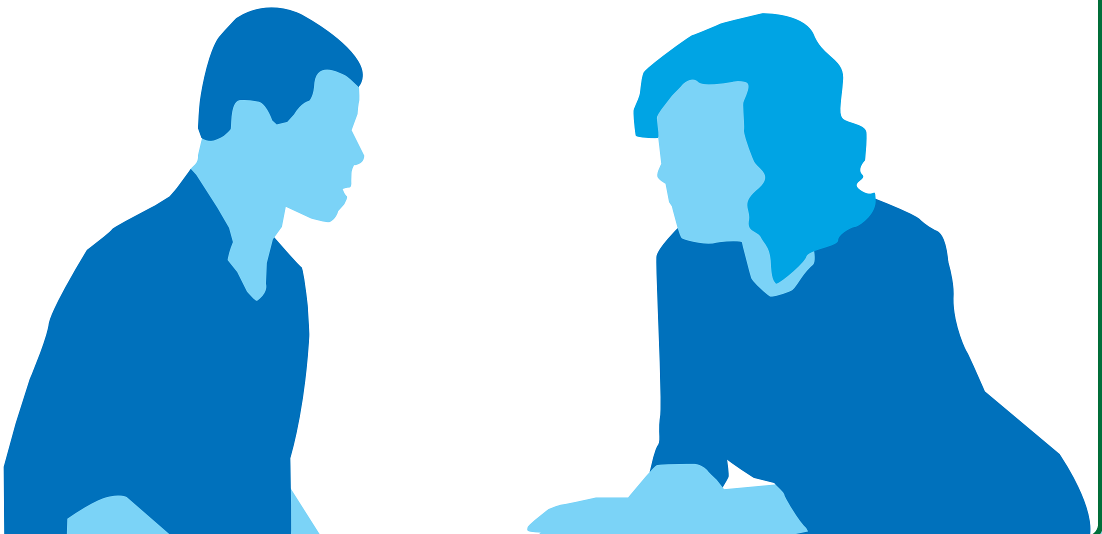
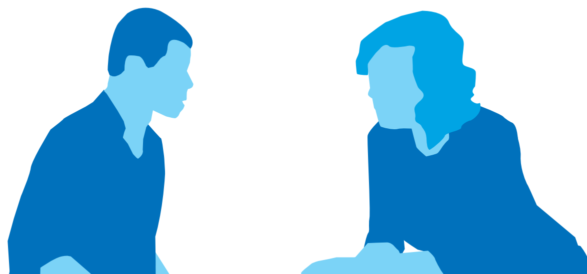
Recognizing and Helping Young People at Risk for Psychosis: A Professional's Guide

Created for the Early Detection and Intervention for the Prevention of Psychosis Program
A Program of the Robert Wood Johnson Foundation



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. The Early Detection and Intervention for the Prevention of Psychosis Program (EDIPPP) team is available for consultation, screening, and treatment of young people demonstrating early signs or risk factors. You'll also find information here about EDIPPP's ongoing research, and what families can expect if they are referred to us.



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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.

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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. The new national research program – called the Early Detection and Intervention for the Prevention of Psychosis Program (EDIPPP) – represents 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.

EDIPPP has awarded four-year grants to replicate the PIER model, which uses a combination of evidence-based pharmacologic and psychosocial interventions to treat the early warning signs. These are often referred to as the "prodromal," "prepsychotic," or high-risk stage of serious mental illness (schizophrenia, bipolar disorder with psychosis, and major depression with psychosis) in people ages 12 to 25. The four sites are: Sacramento, California; Salem, Oregon; Washtenaw County, Michigan; and Glen Oaks, New York. A site in Albuquerque, New Mexico joined EDIPPP in 2008. The PIER Program, located at the Maine Medical Center, also serves as RWJF's National Program Office for EDIPPP.

EDIPPP identifies and treats young people already experiencing prodromal symptoms of early serious mental illness. A year after enrolling in PIER, most of these young people had not experienced a full-blown psychotic episode. This success is 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 to PIER for screening and timely treatment.

