Team Solutions

# Schizophrenia: Understanding Your Illness

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# Schizophrenia: Understanding Your Illness

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# Common Symptoms of Your Illness

This workbook was written to explain what may be causing some of your symptoms. It may also help you find ways to manage your symptoms so that you can feel better and get on with your life.

Schizophrenia and schizoaffective disorder are illnesses that affect the way your brain receives and interprets information from the world around you. These illnesses make it hard for you to organize your thoughts. And you may find it hard to relate well to your friends.

You may have heard your doctor describe some of your symptoms as "positive symptoms," "negative symptoms," and "cognitive symptoms."

# **Positive Symptoms**

Positive symptoms do not refer to symptoms that are "good." They refer to symptoms such as thoughts, beliefs, and sensations that you may experience, but which are not real. You might experience sounds, voices, or images that other people say they don't experience. These are called *hallucinations*. Noises may seem louder than usual. So it might be hard for you to focus on a conversation or to understand what other people are saying. Colors may seem brighter than usual or you might see shadows.

*Delusions* (believing things that others say are not true) are another type of positive symptom. You might feel afraid of being followed, harmed, or killed and not know why. These are all types of positive symptoms.





# **Negative Symptoms**

Negative symptoms may be described as lack of energy or motivation—you don't feel like doing the things you used to do when you were well. They are symptoms that may be hard to explain to other people. Some examples include:

- You don't feel like talking to other people
- You don't have much energy to do things
- You don't care much about how you look

# **Cognitive Symptoms**

Cognitive symptoms refer to problems with learning and concentration. It may be harder for you to concentrate on things like reading a book or watching TV. Also, you may find it hard to learn new information the first time—like getting directions to go someplace new.

You may find it hard to focus on what someone else is saying. Or it may be hard for you to get your thoughts together to explain how you feel.

# **Treatment Can Help**

For many people, proper treatment can help improve positive, negative, and cognitive symptoms. One of the first steps in relieving your symptoms is being able to recognize them. The next few pages will help you with this task.



# Recognizing Your Symptoms

Do you know what symptoms have bothered you the most? Identifying these symptoms can help you gain control over them.

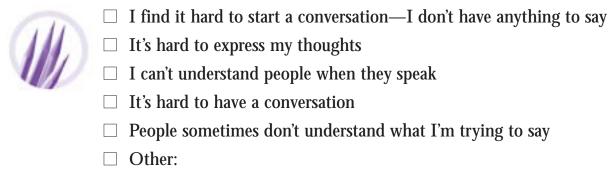
The next few pages are designed to help you recognize symptoms you're having now or those you may have had in the past. Not all of these symptoms will apply to you, or you may have other symptoms not listed here. As you read each statement, place a check in the box next to the statement if you've ever had that symptom.

# **Having Trouble Concentrating**

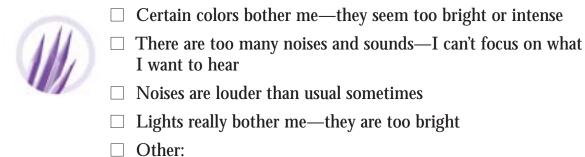
	It's hard to pay attention for long periods of time
	At times, I have too many thoughts
	My thoughts are sometimes jumbled or confused
	At times, I have trouble reading books or following movie plots
	It's sometimes hard to focus on what people are saying to me
	At times, it's hard getting my thoughts together
	I can't hear well over background noises
	Sometimes I lose my train of thought
	Other:



