

# Understanding Psychosis

Resources and Recovery

A vibrant green leaf with a monarch butterfly perched on it, surrounded by other green leaves and water droplets. A diagonal yellow line runs across the top of the image.

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YOUTH



**nami**

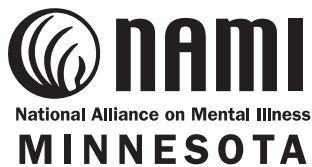
National Alliance on Mental Illness

**MINNESOTA**

Phone: 1-651-645-2948

Toll Free: 1-888-NAMI-HELPS

[www.namihelps.org](http://www.namihelps.org)



NAMI Minnesota champions justice, dignity, and respect for all people affected by mental illnesses. Through education, support, and advocacy we strive to eliminate the pervasive stigma of mental illnesses, effect positive changes in the mental health system, and increase the public and professional understanding of mental illnesses.

# UNDERSTANDING PSYCHOSIS

## *Resources and Recovery*

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## INTRODUCTION

People who have psychosis get better faster when they get help early on. With prompt treatment, they often do better in work, school and their personal lives. Mental illnesses that have psychosis as a symptom, such as schizophrenia and bipolar disorder, respond well to early treatment. The illness is less likely to become disabling with early help.

The average person experiences psychosis for 72 weeks before it is treated. But it is much better if treatment starts within six months of early symptoms. When treatment is delayed, some symptoms may become more severe, and recovery is harder. Undiagnosed psychosis most often begins in young people in their late teens to mid-twenties.

This booklet is for young adults who have had a first episode of psychosis and their friends and families. It offers information about psychosis, treatment, resources, wellness and recovery. It offers information about how to manage after a first episode of psychosis and how to get help from the mental health care system.

Families and friends will learn their role in caring for a loved one, how to provide helpful support and how to work as a team with their loved one. Learning how to advocate for a loved one will help to ensure they are safe and getting all of the help they need.

Learning to share decision making with a loved one can keep them from feeling helpless in the face of a difficult illness. ■

***“Don’t give up finding treatment. There are resources.”***

## PSYCHOSIS

Psychosis is the experience of loss of contact with reality that is not part of the person’s cultural or religious beliefs. A person experiencing psychosis may not know which of their feelings and thoughts are real. They believe the false experiences are actually happening.

Psychosis is a symptom of an illness. It is not an illness itself. Psychosis can involve hallucinations: hearing, seeing, tasting, smelling or feeling things that are not there. It can also involve delusions: fixed false beliefs that are not based on reality. These beliefs are often felt as unfounded fear or suspicion. Delusional beliefs do not change when a person is given facts that show they are false. Disordered thought (thoughts that jump between unrelated topics), speech that does not make sense, and changes in feelings and behavior are also experienced with psychosis.

Psychosis can happen to anyone, and it can be treated. Up to 6% of all people will have a psychotic episode at some point in their life. Young

adults in their twenties are the group most likely to have a first episode of psychosis.

Young adults face many challenges and changes. These can include moving away from home, starting a new job or education program, and developing new relationships. Experiencing psychosis for the first time can make it hard to meet these challenges successfully.

***“I knew something wasn’t right, but I was afraid to tell anyone about my thoughts. . . . Then I got to a point that I was so wrapped up in those delusions and hallucinations, I was helpless.”***

Early assessment, treatment, education and support are very important. Delays in treatment can cause many problems. These can include thoughts of suicide, problems with the police, and drug and alcohol use.

## **Hallucinations**

Hallucinations—having sensations that others do not feel—can be very scary. People who are having hallucinations often feel alone and worry that they cannot get better. They may not want anyone to know what they are experiencing.

*Hallucinations can include:*

- ▶ Hearing voices tell you that you are worthless, that people around you cannot be trusted, that you have superpowers or that you should harm yourself or someone else.
- ▶ Seeing bright, colorful lights or flashes, religious figures such as God or Christ, or people who are not there. Seeing things that are common in your cultural or religious tradition are not considered hallucinations.
- ▶ Tasting something that is not there. The taste is often unpleasant. This is more common in psychosis caused by a medical condition than by a mental illness.
- ▶ Smelling something that has no external cause. The smell is usually unpleasant. Often the person is concerned that the bad smell is coming from them. This is also more common in psychosis caused by a medical condition than by a mental illness.
- ▶ Feeling as if someone is touching you or that there are bugs under your skin.

***“It’s the most soul-wrenching experience anyone can go through. Use every resource to get through it, and then turn around to help those coming up the mountain after you. They need your help.”***

## Delusions

Delusions—fixed false beliefs—can also be very scary. People having delusions often also feel paranoia, so they are not likely to share what is happening.

*Common examples are:*

- ▶ **DELUSIONS OF PARANOIA.** The belief that someone or “they” are out to get them. The young person may believe, for example, that their tap water has been poisoned or that people are listening to their thoughts.
- ▶ **DELUSIONS OF REFERENCE.** The belief that an event or item holds special meaning for them. A person may believe, for example, that a celebrity on TV is sending them special messages.
- ▶ **DELUSIONS OF GRANDEUR.** The belief that they are an important figure, such as Abraham Lincoln or Napoleon. The person may believe that they have superpowers, such as the ability to fly or tell the future.
- ▶ **DELUSIONS OF CONTROL.** The belief that their mind is being controlled by outside forces, such as space aliens or radio waves.

Sometimes a person has both delusions and hallucinations. For example, a person may believe that people with red eyes are evil. The person may then start to see red eyes when they look at their loved ones and become very frightened for their family.

***“The thing about psychosis is that the experience itself can be so terrifying, like a waking nightmare. But then there’s the aftermath, with the stunning realization of what a bizarre experience the person just had. This can be the most frightening part of all.”***

Whatever the type of psychosis, many people have gone through this and are in recovery. Psychosis can be treated.

## The First Episode of Psychosis

The first time someone has psychotic symptoms is called the first episode of psychosis. A person having a first episode of psychosis may not understand what is happening and may feel confused and distressed. They may be afraid to ask for help. Getting help right away is very important. Mental health problems are like physical problems: the sooner they are treated, the easier it is to get better. Delays in treatment may make it hard to recover fully. Some symptoms may not go away at all.

## Causes of Psychosis

Psychosis may occur as a result of many conditions. Psychosis is most commonly found in mental illnesses, including psychotic disorders and mood disorders.

*Psychosis can be related to many other things, including:*

- ▶ The use of cannabis (marijuana). Cannabis has been linked to the onset of schizophrenia in some studies. Some hospitals report very high usage among their first-episode psychosis patients when the episode occurred. Other causes of psychosis include alcohol and other illegal drugs such as amphetamine (speed), cocaine, methamphetamine (crystal meth), mephedrone (MCAT or miaow), MDMA (ecstasy), LSD (acid), psilocybin (mushrooms), ketamine (Special K, Vitamin K) and opiates (heroin).
- ▶ Physical issues such as epilepsy, Parkinson's disease, Wilson's disease (inability to process copper), Huntington's disease, chromosomal disorders, brain tumors, dementia, Lyme disease, multiple sclerosis and stroke
- ▶ Lack of sleep
- ▶ Very poor nutrition
- ▶ The use of some prescription drugs, such as steroids, opiates (codeine, morphine) and stimulants, including medication for ADHD, which is often sold illegally on college campuses

## Phases of Psychosis

A psychotic episode caused by a mental illness usually happens in three phases. The phases may not be easy to identify while they are happening. The length of each phase may vary from person to person.

The first phase is called the prodromal phase. Not everyone will experience this phase. This phase occurs before the development of psychotic symptoms. There are vague signs that “things are not quite right.”

The person may have a range of mild symptoms that gradually appear and shift over time. They may have some symptoms of psychosis that come once in a while and then go away. Changes in feelings, thought, behavior and the way they see their surroundings may occur. But clear psychotic symptoms (hallucinations, delusions, or thought disorders) have usually not yet started. The person may see shadows or other things that do not exist, but they are aware that they are not real. The prodromal phase is hard to identify. This phase can last for years and may never progress to a psychotic illness.



*Symptoms of the prodromal phase include:*

- ▶ Cognitive decline (the brain is not functioning as well as usual)
- ▶ Spending much less time with family and friends
- ▶ Receiving poor grades when grades used to be better
- ▶ Performing poorly at work when performance used to be better
- ▶ Avoiding doing activities that were once enjoyed
- ▶ Avoiding bathing, grooming, and other personal care
- ▶ Avoiding caring for personal living space
- ▶ Seeming anxious, irritable or depressed
- ▶ Having a hard time paying attention or remembering things
- ▶ Thinking all the time about new, unusual ideas
- ▶ Changing sleep patterns
- ▶ Beginning to feel paranoia or having odd thought patterns

People experiencing these symptoms should see a primary care doctor or mental health professional as soon as possible.

The prodromal phase usually lasts several months, but it can be longer or shorter. Family members often say that they can look back on their loved one's experiences and identify this phase. But at the time, it is often hard to see the difference between the normal struggles of being a teenager or young adult and the early warning signs that happen before psychosis.

Phase two is called the acute phase. The person has clear psychotic symptoms such as hallucinations, delusions, and confused thinking in this stage.

***“I was very stressed out, on ‘pins and needles.’ I knew something was off, but I didn’t want to burden my parents.”***

*Family members may notice symptoms such as those listed above as well as:*

- ▶ Depressed mood or anxiety
- ▶ Reduced emotional expression
- ▶ Problems handling everyday stress
- ▶ Increased sensitivity to sights and sounds
- ▶ Mistaking noises for voices
- ▶ Unusual or overly intense new ideas or beliefs
- ▶ Strange new emotions or seeming to have no emotions at all
- ▶ Speech that does not make sense
- ▶ Not recognizing the symptoms they are experiencing. This is called “lack of insight.”

This is usually when others notice the psychosis. The individual may not seek treatment because they do not realize there is a problem. Loved ones should help the young person get the treatment they need as soon as possible so they can recover sooner.

***“It felt like my mind was just exploding. I was out of control. I didn’t know what to do.”***

***“Recovery is a constant struggle, the degree of which cannot be overemphasized.”***

Phase three is called the recovery or residual phase. Recovery takes time and doesn’t happen all at once. While symptoms are treatable, recovery does not always mean the illness is gone or that the symptoms all go away. Some symptoms often remain; the person learns to deal with them and moves on with their life.

## **Common Myths**

Psychosis does not make a person dangerous. People experiencing psychosis may be confused, frightened, and vulnerable. While some people having psychosis may have mood swings and become agitated, most try to stay away from other people. They are much more likely to harm themselves than another person. That is why it is important get treatment right away to keep them safe. Don’t hesitate to call your county mental health crisis line. If you need to call 911, ask for a crisis intervention trained (CIT) officer. You can also take the person to the emergency room if you feel they are in immediate danger.