Replication and widespread dissemination of this early intervention model throughout the U.S. offer 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 whose significance can scarcely be overestimated.

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** whether young people convert to a prodromal stage, a period of early symptoms or changes in functioning that precede psychosis. 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 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 frequently, but not always, 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:*** jumbled thoughts or speech, difficulty concentrating or understanding others' conversations

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

- Symptoms of psychosis are treatable. Full recovery from a first episode of psychosis is common (about 25 percent of cases).

- 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

- 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 genetics, 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 still the subject of ongoing research. Importantly, few findings apply to every person with psychosis.

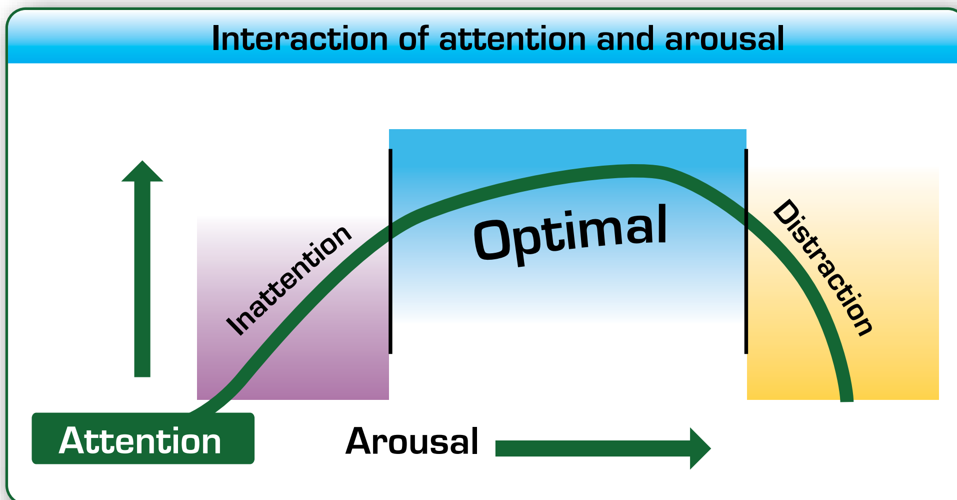
Attention and arousal

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 regulate 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 appropriately. Instead of having *increasing* sharpness of thought, the person experiences *decreasing* mental focus as the brain becomes activated above a normal level.

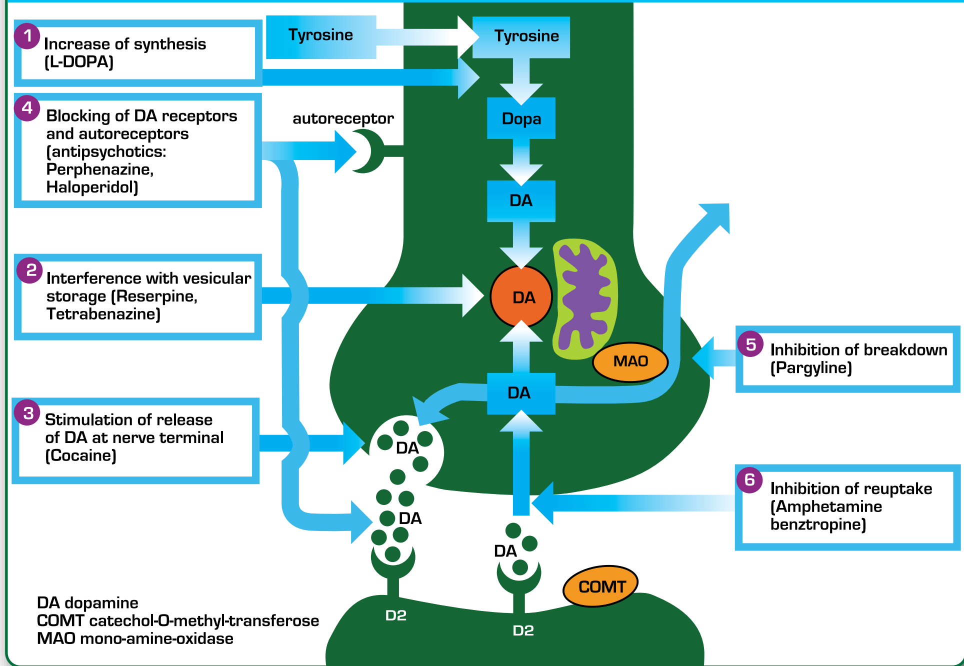
Some people with this problem react by constricting their attention—focusing on a small, irrelevant detail—as a way to gain control and decrease arousal. Unfortunately, this keeps them from being able to think through problems or to see the whole picture.

