

# Recognizing and Helping Young People at Risk for Psychosis

Created by the Portland Identification and Early Referral Program, National Program Office for the Early Detection and Intervention for the Prevention of Psychosis Multisite Study.

A Program of the Robert Wood Johnson Foundation



# Acknowledgements

This 2014 booklet edition has been updated for the National Association of Mental Health Program Directors (NASMHPD) early psychosis website through the generosity of the Robert Wood Johnson Foundation.

The original form of the booklet was prepared by the Portland Identification and Early Referral (PIER) team in July 2001 with updates in 2004, 2008, and 2014. A significant portion of the original text was drawn from materials by William McFarlane, with major contributions and editing from Sarah Lynch, Kristen Woodberry, Donna Downing, James Maier, Douglas Robbins, and Mary Murphy. The PIER team thanks Janice Charek, Kate Chichester, Elizabeth Maier, and Deb Allen for their suggestions and edits with the original booklet.

EDIPPP is indebted to the TIPS, PACE, and EPPIC projects for their pioneering work, which greatly influenced this booklet.

**We especially want to thank the many young people and their families who have had the courage to share their experiences. They have taught us most of what we know.**

## You are participating in a very important effort

Professionals play a central role in identifying young people at risk for psychotic illness and referring them to appropriate services. This booklet is designed to help you do just that. You may refer to specific sections depending on your questions and on your clinical training, but we encourage you to read the entire booklet.

This guide is also a useful resource for families.

# Table of Contents

<b>Acknowledgements</b> .....	<b>ii</b>
<b>Table of Contents</b> .....	<b>1</b>
<b>Introduction to EDIPPP</b> .....	<b>2</b>
What is psychosis?.....	4
<b>Understanding Psychosis</b> .....	<b>4</b>
What you should know about psychosis .....	5
What causes psychosis? .....	5
Attention and arousal .....	6
What you need to know about how the brain works.....	7
How antipsychotic medication works .....	8
The internal experience of psychosis .....	8
What others may observe.....	9
The family's experience .....	10
People who are at risk for psychosis.....	11
<b>Recognizing Psychosis</b> .....	<b>11</b>
<b>Course of onset and illness</b> .....	<b>12</b>
1 - The Prodromal Phase .....	13
2 - The Acute Psychotic Episode .....	14
3 - The Recovery Phase .....	14
How do I know if it's life stressors, adolescence or early signs of psychosis? .....	15
Reducing delays in treatment improves the prognosis .....	15
The role of the professional.....	17
Guidelines for preliminary assessments of early signs .....	18
Diagnosis and medical testing .....	19
<b>Intervention strategies</b> .....	<b>20</b>
<b>Glossary of disorders with psychosis</b> .....	<b>21</b>
<b>Recommended readings</b> .....	<b>23</b>

# Introduction to the Early Detection and Intervention for the Prevention of Psychosis Program (EDIPPP)

On April 10, 2007, the Robert Wood Johnson Foundation (RWJF) launched a national program to build upon and replicate the early success of the Portland (Maine) Identification and Early Referral (PIER) Program for preventing psychotic illness among young people. This national research program – called the Early Detection and Intervention for the Prevention of Psychosis Program (EDIPPP) – represented the Foundation's single largest investment in mental health to date and reflects excitement about the promise that PIER's approach offers for forestalling or preventing debilitating and costly major mental illness.

RWJF awarded grants to sites with different demographics and geography - in Portland, ME; Salem, OR; Ypsilanti, MI; Queens, NY; and Sacramento, CA. A sixth site, in Albuquerque, NM, joined the program in January 2008. The PIER Program, located at Maine Medical Center, also served as RWJF's National Program Office for EDIPPP.

These sites replicated the PIER model, which used a combination of evidence-based psychosocial and pharmacologic interventions to treat the early warning signs of psychosis. These are often referred to as the "prodromal," "prepsychotic," or clinical high-risk stage of serious mental illness (schizophrenia, bipolar disorder with psychosis, and major depression with psychosis) in people ages 12 to 25.

EDIPPP identified and treated young people already experiencing prodromal symptoms of early serious mental illness. The successful outcomes of the EDIPPP study are due in large part to a variety of community outreach efforts to train clinicians, teachers, guidance counselors, medical and mental health professionals, and many others who work with young people to recognize the warning symptoms of serious mental illness and refer quickly for early intervention.

Replication and widespread dissemination of this early intervention model throughout the U.S. offers tremendous hope and optimism for combating some of the most devastating and costly illnesses that can afflict young people and their families. If closing a window of vulnerability at a critical period leads to short-term symptom improvement as well as long-term protection from disability associated with psychotic illness, this is a public health triumph.

**EDIPPP's mission is to reduce the incidence of psychosis in young people and prevent the secondary disability that usually follows psychosis.**

This is accomplished through:

- **Early identification** of young people at risk for or showing early signs of psychosis.
- **Reduction of barriers** to treatment - in particular, reduction of stigma about mental illness and education to counter false beliefs about psychosis.
- **Clinical service** to engage and treat young people who are at risk, along with their families.
- **Research** that monitors symptoms and changes in functioning in young people in the prodromal stage of psychosis. Continue to test psychosocial and pharmacologic interventions.

The hope is that, for young people whose symptoms progress to a prodromal stage, psychosocial services that offer families coping skills, support and information about the illness, along with low doses of medication and support with work and school, will help prevent or shorten a first psychotic episode.

Psychotic illnesses seldom appear out of the blue. Most commonly, they develop gradually over months or years. Because symptoms often worsen and become entrenched over time, **treatment is generally most effective and benign in the earliest stages of illness. Delays in treatment are associated with a slower and less complete recovery.**

People experiencing psychosis and those who love them often suffer greatly, but sufficient knowledge and skill are available to provide excellent care across all phases of illness. This treatment builds on the resiliency, courage, and talents of people whose uniqueness might otherwise be overshadowed by mental illness. Treatment is intended to preserve the personality and strengths of each person affected, while reducing the burden of stress on families.

