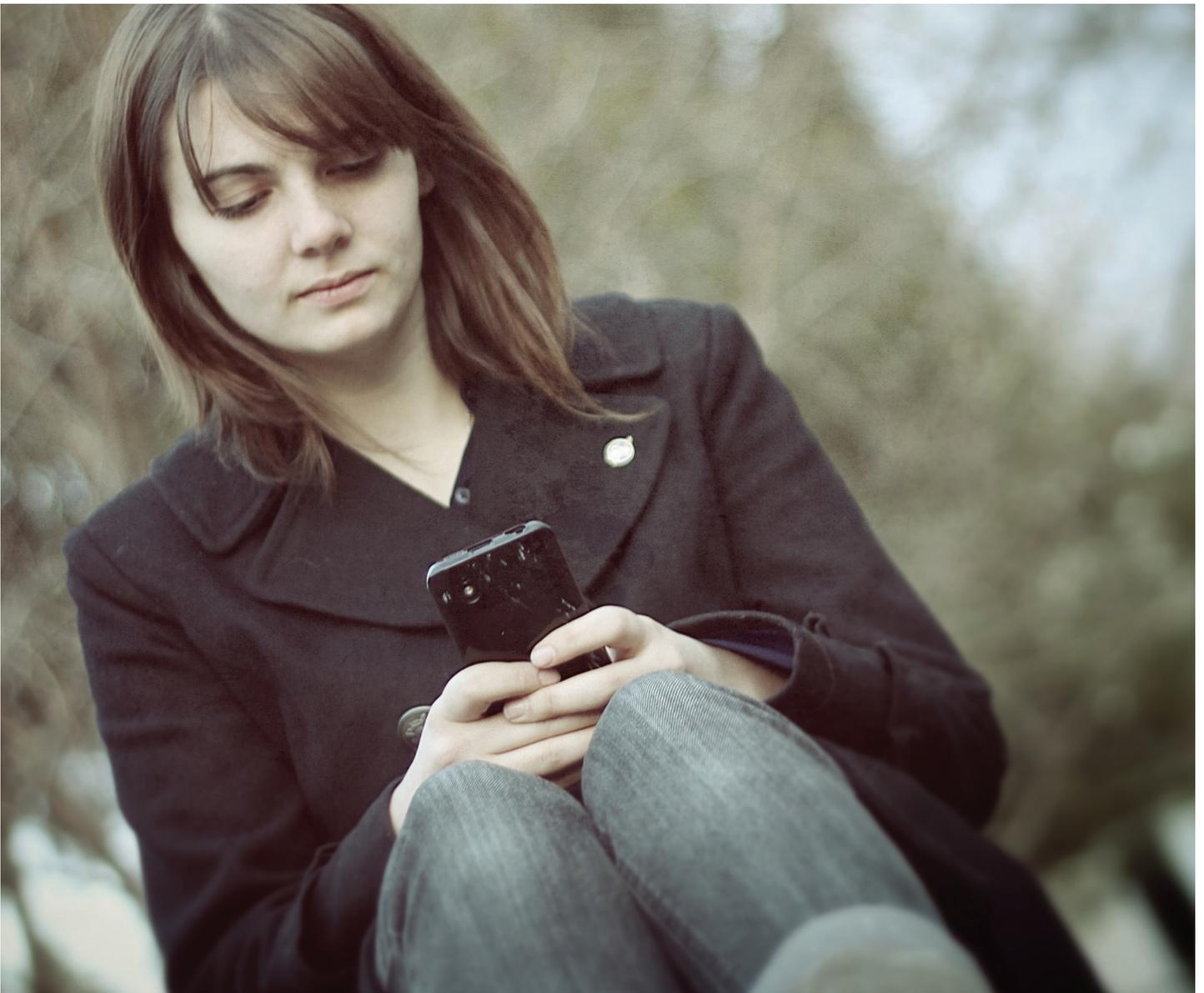


North Bay Regional
Health Centre



Centre régional
de santé de North Bay

FAMILY RESOURCE GUIDE



Regional Early Intervention in Psychosis Program
www.psychosis101.ca

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WHAT IS PSYCHOSIS?