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.



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 her will and a disconnection from her own actions, as well as 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 a general sense of feeling stressed or different from her peers in some way, or having trouble coping. 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.

Recognizing Psychosis

People who are at risk of 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:

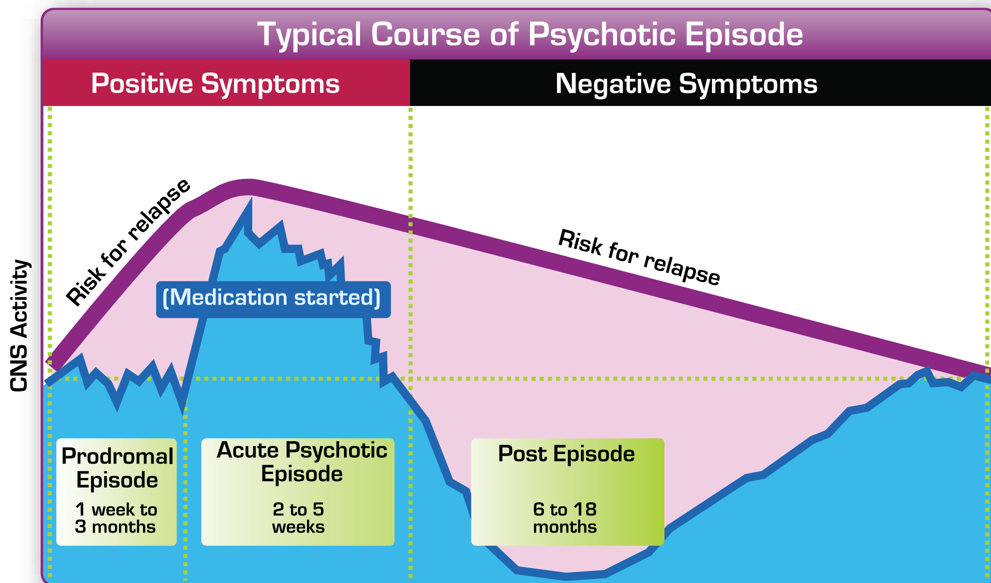
- Youth, specifically ages 12 to 30. The average age of a young person entering EDIPPP is between the ages of 15 and 16, across all sites.
- Family history of a psychotic disorder such as schizophrenia or bipolar disorder—particularly in a close or immediate relative (parent or sibling).
- A history 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:

- **The Prodromal Phase**
- **The Acute Phase**
- **The Recovery Phase**



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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 of those experiencing psychosis, the person will often retain awareness that they are not normal, and will accept help from those they trust. 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 onset of a psychotic disorder can be at least delayed and usually averted altogether.

Common prodromal signs or symptoms can include the following:

Important: It is the combination of symptoms, rather than any one symptom, that suggests a prodromal phase. In many ways, this is a syndrome.

Most of these 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 or Angel Dust (PCP).

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

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

The Acute Phase

The Acute Phase 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 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 may turn out to be helpful with these symptoms but there is no hard evidence yet.

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 12 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.

Recognizing the early signs of psychosis

It can be difficult to determine whether early symptoms are temporary and might disappear with time or more 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 the EDIPPP team in your community.

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 thoughts
    - A dramatic change in sleep or appetite
    - Hearing voices that no one else hears
    - Seeing things that no one else sees
    - Paranoia or unwarranted suspiciousness of others
    - Belief that the person has special powers or is being directed by the devil or TV
    - Extreme fright in situations that do not warrant it
    - Extreme and unreasonable resentments or grudges
    - Jumbled speech or writing

Reducing delays to 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 can become.