# **Having Difficulty Talking to Others**



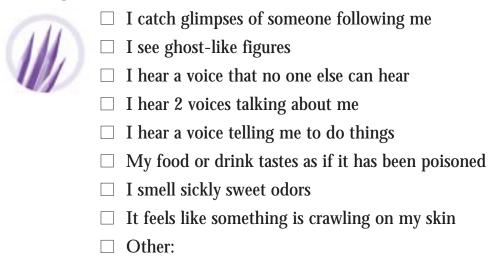
#### **Overstimulated Senses**



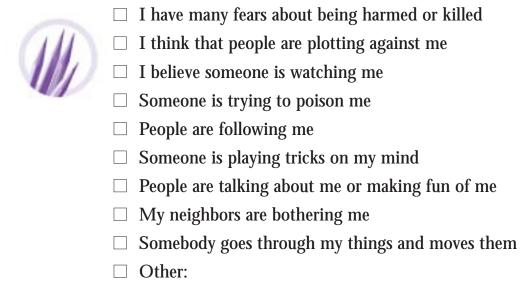




# **Having Hallucinations**

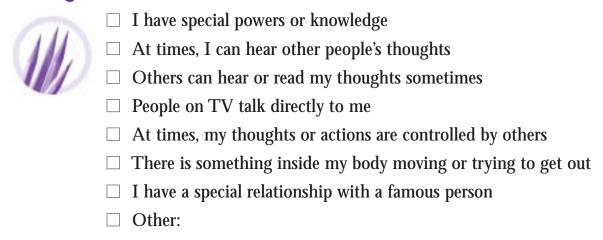


# **Being Overly Suspicious**

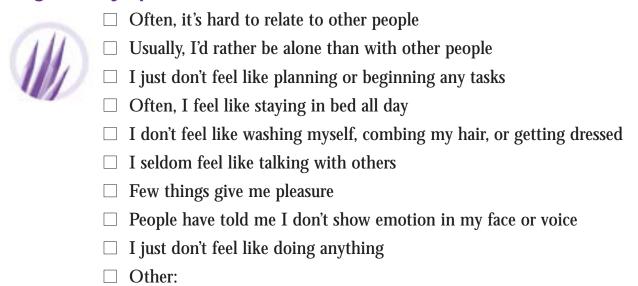




# **Having Delusions**



# **Negative Symptoms**





# Recording Your Symptoms

111	Look at all of the boxes you've marked. Which symptoms have bothered you the most over the past month? List them.
	1
	2
	3
111	Which symptoms never seem to go away?
	1
	2
	3
111	Which symptoms have gotten better within the past month?
	1
	2
	3
	What tends to make these symptoms better or worse?

When you are finished writing your answers, read the next page to find out why you may be having the symptoms you listed above.



# Reasons Why You're Having These Symptoms

The symptoms you have listed on the previous page may be symptoms of schizophrenia or schizoaffective disorder. There are many theories as to why people may experience these symptoms. One explanation is that these symptoms occur when the chemicals in your brain get out of balance. You're not alone—about 1 out of 100 adults suffer from these illnesses. It's not known why this happens to some people and not to others.

One of the best ways to relieve your symptoms is to take medication that will help adjust this chemical imbalance. As you keep taking your medicine, your symptoms are more likely to improve.

Schizophrenia and schizoaffective disorder are illnesses that do not have a known cure yet. But the medicine can help you manage your symptoms. If you stop taking the medicine, your symptoms are more likely to return in the near future. That's why it's important to take your medicine every day, even after your symptoms go away and you're feeling well.

# What Your Brain Chemicals Are Supposed to Do

The brain is a complex network of nerve cells. These nerve cells communicate with each other by electrical impulses and chemical signals. The chemicals in the brain help to:

- 1. Receive accurate information from the world around you
- 2. Process the information (make sense of it)
- 3. Make decisions based on the information you receive and process the frontal cortex helps you make future plans and guides you in new situations



# The Way Your Brain Receives Information

Schizophrenia and schizoaffective disorder affect the information your brain receives in these ways:

#### 1. Too much information overloads your mind.

Your senses may become more sensitive to the world around you—lights may seem too bright. Background noises may be too loud. Background information interferes with messages you want to focus on. It may be hard to filter out this background information—your brain has trouble sorting out what you hear and see. Often, the messages get jumbled.