What Is *Psychosis*



Early Psychosis Intervention Program

The word “psychosis” is used to describe conditions that affect the mind, in which there has been some loss of contact with reality.

When someone experiences symptoms of psychosis, their condition is referred to as a psychotic episode. The terms “early psychosis” or “first-episode psychosis” simply mean that an individual is experiencing psychosis for the first time.

Psychosis affects an individual’s thoughts, feelings, and behaviours. The experience of psychosis varies greatly from person to person and two individuals experiencing psychosis may have very different symptoms.

Who gets psychosis?

- approximately 3% of all individuals will experience an episode of psychosis in their lifetime
- psychosis affects males and females equally
- first episodes of psychosis generally develop in young people in their late teens to mid-twenties
- psychosis occurs across cultures and levels of socioeconomic status

There are three phases to a psychotic episode:

1. Prodromal Phase

Looking back at the period before the psychosis became evident, there are often changes in feelings, thoughts, perceptions

and behaviours. This period is called the “prodrome” and these early changes are referred to as “prodromal” symptoms.

Prodromal symptoms vary from person to person and some people may not experience a prodrome. The duration of the prodromal phase is quite variable, although it usually spans several months.

Some of the more common prodromal symptoms are:

- reduced concentration, attention
- reduced drive and motivation, lack of energy
- depressed mood
- sleep disturbance
- anxiety
- social withdrawal
- suspiciousness
- deterioration in role functioning (no longer attending school or going to work)
- irritability

2. Acute Phase

During the acute phase, typical psychotic symptoms emerge.

The symptoms of psychosis are frequently separated into “positive” and “negative” categories.

Positive Symptoms

These symptoms are referred to as “positive” because they are viewed as an excess or distortion

of the individual’s normal functioning.

Some of the positive symptoms include:

Delusions

Delusions are false beliefs that are firmly held and out of keeping with the person’s cultural environment. These beliefs are very significant to the individual but are not accepted by other people.

Some of the more common delusions include beliefs of:

- being followed or monitored
- being plotted against
- having special abilities or “powers”
- certain songs or comments are communicating a hidden message
- being controlled by forces or other individuals
- having one’s thoughts being broadcast so others can hear them

Hallucinations.

Hallucinations involve seeing, hearing, feeling, smelling, or tasting something that is not actually there. The most common type of hallucination involves hearing things – such as voices or particular sounds.

Disorganized Speech or Behaviour

The speech of individuals with psychosis may be disorganized - the person might frequently move from one topic to the next

or the person's speech may be so disorganized as to not be understandable.

The behaviour of individuals with psychosis also may be disorganized – and the person may have difficulties performing activities of daily living (e.g., cooking, self-care, etc.) or display inappropriate behaviours or affect (e.g., laughing while describing a personal tragedy).

Negative Symptoms

Negative symptoms reflect a decrease in or loss of normal functions. These symptoms are often less evident than positive symptoms and require careful assessment to ascertain if they are indeed psychotic symptoms or if they are related to something else (such as depressed mood or medication side effects).

Some examples of negative symptoms include:

- little display of emotions
- not speaking very much
- difficulties with coming up with ideas or thinking
- decreased ability to initiate tasks
- lowered levels of motivation or drive

Other symptoms or problems apparent during the acute phase

It is common for other symptoms or problems to occur along with the psychotic symptoms.

Some examples of other problems that may be evident include:

- Depression
- Anxiety
- Suicidal thoughts or behaviours
- Substance abuse
- Difficulties functioning
- Sleep disturbance

3. Recovery Phase

“Psychosis is treatable. Recovery is expected.”

With appropriate treatments, the great majority of people recover well from their initial episode of psychosis.

