent dizziness, rise slowly from a lying or sitting position. If you are lying on your bed, first put your feet over the edge of the bed, then sit up slowly. Wait a moment before standing up.

Drinking alcohol

Drinking beer, wine, or other alcoholic beverages can lead to a relapse. Alcohol may upset the balance of the chemicals in your brain and may also interfere with the way your medicine works. Even though drinking may make you feel better in the short run, even a small amount may cause your symptoms to worsen later. That's why it's so important to avoid alcohol.

You may want to speak with your doctor or another member of your treatment team about how to avoid alcohol if you're in a situation where other people are drinking. Here are a few examples of what people have said when they felt pressure from others to have a drink:

- *"I'd prefer a drink without alcohol. What do you have?"*
- *"It's very tempting to go drinking with you, but my doctor told me it could make my illness worse. How about a movie instead?"*

Sometimes it's hard to refuse a drink because other people want you to join them. You may find it easier if you offer an alternative—like asking for another type of beverage such as soda or nonalcoholic beer, or suggesting another activity.

Drowsiness

You may feel sleepy or drowsy, especially at the beginning of your treatment. But this side effect is often temporary and usually improves as you continue with your treatment.

Use caution if you plan to do activities that require you to be alert. You may want to plan to stay home the first day you start your medicine, just to see how you react to it.

If your drowsiness doesn't improve and you're really bothered by it, speak with your doctor or another member of your treatment team. Your doctor may suggest that you take your medicine at a different time of the day to reduce drowsiness.

Having "low energy" is different from feeling drowsy. Lack of energy, or not feeling up to doing the things you used to do when you were well, is a symptom of schizophrenia. As you continue with your treatment, your medicine may help improve this symptom. Over time, you may feel as if you have more energy, and you may look forward to doing more of the activities you used to enjoy.

Dry mouth

When you first begin your treatment, your mouth may feel dry. This is a side effect of your medicine that tends to disappear as you continue your treatment.

If your mouth feels dry, suck on sugar-free, hard, sour candy. You may also want to chew gum, sip water, or suck on ice chips, which can also provide relief.

If this side effect doesn't improve, or if it's really bothering you, speak with your doctor or another member of your treatment team. Your doctor may want to adjust your treatment.

Dystonia

A medical term used to describe uncontrollable muscle spasms. It is also referred to as a "dystonic reaction." Dystonia can be a serious side effect of antipsychotic medicines. It usually feels like a charley horse or writer's cramp. Dystonia may start with a neck spasm that leads to a stiff neck and stiff tongue. The eye muscles may also be involved—the eyes may roll up and back. This reaction can be relieved within minutes with another medicine. If this side effect happens to you, call your doctor immediately or go to the emergency room. Your doctor may want to prescribe another medicine to prevent this reaction from happening again.

Hallucinations

A medical term that describes the experience of seeing something, hearing things, feeling, smelling, or tasting something when nothing is there. You may have heard voices or seen images that other people say they don't experience. Hallucinations are a symptom of schizophrenia that usually improves as you continue with your treatment.

Voices and other hallucinations can be very frightening. Some people have found ways to manage voices and fears by doing things that relax them. Other people focus on certain activities or tasks that help to distract their attention away from the voices. Your health care team can recommend tips on ways that other people cope with voices. Below are ideas you may want to try:

- Taking a shower or bath to relax
- Listening to music to distract you from the voices
- Humming or singing a song to yourself
- Playing an instrument, or doing a project
- Speaking with other people
- Writing in a diary
- Doing exercise or some physical activity, such as running, walking, or swimming (Remember to consult your doctor about your exercise routine)
- Resting or sleeping
- Reading a book aloud

Sometimes it's hard to ignore the voices, no matter what you do. If you're still having trouble coping with the voices or other hallucinations, tell your doctor or another member of your treatment team. You and your doctor may be able to work out a plan to increase your medicine at certain times when the voices get worse. Don't make any changes on your own—work with your doctor.

If the voices are telling you to do things that may cause you to hurt yourself or someone else, call your doctor or other treatment team member immediately. Let family members and friends help you through this rough period of time.