**Early recognition and treatment of psychotic disorders is important to preventing or minimizing disability and reducing the considerable personal, social, and economic strains that these disorders produce.** Medication is sometimes needed. If symptoms are identified early, they may be managed with low doses of medication. In addition, early treatment offers the best chance for normal progress in school, work, and in the development of social skills.

For all these reasons, professionals working with youth and young adults have a crucial role to play in early identification and intervention for every young person at risk.

# Understanding Psychosis

## What is psychosis?

Psychosis refers to changes in the brain that interfere with a person's experience of his or her world. Characteristic symptoms are:

- **Hallucinations:** hearing voices or seeing visions
- **Delusions:** false beliefs or marked irrational suspicions of others
- **Confused thinking:** disorganized thoughts or speech, difficulty concentrating or understanding others

People who have any of these symptoms are identified as experiencing psychosis. In addition, they also commonly experience:

- Social withdrawal
- Disrupted sleep patterns
- Disrupted thoughts, memory, and attention
- Decreased motivation
- Pervasive anxiety
- An inability to enjoy themselves
- Odd, unusual behaviors
- Changes in appetite and eating
- Difficulty with daily activities, such as school and work
- Decreased sense of smell
- Decreased stress tolerance
- Increased sensory sensitivity

Occasionally, people experiencing psychosis have suicidal or homicidal impulses. Fortunately, homicidal impulses are uncommon, despite myths to the contrary. The latest international research suggests that psychotic illnesses first emerge in mid- to late adolescence or early adulthood and are very distressing for young people and their families. Studies are showing that the very early symptoms can start in pre-adolescence, with subtle experiences of psychosis appearing occasionally for years.

Approximately two to three of every 100 people will experience a psychotic episode, making psychosis more common than many chronic diseases in youth. With treatment, many people make a full recovery from a psychotic episode.



## What you should know about psychosis

A key characteristic of psychosis is heightened sensitivity to:

- Incoming sensory information (sights, sounds, smells, touch, movement)
- Prolonged stress and strenuous demands
- Rapid change in expectations, events, or routines
- Complexity of a situation (a lot going on at once)
- Social disruption
- Illicit drugs and alcohol
- Criticism or lack of warmth from others

- Symptoms of psychosis are treatable.
- Recovery from a first episode of psychosis is possible.
- It's no one's fault – neither the symptomatic person nor the family is to blame.
- Symptoms of psychosis should not be ignored, because the longer they persist, the less chance there is for effective treatment and complete recovery.
- Early experience of psychosis can be extremely confusing and traumatic for both the young person and his or her family. Symptoms can cause them considerable distress and disruption.
- Psychosocial interventions can be very effective. These are aimed at reducing stress and stimulation and teaching coping strategies for both the young person and the family.
- Treatment requires a comprehensive biopsychosocial (biological, psychological, and social) approach and a range of specialized treatments that address not only the specific symptoms, but also the impact of these symptoms on the person and his or her family.

## What causes psychosis?

Increasingly strong evidence suggests that schizophrenia and other illnesses producing psychotic symptoms are serious and complex disorders triggered by psychosocial stresses, but caused in large part by a host of biological events or disorders. These include genetic mutations, fetal viral infection, birth complications, paternal age, RH incompatibility, infant or early childhood head injury, and autoimmune disorders. This evidence supports the view of psychotic illnesses as real neurological and/or developmental disorders.

The information presented here is relatively new and is the subject of ongoing research.

## Attention and arousal

The connection between attention and arousal is key to understanding psychosis. When the level of complexity, stimulation, or information in our environment increases, we adapt by becoming more aroused. This helps us increase our attention to handle the situation better. However, if arousal increases too much, our ability to pay attention and handle distraction actually decreases. Most of us manage by calming ourselves and narrowing our attention again. This reduces arousal, screens out excessive stimulation, and maintains our ability to cope effectively.

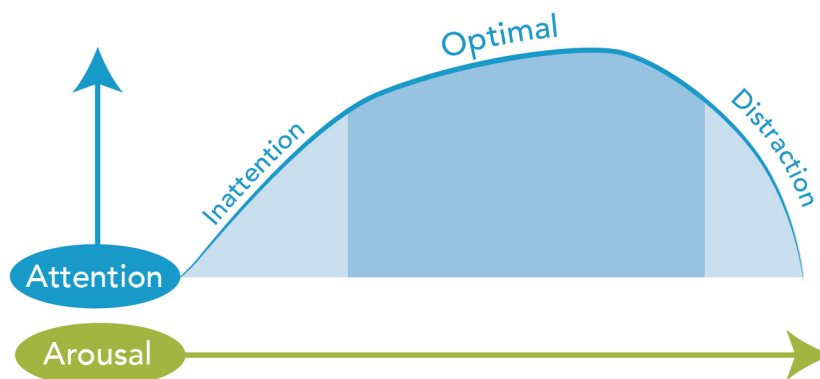
For someone in a psychotic state, this ability to control arousal seems to be impaired. As a complicated situation produces excessive arousal and escalating anxiety, the person becomes increasingly distracted, aroused, and frightened. He or she progressively loses control to think and handle social situations effectively. Instead of having **increasing** sharpness of thought, the person experiences **decreasing** mental focus as the brain becomes activated above a normal level.

Some people with this problem react by constricting their attention -focusing on a small, irrelevant detail - as a way to gain control and decrease arousal. Unfortunately, this keeps them from being able to think through problems or to see the whole picture.

Reducing stimulation and complexity can help people with psychosis. Hospital psychiatric units were once designed to be rather quiet, unstimulating places to allow people with psychotic disorders to regain control of their thoughts.

Today, due to numerous societal pressures and changes, in-patient adolescent and adult psychiatric units are often crowded, noisy, and under-staffed. **Even though psychosis is a disorder of the brain, the environment influences it heavily.** In psychosis, the person becomes over-stimulated and over-aroused at once, leading to decreased attention, memory, and control over thought and action.