Once the psychosis has responded to treatment, problems such as depression, anxiety disorders, decreased self-esteem and social impairment need to be addressed during the recovery phase. Assistance with employment, school, and other responsibilities may also be required at this time.

The recovery process will vary from person to person in terms of duration and degree of functional improvement. Some people will recover from the psychosis very quickly and be ready to return to their life and responsibilities soon after. Other individuals will need time to respond to treatment and may need to return to their responsibilities more gradually.

Following recovery from a first episode, a significant number of

people will never experience a second episode (called a relapse) of psychosis. However, the risk of relapse is greatly increased if medication and other treatments are discontinued prematurely.

The likelihood of a complete recovery is much better with proper treatment.

Diagnosing Psychosis

Psychosis is associated with several different mental and physical disorders.

Some of the more common diagnoses associated with psychosis include:

- schizophrenia
- schizophreniform disorder
- Brief reactive psychotic disorder
- Bipolar disorder
- Psychotic depression
- Schizoaffective disorder

There are also other disorders in which psychosis may occur.

Sometimes, certain specialized types of assessments (such as a brain scan or assessment of cognitive functioning) may aid in clarifying the specific diagnosis and these will be arranged when it is felt they may be helpful.

In order to properly diagnose what specific type of psychotic disorder an individual has, patterns of symptoms must be assessed often over many months. For this reason, determining the diagnosis may take some time.

What Causes Psychosis

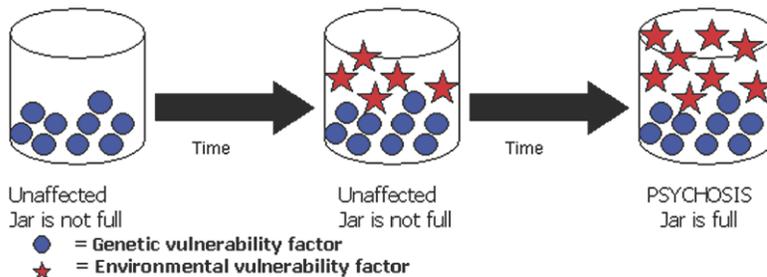


Early Psychosis Intervention Program

What Causes Psychosis

There are many different kinds of psychosis, including organic psychosis, drug-induced psychosis, depressive

these vulnerability factors can combine to cause psychosis. A full jar represents a person with psychosis.



psychosis, schizophreniform disorder, schizoaffective disorder, schizophrenia and bipolar disorder. Although most of these different types of psychosis are caused in much the same way, we will be using schizophrenia and bipolar disorder in the examples below, as we understand these kinds of psychosis better than others.

It is a chemical imbalance in the brain that is thought to cause psychosis. In the last few decades, research has helped us in understanding that this imbalance is most often caused by a **combination** of genetic vulnerability and environmental vulnerability.

Each person will have different levels of these vulnerabilities, but it is important to understand that a combination of **several vulnerability factors**, both genetic and environmental, is needed in order for a person to develop psychosis. The diagram above shows how

Genetic Vulnerability

Our DNA contains genes, which give our bodies the instructions on how to make proteins. Proteins are the building blocks of all the different cells in our bodies, including neurotransmitters, receptors and transporters in the brain.

When there is a mistake in a gene, it is called a mutation. Mutations are common and everyone has some. Because genes contain the instructions on how to make proteins, the ones with mistakes can produce proteins that may not perform their functions as well as they should. When a mutation occurs in a gene that contains the instructions for a brain protein, like a neurotransmitter, it may contribute to a chemical imbalance in the brain, which is one of the factors in the development of psychosis.

Recent research has found mutations in several genes, which scientists think might contribute to schizophrenia and bipolar disorder. Being able to find and identify these genes may lead to better diagnosis and treatment of psychosis.

Environmental Vulnerability

There are many different environmental factors that have each been shown to lead to a small increase in the likelihood of someone developing psychosis. For example, research has shown that it is two times more common for individuals with schizophrenia to have had a difficult delivery at birth. Other environmental vulnerability factors include being born in the winter months, being brought up in a big city, immigration, childhood head injury, stressful life events and use of street drugs.