#### 2. Information that your brain receives is not accurate.

Any one of your senses can "play tricks" on you. You might hear, see, taste, touch, or smell something that others do not experience. This is called a hallucination. Your brain is not receiving accurate information.

## 3. Your brain may store information incorrectly.

As new information is received, your brain may store it with memories that are not related. This may cause you to respond with a wrong emotion, such as laughing at sad news.





# **The Way Your Brain Processes Information**

Schizophrenia may affect the way your brain understands information in these ways:

#### 1. Your brain processes information more slowly.

Your mind may be flooded with information. It can be overworked and overloaded. Your response time may slow down because there is just too much information to think about. It may take you longer to learn a new skill than before you became ill.

# 2. Your brain doesn't have all of the information it needs to understand the message.

Your brain may receive only bits and pieces of information—like pieces of a puzzle. You may have to struggle to fit those pieces together so that the message makes sense.

#### 3. Your brain may reach incorrect conclusions.

Using incomplete messages can lead to illogical or incorrect conclusions—resulting in false beliefs, such as delusions.

# **Making Decisions Can Be Difficult**

Some people who have schizophrenia find it very difficult to make decisions. And sometimes the decisions they make may not be in their best interest. But these might be the best decisions they can manage based on the information they have received and processed.

The good news is that for most people, medicine helps improve the way they receive and understand information. Over time, making decisions may become easier as your skills and confidence increase.



# How Your Illness Was Diagnosed

You may be wondering how your doctor has determined you have schizophrenia or schizoaffective disorder. Diagnosis is complex and can change over time as symptoms change. There are several factors doctors consider in making a diagnosis.

# **Symptoms Are Most Important**

By far, your symptoms provide the most important clues in diagnosing your illness. Your doctor may consider the following:

- The types of symptoms you're having
- How severe your symptoms are
- · How long you've had your symptoms
- What your life was like before your symptoms appeared
- If you've ever had medication to treat your symptoms
- If you did take medication:
  - Did the symptoms improve?
  - If your symptoms improved, how soon after you started treatment?
  - Did any of your symptoms disappear completely?





#### **Other Factors**

The types of symptoms you've described make up only part of the diagnosis. Other factors include:

## Your Age When Your Symptoms First Appeared

Most people with schizophrenia start having symptoms when they are in their teenage years or early twenties.

#### **Your Family History**

These illnesses sometimes seem to be genetic in some families. You may have a relative who has schizophrenia or schizoaffective disorder. One known fact is that these illnesses are not caused by family problems.

#### Lab Tests

Your doctor may use blood tests and brain scans to eliminate other possible causes for your symptoms. Tests to identify alcohol or street drugs are also used because these substances can cause symptoms that resemble schizophrenia or can make symptoms of schizophrenia worse. Your doctor may need to check for the presence of drugs or alcohol as a possible cause for your symptoms.





# How Much Do You Know About Your Illness?

The more you know about your illness, the more you'll be able to help yourself feel better. Read each statement below and decide if it is true or false. See how much you really do know.

1. True or False: "Schizophrenia" means "split personality."

Answer: False. The term "schizophrenia" does not mean split personality. "Schizo-" means split and "-phrenia" refers to the mind. In schizophrenia, the brain has difficulties processing information. Messages from one part of your brain may not be transferred to another part of your brain. Or, messages may be transferred, but not completely. When this happens, you may feel confused because you are getting only pieces of information, not the entire message.

2. True or False: Schizophrenia is not a real disease.

**Answer: False.** Schizophrenia is a real disease. People with this brain disease need medical help to get better.

3. True or False: People with schizophrenia are always disabled and are unable to live on their own.

Answer: False. With treatment, many people are able to go back to school or get a job. However, it may take much longer to complete a school or training program than it would if you were not ill.

4. **True or False:** With continued treatment with medicine, many of my symptoms can be managed.

Answer: True. Although there is no cure, many of your symptoms can be improved or managed if you keep taking your medicine. Your medicine does more than just relieve your symptoms. It helps alter chemicals in your brain where an imbalance may be responsible for your symptoms.