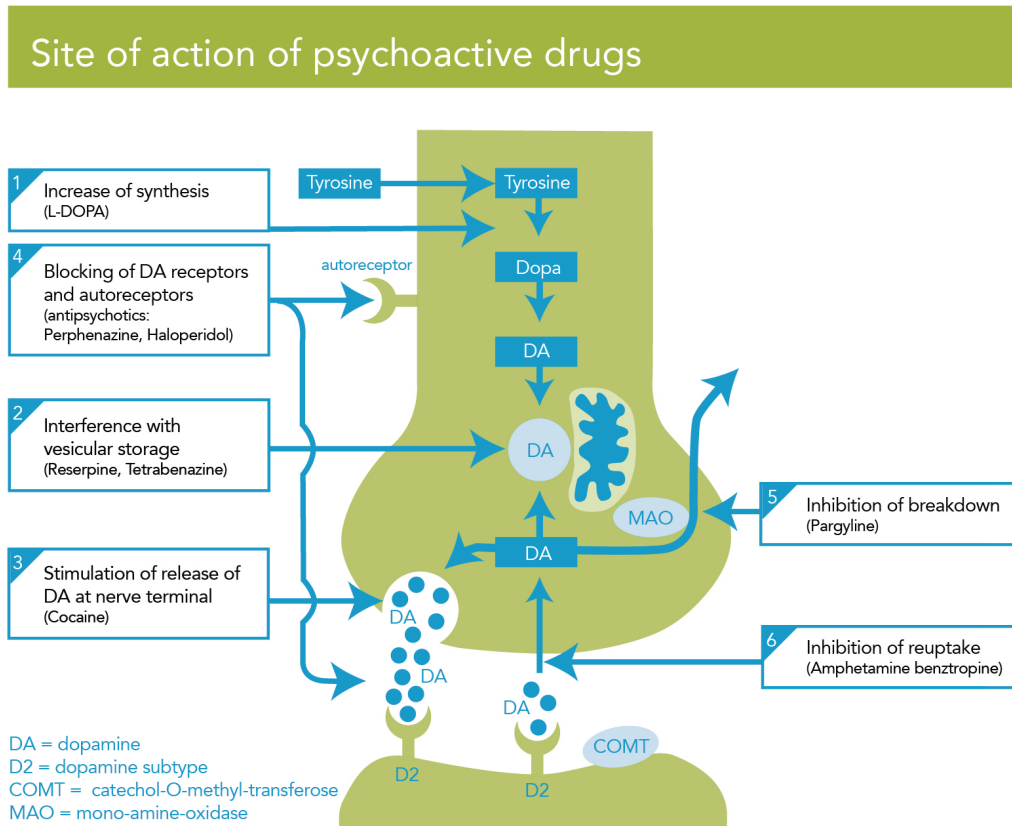
### Interaction of attention and arousal





## What you need to know about how the brain works

The brain consists of approximately 100 billion cells called neurons. They are linked rather like electrical circuits. They communicate through impulses transmitted by **chemical messengers** called neurotransmitters. The impulse involves electrical changes along the membranes of the sending and receiving cells. A neurotransmitter molecule is released by one neuron, travels across the gap, or synapse, between neurons, and is received by receptors on the next neuron, and so on. This diagram shows how the brain's neural activity works within the cell.



There are at least 50 kinds of neurotransmitters, but the **best known of those involved with psychosis is called dopamine**. Recent research has shown that dopamine interacts with other key neurotransmitters - serotonin and glutamine - opening the possibilities of treatment with other drugs that affect them. This particular neurotransmitter plays an important role in activating and controlling the parts of the brain affected by psychosis. If too much dopamine or other neurotransmitter is released or builds up in the synapses, it overstimulates the cell and the general level of electrical activity in the key neurons becomes too high. Such overstimulation in the limbic system can lead to emotional overarousal, excitement, and confusion.

On the other hand, inadequate neurotransmitter activity in the frontal cortex can impair thinking, judgment, and logical action.

## How antipsychotic medication works

After entering the bloodstream, antipsychotic medication travels to the brain and changes the chemistry in the synapse. The medication begins to block receptors for dopamine, thus reducing its overstimulating effects. This begins to tone everything down, allowing the brain to function appropriately. Some people worry that these medications are like tranquilizers, but **they are not tranquilizers** and have little to do with direct reduction of anxiety.

Studies show that drugs that reduce psychotic symptoms also improve attention and filtering, and reduce arousal. So although environmental stimuli may trigger the psychotic process, medication can help allow the person to regain stability and resist stress or overstimulation.

## The internal experience of psychosis

**At first:** People experiencing psychosis often report that their minds are playing small tricks on them. They have difficulty screening out distracting information and sensations, and attending to what is important. However, people can stay focused with greater effort, and can usually dismiss or reject thoughts that they recognize are irrational.

**Then:** Visual experiences may become brighter or distorted in color, shape, or size. Soft or brief sounds may seem loud, and irrelevant background noise distracting. The person experiences an increase in both quantity and quality of sensations. There is a sense of feeling overloaded with jumbled memories, thoughts, and stimulation from the environment.

**As symptoms of psychosis progress:** It becomes harder to concentrate on a book or conversation, or to carry on a conversation that would make sense to another person. It also becomes increasingly difficult to distinguish internal thoughts from external perceptions. For instance, upon hearing a noise outside while thinking about an event that occurred yesterday, the sound registers as something that happened yesterday. Irrational thoughts or beliefs may be accepted as reality, and may become fixed and resistant to logical evidence to the contrary. Many people begin to experience fear of being harmed or injured by other people, even friends and family.

**Finally:** A person experiencing full-blown psychosis loses control over his will, is disconnected from his own actions, and has an inability to follow through on a thought or action.

A person experiencing psychosis might be very anxious, even panicky, and make serious errors in relating to the world. For instance, a person might see a stranger while walking down the street, but, in his confusion, think that he knows this person. He might begin to think that this person is almost everywhere and is following him.