Chances for people to develop psychosis

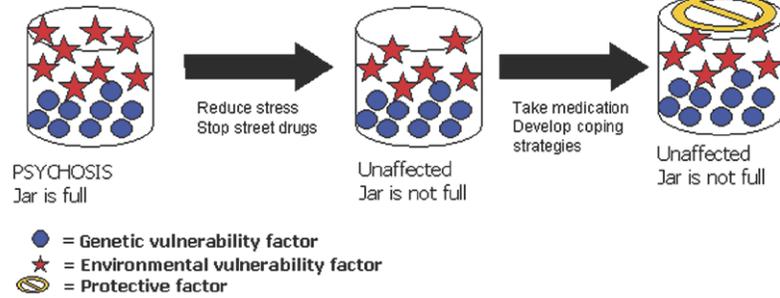
Psychosis is common, affecting about 3% of the population. Schizophrenia affects about 1% of the population, bipolar disorder affects about 1-2% of the population and major depression affects about 5-10% of the population.

The chance for developing these illnesses are higher for people who have a family member who is affected. For example, a person with a brother, sister or parent with schizophrenia or bipolar disorder has a 10 to 15% chance of developing the same disorders themselves (which is

also an 85 to 90% probability of not developing schizophrenia or bipolar disorder!).

For hundreds of years, people have known that some kinds of psychosis seem to ‘run in families’, but the reasons for this were unclear. In the last few decades, research has been helping us to better understand why this seems to happen.

IMPORTANT: If you have a family member with psychosis and you are concerned about the chances of yourself or other family members developing a similar illness, ask your family doctor or psychiatrist to refer you to the local Medical Genetics department for a genetic counseling appointment. A genetic counselor will take a detailed family history and help you to understand the illness in your family, appreciate the way genes contribute to the disorder and educate you about the risk of recurrence.



Reducing the chance of relapse

Stressful life events often precede an episode of psychosis, acting as a trigger. Stressors can range from everyday hassles, to accidents or bereavements. Developing effective methods of managing and coping with stress can help to reduce the chance of relapse. If the person is able to have a supportive, calm and relaxed home life, the problems are less likely to return.

Some types of street drugs can trigger an episode of psychosis in people who have a genetic vulnerability. Some drugs, like amphetamines and cocaine, can cause drug-induced psychosis. Stopping the use of these street drugs can reduce the chance of relapse.

Medications prescribed by your psychiatrist not only reduce the chance of relapse, they also work to reduce symptoms of psychosis. The diagram above shows how medications can reduce the chance of relapse.

WHAT PARENTS CAN DO...

Pay attention to changes in your son's or daughter's behaviours and abilities.

Be aware that a noticeable, persistent change to "who they usually are" or how they function could signal psychosis. Friends, teachers and others who know your child are also likely to notice such changes.

Trust yourself. You know your own child better than anyone. And you are your child's best advocate. If you believe that "something isn't quite right", keep looking until you find the help you need. Psychosis is not the only explanation for a young person's "odd" behaviours, but it's a serious possibility that must be considered.

Don't wait. Psychosis does not typically disappear on its own. If your son or daughter has psychosis, prompt and appropriate treatment is necessary – the sooner the better.

Seek help. Talk to your family doctor or a mental health professional. They can see that your son or daughter receives a thorough assessment. It is important to consult with a medical professional who is familiar with early psychosis. Some cities in Canada now have centres designed specifically for the treatment of early psychosis.

Get the facts. Learn more about psychosis in youth. Information is available. For example, visit the web site developed by the Early Psychosis Prevention and Intervention Centre (EPPIC) in Australia: www.vicnet.net.au/~eppic. Most public libraries provide free internet access.

