

UNDERSTANDING A FIRST EPISODE OF PSYCHOSIS

Caregiver: Get the Facts

What does it mean when a health care professional says a “first episode of psychosis”?



Hearing a health care professional say your youth or young adult is experiencing a first episode of psychosis can be confusing. The good news is that the emotions and behaviors you have been concerned about are often symptoms of a treatable disorder. By engaging in treatment and entering recovery, people with psychoses can feel better and can go on to lead productive, meaningful lives. Recovery does not necessarily mean a cure for people experiencing a first episode of psychosis. It does mean that people are actively moving toward wellness.



It can be scary at first—learning your child has a mental health diagnosis. But, once you really think about it, it is no different than learning your child has asthma or diabetes. You become educated about the condition, you find the resources and professionals your child needs to be healthy, and you continue to love your child just as much as you ever did.

—Malisa, Parent

It is important to talk with a health care provider about treatment options and additional information. Your provider may be a child and adolescent psychiatrist, general psychiatrist, psychologist, pediatrician, social worker, or other health care provider. If you are concerned that your youth or young adult is experiencing a first episode of psychosis, it is important to seek a thorough evaluation. The evaluation includes talking about their symptoms, blood and urine tests, potentially a brain scan, and perhaps other tests to ensure there is no underlying medical condition causing the symptoms. It is also important to ensure that they can tolerate medication, if recommended as part of a treatment plan.

What do we mean by recovery?

Recovery is a process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full potential.¹

Recovery focuses on wellness and resilience, encouraging [people] to participate actively in their own care.²



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What is psychosis, and what is meant by hallucinations, delusions and confused thinking?

Psychosis involves symptoms such as hallucinations, delusions, or confused thinking. When someone has these for the first time, this is considered their first episode of psychosis.

- *Hallucinations* are things you hear, see, smell, taste, or feel that no one else can hear, see, smell, taste, or feel. Hearing voices is the most common type of hallucination.
- *Delusions* are false beliefs that seem real to your youth or young adult. People with delusions may believe that other people are spying on them or want to harm them or someone they care about.
- *Confused thinking* is a change in the way a person thinks. Thoughts may be very fast or slow, they may stop suddenly, or the person might feel that the thoughts are outside their control. These thoughts might show up as disorganized speech, such as shifting rapidly from one topic to another.

What caused this?

Psychosis is a cluster of symptoms that can be due to medical conditions, prescription drugs, substance use, or toxicities, as well as psychiatric disorders. The most common cause of a first episode of psychosis in young adults is schizophrenia. There are other disorders that your health care provider will also consider.⁴ Medical professionals understand how the symptoms of psychosis are produced in only a few of these disorders. Some of the disorders have a genetic basis (i.e., family history of psychotic disorders), others have an environmental basis, and symptoms are frequently the result of a combination of these factors. Your health care provider will help you understand how your youth or young adult may have developed psychosis. Traumatic experiences can also contribute to the development of psychiatric disorders. If your child has experienced a traumatic incident, it is critical to share that information with their mental health specialist and pediatrician.

Should I have known?

It is very difficult for parents and caregivers to know if their youth or young adult is acting like a typical youth or young adult or if their moods and behaviors are actually symptoms of psychosis. Youth or young adults can be moody, and are reluctant sometimes to talk openly about emotions or behaviors. Perhaps you tried to ask questions but were not able to get answers. Working with a health care professional is important to help assess your youth or young adult's situation and understand how to start moving forward.

The symptoms of psychosis make it harder or impossible for a person to know what is real, to think clearly, to communicate, relate to others, and to feel emotions. These symptoms and others may mark the beginning of a serious medical/psychiatric disorder. Psychosis can be treated, and the sooner treatment begins, the better the outcome will be. It is important to get help for your youth or young adult as early as possible. However, in the early stages of psychosis, people often do not know what is happening to them and may not seek treatment right away.



What do we mean by resilience?

Resilience is the ability to respond to stress, anxiety, trauma, crisis, or disaster. It is critical in recovery [from mental disorders].³

What are the treatment approaches?

Medication is essential in the treatment of psychosis. Coordinated specialty care programs offer the most effective early treatment for psychosis and combines an array of services and supports.⁴ Additionally, psychotherapy, including cognitive behavioral therapy, social skills training, and other psychosocial interventions can help your youth or young adult better understand psychosis.⁵ Therapy provides education and treatment for common symptoms and problems. Therapy also emphasizes the importance of staying on medications. You should discuss treatment options with your youth or young adult and their health care provider, and make decisions based on their individual health goals and priorities as well as other types of treatment, such as complementary medicine, and programs that can provide additional support related to education, employment, housing, and vocation and career development. It is also important to encourage good self-care, such as a healthy diet, exercise, sleep, and abstinence from illicit drugs.



Find organizations and people to support you, your child, and family to provide education and support through this time in your life.



—Sue, Parent

Medications

Medications used to treat the symptoms of a first episode of psychosis are referred to as antipsychotic medications. A variety of medications are available and research shows that they are effective. Each person reacts differently to these medications. For that reason, the prescribing health care professional may try different doses and different kinds of medication before finding the most effective approach for your youth or young adult. Treatment may begin with medication. If side effects develop, the prescriber may use a lower dose, add a medication to reduce the side effects, or recommend a different medication altogether.

