

Encouraging Adherence to Care for People with Schizophrenia

Receiving a diagnosis of schizophrenia can be difficult to understand and accept, both as a caregiver and as a patient, due to stigma surrounding the disease. Caregivers can play a significant role in adherence to care. Even patients who understand their diagnosis still may have questions, and concerns, and they can benefit from the support of a caregiver.

Coping with Diagnosis

People with schizophrenia may be less compliant with their medications due to some of the symptoms they may have. They may also not be aware of their illness.

In addition to struggling with diagnosis, people with schizophrenia may not take their medications regularly due to side effects or other reasons.

Therefore, you can play a very important role in your loved ones' journey. You can help them stay on top of their medications, track their symptoms, and talk to their healthcare providers (HCPs).

Supporting Medication Adherence

While schizophrenia is not curable, there are many medications and other treatments that can help manage the symptoms of the disease. However, it is estimated that 70%-80% of patients with psychotic disorders are partially non-compliant with their medications. There are many reasons for this, including: 1,2



Believing that they are not sick.



Experiencing medication side effects.



Feeling stigma from taking medication or the treatment they have been prescribed.



Lacking social support.



Experiencing forgetfulness.

Helping Loved Ones Stay Adherent to Medication

Staying on medication is key to preventing relapse and improving outcomes. ^{1,2} Medication nonadherence may be associated with increased hospitalizations, crisis situations, impaired functioning, decreased quality of life, and self-harm.²

Family support can help improve medication adherence and reduce relapses by approximately 20%. Caregivers play a very important role in helping their loved ones stay compliant, as having a supportive family environment can help improve outcomes.³

Practical Tips

There are many ways you can help your loved one stay on top of their medications:^{2,4,5}



Make sure they take their medication at the same time each day. Tell your loved one to take their pills at the same time they are performing a daily activity, like before eating or after brushing their teeth or before bed to help them remember.

This resource is intended for educational purposes only and is intended for US health care professionals who may choose to share this handout with patients or their caregivers.



If possible, try to be present for each dose to make sure they have taken it or set reminders for them, such as leaving a written note. Place the note where your loved one is very likely to see it every day, such as on their bathroom mirror or on the refrigerator.



Store their medication in the same place so it is easier to remember where it is.



After your loved one has taken their medication, turn the bottle upside down as a visual reminder that they took their dose.



Use a pill box so they know which medications to take every day. Pill boxes can also help you check that your loved one has taken their medications.



Set an alarm for yourself when they need to take their medication or use a digital tool to help track.



Carry extra doses of their medication with you, such as in your purse or in the car, in case they forget to take them when they leave home.



Make sure their medications are refilled on time. It's also important to keep on top of medication changes.

Tracking Symptoms

There are many other things you can do to help your loved one stay on treatment:



Understand their symptoms.

It's important to understand the signs of schizophrenia so you can tell when they may be experiencing a relapse. There are three types of symptom types that they may experience: positive, negative, and cognitive symptoms:⁶

 Positive symptoms: delusions, hallucinations, disorganized thinking and speech, and disorganized/abnormal motor movements

- Negative symptoms: decreased emotional expression, lack of motivation, reduction in speech, depressive behavior, and social isolation
- Cognitive symptoms: memory problems, difficulty with language, trouble processing thoughts, and attention problems



Monitor behavior.

It can be helpful to keep a journal to note behavior daily or record their progress in a mood tracking app.⁷ If you are concerned by any behavioral changes, reach out to your loved one's HCP right away.



Look out for side effects.

Many patients with schizophrenia often stop taking their medication because of side effects. Ask your loved one's HCP about common side effects often experienced on the medications they are taking so you know what to watch out for.⁷



Use a planner.

Consider using a planner to track their medical appointments. If you can, it's helpful to accompany your loved one to an appointment to make sure that they attend.⁷

It's also important to build a good relationship with their HCP since your loved one will require lifelong disease management. Be sure to ask any and all questions you have to their HCPs.



Create a file.

It can also be helpful to store all of your notes in one place that includes important information in case of a crisis situation.⁷

This information may include how to handle a crisis situation, addresses and phone numbers of nearby hospitals, and your loved one's HCP's information, in case you are not present at the time of crisis.

Communicating with the HCP

If your loved one is experiencing signs or symptoms of relapse or medication side effects, don't hesitate to reach out to their HCP. If their symptoms are severe or if you believe your loved one is a threat to themselves or others, take them to the emergency room.⁷

Here are some signs that could indicate a relapse of their condition: ⁷

Experiencing insomnia
☐ Withdrawing from friends and loved ones
Deteriorating personal hygiene
Feeling more paranoid
Acting hostile
Having trouble with speech

Even if your loved one is doing well on their medications, it's still important to keep track of their daily behavior. At each HCP visit, make sure to take your journal or notes to discuss with their HCP so they can evaluate and possibly adjust their medications when needed.

Experiencing hallucinations

Disappearing at times

Learning More

To best support your loved one, it's important to learn more about their disease. Listed below is an educational resource on schizophrenia:

For Your Loved One



Early Psychosis: What's Going On and What Can You Do?

A downloadable resource to help your loved one understand the signs and symptoms of psychosis and how it is treated.

Taking care of a loved one with schizophrenia can be very overwhelming, but remember that you are not alone. Don't ever hesitate to reach out to your healthcare provider with any questions you may have.

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This handout does not replace proper medical care.
Please reach out to your health care provider with any questions or concerns you might have.

References

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