Face your fears. To many, mental illness is a frightening thought. Unfortunately, this fear can discourage people from seeking help early. But neither denial of the problem nor delay will help a young person with psychosis. Much of the fear surrounding mental illness is based on myths and misunderstandings. Mental illness need not be feared. Like other medical conditions, mental illness needs to be treated.

Persistent changes in behaviour, personality or functioning may indicate psychosis.

Psychosis is treatable.

Visit the CMHA National Office
website: www.cmha.ca

Acknowledgements

EPPIC Early Psychosis Training Pack, Gardiner-Caldwell Communications Ltd., 1997.

Nova Scotia Hospital Information Sheets, 1997.

Quotes were provided by parents of youth with psychosis.

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March 2000

Youth and Psychosis

What Parents Should Know...



CANADIAN MENTAL
HEALTH ASSOCIATION
L'ASSOCIATION CANADIENNE
POUR LA SANTÉ MENTALE

“It was hard to believe. My son had been so spontaneous, funny, bright. He seemed to have everything going. Then the picture just changed so drastically. At first, the illness was overwhelming.”

PARENTS CAN HELP...

Psychosis is a serious but treatable medical condition affecting the brain. It is characterized by some loss of contact with reality and can dramatically change a person's thoughts, beliefs, perceptions and/or behaviours. Psychosis is estimated to affect up to 3% of the population. Males and females are affected equally.

It is difficult to know the cause of psychosis the first time it occurs. Psychosis is associated with a number of medical conditions including schizophrenia, depression, bipolar (manic depressive) disorder, and substance abuse, among others. As well, members of families with a history of psychotic illness are at risk for developing psychosis themselves.

While psychosis can happen to anyone, symptoms of psychosis most often develop during adolescence and young adulthood. It can be an extremely distressing condition for the individuals affected, and for their families and friends. Without prompt and effective treatment, psychosis can derail young lives.

Many young people who develop psychosis are still residing with their families. Because of this, parents and other family members can play an important role in helping to identify the signs of psychosis, in seeking out treatment and in promoting the recovery process.

“The people who have the breakdown are not the ones who are necessarily aware of it. It's the people around them. And it's the people around them who need to know what the signs are and how to get help.”

THERE ARE SIGNS...

A person with psychosis may experience one or more of the following symptoms:

- hear voices that no one else hears
- see things that aren't there
- believe that others can influence their thoughts, or that they can influence the thoughts of others
- believe that they are being watched, followed or persecuted by others
- feel their thoughts have sped up or slowed down

Often there are other signs that family members or friends might notice, such as:

- withdrawal and loss of interest in socializing
- loss of energy or motivation
- problems with memory and concentration
- deterioration in work or study
- lack of attention to personal hygiene
- confused speech or difficulty communicating
- lack of emotional response or inappropriate emotional display
- general suspiciousness
- sleep or appetite disturbances
- unusual behaviours

“We thought our daughter was just lazy. She wouldn't do anything. So we'd get annoyed and get on her case. If we'd known she was ill, we wouldn't have pushed her. The stress just probably made it worse.”

Sometimes symptoms appear suddenly and are very obvious to everyone. But, psychosis can also emerge gradually, making it difficult to spot early signs and symptoms. Early identification can also be difficult because the teen years typically are marked by upheavals in behaviour, motivation and mood. But in fact, parents of youth with psychosis often remark in hindsight that they knew “something wasn't quite right”; that their child “just wasn't himself”.

If you see persistent changes that strike you as odd, don't wait. Trust your instincts. Get help.

“We saw things happening. His friends did. His brothers did. They thought it was drugs and thought ‘we'd better keep it from mum and dad, we don't want them to get upset’. But when I started seeing things happening – the monotone voice, the way he walked – just so much was happening within a six month period, I thought ‘there is something wrong here’.”

WITH TREATMENT THERE'S HOPE...

Untreated psychosis is associated with a more difficult recovery and can lead to increased family distress, substance abuse, depression and increased risk of suicide.