Most people recover from psychosis and go on to leave happy, productive lives. Up to 25% of people who have experienced a first episode of psychosis recover completely and never experience psychosis again. Half do well with medication and treatment, and the other 25% need ongoing care. New treatments are being researched. ■

## **MENTAL ILLNESSES WITH PSYCHOSIS AS A SYMPTOM**

Psychosis is a major symptom of some mental illnesses. These are called psychotic disorders. Psychosis can also be a symptom of other mental illnesses, but it is not a major part of them. Many people with these illnesses will not experience it at all.

## **Diagnosing Mental Illnesses**

There are no quick tests for diagnosing mental illnesses. It often can take time to get a diagnosis. Professionals first test to see if a medical condition has caused the psychosis. They will do blood and urine tests. They will ask about the person’s medical history and family history of illnesses. They may also do an MRI (a test that takes pictures of organs

such as the brain) and other assessments. This will help them determine if drug use or a medical condition has caused the psychosis.

Psychological assessments are being developed. But no diagnosis should be made using only psychological testing. Once physical causes have been ruled out, diagnosis is made based on the symptoms the young person is having. Mental health professionals get this information by talking with the young person and their loved ones, and by observing the person. They use the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-V)* to diagnose mental illnesses.

## Psychosis NOS

A person who has a first episode of psychosis often will be diagnosed with **psychosis “not otherwise specified” (psychosis NOS)**. This allows the treatment team to take more time to try to find the right diagnosis. Sometimes a diagnosis is given, but it changes as the treatment team gets more information.

## Psychotic Disorders

**BRIEF PSYCHOTIC DISORDER** occurs most often after a very stressful event, such as the death of a loved one. People with this disorder have short, sudden episodes of psychosis. Recovery is usually quite fast, within about a month.

**SCHIZOPHRENIFORM DISORDER** has the symptoms of schizophrenia, but they do not last at least six months. If the symptoms last six months or longer, then the person is diagnosed with schizophrenia.

**SCHIZOPHRENIA** is the most common diagnosis when psychosis has occurred. Schizophrenia has three categories of symptoms: positive, negative and cognitive.

It may seem odd to call some symptoms of schizophrenia “positive.” Positive means that these symptoms are adding something that most people do not experience. Positive symptoms include psychosis (hallucinations or delusions) and thought disorders.

*Thought disorders include:*

- ▶ Disorganized thinking. The person is not able to organize their thoughts and may not make sense when they speak. They may make connections with words that don’t make sense to anyone else. For example, they may believe words that rhyme make sense when spoken in a sentence.

- ▶ Thought blocking. The person may be talking and suddenly stop speaking. If they are asked why, they may say they feel as if the thought was just pulled out of their head.
- ▶ The person may make up meaningless words, called “neologisms.”

*Delusions are positive symptoms. The different types of delusions include:*

- ▶ **OF REFERENCE:** believing other people are talking about you
- ▶ **PERSECUTORY:** believing other people are conspiring against you
- ▶ **GRANDIOSE:** believing you are an important person, such as the president, or that you have special powers
- ▶ **SOMATIC:** believing your body is grossly distorted
- ▶ **MIND CONTROL:** believing your mind is being controlled by a force outside of you
- ▶ **THOUGHT BROADCASTING:** believing that others can hear or read your thoughts
- ▶ **RELIGIOUS:** suddenly becoming hyper-focused on religious ideas, such as the idea that God has chosen you for a special mission

“Negative” symptoms mean that something has been taken away that most people have. Negative symptoms can include loss of the ability to feel pleasure, inability to concentrate, inability to start and maintain planned activities, speaking very little and “flat affect.” With flat affect, a person’s face shows very little emotion. When they speak, they may speak only in one tone. There are no medications to help with negative symptoms, but research is continuing.

Cognitive symptoms can be hard to recognize. They interfere with a person’s ability to pay attention, use information when it is received (working memory), and understand information and use it to make decisions (executive functioning). When hallucinations and delusions go away, the negative and cognitive symptoms of the illness often remain, making recovery hard.

These symptoms must be present for more than six months for a diagnosis of schizophrenia.

**SCHIZOAFFECTIVE DISORDER** combines the symptoms of schizophrenia with symptoms of a mood disorder, such as depression or bipolar disorder.

**DELUSIONAL DISORDER** is a mental illness that causes a person to have a delusion that lasts for a month or more. The person may believe they are being followed, are married to someone when they are not or have a disease. People with delusional disorder are often able to function well, having difficulty only with the area of their delusion. Delusional disorder does not usually respond well to medication.

**PARAPHRENIA** is a form of schizophrenia that develops very late in life.

**POSTPARTUM PSYCHOSIS** occurs after giving birth. It can come on suddenly, often in the first two weeks after childbirth. The symptoms are those of psychosis, but the mother may also have thoughts about the baby being special and unique (for example, being an angel) and in need of protection from everyone else, including the other parent and family members. **It is critical that the mother be treated immediately to keep her and her baby safe.** Postpartum psychosis can occur by itself or as part of postpartum depression with psychotic features.

## Mood Disorders

**BIPOLAR DISORDER** is also known as manic-depressive illness. It is a mood disorder that sometimes includes psychosis as a symptom. But not everyone with bipolar disorder will have psychosis. Key symptoms of bipolar disorder include periods of depression and periods of mania.

*A person experiencing depression may feel:*

- ▶ A sense of hopelessness
- ▶ Sadness
- ▶ Lack of energy
- ▶ Loss of enjoyment in activities the person once enjoyed
- ▶ Difficulty concentrating
- ▶ Restlessness
- ▶ Irritability
- ▶ Changes in appetite
- ▶ Thoughts of death or suicide

A person experiencing mania may feel a long period of feeling “high” or overly happy, or they may be very irritable. They may require little or no sleep and still have high energy.

People with bipolar disorder may have mania and depression at the same time. This is called a mixed state. A clear manic phase should occur for bipolar disorder to be diagnosed.

**DEPRESSION** (described above) is a mood disorder. A person with depression may also experience psychosis.

**POSTPARTUM DEPRESSION WITH PSYCHOTIC FEATURES** occurs after childbirth. It includes the symptoms of depression along with the symptoms of postpartum psychosis.

## Other Mental Illnesses with Psychosis

People who have borderline personality disorder, post-traumatic stress disorder and anxiety disorders can have psychosis along with other symptoms of their illnesses.

**BORDERLINE PERSONALITY DISORDER** symptoms include having a hard time regulating emotions and thoughts, impulsive and careless behavior, and having a hard time maintaining relationships. People with borderline personality disorder may also experience psychosis.

**POST-TRAUMATIC STRESS DISORDER** (PTSD) occurs after a person has experienced a terrifying event.

*Symptoms of PTSD may include:*

- ▶ Re-experiencing the event through intrusive memories or nightmares about the event
- ▶ Avoiding locations or situations that remind the person of the event
- ▶ Being easily started or irritable, or having a hard time sleeping (being “hyper-aroused”)
- ▶ Feeling like they are losing touch with their surroundings for a time (“dissociation”). This can make the person seem as if they are not feeling emotions or are detached from others.
- ▶ Psychosis

Anxiety disorders include generalized anxiety disorder, panic disorder, obsessive compulsive disorder and social phobia. People may experience psychosis as a symptom of their anxiety disorder. ■

## RECOVERY

There are eight dimensions of wellness, according to the Substance Abuse and Mental Health Services Administration (SAMHSA).

*These include:*

- ▶ **EMOTIONAL:** Coping effectively with life and creating satisfying relationships
- ▶ **ENVIRONMENTAL:** Occupying pleasant, stimulating environments that support well-being
- ▶ **FINANCIAL:** Satisfaction with current and future financial situations
- ▶ **INTELLECTUAL:** Using creative abilities and finding ways to continue to learn
- ▶ **OCCUPATIONAL:** Personal satisfaction from one’s work or education
- ▶ **PHYSICAL:** Understanding and meeting the need for physical activity, healthy foods and sleep

- ▶ **SOCIAL:** Feeling connected to other people and having a support network of friends and family
- ▶ **SPIRITUAL:** Expanding one's sense of purpose and meaning in life

When wellness is achieved in each of these areas, recovery has occurred. If any of these elements is ignored, it can be hard for a young person to recover. Recovery is more than the symptoms going away. People with mental illnesses can learn to manage their symptoms and lead productive, satisfying lives in recovery.

The time it takes to recover from psychosis differs for each person. Some people recover quickly with very little treatment.

Others may need support for a long time. Recovery from the first episode usually takes several months. It may be longer if symptoms remain or return. For some people, it may take months or even years before the psychosis is effectively managed. Most people recover from psychosis, lead satisfying and productive lives, and never have another psychotic episode.

***“It felt like my mind was just exploding. I was out of control. I didn’t know what to do.”***

***“Acceptance of self is key to recovery. This above all, to thy own self be true.”***

People in recovery may feel impatient, depressed, alone and anxious about social situations. They may have lower self-esteem, may not have insight into their illness and

may not want to work with the treatment team. Friends and family can help by trying to build the person's self-confidence and being there to listen. They can also help find activities to keep the young person busy and engaged with the community until they ready to return to school or a job. NAMI Minnesota's booklets *Hope for Recovery: Minnesota's Adult Mental Health Resource Guide* and *Transitions: Supporting Your Young Adult with a Mental Illness* offer community resources that can help with recovery. ■

## ENGAGING YOUNG PEOPLE IN TREATMENT

Engaging young people in treatment is critical to their recovery. If they are not engaged, they are much less likely to make needed changes and much more likely to drop out of treatment. Dropping out of treatment can lead to relapse. Each relapse affects a young person's cognitive abilities. It is important to prevent relapse. Engaging a young person in treatment begins with finding the right mental health providers.

### Finding a Mental Health Provider

Getting help as soon as possible for a person having psychosis is important. It is also important to make sure the professionals working with the person understand psychosis and are a good fit for the person. The right treatment depends on getting an accurate assessment, and that requires the right provider.

*Here are some things to consider:*

- ▶ Is the provider an expert in providing care for people who have psychosis? Some hospitals provide early intervention programs for specific psychoses. There are several of these treatment centers throughout the United States. The University of Minnesota Medical Center has the only treatment center in Minnesota for early or first-episode psychosis.
- ▶ Is the provider aware of the specific needs of young adults?
- ▶ Does the provider understand and respect the need for the young person's family to be involved in treatment?
- ▶ Does the provider use motivational interviewing and shared decision making (see below)? Does the provider encourage the young person to ask questions?
- ▶ Does the provider understand and respect the young adult's race, sexual orientation, religion or other beliefs? If you feel the provider's views will get in the way of making a proper mental health diagnosis, a different provider may be needed.