Hyperthermia

Hyperthermia is a medical term that means “getting overheated.” Overheating is a serious side effect of medicines that can lead to dehydration (your body loses too much water). It’s most likely to happen when the weather is hot and you’re doing activities outside, or when you’re exercising. You can prevent overheating by following these measures:

- Drink plenty of water (4 to 8 cups each day)
- If you do any activities outside, stay in the shade and wear clothing that will keep you cool (a hat and light-colored, lightweight clothing)
- Do outside activities in the early morning or early evening when it’s cooler
- If you exercise, drink fluids and take breaks to cool down

Overheating is a serious side effect, so it’s important to follow the measures above to prevent it. If you begin to feel hot, dizzy, and weak, go inside a building that has air conditioning, or cool yourself by taking a cold shower or bath.

Indifference

You may find that you just aren’t interested in anything—friends, favorite activities, or even the way you look. Or you may find that you don’t get pleasure in doing the things you’ve always enjoyed. This lack of interest or pleasure is a common symptom of schizophrenia.

As you continue with your treatment, this symptom may improve. Meanwhile, you can do a few things to help yourself feel better. Talk to a friend—even a short conversation can help. You might also want to make a commitment to yourself that you’ll take a walk once a day—a short walk up the block is a good way to start. As you begin to feel better, increase the length of your walk.

Laboratory tests

Your doctor may order some tests at the beginning of or during your treatment to screen for any side effects you may not be aware of. These may include several types of blood tests, an EKG (electrocardiogram), etc. If you have questions about a specific test, ask your doctor.

Loneliness

Loneliness is not a symptom of your illness, nor is it a side effect of your medicine. However, loneliness can be a result of your illness. At times, you may feel that it's easier to be alone than to be with other people. Symptoms of schizophrenia can make it uncomfortable to be around others. Many people with schizophrenia just choose to avoid being with other people.

When you're feeling better, you might want to seek out other people—find a friend or someone you can speak with whenever you're feeling lonely. Joining a group of people who share the same interests you have may be very helpful.

Organizations such as the National Alliance for the Mentally Ill (NAMI) may provide you with support to help you deal with issues that are concerning you at this time. They are also a good source for meeting other people who have similar concerns and who can tell you how to get the help you need. For more information on NAMI and other national mental health organizations that offer support, see page 25.

Memory problems

You may find it harder to remember things that happened or recall things you've just learned. This is a common symptom of schizophrenia. Because of this problem, many people think they cannot return to school and get their degrees. This is not true—you may be able to complete a high school or college program. But it might take longer for you to complete your course work now than it would have before you became ill.

If your goal is to return to school, discuss the options with your educational specialist or other member of your treatment team. They may be able to help you choose a program that matches your interest and ability. Keep following your treatment plan—this symptom is likely to improve over time.

Overcoming Memory Problems

If you're looking for ways to help yourself remember day-to-day events and other important things, here are a few tips from other people:

- *“I carry a small calendar with me to keep track of where I have to be from day to day. Some days I have classes and other days I have my group sessions or appointments. It's just easier to remember it all if I put it on my calendar. The one catch is that you have to look at your calendar every day. That's something I never used to do and I used to miss things sometimes.”*
- *“I like to list all the things I have to do. As I do each thing, I cross it off the list. That way, I don't miss anything. Also, it feels great to cross things off—I feel like I got a lot done.”*
- *“I have a monthly calendar in my room that I use to keep a record of special things that are going on. I also use it to keep track of my symptoms—if I get a new symptom or just feel worse. That way I can tell my doctor exactly what happened and when it happened, the next time I see him.”*
- *“I use a small notebook to write myself notes. I also use it to write down questions or things I need to tell other people. One page is just for things I need to ask my doctor. I don't see her that much, so it really helps to keep my questions in one place.”*

Milk leaking from breasts

This is an uncommon side effect of antipsychotic medicines. If this happens to you, tell your doctor. Your doctor may want to adjust your medicine.

Missed menstrual periods

If you have missed one or more menstrual periods, be sure to tell your doctor about it at your next office visit—this may be a side effect of your medicine. Your doctor may want to adjust your dosage or change your medicine. Do not make any changes on your own.