Proper early treatment reduces the need for hospitalization and promotes full recovery. Treatment consists of low-dose, anti-psychotic medications, education, training and support. Newer medications can effectively treat psychotic symptoms without the side effects common in the past. Young people with psychosis are encouraged to maintain their routines as much as possible. Recovery is also improved when the family itself is accepting, non-confrontational and supportive; stress can make psychosis worse.

Psychosis is nobody's fault. It can happen to anyone. It is important to seek help as soon as symptoms appear.

Psychosis is a medical condition that responds well to treatment. With prompt and appropriate treatment, most people will recover fully.

WHAT DOES PSYCHOSIS
LOOK LIKE?

Symptoms of Psychosis & What to Do About Them

A Guide for Family and Friends

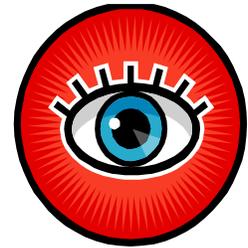
“Who knew I’d have to learn to cope with living with someone with psychotic symptoms? I sure didn’t. Gradually I’ve learned how to help my brother live with his symptoms, and to adjust to being around him successfully in the good times and the difficult ones.”

Delusions & hallucinations

How a person might act:

Note: Unusual beliefs and behaviour may be part of a person’s normal belief system or culture. If they are, they may have nothing to do with their mental illness.

- ⇒ Talking to voices that are not there
- ⇒ Talking about a strongly held false belief (delusion) or something they hear, see or feel that is not there (hallucination).
- ⇒ Behaving oddly because they have a false belief or are hearing, seeing or feeling something that is not really there. e.g.: avoiding water because the person thinks it is poisoned
- ⇒ Preaching because they believe they are Jesus Christ
- ⇒ Being distracted and unable to concentrate (see below as well).



Helpful things to do:

- ♥ Avoid arguing with the person about their delusions. Delusions are extremely fixed and difficult to change
- ♥ Connect with the emotion of the delusion or hallucination e.g. ‘It must be frightening to believe that you are Jesus Christ’
- ♥ Calm things down - reduce the number of people and noise around the person
- ♥ Show compassion for the how the person feels about their false belief and do what you can to help where possible when the person is acutely unwell e.g.: turn off the TV if they think it is talking to them.



Symptoms of Psychosis and what to do about them

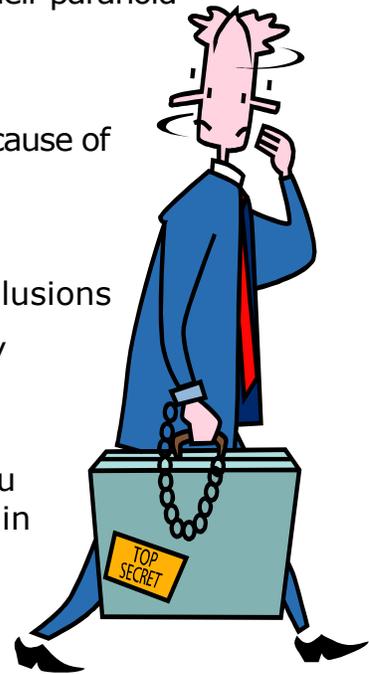
Being Paranoid (a delusion)

How the person might act:

- ⇒ Behaving as though they are being followed, tricked or spied on
- ⇒ Being overly sensitive and suspicious
- ⇒ Behaving in a way that goes along with what their paranoid belief
- ⇒ Being irritable
- ⇒ Being aggressive – the person could be afraid because of the delusion and may act out of that fear.

Helpful things to do:

- ♥ Avoid arguing with the person about their delusions
- ♥ Let them know you can understand why they would feel afraid, given the things they are thinking.
- ♥ Show them with your body language that you are on the same side. Sit beside rather than in front of the person
- ♥ Stay calm
- ♥ Consider the safety of you and the person.