In an extreme state, this situation would become quite frightening. The person would miss more subtle cues that would correct his distortions; consequently, he would become completely out of touch with reality.



## What others may observe

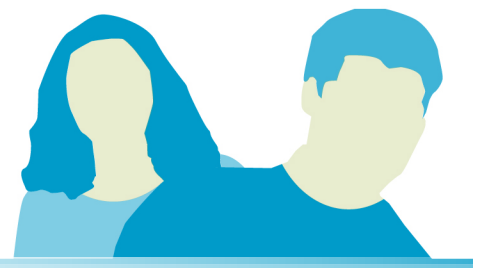
**At First:** Others, especially family members, may notice that their loved one starts to think and act differently, without knowing just what is wrong.

**Then:** As the person's level of functioning declines and symptoms become more obvious, it is harder to rationalize or explain away the unsettling realization that something is markedly wrong. The pre-psychotic or "prodromal" symptoms described in this booklet may persist for weeks or months unchanged but generally intensify as the person becomes overtly psychotic.

**As prodromal symptoms progress:** The person may have trouble expressing opinions or thoughts because she can't concentrate for long. When talking to a professional, a young person may express stress, trouble with coping, or may feel different from her peers in some way. Her speech may be vague and she may have odd ideas. **Initial complaints to professionals often focus on somatic, or physical, symptoms, particularly sleep disturbance and difficulties with memory and concentration.** Others have vague physical symptoms that move around the body and that defy ordinary medical diagnoses.

**With time:** People experiencing early symptoms of psychosis tend to avoid social contact. They may also be less expressive or spontaneous. It is important to recognize that such behavior is part of an illness process - not rudeness or laziness. Insignificant critical comments or subtle looks can send these young people into extreme states of self-doubt, irritability, or paranoia. Other people may feel uncomfortable around them. As young people realize this, they may become demoralized and depressed. In addition, they may be guarded and try to conceal their difficulties, especially from professionals.

**Finally:** As symptoms become more serious, a person's speech may seem fragmented or even incoherent. He may appear very suspicious and express bizarre ideas or even whole belief systems that are disconnected from reality. For example, he might be convinced that someone is reading his mind, that someone is controlling his thoughts with wires in his head, that others can hear his thoughts as if they were spoken out loud, or that someone is inserting thoughts into his head. The person is most likely desperately trying to make sense of his experience or thinking but is reaching distorted and inaccurate conclusions.



## The family's experience

Family members are often quite frightened or frustrated. They have seen an alarming change in their loved one's behavior and may be unsure of what is going on. If they suspect a mental illness, they may be afraid to have their suspicions confirmed; their child or sibling may remind them of a family member with serious mental illness. They may feel ashamed or afraid that it is their fault. Some families may have religious or cultural beliefs that reject the possibility that the changes in their loved one are due to mental illness. In all situations, the professional needs to be encouraging and supportive. Most importantly, professionals need to listen to the family's experience and concerns.

Often, families and friends ask how they should behave and talk to a person who is psychotic or showing early signs of a psychotic illness. There are no set rules, but some general guidelines are helpful:

1. Be yourself. Understand that this is not your fault.
2. Get information to help you understand the illness that is afflicting your loved one and how it affects his behavior.
3. Try not to take it personally if your loved one says hurtful things to you when he is unwell. Minimize arguments or long discussions. Stay as positive as possible.
4. Reduce stressors. Tone down emotions. Research shows that keeping the emotional atmosphere as calm as possible can speed recovery and help prevent relapse.
5. Communicate simply and clearly.
6. Solve problems step by step.
7. Ask for help from professionals if you have questions.
8. Don't ignore violence or risk of suicide.
9. Hopefully, you are involved in your loved one's treatment. Whether or not the provider working with your loved one has permission to speak with you, you can always offer information and observations.



# Recognizing Psychosis

## People who are at risk for psychosis

Psychosis can affect individuals of any race, religion, or income. **It is not the result of personal weakness, lack of character, or poor upbringing, despite many stigmatizing beliefs to the contrary.** Development of a psychotic disorder appears related to a specific vulnerability. The major causes of this vulnerability are biological, but the development of a psychotic syndrome is influenced by both biological and environmental stressors. It can be caused by certain medical conditions as well.

International research has identified the following risk factors for psychotic illness:

- Youth, specifically ages 12 to 30. The average age of the young people in EDIPPP was between the ages of 16 and 18, across all sites.
- Family history of a psychotic disorder such as schizophrenia or bipolar disorder particularly in a close or immediate relative (parent or sibling).
- A history of difficulty making friends, along with unusual thoughts and odd or eccentric behaviors (schizotypal personality disorder).
- A marked change in behavior, emotions, or thinking for a month or more, especially when accompanied by social withdrawal and deterioration in school or work performance.
- Sub-threshold psychotic symptoms that include suspiciousness or irrational delusional thinking, sporadic or fleeting hallucinations, and/or confused, disorganized communication.

Young people presenting most of these features may be at high risk for experiencing an acute psychotic episode.