### **Motivational Interviewing**

Motivational interviewing is a respectful, person-centered approach to helping a person make a change in their life. People who have psychosis with the "lack of insight" symptom often do not want to get treatment. The proper use of motivational interviewing can help in avoiding resistance to treatment.

Motivational interviewing helps the young person identify their goals and the challenges that keep them from meeting their goals. The young person does not have to accept a diagnosis of mental illness to move ahead in treatment. Treatment seeks to help the young person meet the



goals they identify. The young person determines their own reasons and timing for making a change such as seeking treatment. For example, the young person may not realize they are experiencing psychosis but may recognize that anxiety or other issues are keeping them from doing well in school. They may be willing to seek help for these reasons. Mental health providers who are familiar and comfortable with motivational interviewing will often be the most successful at getting a young person to engage in and continue with treatment.

### **Shared Decision Making**

The young person, their loved ones and the treatment team may not always agree on what type of treatment or medication is best. Shared decision making can help in reaching agreement. In shared decision making, the treatment team gives information about treatment options to the young person and their loved ones. Together, they discuss the advantages and disadvantages of each option and reach a treatment decision. When shared decision making is used, a person having psychosis is more likely to follow the treatment plan.

Ultimately, it is up to the young adult whether they will take a medication or follow a specific treatment plan. Insisting that a young person take a medication or follow a specific plan may cause the young person to resist even more. Loved ones can find help in communicating with the young person in such books as *I Am Not Sick, I Don't Need Help! How to Help Someone with Mental Illness Accept Treatment and I'm Right, You're Wrong, Now What? Break the Impasse and Get What You Need*. These books were written by Xavier Amador, a doctor whose brother lived with schizophrenia. They discuss the LEAP method of communication: Listen, Empathize, Agree and Partner. ■

## **MENTAL HEALTH TREATMENT FOR PSYCHOSIS**

Psychosis caused by a medical condition is treated by treating the medical condition. Other psychosis is treated for the underlying mental illness that caused the psychosis. Intensive treatment must be started early. Delaying treatment can lead to long-term disability, problems in school, job loss, damage to relationships, involvement with police, jail or prison time, or even suicide. Treatment must be started as soon as a problem is noticed.

The best treatment includes more than medication and therapy. It includes education for the young person and their loved ones, cognitive remediation and social skills training. It may also include vocational and educational rehabilitation. Loved ones may need to advocate for

the young person with the treatment provider and the health insurance plan. They may need to insist that all necessary services are provided as part of the treatment plan.

Treatment may start with hospitalization, or it may be outpatient. Hospitalization can keep a person in danger of harming themselves or someone else safe until the crisis has passed. Intensive treatment for the psychosis can begin in the hospital.

*To be hospitalized, a person must be experiencing a combination of the following:*

- ▶ Suicidal or homicidal behavior, with a plan and a means to carry it out
- ▶ Chaotic communication, threatening behaviors, minimal impulse control, withdrawal from social interactions, neglect of personal hygiene and inability to care for themselves
- ▶ A medical condition that is not being controlled or substance abuse
- ▶ A highly stressful living environment, such as experiencing trauma or loss of housing
- ▶ No financial or emotional supports
- ▶ Limited or no success with previous treatments
- ▶ Little or no insight into the mental illness
- ▶ At risk of being harmed by others

Wherever treatment is obtained, the treating team should engage the family in making a treatment plan. Family and friends may need to ask a lot of questions and push the treatment team to include them. No one gets through a serious illness by themselves.

## **Recovery After an Initial Schizophrenia Episode (RA1SE)**

RA1SE is a research project of the National Institute of Mental Health. The purpose of the project is to show that intensive early intervention with coordinated specialty care (CSC) can improve outcomes.

Coordinated specialty care means a team of people working together to make sure the person has everything they need to recover. The team works with the young person and their loved ones to develop the best treatment plan. The treatment plan commonly includes antipsychotic medication, but that is only a small part of a good treatment plan. CSC also includes other services based on need.

*These can include:*

- ▶ Case management
- ▶ Psychotherapy
- ▶ Psychoeducation and support for family members
- ▶ Cognitive remediation
- ▶ Supported employment and/or education

As the RAISE project continues to collect data, new information will help providers continue to improve outcomes for young adults who experience psychosis. The RAISE sites in Minnesota were North Point Health and Wellness in Minneapolis and the Human Development Center in Duluth. While the RAISE project is no longer accepting new patients, the research and information gathered from the project should improve treatment outcomes in the future.

## Therapy

Cognitive behavioral therapy (CBT) can be very helpful with schizophrenia. It can also be used for depression, bipolar disorder, borderline personality disorder, post-traumatic stress disorder and anxiety disorders. CBT focuses on how thoughts, behavior and feelings are connected. It helps a person understand their thoughts and learn to change negative ones to more positive thoughts. For example, a person who believes “I am worthless” will be taught to challenge that belief and tell themselves, “I am valuable.” CBT can help a person with psychosis understand which of their thoughts and feelings are not real. CBT often involves homework where the client practices the skills learned in therapy outside the therapist’s office with friends and loved ones.

Supportive therapy is another effective psychosis treatment. This treatment helps people understand their situation, how they might respond to the situation and how they feel. It also seeks to improve a person’s self-esteem and instill hope. It can be combined with CBT and other techniques.

## Psychoeducation

Psychoeducation teaches a person who has had psychosis and their loved ones about the illness. They learn what caused the psychosis, information about their diagnosis, communication techniques, and problem-solving and coping skills. Several weeks of classes are common. The person who had psychosis often takes a class with others who have had the same experience. Loved ones are often educated separately in groups with other families. This helps both the young person and their loved ones get help from their peers and understand what kind of support is helpful. When psychoeducation is part of a treatment plan, people with psychotic disorders are less likely to have their symptoms come back or grow worse. It helps them to move on with their lives more quickly.

NAMI Minnesota provides free psychoeducation classes for family members, including *Family to Family*, *Hope for Recovery* and *Understanding*

*Early Episode Psychosis.* Dates and times for these classes can be found on the NAMI Minnesota website at [www.namihelps.org/classes](http://www.namihelps.org/classes).

## Cognitive Remediation

Cognitive remediation is training designed to address attention and thinking problems experienced with schizophrenia and other psychotic disorders. Cognitive remediation helps the brain relearn to concentrate and use information. It is most often offered as a computer game. The most helpful programs get harder as the player gets better at the game. If cognitive remediation is not offered as part of treatment, programs can be bought online.

## Social Skills Training

People who have experienced psychosis often lose some ability to relate to others as a result of their symptoms. Being able to communicate with others in many settings helps the young person maintain relationships and return to work or school. Social skills training usually takes place in groups where a young person can safely receive feedback with assignments to practice at home with friends and family.

## Other Promising Approaches

Research continues on the best treatments for mental illnesses with psychosis.

*Some promising approaches, which may be available in some areas, are:*

- ▶ **COGNITIVE ADAPTIVE THERAPY:** A mental health practitioner visits the young person each week to help them adapt their living space to make it easier to remember to take medications, groom properly, make appointments, make meals and care for themselves.
- ▶ **HEALTHY LIFESTYLE INTERVENTION:** The treatment team pays more attention to the young person's diet and helps them follow a healthy diet and exercise program.
- ▶ **SOCIAL REHABILITATION (CLUBHOUSE MODEL):** Clubhouses are places where people with mental illnesses can go to socialize with other people and find meaningful activity and support. Clubhouse members take part in activities and work on a voluntary basis.
- ▶ **SUPPORTED EDUCATION:** Providing extra support for people who have had psychosis appears to improve educational and employment outcomes. At this time, supported education is not often offered as part of treatment. However, as research into how educational support can help with recovery, this should become more common. ■

## MEDICATIONS

### Antipsychotics

Antipsychotic medications can reduce hallucinations and delusions. They can also improve thinking and behavior. Some people with psychosis may also be given mood stabilizers or antidepressants. Medications are generally safe to use, but all medications have risks and benefits.

It is important to ask the doctor about the risks and benefits of each medication. Family and friends may need to ask these questions when the young person is having hallucinations or delusions. As the young person starts to recover, they may be more able to ask questions and speak up for themselves. Family and friends should then support the young person as they learn to advocate for themselves. Because loved ones are often caregivers, their opinions still matter. As the young person recovers, the opinions of caregivers should be balanced with the young person's need to regain some control of their treatment. This is an important time to use shared decision making.

*There are many things to think about when deciding which medication to try. These include:*

- ▶ Is the medication covered by your health insurance? If not, it may be very expensive. If other medications have not worked or have intolerable side effects, talk with your insurance company. Most insurers have an exception process that may allow the young person to get the drug covered by their plan.
- ▶ Will daily medication be easy to keep up with, or is a monthly injection a better option? Injectable antipsychotic medication can help prevent relapse if a young person does not want to take pills or think about their illness each day as they take them. Injectable antipsychotics also offer a more stable dose in the bloodstream over time.
- ▶ What are the side effects of the medication? Which side effects will be tolerable?
- ▶ Is it reasonable to expect the young person to be able to take the medication as scheduled? For example, taking pills several times a day may work in the hospital but be hard to keep up with at home or in the community. Shift work or working nights can also interfere with a drug schedule.

There are two main groups of antipsychotics. “First generation” or “typical antipsychotics” are older drugs. “Second generation” or “atypical antipsychotics” are newer drugs. The main difference between the two groups is their possible side effects. They may come as tablets, syrup or

an injection. (The injection is called a “depot,” pronounced *deh-poh*). Injections are useful for someone who may not remember to take their medications or does not want to take medication at all. Injections can be given one or two times a month.

Antipsychotics can cause various side effects. These side effects differ from person to person. The goal is to find the right medication and dose to give the best symptom relief with the fewest side effects. This is done by starting with the lowest possible dose and then slowly increasing the dose, if needed. Sometimes this can take a long time. This can be frustrating for everyone. The process may involve trying a medication, then changing the dose or the drug altogether.

Antipsychotics usually start to work after a few weeks. It may be many weeks before the young person feels the full effect of the medication. Much of the improvement will occur in the first six months of treatment. The doctor should monitor the medication closely as it takes effect.

Antipsychotics do not cure the illness causing psychosis. They help control some symptoms as long as the person takes the medication. If a person stops taking the drug, the symptoms may return or even become worse. For some, the symptoms return immediately. For others, it can take days or weeks for a relapse to occur. Still others may never have another episode of psychosis and are considered to be in remission but not cured. The key to preventing a relapse is to take medications as prescribed and work with the treatment team to manage symptoms that do not go away.