5. **True or False:** Medicine alone is all I need to get better.

Answer: False. While medicine is a necessary part of your treatment, most people with schizophrenia find that additional therapies are helpful for issues such as regaining self-esteem and learning new job skills.

6. **True or False:** I can stop my medicine when my symptoms get better or are gone.

Answer: False. It's extremely important to take your medicine the right way, every day. If you miss doses or stop taking it completely, your symptoms are likely to return in a few days or weeks.

7. **True or False**: My illness was caused by family conflicts during my childhood.

Answer: False. Schizophrenia and schizoaffective disorder are medical health problems just like diabetes and high blood pressure. They are not caused by family problems, but by physical causes such as a chemical imbalance.

8. True or False: People who have schizophrenia or schizoaffective disorder have low intelligence.

Answer: False. Like other illnesses, schizophrenia and schizoaffective disorder can affect people with any level of intelligence. However, poor control of symptoms or multiple recurrences may not allow a person to function as well as he or she did before the illness began.

9. **True or False:** It's important to tell your doctor or case manager if you think your symptoms may be getting worse or if you notice new symptoms.

Answer: True. If you have new symptoms or old symptoms that are getting worse, your doctor may want to adjust your treatment. Be sure to tell your doctor or case manager about any possible symptoms.



# Coping With a Difficult Illness

When bad things happen to people, they often go through a series of emotions. This happens in serious medical conditions, for example, when someone gets a diagnosis of cancer. These emotional reactions are perfectly normal. You may have some of these feelings because of your illness.

# **Recognizing Your Feelings**

Having a mental illness can cause problems that are more upsetting than the symptoms of the illness itself. Loneliness and isolation are some of the biggest problems. People with a serious mental illness may feel embarrassed about having a disabling condition. And many find that their symptoms get worse when they're with other people. So they choose to be alone much of the time.

Many people feel disappointed or even angry that they can't do the things they used to do. Going back to school, getting a job, or having a steady relationship are much more difficult when you have a mental illness that is not controlled.

An important step in managing your illness is to recognize the way you're feeling. Then you'll be better able to cope with your feelings. It's all a part of the process to help yourself feel better.

On the lines below, describe the feelings you've had since you've been



liagnosed with your illness.	·	·	



# No Fault, No Shame, No Blame

Many people don't understand that a mental illness is a medical illness. They wonder why it happened to them. They feel ashamed they can't keep up with the plans they had before they became ill. Sometimes, they blame themselves (or others) for their illness.

New research has shown that whatever causes schizophrenia probably happens before birth. This means that you didn't get this illness because of family problems. And you didn't get this illness because of conflicts that happened during your childhood.

Just like people who get diabetes, you had no choice in getting your illness. And it's *not your fault* that you have this illness!





# **Rating Your Feelings**

Listed below are some of the painful feelings people have described as they've tried to adjust to having a mental illness. How are you feeling at this time? Rate your feelings on a scale of 1 (bothers you the most) to 5 (doesn't bother you).



Bothers you the most					Doesn't bother you	
Embarrassed	1	2	3	4	5	
Guilty	1	2	3	4	5	
Angry	1	2	3	4	5	
Like it's your fault	1	2	3	4	5	
Afraid	1	2	3	4	5	
Ashamed	1	2	3	4	5	
Lonely	1	2	3	4	5	



Which feelings bother you the most?

How do you usually handle your feelings? Name some of the ways you react to your feelings.



# Reacting to Your Feelings

People who have a serious illness tend to go through a series of emotional reactions. At first, they may not believe they have an illness. "How can this happen to me? It's just not possible."

It's common for people to doubt their diagnosis at first. Some people may even deny they have an illness and miss an opportunity to get better by starting treatment early. When their symptoms don't get better, most people eventually realize that it's true—they really do have an illness that has changed their life.