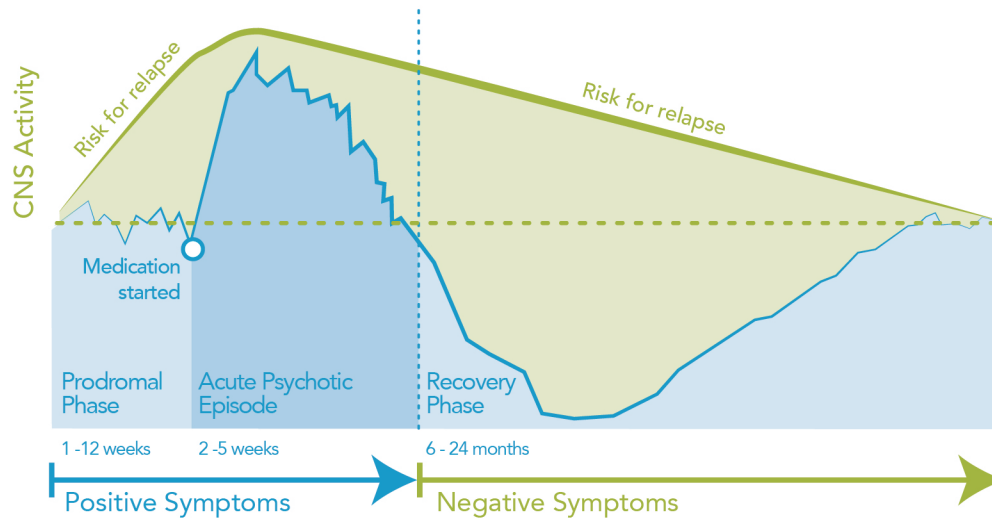


# Course of onset and illness

Psychotic disorders rarely emerge fully developed but progress through an illness process. The typical course of an initial psychotic episode can be described as occurring in three phases. These are:

1. The Prodromal Phase
2. The Acute Psychotic Episode
3. The Recovery Phase

## Typical course of psychotic episode



## 1 - The Prodromal Phase

The Prodromal Phase encompasses the period of early symptoms or changes in functioning, which precede psychosis. Symptoms during this phase may be quite obvious or hardly noticeable. They can occur over a matter of days or months. For many experiencing onset, these symptoms are stressful, even painful and frightening. Unlike most people who are experiencing psychosis, the individual in the prodromal phase of psychosis will often retain awareness that what he is experiencing is not normal, and will accept help from those he trusts. It is only during this period that prevention is both possible and safe. If an observing professional identifies this condition early, it is likely that the onset of a psychotic disorder can be at least delayed, and usually averted altogether.

Most of the common prodromal symptoms and signs arise gradually, but are new and uncharacteristic of the person's recent functioning and personality. Because they are the result of progressive loss of brain function involving a spread from sensory to motor to cognitive areas, they tend to occur in the following order:

- Sensory sensitivity to light, sound and touch
- Decreased sense of smell
- Reduced concentration, attention and memory
- Difficulties understanding others and being understood in conversation
- Suspiciousness, paranoia or baseless fearfulness
- Subtle, very brief and infrequent illusions or hallucinations
- Odd ideas and behavior that are new and uncharacteristic
- Delusional thinking, but without conviction
- Progressive and marked deterioration in functioning at work or school
- Withdrawal from friends and even family members

Other factors that greatly increase the likelihood of an imminent episode include:

- Family history of a psychotic or major mood disorder;
- Any substance abuse, especially frequent or daily use of marijuana; psychostimulants, such as 'meth;' or psychotogenic drugs, such as LSD, Ecstasy (MDMA), Angel Dust (PCP), or "Bath Salts".

Most young people having an onset of a psychosis also experience:

- Anxiety
- Irritability
- Depressed or unstable mood
- Reduced drive, motivation and energy
- Sleep disturbance
- Changes in appetite

## 2 - The Acute Psychotic Episode

The Acute Psychotic Episode is marked by the appearance of clear-cut, persistent, psychotic symptoms, such as hallucinations, delusions, or markedly confused thinking. These are called “positive” symptoms, not because they are beneficial or pleasant, but because they are **added on** by the psychotic state and are not present in normal mental functioning. The acute phase typically lasts until stressors are adequately reduced or treatment is begun. Treatment of positive symptoms usually requires appropriate antipsychotic medication. Antipsychotic medications may take a few days or a week to have an effect, so patience and a gradual increase in dosage may be needed if symptoms are slow to resolve.

“Negative” symptoms (so called because they imply the absence of usual thoughts, feelings, and behaviors) may be present also. Common negative symptoms are social withdrawal; diminished motivation and energy; poor concentration, memory, and attention; and constricted emotional responsiveness. Negative symptoms may persist longer than positive symptoms, and they can be quite distressing and disruptive. Newer medications target these symptoms as well, but these symptoms can appear **before** positive symptoms and persist for long periods even after positive symptoms are eliminated.

Researchers in the area of early intervention for psychotic illnesses are paying more attention to cognitive symptoms, which can include impairment of short-term or working memory, executive functioning, slowed thinking, impairments in expressing thoughts, and other difficulties that can hinder academic or work productivity. Some medications and cognitive interventions may turn out to be helpful with these symptoms, but there is no hard evidence yet.

## 3 - The Recovery Phase

The Recovery Phase varies from person to person, but with available treatments, many people recover well (sometimes fully) from their initial episode of psychosis. The process is dynamic and affected by a number of factors, including:

- The treatment environment;
- Medication, psychological, and/or psychosocial therapies;
- The individual’s personality traits, such as determination;
- Factors within the person’s family and social environment, such as supportive, positive relationships that stay intact.

The recovery period may take 6 to 24 months, even though the more dramatic psychotic symptoms may be alleviated quite rapidly. The negative symptoms take longer to diminish, as a person’s tolerance for stress and readiness for rehabilitation increases only very gradually.



## How do I know if it's life stressors, adolescence or early signs of psychosis?

It can be difficult to determine whether early symptoms are temporary and might disappear with time or effective coping strategies or whether professional help is indicated. Here are some guidelines to help you make an assessment. If you are in doubt, don't hesitate to consult with a professional.