Muscle stiffness

This may be a side effect of your medicine. People who have this side effect may feel a tightness in the muscles. They may have a tremor in their hands or walk slowly. They may walk with very short steps and may not have much of an arm swing. If you feel any of these symptoms, tell your doctor. Your doctor may want to adjust your medicine dosage. Or, your doctor may prescribe another medicine to control these side effects. Do not make any changes on your own.

Neuroleptic malignant syndrome

This is a medical term for a rare, but serious, side effect of antipsychotic medicines. Muscles get very stiff over one to three days, and you may feel very confused. A high fever develops. If you start to feel these symptoms, get medical help immediately. Go to the emergency room if you cannot reach your doctor.

Oversensitivity to sound and light

At times, sounds and voices may seem much too loud. Light and color may seem very intense. Your senses may be unusually sensitive to the world around you. The opposite may also occur—voices may seem garbled, and color may seem more dim than usual. These changes in the intensity of sound and light are symptoms of schizophrenia that should improve as you continue with your treatment.

Seizures

Although rare, seizures can be a serious side effect of some medicines that are used to treat schizophrenia. Dizziness, hot flashes, or other sensations may happen just before a seizure begins. People describe these sensations as an “aura.” During the seizure the person loses consciousness, muscles get tense, and the body moves uncontrollably.

Some medicines make people more prone to having seizures. This is especially true for people who have seizure problems and those who are taking certain other medicines. If you have a seizure, get medical help *immediately*.

Self-care

When you're not feeling well, it is often hard to take the time to take good care of yourself. You just may not feel like brushing your teeth, showering or bathing, changing your clothes, or combing your hair. You may not even feel like getting out of bed in the morning. These feelings are a symptom of schizophrenia.

As you continue your treatment, you're likely to feel better and take more of an interest in looking your best.

Sexual difficulties

Some people may have less sexual desire and fewer orgasms. Some men may have difficulty with erections or ejaculation. Many of these problems may be caused by side effects of antipsychotic medicines. However, lack of sexual desire could also be a symptom of schizophrenia.

If you are having sexual difficulties, it's important to talk with your doctor. Your doctor may be able to tell you if the problem is being caused by your medicine or your illness. If it is caused by your illness, the problem may improve as you continue with your treatment. If it's your medicine that's causing the problem, your doctor may want to adjust your dosage or change your medicine. Do not make any changes on your own—work with your doctor to find the treatment that works best for you.

Sleep problems

Not being able to sleep at night, or sleeping all day, may be an early warning symptom of relapse. If you've had two sleepless nights in a row, speak with your doctor or a member of your treatment team right away. If you are starting to relapse, you'll be able to take action to stop the relapse before you become very ill.

You may want to use some of the techniques below to help you sleep better:

- Go to sleep and get up at about the same time every day, even if you had trouble sleeping
- Get enough exercise during the day so that you'll feel more tired at night
- Avoid foods and beverages that contain caffeine
- Take a warm shower or bath—you may feel more relaxed afterwards and fall asleep more easily
- Do some reading in bed just before going to sleep—many people say that reading relaxes them
- Listen to soothing music as you're trying to fall asleep

You may also be able to improve your sleep by following a daily routine—wake up, eat your meals, exercise, and go to sleep at about the same times each day.

Street drugs

Using street drugs (such as marijuana or cocaine) can lead to a relapse. These drugs can cause symptoms similar to schizophrenia. And they can make any symptoms you already have worse, even if you get high only once.

Street drugs can upset the balance of the chemicals in your brain and may also interfere with the way your medicine works. That's why it may be more difficult to treat your illness if you use street drugs. Keep in mind that you may not feel your condition get worse right after getting high, but your symptoms may worsen later. That's why it's so important to avoid street drugs.

Suicidal thoughts

People sometimes think about hurting or killing themselves when they are going through difficult times. And for most people schizophrenia is a difficult illness to live with.

Suicide is not a side effect of medicines. It is related to schizophrenia—feeling hopeless, that “things can't get better,” and that “things will never return to normal.” But these feelings are usually temporary—they almost always get better with time and treatment.

If you have thoughts of suicide now, it's critical that you get help immediately. Treatment can help relieve suicidal feelings. So, speak to the members of your treatment team if you have these feelings—or have ever had these feelings. That way, you'll be able to plan whom to call if suicidal feelings return and you need help.