Some people feel victimized and may react by giving up. "I have this illness and there's nothing I can do about it." They feel defeated and come to believe they can't do very much to help themselves.

Many people feel discouraged, even angry. They try to find a reason why this has happened to *them.* They may blame themselves or others.

These are all normal reactions. And most people facing serious illnesses seem to go through them. But being trapped by these emotions can make progress difficult. They may occupy your thoughts and can drain much of your energy. A good way to start feeling better is to start working on ways to manage your illness. Use your energy to focus on how you can best recover.





# Building a Road to Recovery

Choosing to build a road to recovery can be a very positive step. Things can begin to move to a more normal state, but it will probably be a "new" normal. You may have to work out new ways to do many of the things you used to do. Going back to school or getting a job may not be best for you right away. You may want to start spending more time doing some of the things you enjoy.

# **Start With an Easy Activity**

One of the toughest things for many people to do is to start an activity or project. If you're having trouble getting started with things you want to do, start with an activity that's easy and enjoyable. Then increase your activity level gradually. Change to other activities when you may be ready for them.

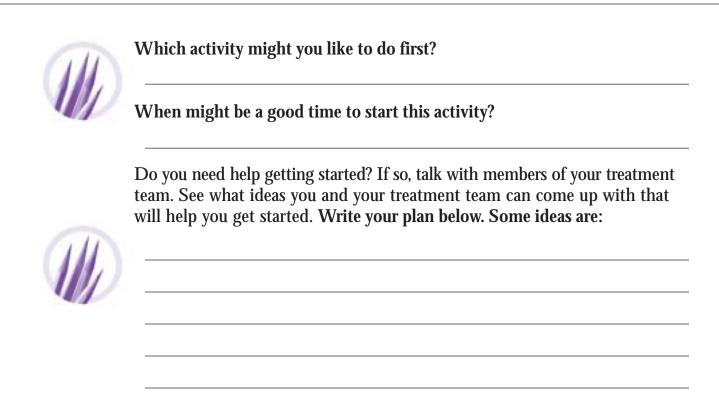
Think about the kinds of activities you might like to do. On the lines below, list the ones you'd like to do when you're feeling better.



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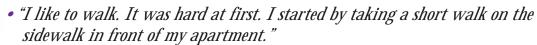


# Other Things You Can Do to Feel Better



As you begin to recover from your illness, you might want to do some of the things other people have done to help themselves feel better. Here are their suggestions:

- "I like to take a shower in the morning. The warm water is relaxing."
- "I find that listening to music relaxes me. When I go out, I like to take my cassette player and a favorite tape with me."
- "I go to sleep the same time every night and get up the same time every morning. I feel less nervous that way."



- "I belong to a support group—talking to other people who have similar problems has helped me a lot."
- "One thing I know I've got to do is take my medicine every day. Twice I felt better and tried to stop it. And twice I had to go back to the hospital. It's easier just to keep taking it."
- "The one thing that used to mess me up was partying with my friends. I didn't drink that much booze, but I guess it was enough to upset my condition. I still see my friends, but I don't drink or do street drugs anymore. It's not easy."
- "Getting away from the radio and TV can be a good idea. Sometimes I seem to get overwhelmed with all that information."









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Have you heard of any other suggestions? If so, list them here:
What are some of the things you might do to help yourself feel better? Write them below:



# The Danger of Relapse

Many people begin to feel better after a few weeks of treatment. But even if you're feeling well, a relapse (return of your symptoms) can happen. People who have a relapse may have to go to the hospital for treatment.

There are ways you can prevent a relapse and avoid the hospital:

- Be aware of your symptoms
- Keep track of your symptoms every week
- Let someone close to you know how you are doing, especially if you're not feeling well
- If your symptoms get worse, or new ones appear, call your doctor or case manager right away so they can help you
- Avoid making several changes in your life at one time—too much stress can lead to a relapse
- Take your medicine every day—missing doses or stopping your medicine can upset your body's chemical balance and cause a relapse. Talk to your doctor about what to do if you miss a dose.
- Stay away from alcohol and street drugs—they can cause a relapse by upsetting the chemical balance in your brain and interacting with your medicine.