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 compliance. 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:

1. You may be the *first contact* for most of these young people and their families.

2. 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 those 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 EDIPPP if you are unsure whether you are seeing prodromal symptoms. Our 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 EDIPPP** 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. **However, this screening is not necessary before calling EDIPPP.**

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. Do not be reluctant to contact a person who does not show up for an appointment.

7. **Do not hesitate to consult with EDIPPP staff** about managing this early assessment and referral process. The key aspects of a case can be discussed anonymously.

8. 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.

9. 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.

10. 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.

11. If there is no clear evidence of psychotic symptoms, but you suspect an emerging psychosis, contact EDIPPP and closely monitor the person. If necessary, EDIPPP staff can come to your office or to the young person's home.

12. 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 EDIPP Program, he receives 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 EDIPPP 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.

In addition, psychological testing or neuropsychological testing may help clarify a possible diagnosis, especially in the early stages.

Intervention Strategies

EDIPPP encourages young people who are experiencing symptoms to seek help early because research shows that they have a better chance of getting well with early intervention.

When a person is referred to EDIPPP, a phone screen determines the need for further assessment. If the person referred has possible signs of prodromal psychosis, an orientation session with the family is arranged to discuss the research, intake process, and treatment program. At that time, a research consent form is reviewed with the individual and family to explain the conditions of the EDIPPP research protocol.

If the young person signs the research consent form to participate, the research coordinator conducts formal assessments to evaluate symptoms and gather historical information. These assessments may be done in a place that is comfortable for the young person, such as her home, school, doctor's office, or EDIPPP offices. Sometimes, a physical exam or substance abuse screening is recommended to rule out an organic or substance abuse problem as the basis for the presenting symptoms.

If a young person meets criteria for EDIPPP, she is assigned to one of two research conditions, based on need: "treatment" or "control". Those individuals assigned to the control condition demonstrate questionable risk of illness but are asked to participate in monthly symptom monitoring as part of the research.

Treatment might include a combination of the following:

- Crisis intervention and stabilization
- Environmental accommodations to reduce stress at home, school, or work
- Single or multi-family psychoeducation (in a group) to help reduce blame, guilt, and a sense of helplessness
- Therapy for the young person to teach coping skills, promote adjustment to the illness, and support protective measures
- Substance abuse counseling and support
- Supported education/supported employment, which can consist of collaboration with school personnel or employers to develop strategies for a successful return to those environments
- A low-dose medication regime to control the most troubling symptoms so that the young person can think more clearly and cope with daily life. This regimen is developed with a psychiatrist
- Psychological testing to better clarify diagnosis and specific functioning

Recommended Readings

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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.

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, 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.

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. These psychoses are often characterized by visual or olfactory hallucinations rather than auditory hallucinations. They may be associated with delirium, symptoms of which include fluctuating levels of consciousness and disturbances of short-term memory.

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 bizarre delusion – for example, that 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.

Schizophrenia:

This is a severe disorder characterized by delusions, hallucinations (most often auditory), and disorganized thinking and speech. A schizophrenic person's behavior is disorganized, often with lack of attention to normal hygiene and expectations. The person may show "negative" symptoms, including apathy or a 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.

Bipolar Disorder *(previously known as Manic-Depressive Illness):*

Bipolar disorder is characterized by severe variations in mood, with episodes of severe depression and episodes of severe 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 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.

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.

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.

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.

How to contact EDIPPP

The EDIPPP team is available to help those experiencing symptoms, their family or friends, and professionals working with them. We can help determine whether a referral is appropriate and give advice about how to best engage or support a young person and family in the referral or treatment process.

The EDIPPP National Program Office is located in Portland, Maine.
For further information about the EDIPPP Program in your area, please visit this website: **www.preventmentalillness.org.**

To learn more about advocacy in this area, log on to: **www.ChangeMyMind.org.**

You will find contact and other valuable information there.

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