Antipsychotics are most helpful in giving relief from positive symptoms and acute episodes. They reduce suicidal behavior and aggression. They also help prevent relapse. They do not typically help with negative symptoms or cognitive symptoms. But professionals are continuing to research what can help with these symptoms.

Doctors usually prescribe newer antipsychotics first. The most commonly used atypical antipsychotics are olanzapine (Zyprexa), risperidone (Risperdal), quetiapine (Seroquel), aripiprazole (Abilify) and clozapine (Clozaril). Doctors don't prescribe clozapine unless other antipsychotics haven't worked. Its use is closely watched with regular blood tests because it tends to lower white blood cell counts, which can be dangerous. If clozapine doesn't work, doctors may try other medications, a combination of medications or other techniques, including electroconvulsive therapy.

*Side effects of atypical antipsychotics can include:*

- ▶ Sleepiness and slowness (sedation)
- ▶ Severe weight gain (obesity)
- ▶ An increased risk of diabetes
- ▶ Constipation
- ▶ Dry mouth
- ▶ Blurred vision

Older, typical antipsychotic drugs include haloperidol (Haldol), chlorpromazine (Largactil) and fluphenazine (Modectate). These drugs often have side effects associated with movement, called “extrapyramidal symptoms.”

*These symptoms include:*

- ▶ Stiffness and shakiness of muscles
- ▶ Uncomfortable restlessness
- ▶ Long-lasting unusual movements, usually of jaw, lips and tongue. This can be a serious side effect called “tardive dyskinesia.”
- ▶ Sexual problems

Atypical antipsychotics are less likely to cause movement side effects. When tardive dyskinesia (see above) occurs, the drug may be replaced with another. If switching drugs does not help, there are medications that can help with side effects. Some antipsychotic medications have other rare but serious side effects.

Each time a new drug is prescribed, ask the doctor what side effects to watch for and what to do if they occur. Most side effects are not serious. Many people tolerate the medication with only minor side effects.

*Serious side effects are not common but require immediate medical attention. These include:*

- ▶ Skin rash or itching
- ▶ Unusual headaches
- ▶ Persistent dizziness or fainting
- ▶ Vomiting
- ▶ Loss of appetite
- ▶ Feeling very sleepy and losing energy (lethargy)
- ▶ Weakness
- ▶ Fever or flulike symptoms
- ▶ Soreness of the mouth, gums or throat
- ▶ Yellow tinge in the eyes or to the skin
- ▶ Dark-colored urine
- ▶ Inability to pass urine (for more than 24 hours)

- ▶ Inability to have a bowel movement (for more than two to three days)
- ▶ Fever (high temperature) with muscle stiffness. This may indicate a life-threatening condition called “neuroleptic malignant syndrome.”

Contact the doctor who prescribed the drug right away if any of these side effects occurs or if the drug does not help with the symptoms. No one should ever stop taking antipsychotics without talking with the doctor. Some drugs need to be stopped gradually to keep symptoms from coming back or getting worse. The views and concerns of the young person and their loved ones about medication, side effects and treatment should always be discussed and taken into account by the doctor. It is important to tell the doctor about any other drugs being taken because antipsychotics may interact with them.

## **Mood Stabilizers**

Mood stabilizers are used to control mood swings in bipolar disorder and to treat depression in schizophrenia and other psychotic disorders. Lithium is considered by many as the best drug for manic episodes. Too much lithium is toxic, so doctors need to check the amount of lithium in a person’s blood regularly to make sure the dose is correct.

Other mood stabilizers treat seizures. These anticonvulsant drugs include valproic acid (Depakote), lamotrigine (Lamictal), gabapentin (Neurontin), topiramate (Topamax) and oxcarbazepine (Trileptal). Atypical antipsychotics can also be used to treat mania in bipolar disorder.

*Side effects of mood stabilizers include:*

- ▶ Weight gain
- ▶ Restlessness
- ▶ Dry mouth
- ▶ Indigestion
- ▶ Acne
- ▶ Joint or muscle pain
- ▶ Drowsiness
- ▶ Dizziness
- ▶ Headache
- ▶ Diarrhea
- ▶ Heartburn
- ▶ Stuffed or runny nose
- ▶ Mood swings

Some mood stabilizers have rare but serious side effects. Always ask the doctor about potential side effects, and tell the doctor if they occur.



## Antidepressants

Antidepressants can be used for depression related to bipolar disorder, schizophrenia, depression and other mental illnesses. People with bipolar disorder who take antidepressants should be monitored carefully to make sure the drugs do not trigger mania.

There are several different types of antidepressants. Doctors prescribe antidepressants based on the symptoms and whether a particular drug has worked with a close relative who had the same problems.

### **Selective serotonin reuptake inhibitors (SSRIs)**

SSRIs are often the first type of antidepressant doctors will prescribe.

*Common SSRIs include:*

- ▶ Citalopram (Celexa)
- ▶ Escitalopram (Lexapro)
- ▶ Fluoxetine (Prozac, Prozac Weekly, Sarafem)
- ▶ Fluvoxamine (Luvox, Luvox CR)
- ▶ Paroxetine (Paxil, Paxil CR, Pexeva)
- ▶ Sertraline (Zoloft)

These medications can cause sexual side effects, including the inability to achieve orgasm in women and delayed ejaculation in men.

### **Serotonin and norepinephrine reuptake inhibitors (SNRIs)**

SNRIs may work if SSRIs are not effective. Common SNRIs include venlafaxine (Effexor XR) and desvenlafaxine (Pristiq). Both of these drugs can cause elevated blood pressure and sexual side effects. Overdose can be dangerous or fatal. Duloxetine (Cymbalta) side effects include nausea, dry mouth and constipation.

### **Atypical antidepressants**

Atypical antidepressants don't fit neatly into other categories. These medications usually have fewer sexual side effects.

*Atypical antidepressants include:*

- ▶ Bupropion (Wellbutrin, Wellbutrin SR, Wellbutrin XL). This drug may cause reduced appetite. It should be avoided by people with seizure disorders, anorexia or bulimia.
- ▶ Trazadone (Olepto). It can have a sedative effect.
- ▶ Mirtazapine (Remeron, Remeron SolTab). This drug can be sedating and increase cholesterol.
- ▶ Nefazodone. This drug is often linked to dangerous liver problems.

## **Monoamine oxidase inhibitors (MAOIs)**

MAOIs have numerous side effects, so they are not used unless other medications haven't worked.

MAOIs include:

- ▶ Isocarboxazid (Marplan)
- ▶ Phenelzine (Nardil)
- ▶ Tranylcypromine (Parnate)
- ▶ Selegiline (Emsam, Eldepryl, Zelapar). Emsam is available as a patch and has fewer side effects in this form.

Side effects of MAOIs include dizziness, dry mouth, upset stomach, difficult urination, twitching muscles, sexual side effects, drowsiness and sleep problems. MAOIs can cause extremely high blood pressure when combined with certain foods, beverages or other medications. They require a special diet to lower the risk of severe reaction.

## **Medication Resistance**

*Young people may resist taking medication for a variety of reasons:*

- ▶ Feeling so well after taking medication that they think they no longer need it
- ▶ Stigma (feeling ashamed of having a mental illness)
- ▶ Cost of the medication and not having insurance that will cover the cost
- ▶ Fear of loss of control
- ▶ Resentment for having to take medication
- ▶ Unpleasant side effects
- ▶ Cognitive symptoms caused by the illness, including problems with memory, concentration and focus
- ▶ Having the delusion that medication is in some way harmful (for example, poisonous) as a symptom of the psychosis

Another common reason a person may not want to take medication is called *anosognosia*. *Anosognosia* means "without insight." Anosognosia is a symptom of some mental illnesses that occurs when the person cannot believe that they have an illness and do not recognize their symptoms. This can happen to up to 85% of people who have had full psy-

chosis. This is because psychosis damages the part of the brain that is used to understand what has happened. This is not the same as denial of an illness. This is a very troubling symptom for friends and family members because it can cause their loved one to resist treatment. This is a troubling symptom, but insight is not needed to recover.

It is important not to make this into a battle. If the young person refuses medication, find some common ground to agree on. For example, instead of taking the drug to prevent psychosis, the young person may take it to stop the voices, reduce anxiety, help with sleep disturbances or for other reasons that can be agreed upon.

If the young person still will not take medication, keep the lines of communication open. Remind them of the benefits of taking the drug and the risks of not taking it. Encourage them to talk about this with their psychiatrist. Find information about the drug on doctor-approved websites. Talk about any new concerns with the treatment team. It may be hard for young people who have had first-episode psychosis to accept that they have an illness and need to take medication every day. Consider discussing options such as injectable medications with the young person and their doctor.

In the end, it is up to the young adult whether they will take medication or follow a particular treatment plan. Loved ones who insist that a young person take medication or follow a specific plan may cause the person to resist even more. Friends and family members may find it helpful to read books about communication such as Xavier Amador's *I Am Not Sick, I Don't Need Help!*

Having loved ones who understand the challenges and importance of taking medication is very important. Parents, caregivers and friends can encourage the consistent use of medications without nagging. For example, they can suggest that the person use a pill organizer, put medications by their toothbrush or set an alarm on a phone. Friends and family can also help by helping the young person understand what the medication does and asking them about side effects. The young person should be encouraged to talk with their doctor about side effects that are difficult to live with. ■

## PSYCHOSOCIAL INTERVENTIONS

There are also nonmedical tools to help with recovery and independence. You may hear these referred to by professionals as “psychosocial interventions.” These nonmedical tools focus on the Substance Abuse and Mental Health Services Administration’s eight elements of wellness: emotional, environmental, financial, intellectual, occupational, physical, social, and spiritual. Friends and family can help the young person recover in each of these dimensions. Wellness involves developing and using a set of life skills that promote well-being.