# **Keeping Track of Your Symptoms**



Even when you're feeling better, you may have some symptoms that haven't completely disappeared yet, but they don't bother you as much as they used to. These are your *residual symptoms*. They may not get better or worse for a long time—they seem to stay the same.

Turn back to page 8. Look at all the symptoms you've listed in the section, "Which symptoms never seem to go away?" These are residual symptoms. List any other residual symptoms you think you may have:



If these symptoms are	bothering you, discuss	them with your	doctor.
There may be ways to	handle some of them.		



# **Early Warning Symptoms**

New symptoms that suddenly appear, or residual symptoms that get worse, warn you that a relapse may be near. Most people describe early warning symptoms as changes you notice when you first start getting sick again. Some of these changes may include:

- Having trouble sleeping at night
- Finding it harder to concentrate—watching a TV show might be more tiring than usual
- Forgetting things more often than usual
- Feeling nervous or worried all the time
- Hearing voices or seeing images
- Feeling afraid of people, places, or things that you usually feel comfortable with
- Having thoughts that people are talking about you or laughing at you
- Withdrawing from others or staying in your room a lot







If you're not sure what your early warning symptoms are, talk to your doctor,
case manager, family members, or friends. If you've ever had a relapse,
think about the symptoms you had when you first started to get sick.
Describe them on the lines below:

Watching for early warning symptoms is the best way you can catch a relapse before you get too sick and have to be hospitalized. One way to keep track of your early warning symptoms is to write them on a calendar on the right date. Also, write down if the symptom has gotten worse since the last time you checked it. That way, you can tell your doctor when your symptoms first started bothering you and if they've gotten worse over time.

# You Can Help Prevent Relapse

- Check your symptoms on the same day every week
- Call your doctor, case manager, or other members of your treatment team immediately if you notice early warning symptoms



# Feelings of Anxiety or Depression

# **Anxiety**

Almost everyone feels anxious (nervous) every once in a while. But for some people, feelings of anxiety can be worse than their other symptoms caused by schizophrenia. There are many causes of anxiety:

- Stressful situations—such as not having enough money, or preparing for a job interview
- Positive symptoms—for example, if you believe your food is poisoned, you'll probably feel fearful when you eat
- Alcohol and street drugs—these can cause anxiety, especially from the "crash" that happens when the "high" is over
- Akathisia—a feeling of restlessness caused by some medicines used to treat schizophrenia

If you think you may be having feelings of anxiety, talk to your doctor or other members of your treatment team. People often feel better when they know what's causing their anxiety.





# **Depression**

There are many reasons why you might feel sad. You may be having a bad day, or you might feel upset because of an argument you had with a friend. Or, you may be feeling disappointed because of a setback you had in your life. Feeling depressed for all of these reasons is normal.

But, having *clinical depression* means something else—it's when a depressed mood continues for weeks at a time, or there is a feeling of hopelessness all the time.

Just like everyone else, people with schizophrenia can experience periods of depression. Sometimes, depression can happen to people when their symptoms of schizophrenia start to improve. This is called *postpsychotic depression*. This kind of depression can be treated with medicine.

People who have postpsychotic depression usually 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. If you're not being treated for depression but think you're having symptoms, talk to your doctor.



# Handling Thoughts of Suicide

Suicide can be a serious problem, especially for people who have schizophrenia. People may think about suicide during tough times. 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 who to call if suicidal feelings return and you need help.