Therapy

Psychotherapy, including cognitive behavioral therapy, social skills training, and other forms of therapy can help your youth or young adult. Therapy can help reduce common symptoms and problems that your youth or young adult may experience. Therapy can also help your youth or young adult manage stress, avoid triggers, and learn coping strategies. Recovery After an Initial Schizophrenia Episode (RAISE) is an emerging evidence based practice that uses a coordinated specialty care approach to improve the lives of youth and young adults who are experiencing a first episode of psychosis.

Support

Peer and family support are also important for people with psychosis. Family members with positive attitudes, caregivers, and peers who are recovering from similar disorders can be great assets to the team or youth or young adult. As a partner on this team, you can help to identify problems early and provide important support and encouragement that help your youth or young adult. You can also help them stay focused on reaching treatment and recovery goals. Youth or young adults of consenting age may need to provide written consent for parents or caregivers to participate on the treatment team. Additionally, talking with other caregivers who also have a child diagnosed with a first episode of psychosis can help you to learn more and know what to expect. You may benefit from having someone further along in the process with whom to discuss your own questions, thoughts, and feelings.

Is this my fault?

No, it is not. Decades of medical research provide evidence that psychosis is the result of a complex interaction of genetics and biological, environmental, social, physical, and emotional influences. None of the contributing factors alone are sufficient to cause psychosis. Your youth or young adult is not to blame and neither are you.



How common is this disorder?

The worldwide rate of schizophrenia is approximately 1%, with some variation noted across studies and populations. The peak ages of onset for the disorder ranges from 15 to 30 years. Early onset schizophrenia tends to occur more often in male individuals. As age increases, males and females tend to have the same rate of schizophrenia.⁶



How can I help?

Parents, caregivers, and family members can be important partners in treatment and recovery from psychosis. You can play a major role by monitoring symptoms and responses to medication changes and encouraging your youth or young adult to stick with their treatment and treatment plan. Alert your health care providers about your youth or young adult's symptoms, such as any particular fears or phobias, including social situations, insomnia, or persistent low mood, as well as if they use drugs, excessive caffeine, nicotine, or alcohol. Seek help immediately if your youth or young adult has thoughts or plans of harming themselves or others (For more information, see the hotline and website below*). There is significant evidence that your involvement can improve treatment outcomes. Your own self-care is also an important part of caring for a child with a mental health disorder. Self-care may include talking to your own mental health professional, friends, or family, as well as joining a local support group through the National Federation of Families for Children's Mental Health or the National Alliance on Mental Illness, exercising, getting a good night's sleep, or meditation.

* **National Suicide Prevention Lifeline: 1-800-273-TALK (8255).** <http://www.suicidepreventionlifeline.org>

EDUCATION



TREATMENT



SUPPORT



RECOVERY
AND
RESILIENCE

Where can I learn more and get support?

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¹ (2012). *SAMHSA's Working Definition of Recovery*. SAMHSA.

² American Psychiatric Association. (2005). *Position Statement on Use of the Concept of Recovery*.

³ (2013). *SAMHSA Annotated Bibliography*.

⁴ (2016). *RAISE: Coordinated Specialty Care Fact Sheet and Checklist*

⁵ American Psychiatric Association. (2015). *Understanding Mental Disorders: Your Guide to DSM-5*. (D. W. Black, Ed.) Washington DC: American Psychiatric Publishing.

⁶ McGrath, J.J. (2006). Variations in the Incidence of Schizophrenia: Data Versus Dogma. *Schizophrenia Bull* 32, 195-197.

American Academy of Child and Adolescent Psychiatry

<http://www.aacap.org>

American Psychiatric Association

<http://www.psychiatry.org>

American Psychological Association

<http://www.apa.org>

American Psychological Association

<http://www.apa.org/topics/bipolar/index.aspx>

Encouraging People to Seek Help for Early Psychosis

[https://www.nami.org/getattachment/Learn-More/Infographics-Fact-Sheets/tipsheet_earlypsychosis_04v2-\(1\).pdf](https://www.nami.org/getattachment/Learn-More/Infographics-Fact-Sheets/tipsheet_earlypsychosis_04v2-(1).pdf)

HelpGuide.Org

<http://www.helpguide.org>

Institute of Medicine/NAP

<http://www.iom.edu>

Kids Health-Information for Parents

<http://kidshealth.org/parent/dictionary/p/az-psychosis.html>

National Alliance on Mental Illness

www.nami.org/earlypsychosis

National Center for Complementary & Integrative Health

<https://nccih.nih.gov/health/integrative-health>

National Federation of Families for Children's Mental Health

<http://www.ffcmh.org/>

National Institute of Mental Health

<http://www.nimh.nih.gov/health/topics/schizophrenia/index.shtml>

National Suicide Prevention Lifeline

<http://www.suicidepreventionlifeline.org>
1-800-273-TALK (8255)

Ok2Talk

<http://ok2talk.org>

Parents Med. Guide

<http://www.parentsmedguide.org>

RAISE Resources for Patients and their Families

<https://www.nimh.nih.gov/health/topics/schizophrenia/raise/raise-resources-for-patients-and-families.shtml>

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<http://www.samhsa.gov/disorders/mental>

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(SAMHSA) National Helpline: <http://www.samhsa.gov/find-help/national-helpline>

The Family Run Executive Director Leadership Association

<http://www.fredla.org>

What is Early and First-Episode Psychosis?

https://www.nami.org/getattachment/Learn-More/Infographics-Fact-Sheets/tipsheet_earlypsychosis_01v3.pdf

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