*These skills are known to help prevent mental illnesses. They include:*

- ▶ Making goals in each of the eight dimensions of wellness. Start with small, short term-goals and work toward larger, longer-term goals.
- ▶ Understanding yourself and allowing yourself to make mistakes without feeling guilty
- ▶ Learning new coping skills
- ▶ Understanding how exercise can improve mental health and reduce stress
- ▶ Working with the treatment team to make a plan to develop resilience. The plan may include steps to help maintain close relationships, keep a positive view of yourself and work toward goals.
- ▶ Effectively using social supports
- ▶ Maintaining a healthy diet and regular sleep patterns
- ▶ Using yoga, meditation and mindfulness techniques
- ▶ Being open to and using mental health counseling and advice
- ▶ Avoiding alcohol and other drugs
- ▶ Volunteering, which provides a supportive environment and a sense of purpose
- ▶ Attending community support programs (CSPs) and clubhouses, which are drop-in centers for adults living with mental illnesses. The services these programs offer vary, but most offer independent living skills classes, social activities and peer support. For more information on CSPs and clubhouses, contact your county’s adult mental health department.
- ▶ Developing a wellness recovery action plan (WRAP). WRAP training teaches self-management skills and strategies to complement other treatment options. Free WRAP training is provided in Minnesota by the Mental Health Consumer/Survivor Network. These classes fill up quickly. The Mental Health Consumer/Survivor Network can be contacted at 651-637-2800 or [www.mhcsn.org](http://www.mhcsn.org). ■

## INTENSIVE SUPPORTS

Sometimes, the young person needs more intensive supports to recover from a first-episode psychosis. Detailed information about these resources can be found in NAMI Minnesota’s booklet *Hope for Recovery: Minnesota’s Adult Mental Health Resource Guide*. Some of these services are offered at no cost, while others require the person to be on Medical Assistance or MinnesotaCare to get them.

*Some of the most common supports are:*

- ▶ **ADULT CASE MANAGEMENT:** Case managers help adults with mental illnesses determine their needs and goals, and find and get the services they need to live independently. A young adult who was eligible for case management as a child may remain eligible until they reach age 21. Before the county can discontinue case management between the ages of 17 and 21, it must develop a transition plan that includes plans for health insurance, housing, education, employment and treatment.
- ▶ **ADULT REHABILITATIVE MENTAL HEALTH SERVICES** helps people living with mental illness develop social skills, psychiatric stability and independent living skills.
- ▶ **YOUTH ASSERTIVE COMMUNITY TREATMENT (ACT) TEAMS** help youth with severe mental illness and/or substance abuse disorders. The team provides care coordination and services such as case management, psychoeducation for the young person and their loved ones, medication management, crisis assistance, and integrated treatment for mental illnesses and substance abuse disorders. To qualify for Youth ACT Team help, the person must:
  - Be between ages 16 and 20;
  - Have a diagnosis of serious mental illness or co-occurring mental illness and a substance abuse addiction;
  - Have a level of care determination for “intensive integrated intervention without 24-hour monitoring” and a need for extensive collaboration among multiple partners;
  - Have a functional impairment and a history of difficulty functioning safely and successfully in the community, school, home or job or be likely to need services from the adult mental health system within the next two years; and
  - Have a recent diagnostic assessment that documents the medical necessity of the service.
- ▶ **ADULT ACT TEAMS** provide a very similar service to that provided by Youth ACT Teams. One difference is that a vocational specialist is included on the team. ■

## INSURANCE

Successfully treating psychosis is very expensive. It's important, even in the midst of crisis, to take the time to review insurance coverage to ensure it is adequate for mental health care. Young people can be covered by a parent's employer-sponsored health insurance up until age 26 when dependent coverage is offered. Insurance providers cannot deny coverage to anyone because of a pre-existing condition.

### MNSure

MNSure, Minnesota's health insurance exchange, is a way to buy private insurance or enroll in public health care programs, including Medical Assistance (MA) and MinnesotaCare. MNSure is available to Minnesota residents and noncitizens lawfully residing in the United States who do not have affordable health insurance through their employer. MNSure is not an insurance provider itself. It is a way to buy health insurance.

Insurance plans can be compared side-by-side on MNSure. Enrollment can be done online, by phone, or by mail. All plans offered through MNSure are required to cover mental health and substance use disorder treatment in the same way that other health conditions are covered.

Visit [www.mnsure.org](http://www.mnsure.org) for more information. NAMI Minnesota has MNsure navigators who can help with the enrollment process at no extra cost.

### Medical Assistance

Medical Assistance (MA) is Minnesota's Medicaid program for people with limited income and people with disabilities.

*MA covers a wide range of mental health services, including:*

- ▶ Case management
- ▶ Intensive rehabilitative mental health services
- ▶ Adult rehabilitative mental health services
- ▶ Crisis services
- ▶ Telemedicine
- ▶ Assertive community treatment
- ▶ Psychiatric consultations
- ▶ Medication therapy management
- ▶ Medical transportation
- ▶ Home care services

MA also covers basic health care needs, dental care, vision care and prescription medication. MA does not have a premium (monthly fee).

Instead, it has small co-pays for some services and medications, usually \$1 to \$3. There is a cap on the total amount of co-pays paid for medications. But there is no co-pay for antipsychotic medications.

Many mental health providers accept MA. Contact your county for a list of providers who accept MA. You can also get this information from the Minnesota Department of Human Services website ([www.mn.gov/dhs](http://www.mn.gov/dhs)). Visit [www.namihelps.org](http://www.namihelps.org) (click on “Support” and then “Mental Health Resources”) for a list of county and tribal human services offices, as well as for a list of providers that accept people on MA.

MA can cover medical expenses retroactively up to three months from the date of application. Young people who are still on their parent’s employer-sponsored plan may not qualify for MA. NAMI Minnesota’s MNsure navigators can help you determine whether MA is an option. ■

## CO-OCCURRING SUBSTANCE USE DISORDER

Many young people who experience psychosis also report substance use and abuse. The most common drugs used by people with psychosis are cigarettes, alcohol and marijuana. It is estimated that 75 to 90% of people with schizophrenia smoke cigarettes and that 50% of people living with mental illnesses also have a substance use disorder.

Many young people stop using these substances once the psychosis has been treated. But a large number do not. It is important that the treatment for psychosis include psychoeducation so that the young person learns that alcohol and drug use can worsen symptoms of psychosis or cause relapse. It can be frustrating for the treatment team, family and friends when the young person does not stop using these substances.

*Reasons the person continues to use or abuse substances include:*

- ▶ Lack of insight: The young person does not recognize that they have an illness.
- ▶ Belief that the substances will help with symptoms
- ▶ Desire to continue to fit in with their social group
- ▶ Addiction

A person diagnosed with both a mental illness and a substance use disorder has a “dual diagnosis.” When seeking treatment for addiction with a dual diagnosis, it is important to find a treatment center that understands how mental illness and substance abuse interact. There are three treatment options for dual diagnosis: sequential, parallel and integrated.

*Each option has pluses and minuses:*

- ▶ **SEQUENTIAL TREATMENT** means that first either the addiction or the mental illness will be treated, then the other one. This is most effective if one of the disorders is mild and the other more severe. It is less effective if both illnesses are severe.
- ▶ **PARALLEL TREATMENT** means that the mental illness and addiction are treated at the same time by different providers. This can be challenging, especially if the young person gets conflicting advice from the providers.
- ▶ **INTEGRATED TREATMENT** means that both conditions are treated at the same time by the same provider. The provider has a strong understanding of both mental illness and addiction and how they impact each other. This is the best option for a young person with severe mental illness and severe addiction.

Providers take varying approaches to drug and alcohol abuse. Some require strict “abstinence:” this means not using the substances ever again. Some will not accept patients for treatment unless they have already stopped using substances and agree to never use them again.

Others use a “harms reduction” model. In this model, an organization may provide free needles, for example, to prevent the spread of HIV/AIDS or may offer education on preventing overdoses. The harms reduction model acknowledges that drugs and alcohol are not good for people who have experienced psychosis. It just meets people where they are. Team members may talk with the young person about how drugs and alcohol make them feel and suggest gradually giving them up as a way to get better. They focus on keeping the young person safe in the meantime. Motivational interviewing is often used to encourage the young person to decide to stop using substances. ■

## **RELAPSE PREVENTION**

A relapse is a return or worsening of psychotic symptoms. Preventing a relapse is very important. Each time a young person relapses, recovery becomes harder and cognitive symptoms become stronger. The most common reason for a relapse is not taking prescribed medication. Other causes may include the use of alcohol and street drugs, stress and loss of support. Sometimes a relapse just happens because of the illness, and a cause cannot be identified. A relapse into psychosis rarely happens without warning. Sometimes the signs are apparent to the ill person only. They are often different for each person. Family members and loved ones who know their young person’s habits and the symptoms of psychosis may note signs of relapse.



*Common warning signs include:*

- ▶ Spending less time with other people
- ▶ Having a hard time concentrating
- ▶ Feeling depressed
- ▶ Having a hard time sleeping or having bad dreams
- ▶ Feeling anxious
- ▶ Feeling paranoid or like people are trying to harm them
- ▶ Feeling irritable
- ▶ Being more sensitive to light or sounds
- ▶ Experiencing an increase or return of psychotic symptoms
- ▶ Missing work or school

Notify the treatment team right away if warning signs appear. Early response can prevent relapse.

Young people can use a number of strategies to reduce the chances of the psychosis coming back.

*These strategies include:*

- ▶ Taking medications as prescribed
- ▶ Attending programs that assist with treatment and recovery
- ▶ Not using street drugs and alcohol
- ▶ Taking care of their physical health by eating properly, getting enough sleep and exercising
- ▶ Establishing a routine
- ▶ Reducing stress as much as possible
- ▶ Developing good communication and problem-solving skills to deal with stress that cannot be avoided
- ▶ Developing and maintaining good relationships
- ▶ Having stable housing
- ▶ Keeping a sense of hope
- ▶ Having a meaningful job, education or hobbies ■

***“Don’t take on too much too soon. Recovery is a slow process.”***

***“Being honest with myself and open with my friends and family has made me as well as I am now.”***

## MENTAL HEALTH CRISIS

A mental health crisis is a situation in which a person is at risk of hurting themselves or others and they cannot resolve the situation with the skills and resources at hand. Such situations require immediate medical attention. Seek help right away by calling your area crisis team or 911. If you call 911, be sure to request a crisis intervention trained (CIT) officer and say that this is a mental health crisis.

### Crisis Phone Lines

Each county in Minnesota has a 24-hour crisis phone line. These crisis lines are staffed by trained workers who help callers with mental health crises, make referrals and contact emergency services, if needed. If the call is made after normal business hours, the crisis line will connect the caller to a mental health professional within 30 minutes. They are available 24 hours a day, seven days a week, 365 days a year. Some counties have crisis teams that will meet the person face-to-face, if necessary. It's a good idea to have the phone number of your local crisis team programmed into your phone.

### Recognizing Crisis

Family and friends may be able to notice that a crisis is coming. Other times, crises arise with no warning at all.