1. If a person responds to a known stressor with increased irritability, tearfulness, anger, self-involvement, or withdrawal, these behaviors may very well be temporary and part of a normal coping response. Stressors could include the break-up of a relationship, failing an exam, the death of a loved one, illness, a family crisis, or a move. If the behaviors extend longer than a few weeks, or seem out of proportion to the situational stressor, a professional should be consulted. This young person needs assessment and monitoring.
2. If a person shows rather sudden changes that are out of character or bizarre, she should receive professional attention as soon as possible. Examples include fear of leaving the house; extreme preoccupation with a specific theme (such as politics, religion, or death); a dramatic drop in school or work performance; or significant changes in concentration, memory, or emotional response.
- 3. Symptoms that are definite indications for immediate attention:**
  - Suicidal or homicidal thoughts
  - Dramatic changes in sleep or appetite
  - Hearing voices commanding you to do certain things
  - Believing without reason that others are plotting against you
  - Extreme unreasonable resentments or grudges
  - Severely disorganized communication

## Reducing delays in treatment improves the prognosis

We know that many people struggle with symptoms of psychiatric illness without seeking help for a variety of reasons, including the following:

1. They think that their symptoms are transient and will pass.
2. They feel embarrassed to seek professional help because they fear what others may think.
3. They are not aware of what is happening to them or where to go for help.
4. They don't want to believe that they have a problem, or their culture does not endorse mental illness.
5. They are afraid of how their life may change if a professional suggests that a mental illness is causing their symptoms.

Unfortunately, the longer a person waits to seek help, the more serious the problem becomes.

### Delayed treatment can result in:

- Disruption of psychological and social development
- Strain on relationships or loss of family and social supports
- Disruption of parenting role in young parents
- Distress and increased psychological problems for the individual and family
- Disruption of education
- Loss of employment
- Slower or less complete recovery
- Poorer prognosis
- Depression and suicide
- Substance abuse
- Hospitalization
- Incarceration
- Possible long-term damage to brain and cognitive functioning
- Increased costs to the community

### Early identification and treatment can result in:

- Preservation of brain function
- Preservation of psychosocial skills
- Reduced morbidity
- Decreased need for hospitalization
- Preservation of family and social supports
- More rapid recovery
- Better prognosis
- Possibly less need for medication

Like many other illnesses, psychiatric illnesses are easier to treat when discovered and treated early. Medication, if needed at all, may be effective in very low doses in the early phases, which can reduce side effects and increase medication adherence. This can be critical to recovery, because omitting or quitting needed medication is a major contributor to relapse.

## The role of the professional

Although presentation of a developing first-episode psychosis happens infrequently in an office practice, school, or agency, professionals in these settings still have a crucial role to play:

You may be the **first contact** for most of these young people and their families. **You may also be the only person in a position to correctly identify** the warning signs of impending psychosis and direct people to appropriate care in time to prevent serious illness. People experiencing early symptoms may be particularly guarded and may attempt to conceal their difficulties. You may need to provide reassurance and gentle persistence. By focusing on the specific concerns of the person and family, and asking for their perspectives, you may elicit more information.

Remember that a person experiencing early symptoms of psychosis may have trouble expressing opinions or conclusions because she is having difficulty concentrating or does not know how to articulate odd experiences because they “come and go”. Her speech may be vague and hard to follow. When talking to a professional, she may speak of “feeling stressed” or “having trouble coping.” Be alert to such cues, particularly if the young person has a history of persistent psychological difficulties, a drop in functioning, or a family history of significant psychiatric problems. Also remember that initial complaints to professionals often focus on somatic or physical symptoms, particularly sleep disturbance.

Professionals, family members, or young people themselves often report having a sense that “something’s not quite right” or a feeling of foreboding. Pay attention to such reports. Prodromal symptoms can be subtle, changeable from day to day, and hard to elicit. Don’t hesitate to contact a professional if you are unsure whether you are seeing prodromal symptoms. The screening process can help determine whether there is reason for concern.

**Don’t forget the important role and needs of family members.** They may have key information about changes they have observed. They may also be quite distressed and unsure of what is happening. Remind families that the focus on their symptomatic young person can leave siblings feeling confused, ignored, scared, or angry. It is important to continue to pay attention to siblings’ emotional needs as the referral process moves forward.

If the person or family is not responding adequately to your concerns or will not allow you to make a referral, you may call for support and suggestions without giving any identifying information. In any event, **don’t give up your efforts** to engage the young person and family because early intervention can help arrest, or at least attenuate, the course of a serious and potentially life-long disabling illness.



## Guidelines for preliminary assessments of early signs

The following suggestions are offered to professionals with some training who may wish to do their own initial screening. We advise that you use the Prodromal Questionnaire-B (PB-Q) (Loewy, 2011) or the PQ-16 (Ising, 2012). See appendix for references.

1. Establish rapport and trust quickly, particularly if a person is fearful or anxious. People have expressed fear about reporting psychotic symptoms to professionals, sometimes because they hear voices commanding or threatening them not to tell. They may feel reassured when a professional calmly asks about specific symptoms, psychiatric and medical history, and family and personal history.
2. At the same time, allow the young person to express his problems in his own words. You are trying to get a picture of the person, problems, and social situation. You are balancing the establishment of rapport, assessment, and assistance.
3. Specific areas that you need to review include psychotic and any prodromal symptoms, substance abuse, suicide risk, and risk of violence toward others.
4. Discuss your impressions and plan with the young person and, if possible, with the family. You may need to negotiate the next step carefully so that the young person will feel sufficient respect and confidence to proceed with a referral to appropriate care.
5. Consider using more than one session for this process if appropriate. The severity of symptoms and your own level of training and experience will influence the time needed.
6. Make sure to contact a person who does not show up for an appointment. They may be struggling with organization.
7. Get supporting information from family members or others who interact with the young person. Permission to speak with family must be obtained if the person is 18 or older. Explain that you need more information to provide the most appropriate help. Stress that your goal is getting information rather than sharing it, though it is helpful also to get permission to share concerns with the family. This would be particularly important if paranoid ideas or symptoms are present.
8. If the person is clearly psychotic and at risk, you may need to involve family members and professionals without the person's permission. In this case, a psychiatric evaluation is needed in a very timely manner, possibly by crisis staff or at the local emergency room. Outpatient or partial hospitalization services can often avert the need for inpatient hospitalization (or other intensive treatments), decreasing complications and avoiding unnecessary trauma.
9. Hospitalization may be needed for proper medical and psychiatric assessment and to manage health and safety risks. If there are insufficient supports for outpatient or community treatment, or high levels of stress in the home environment, hospitalization may be the only way to stabilize the person and begin treatment.
10. If there is no clear evidence of psychotic symptoms, but you suspect an emerging psychosis, contact a multidisciplinary psychiatric team to make a referral.
11. Remember that making a clear diagnosis may be quite difficult and often premature, as the true nature of a psychotic illness may emerge only over time and with continuing observation. A correct diagnosis is not as important as intervening early in an illness process.

