A Guide for Caregivers

Understanding Schizophrenia Relapse

Caregivers can play an important role in helping their loved one who has schizophrenia
Caregivers can play an important role in helping their loved one who has schizophrenia. Supporting a person who lives with schizophrenia can be hard. Sometimes caring for yourself can be difficult too. But you can help care for your loved one with schizophrenia by gaining an understanding of the disorder, learning to recognize the potential warning signs of relapse, and partnering with your loved one’s treatment team to help determine the best treatment plan.

How You Can Help

Be an advocate for your loved one. Get to know the treatment team and help your loved one work with those who are caring for him or her.

The Treatment Team

• Psychiatrist
• Psychologist, psychiatric social workers, counselors
• Nurse practitioners and physician assistants
• Nurses
• Social workers
• Case managers
• Occupational therapists or employment counselors

These are things that your loved one can do to get connected to others:

• Having an active social life; keeping up with friends and family
• Holding a job (paid or volunteer)
• Taking classes
• Doing hobbies and having fun
Understanding Schizophrenia and Relapse

Schizophrenia is a chronic disease, meaning it may affect your loved one for life. Schizophrenia affects the brain and can change how people think, feel, act, and live. While schizophrenia can be managed, relapses can still occur. Remember that schizophrenia is not your loved one’s fault, and you can help him or her through the difficult times.

“Feeling well” means different things to different people. For some people with schizophrenia, it may mean feeling safe and trusting their own thoughts.

A relapse happens when symptoms of schizophrenia come back or get worse after your loved one has been feeling well for a period of time. Relapses can keep happening, and for some, may get worse over time. To help reduce the risk of relapse, people with schizophrenia and their caregivers can learn to watch for warning signs of relapse.

Recognizing Warning Signs of Relapse

Below are some symptoms of schizophrenia. If your loved one experiences any of these symptoms or they become severe, it could be a sign of relapse and you should contact the treatment team right away:

- Feeling tense, angry, or afraid
- Difficulty sleeping such as sleeping during the day or nighttime activity
- Having difficulty concentrating or feeling confused
- Hearing, seeing, or sensing things that others do not (for example, delusions and hallucinations)
- Having unusual thoughts or beliefs that are untrue (for example, about fame, power, wealth, and abilities)
- Thinking, speaking, or behaving in a way that is chaotic, confused, and does not make sense to others
- Having disorganized speech
- Not being able to follow conversations
- Not trusting other people
How You Can Help

Stay alert for the warning signs of an acute episode, relapse, or possible side effects of medication.

The warning signs on the previous page are examples of symptoms that people with schizophrenia may have during a relapse. The symptoms people experience are unique to them. As a caregiver, you may know your loved one better than anyone else and will likely know what his or her own personal signs of relapse are. By helping to identify these warning signs, you may help your loved one stay well.

Some Possible Causes for Relapse

Many people with schizophrenia will have multiple relapses. It is important to remember, though, that people with schizophrenia are not always to blame for having a relapse.

Some common causes of relapse include the following:

- Not taking antipsychotic medication as the doctor directed
- Alcohol or drug use
- Stressful life events
- Medication side effects that can’t be tolerated
- Missing office visits with the doctor and/or treatment team

Sometimes a relapse occurs as a result of the natural course of schizophrenia disorder despite staying on track with medications and office visits. Talk to the treatment team about other ways you can be an advocate for your loved one with schizophrenia.
Managing Schizophrenia and Relapse

Talk to the treatment team about developing an action plan before your loved one with schizophrenia experiences a relapse. Having a plan in place may help.

Here are a few tips for managing schizophrenia and relapse:

• Learn as much as you can about schizophrenia, including the signs of relapse and worsening symptoms and treatment options.

• Know the early warning signs of relapse and act quickly. Call the treatment team if you think you notice signs of relapse.

• Stay in touch with the treatment team. Help make sure your loved one has a way to get to appointments on time.

• Make sure your loved one takes his or her medicine exactly as directed. Know the common side effects of the medications and talk to the treatment team if you notice your loved one experiencing them.

• Help your loved one set up a routine to remember to take his or her medication, such as taking medications at the same time every day and/or combining it with a daily routine like brushing teeth. If your loved one is taking a long-acting injectable, help him or her schedule and remember the next injection date.

• Keep a record of emergency numbers, doctors, daily medications, special diets, people who can help, and other information relating to your loved one’s care.

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How You Can Help

Remind your loved one to take his or her medication, which may help reduce the risk of relapse.
• Help your loved one have a plan for managing stress. Making healthy lifestyle choices may lower stress.

• Encourage your loved one to become involved in activities, like a hobby or volunteer work.

• Faith-based support, such as becoming an active member of a religious congregation, may also be a source of comfort and strength.

• Look into alternative therapies such as acupuncture, meditation, and other approaches. Although these practices have not been studied as much as conventional Western medicine, and do not carry scientific evidence, they may help.

**How You Can Help**

Partner with your loved one and the rest of the treatment team to help find an appropriate treatment plan.

**Taking Care of Yourself**

Caring for a loved one with schizophrenia can be rewarding and difficult at the same time. It is common for caregivers to experience burnout, depression, and anxiety when caring for a loved one with schizophrenia. It can be difficult to care for others when you have not taken care of your own needs as well.
How You Can Help

Remember to take time for yourself.

Here are a few coping tips that may help you:

• **Join a support group.** There are several online and in-person support groups that may give you a chance to talk about your situation and hear from others who are dealing with similar issues. In addition to emotional support, you may pick up practical tips as well. If joining a support group is not possible, try to find another caregiver you can talk with.

• **Reinforcements.** Put together a care team in case an emergency arises and you cannot care for your loved one. You should be willing to tell others what you need and to accept their help.

• **Make time for yourself.** Schedule time away from your loved one to avoid becoming frustrated or angry. Taking time off from your responsibilities can help you keep things in perspective and have more patience and compassion for coping or helping your loved one.

Recognizing a relapse in people with schizophrenia can be difficult because relapse is often different for each person. Understanding as much as you can about schizophrenia and being supportive may help your loved one. Taking care of yourself can be beneficial for both of you.

Never underestimate how important your role is as a valuable source of emotional support and long-term stability for your loved one.
Resources
Here are some resources that can help you get more information about schizophrenia and staying well.

International Center for Clubhouse Development (ICCD)
http://www.iccd.org/
A multinational nonprofit organization that helps communities around the world create sustainable solutions for mental illness by developing and nurturing new and existing clubhouses.

National Alliance on Mental Illness (NAMI)
http://www.nami.org/
A United States mental health organization dedicated to building better lives for the millions of Americans affected by mental illness.

Mental Health America (MHA)
www.nmha.org
A community-based network, with affiliates across the United States, dedicated to helping all Americans live mentally healthy lives through advocacy, education, programs, and services.

National Institute of Mental Health (NIMH)
www.nimh.nih.gov
A United States mental health organization focused on prevention, recovery, and cure of mental illnesses through basic and clinical research. The Institute also conducts research to help find optimal ways to provide available treatments and services directly to the community.