*Warning signs that a crisis may be close include:*

- ▶ Changes in sleep and hygiene
- ▶ Mood swings
- ▶ Increased agitation
- ▶ Abusive behavior
- ▶ Psychosis
- ▶ Isolating behavior
- ▶ Increases in physical symptoms such as aches, pains and headaches

### Dealing with Crisis

*Try to remain calm. You should:*

- ▶ Give space by not crowding the person or getting too close.
- ▶ Create a quiet area by asking others to leave the room.
- ▶ Turn off devices such as the TV and radio to make the area quiet.
- ▶ Speak slowly and clearly, using simple sentences.
- ▶ Invite the person to sit down and talk about what is bothering them.
- ▶ Listen to what they say without judging, even if what they say doesn't make sense.
- ▶ Sit at the person's side if possible.

*You should not:*

- ▶ Shout, argue, criticize or insult the person
- ▶ Block the doorway or not allow the person free movement
- ▶ Make too much eye contact
- ▶ Appear overly emotional or judgmental

If you are unable to calm the situation, seek help from mental health professionals. Call your treatment team, the mental health crisis phone line or a mobile crisis team in your county.

**MOST IMPORTANT:** If you are concerned about suicide, ask if the person is thinking about it and if they have a plan. You will not “plant” the idea; even a half-baked plan indicates higher risk. If safety is a concern, **do not hesitate** to call 911 and let them know that you have a mental health emergency.

For more detailed information on mental health crises, see NAMI Minnesota’s booklet *Mental Health Crisis Planning: Learn to Recognize, Manage, Prevent and Plan for Your Loved One’s Mental Health Crisis*. ■

## PHYSICAL HEALTH CONCERNS

People with mental illnesses often have a shorter life expectancy than people without a mental illness. Causes of death are the same: cancer, heart disease, diabetes and pulmonary disease. These conditions often start earlier in people with mental illnesses because of medication side effects. Many drugs can cause extreme weight gain, for example. People with mental illnesses are also more likely to smoke and abuse substances. Symptoms of mental illness such as lack of motivation can make it difficult to plan healthy meals and get enough exercise. Poor diet and lack of exercise can also contribute to health problems. Avoiding smoking and substance abuse, getting plenty of rest and exercise, and eating a healthy diet are keys to good health and controlling symptoms.

It is very important that young people with mental illnesses see their primary care doctor regularly. Primary care doctors can help monitor weight and other health concerns. They can also help with quitting smoking, starting an exercise program and making healthy diet choices.

All health information needs to be shared among all the professionals working with the young person. The person’s needs and concerns also need to be respected by all professionals. It is important that the young person speaks up for themselves. They may also want to bring a friend or family member to appointments to help them take notes and ask questions. If the medical professional is not listening, it may be time to find a new provider. ■

## DATA PRIVACY AND DISCLOSURE

The federal Health Insurance Portability and Accountability Act (HIPAA) ensures the privacy of medical records for people over 18 years of age. The medical records of people under the age of 18 may be shared with parents or guardians.

Friends who witnessed a first episode of psychosis may ask questions when the person returns to work or school. If the young person decides to tell them about their experience, it is important to be as accurate as they can. There is a lot of misinformation about mental illnesses.

Educating friends may be the first step to stopping these myths and the stigma that comes with them.

Telling close friends and roommates may be helpful because these people can offer support and help to ensure the young person stays well.

***“I found out that my friend has a similar illness as I do and I didn’t even know. . . . If they are your friends, they will understand where you are coming from.”***

### Tips for the Young Person

It takes courage to let people know you have a mental illness, because you don’t know how they will respond.

*Here are some tips to make it easier:*

- ▶ Prepare yourself by thinking about how the person may react, both positively and negatively. That way you’ll be ready for whatever comes.
- ▶ Be careful about timing. Make sure you are in a quiet location and both have time to talk things through.
- ▶ Be prepared for a lot of questions, but know that the person may need time to think before they respond. They may be quiet at first and come back later with questions.
- ▶ Remember that the person’s initial reaction may not last forever. If they react negatively right away, give them time to think; they may realize that they made a mistake.
- ▶ Have information ready. Remember, a quarter of all adults experience a mental illness in a given year. You are not the only one. Mental illnesses are caused by a combination of genetics, life experience and brain chemistry. This is not your fault.
- ▶ Remember there are no guarantees. Some people just may not be supportive. But your courage might be contagious.
- ▶ As you talk about your condition, you are able to give and get care and support from others.

If you are having a hard time talking about your mental illness with people you know, consider joining a peer support group. This will provide a safe environment to talk about what you are going through. You can learn about talking about your illness from the experiences of others. NAMI Minnesota provides free peer support groups for people with mental illnesses and their families, including groups specifically for young adults. Go to [www.namihelps.org/support](http://www.namihelps.org/support) or [www.namihelps.org/info-and-support](http://www.namihelps.org/info-and-support) for more information. ■

## RETURNING TO WORK AND SCHOOL

People who have had psychosis do not need to give up their dreams of work or education. It is very important to help them return to work or school as soon as possible with the supports they need to succeed. Supportive employment and education programs can help with this.

Resources and supports differ based on whether the person is under or over the age of 18 and whether they are in or out of high school. This is mainly because of differences in services in the children's mental health and adult mental health systems.

Young adults who have a first episode of psychosis need to understand their strengths, their illness and the limitations it causes, and their medication side effects. Knowing these and being able to describe them to others will help them determine the supports they need to succeed in school, work and their personal life. ■

## EMPLOYMENT

Having a job helps with recovery. Part-time work can be a great way to start if the young person isn't ready for full-time work yet. The counselor on the treatment team should meet with the young person to learn about their skills and interests, and explain that they can return to work. Supportive employment programs should be based on the interests and desires of the young person.

## Vocational Rehabilitation Services

Vocational rehabilitation counselors help people with disabilities get the training and support they need to succeed at work. Anyone with a disability that affects whether they can find and keep a job can apply for vocational rehabilitation services. Not everyone will get help, though. There are not enough funds for vocational rehabilitation services for everyone who qualifies, so an order of selection is used. This ensures that those with the greatest need are served first. Others are placed on a

waiting list for services. The order of selection is based on the number of “functional limitations” that affect a person’s ability to work. These limitations are mobility, communication, self-care, self-direction, work tolerance, work skills and interpersonal skills.

When a person is chosen to get vocational rehabilitation services, they meet with a counselor who assesses their career goals and determines what training and supports they need to find and keep a job. The counselor and the client create an Individual Plan of Employment (IPE). IPEs can include education, job training, help finding a job, support on the job and more. Clients who qualify financially may get help paying for education programs, tools or transportation. The client does not pay for vocational rehabilitation. To seek vocational rehabilitation services, contact your local Minnesota Workforce Center.

Experiencing symptoms should not disqualify a person from working. The counselor should help the young person develop the skills they need to succeed at work while experiencing symptoms. Once the young person has a job, the counselor should offer support at work for as long as the young person wants it. Support can be provided during work, during breaks or outside of work.

## **Employment Support Programs**

If a young person continues to struggle with finding and keeping a job, Extended Employment for People with Serious Mental Illness (EE-SMI) can help. EE-SMI offers individualized support to help people with serious mental illnesses find and keep jobs. Supports offered include job coaching, coordination of support services, job placement and money management. The program also encourages employers to hire people with mental illnesses and helps them make accommodations for employees with serious mental illnesses. The program is a collaboration between the Minnesota Departments of Human Services and Employment and Economic Development. EE-SMI can be accessed through a county mental health case manager or vocational rehabilitation provider.

Research shows that the individual placement and support (IPS) model works well to help people with mental illnesses find and keep jobs. The IPS supported employment model is provided by a team. The team is made up of the client, a rehabilitation counselor, a mental health case manager, mental health provider(s) and an employment specialist. The team may also include substance use specialists, nurses and psychiatrists.

The IPS model is available in limited areas in Minnesota, but coverage is expanding. Because IPS is proven to work, it is important to advocate with the state for additional funding for better coverage.

The young adult should be encouraged to ask their vocational rehabilitation counselor about other services they may be eligible for.

## **Legal Rights at Work**

The Americans with Disabilities Act (ADA) protects people with disabilities from discrimination and gives them equal access to employment.

*The ADA defines disability this way:*

An individual with a disability is a person who: (1) has a physical or mental impairment that substantially limits one or more major life activities; OR (2) has a record of such an impairment; OR (3) is regarded as having such an impairment.

People do not have to disclose they have a mental illness. Employers cannot legally ask about a disability (including mental illness) when hiring, and prospective employees do not need to say if they have one. If an employer learns about a mental illness, that illness cannot be a reason not to hire someone. Once a job offer has been made, employers may ask more questions about an employee's ability to perform their job duties, as long as they ask all employees the same questions.

Employers may not discriminate because of disability. However, employees must be able to do the job with reasonable accommodations. A reasonable accommodation is a change to a workplace or position that allows the employee the same access to the workplace that people without a disability have. If an employee needs and asks for a reasonable accommodation, the employer must give it. The employee may be required to get a letter from their doctor or treatment team member showing the limitations caused by the disability. The accommodation cannot pose a large burden on the employer. The employer does not need to lower performance standards or remove essential job functions.

*Examples of accommodations for an employee with a mental illness include:*

- ▶ For help maintaining stamina:
  - Flexible scheduling
  - Ability to job share
  - Backup employees for when extra breaks are needed
- ▶ For difficulty concentrating:
  - Less distractions in the work area
  - Big jobs divided into smaller tasks
  - Space enclosures or arrangements that enhance privacy

- Additional time to learn new responsibilities
- Use of an iPod or headset
- More frequent but shorter breaks
- Use of an electronic device such as a Motivaider that vibrate at timed intervals to help maintain focus
- ▶ For staying organized and meeting deadlines:
  - Calendar to track meeting dates and deadlines
  - Daily checklists
- ▶ For clear communication:
  - Written instructions
  - Clear, written expectations and what will happen if they are not met
  - Regular and frequent meetings for feedback
  - Gradual updates of changes that are coming
  - A clearly identified person the employee can go to with questions or concerns about the job
  - Allowing the presence of a job coach to help with training and reading social cues

The Job Accommodation Network provides a searchable database of job accommodations that may be helpful. This information can be found online at [www.askjan.org](http://www.askjan.org).

## Disclosure at Work

No one is ever required to discuss their mental illness with anyone. But talking about a mental illness to key people at work, such as human resource professionals, allows employees to get needed accommodations. Each person with a mental illness will decide for themselves whether to disclose a disability and ask for accommodations. There are pluses and minuses to consider. If a person chooses to disclose at work, they do not need to do this before they are hired. It pays to be cautious about disclosure.

Deciding whether to disclose is a very personal decision. Despite the laws, it can sometimes be hard to fully protect employees from the stigma of a mental illness. Not everyone understands mental illnesses. Stigma can hurt employees. People may wrongly assume that a person with a mental illness can't do the job, won't be reliable or could be dangerous.