# When to Call Your Doctor



Call your doctor or another member of your treatment team:

- When your symptoms get worse—you have more symptoms, or the ones you usually have bother you more or happen more often
- When you begin to have "early warning symptoms," especially two sleepless nights in a row
- When you think you may have developed a new side effect from your medicine or have a side effect that's getting worse
- When you feel extremely discouraged and have suicidal thoughts
- When you feel like you might hurt yourself or someone else
- When you're in a crisis—call immediately



# Handling Emergencies

Sometimes it's difficult to know what to do when there's an emergency or you need help. Sometimes it's difficult to remember all of the things you want to tell your doctor or case manager once you've reached them on the phone.

The *Emergency and Assistance Plan* on the next page will help you organize your thoughts. It will also help prepare you in case there is an emergency or if you need help. People you may want to call include:

- Your doctor or nurse
- Your case manager or counselor
- A friend or family member





# Your Emergency and Assistance Plan

Use this chart to help yourself plan what to do in case there's an emergency or problem. Ask a member of your treatment team to help you fill in the blank spaces below. The first line provides an example of the information you need to fill in.

Problem	Person to call	Phone number	Things you need to discuss
You've run out of your medicine.	(Member of treatment team)	555-XXXX	How to get prescription refilled     Need help picking up medicine from pharmacy
You've run out of your medicine.			
You've missed two or more doses of your medicine.			
Your symptoms are getting worse or you begin to have early warning symptoms.			
You need assistance solving a difficult problem.			
You are having unbearable side effects from your medicine.			
You are feeling suicidal or are fearful you may hurt someone else.			
Other:			



# You Are Not Alone

People who have an illness such as schizophrenia or schizoaffective disorder often feel isolated. They might try to fight this illness on their own. You may find it easier if you reach out to others. Think about all of the people in your life who care about you—your friends, family, case manager, doctor, nurse, and other members of your treatment team. Most will understand how difficult this illness can be for you.

Keeping them informed about your illness and your symptoms will help you in many ways. You'll feel better if you're able to share your experiences with them. Also, they'll know how to help you when you need support.

Remember there are many people like you who have this illness. Getting to know others who have the same challenges you have can be very helpful to you. Most areas have clubs, drop-in centers, and other organized groups for people to meet and exchange ideas and experiences.

# **Your Helpful People List**

Sometimes when people are not feeling well, they lose contact with their friends and family. Use this list to help yourself remember who you'd like to contact or stay in touch with. Update your list as you meet other people you can reach out to. Write the person's name and telephone number in the space provided on the next page.





# Helpful People List



Helpful Person	Phone Number
Family member	
Friend I met in treatment	
Friend I met at support group	
Friend from church	
Neighborhood friend	
Friend from volunteering	
Friend from work	
Hobby friend	
Doctor	
Nurse	
Case Manager	
Counselor	
Vocational Rehabilitation Counselor	
Other	
Other	



Friends can help in different ways. Some may help you solve special problems. Others may help you by being there or by listening.

If you want to reach out to make friends, talk with people you meet every day. Support groups can also be useful. You'll meet others going through similar experiences.

The National Alliance for the Mentally III (called "NAMI") can also help you find people you can talk to. You can call them at 1-800-950-6264. They can give you information about the support group in your area.





# What Can You Expect in the Future?

Most people want to know how their illness will affect their lives. "Will I ever get back to normal?" is a question they often ask their doctors. No one can predict what will happen to you. However, schizophrenia is an ongoing mental illness that gets better, but can't be cured. Most people who have schizophrenia will have to work at controlling their illness. In many ways, it's similar to the way people with diabetes need to work at controlling their illness.

Frequent relapses can make your illness worse and make it hard for you to stay well. Do everything you can to prevent relapses:

- Take your medicine regularly
- Visit your doctor regularly
- Keep track of your symptoms
- If symptoms get worse, tell your doctor or case manager immediately

As you continue with your treatment, stay focused on recovery. Schizophrenia and schizoaffective disorder are *medical* illnesses that *can* be treated. There is no cure for these illnesses at this time. But for many people, symptoms *can* be managed. And your life *can* get back to health —a new level of health.



# Team Solutions | Workbook 1 Schizophrenia: Understanding Your Illness

# Notes