## Diagnosis and medical testing

The diagnosis of prodromal psychosis is made from observations, a psychiatric interview, history-taking, and additional information from family members or others. There is no specific lab test for diagnosing psychosis, but physicians are encouraged to consider the following in their assessments:

- Pregnancy test
- Fasting glucose
- HbA1c
- Lipid profile
- Comprehensive metabolic panel (liver and kidney function tests)
- CBC
- TSH

When a young person is admitted to an early psychosis program or multidisciplinary team, he should receive an assessment of blood pressure, weight, height, and BMI, along with the above laboratory tests if they have not already been done. Blood tests are done at three, six, and 12 months and then yearly to monitor medication side effects and medical issues, should they arise.

## Procedures

1. After taking a new client's measurements, the doctor or nurse calculates the client's weight. A 5% increase is a red flag that the client is gaining weight as a result of the medication he or she is taking.
2. A growth chart is placed in every client's chart.
3. In addition, psychological testing or neuropsychological testing will help clarify a possible diagnosis, especially in the early stages.

# Intervention strategies

We encourage young people who are experiencing symptoms to seek help early, because research shows that they have a better chance of accepting help and a more rapid recovery in early intervention.

## Evidence based interventions in first episode psychosis include:

- Family psychoeducation (multifamily group or single family format) to help reduce blame, guilt, and to learn individualized coping skills
- Coordinated treatment by a multidisciplinary team
- Cognitive behavioral therapy for psychosis
- Medication management
- Supported employment and education
- Community outreach and education

## Treatment might also include a combination of the following:

- Crisis intervention and stabilization
- Environmental accommodations to reduce stress at home, school, or work
- Supportive Therapy for the young person to teach coping skills, promote adjustment to the illness, and support protective measures
- Substance abuse counseling and support
- Psychological testing to better clarify diagnosis and specific functioning



# Glossary of disorders with psychosis

Everyone's experience of psychosis is different, so attaching a specific name or label to the psychotic illness is not always useful or accurate in the early stages. At the same time, this uncertainty can create a great deal of anxiety and frustration for young people and their families and should be addressed in a manner that can help them cope.

**Bipolar Disorder (previously known as Manic-Depressive Illness):** Bipolar disorder is characterized by extreme variations in mood, with episodes of severe depression, elation or irritability. These episodes are marked by disturbances of sleep, appetite, levels of physical activity, and behavior. Both the elated/irritable (manic) episodes and the depressive episodes may include psychotic symptoms. The psychotic symptoms may be consistent with the mood disturbance. For example, in a manic episode, a person may have grandiose delusions and hallucinations that appear to confirm exaggerated importance or powers - for example, he may believe that the president has appointed him to organize an important event. On the other hand, a severely depressed person may literally believe he is toxic to others, or is the cause of misfortunes he did not really cause. Sometimes a person displays both depressive and manic symptoms at the same time, on a continuous rather than episodic or intermittent basis. Quite often this is the case in early onset bipolar disorder. When this occurs in a young person, it makes diagnosis more difficult.

**Brief Psychotic Disorder:** All the symptoms of psychosis may be present – disorganized thought and speech, delusions, or hallucinations – but last only a month or less. The person then fully returns to her previous level of functioning. Often an overwhelming stress can be identified. Short-term postpartum psychosis is a form of this psychosis.

**Delusional Disorder:** Persons with this disorder experience delusion, or fixed belief. For example, a person may believe he is being persecuted, followed, poisoned or infected, or that he is the object of romantic love by someone from afar. Illogical thinking or bizarre behavior may not be apparent, except regarding the specific delusion.

**Drug-induced Psychosis:** Psychosis may result during intoxication with or during withdrawal from a wide variety of substances, including known substances of abuse, prescribed and over-the-counter medications, and toxins. Hallucinogenic drugs and stimulants (LSD, Ecstasy, "Angel Dust" or phencyclidine, cocaine, "Bath Salts" and many others) are especially likely to cause psychosis in vulnerable young persons. Sometimes a psychosis can develop with withdrawal from one or more drugs. In some cases, psychotic symptoms may persist after the substance is no longer present. A history of substance use, physical examination, and a blood or urine toxicology evaluation often clarify this etiology of psychosis.

**Major Depression with Psychotic Features:** Persons who experience episodes of severe depression may also experience symptoms of psychosis. As in bipolar disorder, the psychotic delusions or hallucinations may be consistent with a person's depressed view of herself and the world, such as believing that she has sinned and is to be punished. But as the person recovers from the mood disturbance, the psychotic symptoms improve.

**Organic Psychosis:** Many medical illnesses affect the nervous system and may cause psychosis. Examples include central nervous system infections or tumors, hepatic or renal failure, and thyroid and other endocrine disorders. Organic psychoses are often characterized by visual or olfactory hallucinations rather than auditory hallucinations. They may also include delirium, or fluctuating levels of consciousness and disturbances of short-term memory.

**Psychosis Not Otherwise Specified:** Some episodes of psychosis do not fit clearly into the defined patterns described above. In some of these instances, with further information or with the passage of time, a more specific diagnosis can be made.

**Schizoaffective Disorder:** People with this disorder have manic or depressive symptoms of schizophrenia or schizophreniform disorder, but they also have delusions or hallucinations in the absence of severe mood disturbance.

**Schizophrenia:** This is a severe disorder characterized by delusions, hallucinations (most often auditory), and disorganized thinking and speech. A person with schizophrenia can show a lack of attention to normal hygiene and expectations. The person may show “negative” symptoms, including apathy or lack of emotional expression, loss of enthusiasm, motivation, or interest, and social withdrawal. Social, occupational, or school functioning is seriously impaired and the disturbance continues for at least six months.