Any conversation an employee has about their disability or accommodations is confidential. If they speak to someone in the human resources department, their direct supervisor and coworkers will not be told what the disability is. At a company that doesn't have a human resources department, the supervisor may know about the disability because the



employee may need to ask them for accommodations. The information is still confidential and cannot be shared with coworkers. Young people should always consider whether their coworkers need to know about their mental illness. Maintaining privacy is sometimes the best choice.

A supported employment counselor can support the young person in making this decision and help with these conversations. ■

## **EDUCATION**

Education also can be an important part of a person's recovery. If the person was in high school or college when the psychosis occurred, they need to know they can return to their education. Experiencing symptoms should not be a reason for not returning to school. It is important that the young person learn to be successful while living with symptoms.

The young person may need help selecting and applying for school. They also may need help talking with the school about accommodations, developing study skills and dealing with symptoms that may interfere with success.

### **High School**

If the young person is in high school, the school will need to be involved to give them educational services if they are hospitalized, in day treatment or unable to attend during the traditional school day. Loved ones should work with school officials to develop a plan for completing any work that was missed during the crisis. Students should have a chance to make up missed work if they want to. Time out of school for mental health reasons should be treated the same as for any other condition, such as cancer.

When the student returns to school, they will likely be taking antipsychotic medication. Side effects of antipsychotics that can affect a student at school include drowsiness or lack of energy, dizziness, dry mouth, blurred vision and constipation. Changes in the school day or other accommodations may be needed. An accommodation for someone with a side effect of drowsiness or lack of energy, for example, might be to have a study hall in the first period, when the fatigue is greatest, or arrange to start the school day later.

Before the student returns to school, meet with school officials to create a plan to ensure success. The school nurse may need to be in this meeting to arrange for medications that need to be taken at school, discuss

side effects and develop a crisis plan, should one be needed. Be prepared to advocate for the rights of the student returning to school.

People with disabilities have the same access to public education as any other student. This is ensured by the Americans with Disabilities Act. Under the law, schools must provide reasonable accommodations to anyone with a disability, including mental illness. Small accommodations such as scheduling a study hall first thing in the morning can be arranged by using a document called a 504 Plan, named after a section of the law.

If the student needs more help than a 504 Plan can give, an evaluation for special education services may be needed. The law that requires schools to provide special education for students with disabilities is the Individuals with Disabilities Education Act (IDEA). Start the process by requesting an evaluation. A request can be made with the teacher, school social worker or principal. It can be made verbally or in writing. It is best to make all requests related to special education in writing. Sign and date the request, and keep a copy for your records. An e-mail request is also acceptable. The school will have 30 school days to complete the evaluation.

After the evaluation is done, a meeting will be held to discuss the results. The school will notify you if it feels special education support is needed. As parent or guardian of the student, you should be invited to all meetings. You should feel free to offer suggestions, ask questions and approve or disapprove of any action of the special education team. You have the right to appeal the school's decision if you do not agree with it.

If special education is agreed to, a meeting will be held to decide what extra help and support the student will get. The plan that outlines the student's needs and the support they will get is called an Individual Education Program (IEP). Under IDEA, students can be educated until the age of 21.

Young people who want to go on to college or job training should talk with their high school guidance counselor about accommodations in college or trade school. They can also get accommodations for taking standardized tests such as the SAT and ACT. This is the time the young person should be learning about their educational rights.

## **College**

College or job training is an achievable goal for young adults with mental illnesses. The American with Disabilities Act requires colleges and trade schools to provide reasonable accommodations for students with

mental illnesses. Young people thinking of going to a college or trade school should visit the school's disability services office. If there is no formal office, they can ask the admissions counselor whom to contact.

The student might not think extra help will be needed. But it is important for them to know whom to contact if help is wanted or needed later. It is also important for them to become comfortable asking for accommodations.

Accommodations should help people with disabilities get an education while not posing a health or safety risk to other students. They should not make a big change to the degree plan or be a big burden to the school. Colleges may ask for a letter from the treatment team or work with the student to select accommodations. The student should meet with school disability services staff every time they register for classes to see if more accommodations are needed.

Bouts of depression, anxiety, difficulty with concentrating and other symptoms, as well as medication changes and side effects, can make college success a challenge. But it is possible. Getting a degree is not a race. A young adult may need to take one class at a time or take breaks from college to recover from a crisis.

***“If things got better after I was started on medication, that would have been awesome. Now I also have to deal with life.”***

### ***Living on Campus***

A student with mental illness who is moving away to college may need to find a treatment team near the school. They will need to decide if they will be close enough to home that they can come back for appointments with their current treatment team. They will need to find a team near the school if it is too far away. The student may come home for summer or need to take occasional breaks from school, so it is a good idea to have a treatment team near school and another near home. The teams should be encouraged to communicate with each other to keep care consistent.

#### ***Other things to consider:***

- ▶ Does the school have a mental health clinic? If so, is it a reasonable replacement for the student's current team? How much does it cost to use the clinic? Does it accept the student's insurance? Does the clinic have a psychiatrist or other professional who can prescribe medication?
- ▶ Is there a pharmacy nearby where meds can be refilled?
- ▶ If the school's mental health resources are not acceptable, are there off-campus professionals the student is comfortable using?

- ▶ Is there someone at or near the school the student can contact in the event of a mental health crisis?
- ▶ If the student will live on campus, how much education are resident advisors (RAs) given about mental illnesses? Are they trained to understand the day-to-day needs of students with mental illnesses? Do they know how to respond to a crisis? Is it necessary to disclose the student's illness to the resident advisor? If so, how much?
- ▶ If the student goes out of state to school, are mental health professionals there in their insurance network? Contact your health insurer to find out what coverage is available in the state being considered.
- ▶ Some colleges offer medical coverage for a fee. Does the college offer insurance, and does it cover mental health services?

### **Living off Campus**

If the student wants to live at home and most of the students live on campus, will they feel left out of campus life? Consider a community college. Community colleges have commuter students and can cost less in tuition. They also do not require students to take the PSAT, SAT or ACT exams. Taking tests for several hours can be a challenge for students who have concentration, anxiety or other issues.

An associate degree from a Minnesota community college can be transferred to a four-year school. Minnesota State Colleges and Universities (MnSCU) schools have a common liberal arts general education curriculum known as the Minnesota Transfer Curriculum (MnTC). A student who completes 40 credits in this curriculum can transfer their general education coursework to any MnSCU school. For more information, check out *A Guide to Transfer Information in Minnesota Higher Education* at [www.mntransfer.org](http://www.mntransfer.org) or speak with an admissions counselor.

### **Other Factors to Consider When Looking for a College**

*Factors to consider include:*

- ▶ Are there groups on campus or nearby such as NAMI on Campus, Active Minds or support groups?
- ▶ Does the school have an acceptable plan for dealing with a mental health emergency? Does it notify parents? Minnesota law allows the release of information in mental health emergencies. This might not be the case if the young person goes to college outside Minnesota.
- ▶ Is the student comfortable with the school's disability services staff? Do they feel they will be supported with accommodations if they need them?

- ▶ Does the school offer “tuition refund insurance”? This insurance refunds all or a part of the tuition if a student is unable to complete a college term due to illness or other covered emergency. Be sure to check any tuition refund insurance policy for mental health coverage. Some policies offer no or reduced coverage for a mental health crisis.

***“Peer support was very essential during my transition. You do not totally get it if you have not been through this.”***

### ***Educational Privacy***

The federal Family Educational Rights and Privacy Act (FERPA) allows only the student over the age of 18 to have access to their education records. For this reason, school employees cannot speak with parents about how the young adult is doing. If the student has signed a release, certain information may be given to parents. Minnesota law allows the release of information in the case of safety, medical or mental health emergencies. Most professors likely will not be comfortable talking with parents about a student’s progress.

Parents should ask the college about its policy on sharing mental health safety information. Some schools will share more information in the case of a mental health crisis or hospitalization with the proper release forms than they normally would. This can help families advocate for their student. A common request is to allow an “incomplete” grade for a class being taken when the symptoms began so that the student can finish the class without it harming their grade average. Becoming familiar with the college handbook, which contains tuition refund policies, exam times and other critical dates, can help parents understand when a student may need extra support.

Parent should share any information that they feel the school should have to keep the student safe. They should let the school know right away any concerns they have about their young adult’s health or safety. ■

## INDEPENDENCE

A first-episode psychosis is traumatic for the individual and the family. Families need to learn about the illness. They need to give emotional and practical support while treating the person as an adult. It helps to have reasonable expectations based on the person's stage of recovery.

The best way to speed up a young adult's recovery is to learn to accept the illness and encourage them to do the same. Support their involvement in psychoeducational and support groups. Attend family or friend support groups to learn as much as possible about the illness. Seek out supportive relatives and friends. It is important not to become isolated.

Tensions can arise when a young person who has left home needs to live with parents again after they have a first-episode psychosis. The young adult experiences a sense of loss of freedom and fear for their future. They may be worried about adjusting to a major change in their life plans. Parents are worried about their child, don't know how to parent them without treating them like a child and may be worried about causing stress by setting boundaries. Both the young person and their parents can benefit from peer support. Peer groups can provide a safe place to vent and obtain advice from others who are sharing the same journey.

Parents may be concerned about day-to-day issues such as sleep, diet and grooming. Sometimes a person with a mental illness can go through times when such things are not important to them or are hard to maintain. Parents can help by finding a way to set up a schedule for the young person or give reminders without nagging. But they should not allow battles to start over things that are not going to be important later.

Recovery can be very stressful. The young adult will need a lot of support to return to high school, college or work after a first episode. It helps to start preparing them for independence by encouraging them to take control of their medications, daily routine and well-being. At the same time, it is useful to show a willingness to support them for as long as they need. Most importantly, make sure the young person knows what to do in the event of a crisis by developing a crisis plan. A crisis planning worksheet is included in the back of this booklet.

People who have had a first-episode psychosis have suggestions for how to help someone who has psychosis. Not all of the suggestions will work for all people. Consider your young person's interests and how interested they are in getting help.

*Some suggestions for how to help someone who has psychosis:*

- ▶ Identify problems early.
- ▶ Listen patiently and compassionately, without making judgments.
- ▶ Make suggestions without being confrontational; remain gentle and calm.
- ▶ Keep them safe.
- ▶ Take them to an emergency room.
- ▶ Help them make appointments and provide rides and support at appointments.
- ▶ Provide a safe place to rest and recover.
- ▶ Spend time with them, regardless of the distance.
- ▶ Help them understand the illness and what is happening.
- ▶ Build trust by including them in decision making.
- ▶ Help them get the right medication and treatment.
- ▶ Cook for them and help with daily chores.
- ▶ Provide financial support.
- ▶ Help them return to normal as soon as possible by encouraging them to finish school or return to work as soon as they are able.