Sunburn

Some medicines can make your skin very sensitive to sunlight. Areas of your skin that are exposed to sunlight even for a short period of time can get sunburned. Or a red, itchy rash can develop.

Ask your doctor or pharmacist if the medicine you're taking can make your skin more sensitive to sunburn or rash. If so, be sure to take these precautions:

- Wear clothing that will protect your skin from the sun, such as a long-sleeved shirt, long pants, and a hat
- Use sunscreen on areas of your body that can't be covered, such as your face and hands. Choose a sunscreen that has a protective factor of 15 or higher
- Stay indoors when the sun is most intense (midday)
- When you go outside, stay in the shade as much as possible. Use a sunscreen even if you stay in the shade
- If you do get a sunburn or skin rash, seek medical help as soon as possible

Tardive dyskinesia

Involuntary muscle movements, especially of the tongue and mouth, are a possible side effect of some antipsychotic medicines. This side effect most often occurs after months or years of taking the medicine. It is serious and can still occur even after the medicine is stopped. It can cause involuntary movements of the tongue and mouth, such as chewing or sucking motions, lip smacking, and puckering of the cheeks. Sometimes, the arms and legs can be affected. If you have any of these side effects, tell your doctor during your next office visit.

Thirst or excessive urination

Feeling thirsty to the point that you drink too much water is a symptom of schizophrenia. Excessive water drinking (also called “polydipsia”) can result in weight gain. Too much water, soda, and other beverages can also upset the balance of minerals in your body—minerals that your body needs to function properly.

If you drink more than eight cups of water or other fluids daily, be sure to tell your doctor. Medicines can help improve this problem.

Tremors

Some people may develop a mild tremor (for example, shaking in their hands). Tremors are a possible side effect of medicines that usually occurs when people begin their treatment or get an increase in their dosage. This side effect is usually temporary and should improve as you continue with your treatment.

Urinary retention

Urinary retention is a medical term that means “having difficulty urinating.” Urinary retention is a side effect of antipsychotic medicines. You may have the urge to urinate but may not be able to empty your bladder completely. You may be able to void only small amounts of urine at a time, so you may have urges to urinate more often than usual. If you have difficulty urinating, call your doctor as soon as possible.

Weight gain

Some people may gain weight after several weeks or months of treatment. Increased appetite and weight gain are side effects of some antipsychotic medicines.

If you start to gain weight, ask your doctor to recommend a balanced, low-calorie diet that will provide good nutrition. Also, exercise regularly to prevent yourself from gaining weight. Walking at a fast pace for 30 minutes, three times a week may be enough to keep your weight stable. Swimming, jogging, or doing aerobic exercises regularly may help you reduce your weight. Remember to speak with your doctor before beginning your exercise routine. Also, you may want to speak with someone on your treatment team to learn more about preparing low-calorie recipes.

Weight loss

Decreased appetite or weight loss is usually a symptom of schizophrenia. Sometimes people refuse to eat because they fear that others are trying to poison them. If this is happening to you, speak with your doctor or someone else on your treatment team. They may be able to suggest ways for you to manage this symptom so that you'll be able to eat.

Decreased appetite may also be a symptom of depression. If you're feeling depressed, speak with your doctor. Your doctor may be able to tell you about treatments that can help you feel better. (See *Depression* on page 10 of this booklet.)

National Organizations That Can Provide Information and Support

Below are two of the national organizations that offer support for those who have a mental illness and their families:

- *The National Alliance for the Mentally Ill (NAMI)*
NAMI is an organization for consumers with mental illnesses and their families. Although the NAMI headquarters is located in Washington DC, there are local chapters all across the United States. Many people join their local chapter of NAMI for support and friendship. NAMI is also a great source for information about mental illnesses and their treatments. You can reach NAMI at 1-800-950-6264.
- *The National Mental Health Consumer's Self-Help Clearing House*
This organization is geared more toward family members than consumers. For more information about self-help groups, call 1-800-553-4539. The mailing address is 311 South Juniper Street, Suite 1000, Philadelphia, PA 19107.