**Schizophreniform Disorder:** Persons with this disorder have all the symptoms of schizophrenia, but the disorder lasts less than six months. Many people with this disorder do not go on to develop schizophrenia.



# Recommended readings

- Downing, D. T. (2006). The impact of early psychosis on learning. *OT Practice*, 11(12), 7-10.
- Edwards, J., Cocks, J., & Bott, J. (1999). Preventive case management in first-episode psychosis. In McGorry, P.D. & Jackson, H.J. (eds.) *Recognition and management of early psychosis: A preventive approach*. New York: Cambridge University Press.
- Edwards, J. & McGorry, P. (2002). *Implementing early intervention in psychosis: A guide to establishing early psychosis services*. Trowbridge: The Cronwell Press.
- Fusar-Poli, P., Borgwardt, S. J., Bechdolf, A., Addington, J., Riecher-Rossler, A., Schultze-Lutter, F., ... Yung, A. R. (2013). The psychosis high-risk state: a comprehensive state-of-the-art review. *JAMA Psychiatry*, 70(1), 107-120.
- Hardy, K. V., & Loewy, R. (2012). Cognitive behavioral therapy for adolescents at clinical high risk for psychosis. *Adolescent Psychiatry*, 2, 172-181.
- Hatfield, A. B. (1979). The family as partner in the treatment of mental illness. *Hospital and Community Psychiatry*, 30, 338-340.
- Ising, H. K., Veling, W., Loewy, R. L., Rietveld, M. W., Rietdijk, J., Dragt, S., ... van der Gaag, M. (2012). The Validity of the 16-Item Version of the Prodromal Questionnaire (PQ-16) to Screen for Ultra High Risk of Developing Psychosis in the General Help-Seeking Population. *Schizophrenia Bulletin*, 38(6), 1288-1296.
- Jamison, K. R. (1996). *An unquiet mind: A memoir of moods and madness*. New York: Vintage Books.
- Klosterkötter, J., Hellmich, S., Steinmeyer, E. & Schultze-Lutter, F. (2001). Diagnosing schizophrenia in the initial prodromal phase. *Archives of General Psychiatry*, 58, 158-164.
- Loewy, R. L., Pearson, R., Vinogradov, S., Bearden, C. E., & Cannon, T. D. (2011). Psychosis risk screening with the Prodromal Questionnaire-Brief version (PQ-B). *Schizophrenia Research*, 129, 42-46.
- McFarlane, W. R., Cook, W. L., Downing, D., Ruff, A., Lynch, S., Adelsheim, S., ... Milner, K. (2012). Early Detection, Intervention and Prevention of Psychosis Program: rationale, design, and sample description. *Adolescent Psychiatry*, 2(2), 112-124.
- McFarlane, W. R., Cornblatt, B., & Carter, C. S. (2012). Early intervention in psychosis: Rationale, results and implications for treatment of adolescents at risk. *Adolescent Psychiatry*, 2, 125-139.
- McFarlane, W. R., Levin, B., Travis, L., Lucas, F. L., Lynch, S., Verdi, M., ... Spring, E. (2014). Clinical and Functional Outcomes After 2 Years in the Early Detection and Intervention for the Prevention of Psychosis Multisite Effectiveness Trial. *Schizophr Bull*. doi: 10.1093/schbul/sbu108
- McFarlane, W. R., Lynch, S., & Melton, R. (2012). Family psychoeducation in clinical high risk and first-episode psychosis. *Adolescent Psychiatry*, 2, 182-194.

- McFarlane, W. R. & Cook, W. L. (2007). Family expressed emotion prior to onset of psychosis. *Family Process*, 46, 185-197.
- McFarlane, W. R., Cook, W. L., Downing, D., Verdi, M. B., Woodberry, K. A., & Ruff, A. (2010). Portland Identification and Early Referral: A community-based system for identifying and treating youths at high risk of psychosis. *Psychiatric Services*, 61, 512-515.
- Migliorati, M., Salvador, M., Spring-Nichols, E., Lynch, S., Sale, T., & Adelsheim, S. (2012). In the first person: A window into the experience of early psychosis and recovery. *Adolescent Psychiatry*, 2, 146-152.
- Miller, T., Sarnoff, A., Mednick, T. H., McGlashan, T., Libiger, J., & Johannessen, J. O. (Eds.) (2001). *Early Intervention in Psychotic Disorders*. Dordrecht, The Netherlands: Kluwer Academic Publishers.
- Mueser, K. T., & Gingerich, S. (2006). *The complete family guide to schizophrenia: Helping your loved one get the most out of life*. New York: Guilford Press.
- Rey, J. (2007). Does marijuana contribute to psychotic illness? *Current Psychiatry*, 6, 36-47.
- Pearson, R., Stuart, B., & Loewy, R. (2012). The assessment of attenuated psychotic symptoms in adolescents: Concepts, practical approaches and prediction of risk. *Adolescent Psychiatry*, 2, 153-162.
- Rose, D., & Graeber, D. (2012). Pharmacologic treatments in "prodromal psychosis:" Making clinical decisions in the absence of a consensus. *Adolescent Psychiatry*, 2, 195-208.
- Ruff, A., McFarlane, W. R., Downing, D., Cook, W. L., & Woodberry, K. A. (2012). A community outreach and education model for early identification of mental illness in young people. *Adolescent Psychiatry*, 2, 140-145.
- Saks, Elyn R. (2007). *The center cannot hold: My journey through madness*. New York: Hyperion.
- Schlosser, D. A., Pearson, R., Perez, V. B., & Loewy, R. (2012). Environmental risk and protective factors and their influence on the emergence of psychosis. *Adolescent Psychiatry*, 2, 163-171.
- Yung, A. R., McGorry, P. D., McFarlane, C. A., & Patton, G. C. (1996). The PACE Clinic: Development of a clinical service for young people at high risk of psychosis. *Australasian Psychiatry*, 3, 345-351.