Every family will need to find the right balance between supportive and overly controlling. Some young adults will accept a great deal of parental support; others will want complete independence. Most will fall in between the two extremes. Parents and young adults need to talk about what sort of help is wanted. ■

***“You cannot do it alone. Period. Some form of support is vital.”***

## **FAMILY SUPPORT**

A recent survey found that 68% of caregivers of people with schizophrenia are parents; 12% are siblings; and 7% are spouses or partners. Caregivers often feel alone after a young person has experienced psychosis. People around them may stay away because they aren't sure what to say or do to help. Others may stay away because of fear or stigma. Families need support at this time, too. Sometimes they need to be very direct with others about what they need. Well-meaning but uncertain friends and family may need specific requests for what would help best.

*Here are some things friends and families can do:*

- ▶ Let them know if they see symptoms.
- ▶ Help care for the young person.
- ▶ Give a referral to psychiatrists or counselors.
- ▶ Recommend NAMI's education and support programs.
- ▶ Provide information and books about the illness.
- ▶ Provide moral support.

- ▶ Listen without judging.
- ▶ Share stories of hope.
- ▶ Provide spiritual guidance and support.
- ▶ Help with other responsibilities such as cooking and child care.
- ▶ Provide financial assistance.

When a person is first diagnosed with an illness with psychosis as a symptom, family members often feel sadness, anger, disbelief and denial.

This is normal. But it can disturb the balance of family life. Family members need to give themselves time to adjust to this new reality.

***“The illness affects the entire family, including how family members interact with each other. . . . Be loving and patient with each other.”***

Families often focus on supporting the person with psychosis and forget about taking care of themselves. They need to find a balance between these.

The caregiver’s well-being is directly tied to their loved one’s progress. People with psychosis who are in stressful family environments usually have a harder time recovering. Learning to recognize and manage stress can help family members avoid burnout. It can also improve the well-being of the entire family.

Young people with psychosis feel good when their family goes back to its regular routines. Each family member needs to learn to recognize their own symptoms of stress. They need to pay attention to their physical and mental health.

*Some tips for family members include:*

- ▶ Try to make taking care of yourself a habit. Don’t let self-care fall away when things get hard.
- ▶ Keep busy so that you don’t keep worrying.
- ▶ Eat healthy foods. This can make you feel better physically and mentally.
- ▶ Get plenty of sleep.
- ▶ If you can, make changes in your work or family situation (such as schedule, workload, household chores) to lighten the load. Do the essential tasks and let the rest go for now.
- ▶ Take part in activities outside the family that are not connected with mental illness.
- ▶ Stay involved with activities away from home. This will help prevent you from losing track of your own needs.



- ▶ Do things that help reduce stress such as walking, working out, taking part in sports, gardening, going to movies or doing other activities that you enjoy.
- ▶ Try to give yourself the time and space to move through this difficult time in your life.
- ▶ Remember the importance of humor. Let yourself have fun with the people you enjoy. You are entitled to laugh and find joy in your life.
- ▶ Get respite when needed. Remind yourself that nobody can be on call 24/7. If you are able to go away on a trip or holiday, do so. If you are not, devote some special time to yourself each day: have a massage, take a bubble bath or engage in meditation, relaxation exercises, yoga or prayer.

Try to separate the person from the illness. Appreciate and accept your young person as they are in the present. Focus on their strengths and positive qualities rather than on their problems.

Change occurs slowly. There will be gains and setbacks. It is important not to put too much emphasis on either one. Remember that negative feelings are normal. Give yourself permission to feel angry toward your young person or the illness. Remember that you are not to blame for the illness. You cannot always control everything that is happening around you. But you can learn how to change your response to the stressor or situation.

Most families are able to move forward and, with time, to grow and flourish. Families develop coping skills and recognize that recovery is not a linear process. They learn how to best support their loved one as they find pathways to recovery. ■

***“I think the most important thing is to accept the disorder like any other medical disorder, that treatment works and that recovery is not only possible but probable.”***

## RESOURCES

### **American Academy of Child and Adolescent Psychiatry**

[www.aacap.org](http://www.aacap.org)

### **Cannabis and Psychosis**

<http://cannabisandpsychosis.ca/home/>

### **Dealing with Psychosis Toolkit**

[www.psychosissucks.ca](http://www.psychosissucks.ca).

### **Mental Health Consumer/Survivor Network**

[www.mhcsn.org](http://www.mhcsn.org)

651-637-2800 or toll free 1-800-483-2007

### **NAMI (National Alliance on Mental Illness) Minnesota**

[www.namihelps.org](http://www.namihelps.org) or [www.namihelpsyouth.org](http://www.namihelpsyouth.org)

1-888-NAMI-HELPS (626-4435)

### **NAMI: 2011 First Episode of Psychosis Survey Results**

[http://www.nami.org/Content/NavigationMenu/First\\_Episode/About.htm](http://www.nami.org/Content/NavigationMenu/First_Episode/About.htm)

### **National Institute of Mental Health**

[www.nimh.nih.gov/health/topics/schizophrenia/raise/index.shtml](http://www.nimh.nih.gov/health/topics/schizophrenia/raise/index.shtml)

### **A Sibling's Guide to Psychosis**

<http://www.marketingisland.com/cmha/pages/product.asp?id=3083>.

### **University of Minnesota Medical Center First Episode Program**

Inpatient Programs: 612-672-6600 or 1-800-233-7503

Lodging and Outpatient Day Programs: 612-672-2736

or 1-800-233-7503 ■

## COMMON TERMS

**Acute phase:** The second stage of psychosis. During the acute stage, a person is at their most ill and is experiencing delusions or hallucinations.

**Anosognosia:** A symptom of some mental illnesses; the person is not able to understand that they have a mental illness and so may not accept treatment.

**Cognitive behavioral therapy (CBT):** A form of therapy that looks at a person's negative thought patterns and teaches them a healthier, more productive way of thinking

**Cognitive remediation:** Training designed to help a person recover attention

**Coordinated specialty care (CSC):** A treatment team working together to provide all aspects of care, including medication management, therapy, cognitive remediation and vocational and educational rehabilitation

**Delusion:** A false belief that a person still believes even when shown evidence that it is not true. This false belief is not part of a person's religion or culture.

**Extrapyramidal symptoms:** Side effects associated with older, first-generation antipsychotic medications associated with movement, including stiffness and shakiness of muscles, restlessness, long-lasting and unusual movements of the jaw, lips and tongue, and sexual problems

**Hallucination:** False perceptions that others do not experience. These can be seen, heard, tasted, felt or smelled.

**Neologism:** A new word that has no meaning to anyone but the person who uses it

**Neuroleptic malignant syndrome:** A rare but serious side effect of some antipsychotic medications. Symptoms include high fever, muscle stiffness and rigidity.

**Prodromal phase:** The first, "warning" stage of psychosis. Symptoms include changes in feelings, thought, behavior and how a person sees their surroundings.

**Psychoeducation:** Education about mental illnesses and ways to communicate, solve problems and cope

**Psychosis:** The experience of loss of contact with reality that is not part of the person's cultural or religious beliefs

**Psychosocial interventions:** Treatments for mental illnesses other than medications and therapy. Psychosocial interventions help a person in recovery from a mental illness return to all aspects of their life.

**Recovery phase:** The third stage of psychosis. The person is beginning to feel better, has learned to deal with symptoms that still remain and is moving on with their life.

**Tardive dyskinesia:** A serious side effect of some antipsychotic medications that includes long-lasting, unusual movements of the jaw, lips and tongue. ■

## RECOMMENDED READING

*The Center Cannot Hold: My Journey Through Madness*, Elyn R. Saks

*Coping with Schizophrenia: A Guide for Families*, Kim T. Mueser, PhD., and Susan Gingerich, M.S.W.

*The Day the Voices Stopped*, Ken Steele

*I Am Not Sick, I Don't Need Help! How to Help Someone with Mental Illness Accept Treatment*, Xavier Amador

*I'm Right, You're Wrong, Now What?* Xavier Amador

*Living with Someone Who's Living with Bipolar Disorder: A Practical Guide for Family, Friends and Co-workers*, Chelsea Lowe

*Loving Someone with Borderline Personality Disorder: How to Keep Out-of-Control Emotions from Destroying Your Relationship*, Shari Y. Manning, PhD.

*Quiet Room: A Journey out of the Torment of Madness*, Lori Schiller and Amanda Bennet

*A Sourcebook for Families Coping with Mental Illness*, edited by Michael R. Berren, PhD.

*Welcome to the Jungle: Everything You Ever Wanted to Know About Bipolar but Were Too Freaked out to Ask*, Hillary Smith

November 2014 ■

## **SAMPLE CRISIS PLAN**

### **Individual/Family Information:**

<b>Person's Name:</b>	<b>D.O.B.</b>	<b>Diagnosis(es):</b>	<b>Date of Plan:</b>
<b>Medications:</b>	<b>Dosage:</b>	<b>Physician Name / Phone</b>	<b>Pharmacy Name / Phone:</b>
<b>Support Contact Name:</b>	<b>Phone(s):</b>	<b>Support Contact Name:</b>	<b>Phone(s):</b>

### **Description of immediate needs:**

### **Safety concerns:**

### **Treatment choices:**

Interventions preferred:

Interventions that have been used:

Interventions that should be avoided:

**Professional involvement:**

<b>Psychiatrist Name / Phone:</b>	<b>Therapist Name / Phone:</b>	<b>Work Contact / Phone:</b>	<b>Case Mgr Name / Phone:</b>
<b>Crisis Team Phone:</b>	<b>Doctor Name / Phone:</b>	<b>Hospital Name / Phone:</b>	<b>Other:</b>

**Supports to use in crisis resolution:**

<b>Name / Phone:</b>	<b>Name /Phone:</b>	<b>Name/Phone:</b>	<b>Name / Phone:</b>
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**Resources:**

<b>Advocacy Group:</b>	<b>Support Group:</b>	<b>MH Agency:</b>	<b>Other:</b>
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For up-to-date information about county crisis services in your community, visit the NAMI Minnesota website at **[www.namihelps.org](http://www.namihelps.org)** or contact your county. ■

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University of Minnesota Fairview First Episode Program

**NOTES**

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**800 Transfer Road, Suite 31  
St. Paul, MN 55114  
Phone: 651-645-2948  
Toll Free: 1-888-626-4435  
Fax: 651-645-7379**

**E-mail: [namihelps@namimn.org](mailto:namihelps@namimn.org)  
Web: [www.namihelps.org](http://www.namihelps.org)**