Disordered thinking and behaviour

How the person might act:

- ⇒ They may talk in a disorganized way, and not make much sense.
- ⇒ They might not seem to cooperate or seem 'spacey' and 'not there'
- ⇒ Have a hard time doing regular things like as making meals and keeping themselves clean
- ⇒ Dressing inappropriately or strangely e.g. lots of clothes on a hot day.



Symptoms of Psychosis and what to do about them

Disordered Thinking & Behaviour

Helpful things to do

- ♥ Speak to the person in a clear and simple way
- ♥ If necessary, repeat things talking slowly and allowing plenty of time for the person to answer.
- ♥ Give step-by-step instructions.



Not showing a wide range of feelings (Affective flattening)

How the person might act

- ⇒ The person's face may seem not to move or respond, or have no expression
- ⇒ The person may not meet your eye or look away
- ⇒ The person may not express much using their body.

Helpful things to do

- ♥ Be aware that this is a symptom of the illness; don't take it personally.
- ♥ Try not to get frustrated or hurt that the person isn't showing their feelings much.
- ♥ Be aware that just because the person is not showing their feelings very much, it does not mean that they are not feeling anything.



Symptoms of Psychosis and what to do about them

Being silent or not talking much



What the person might do

- ⇒ Speak or communicate less
- ⇒ Give short and empty replies
- ⇒ Seem to have difficulty putting words together
- ⇒ The person appears to be thinking less.

Helpful things to do

- ♥ Speak simply and clearly to them and accept it when they speak simply in return
- ♥ Keep talking to them no matter how they respond – don't assume the person cannot understand you, even if they don't respond much.

Having trouble starting and keeping going with activities or getting things done

What the person may do

- ⇒ Sitting for a long time doing nothing
- ⇒ Not showing much interest in participating in any sort of activity
- ⇒ Not have much motivation.



Helpful Things to do

- ♥ Understand and acknowledge that these are again symptoms of the illness. The person is not behaving this way on purpose.
- ♥ Try not to become frustrated with how they are acting
- ♥ Encourage them gently to participate in activities.

Psychosis and Depression

Depression

Depression is not a symptom of psychosis but people who have psychosis often are depressed as well. Also, psychotic symptoms can be part of depression.

How a person might act

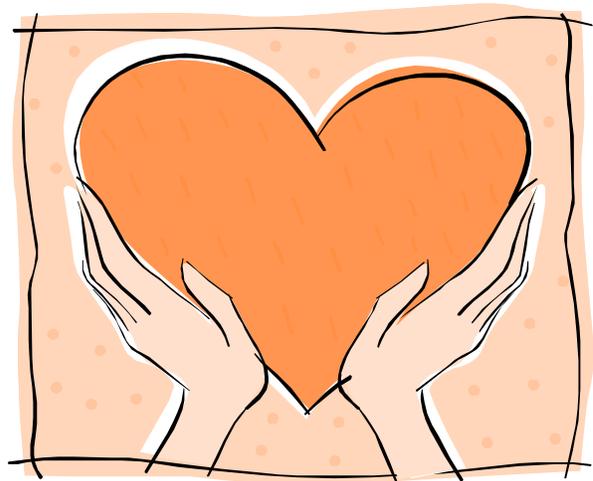
- ⇒ A person might talk about feeling helpless or hopeless
- ⇒ The person seems depressed most of the day and spends a lot of time crying
- ⇒ They don't seem to be interested or feel pleasure in activities. The person may not move much at all but just sit staring into space
- ⇒ The person may be tired and not have much energy
- ⇒ Weight loss or gain
- ⇒ Difficulty sleeping and early waking (usually between 2 and 4 am)
- ⇒ The person may feel worthless or guilty. They may have the belief that they have done something terrible and need to be punished
- ⇒ Having a hard time concentrating and thinking. Having a hard time putting sentences and thoughts together, and may give very short responses and need prompting.
- ⇒ Thinking about death a lot
- ⇒ Skin may become coarse and dry, and hair limp and greasy or sparse.



Psychosis and Depression

Helpful Things to Do

- ♥ Be aware that depression is a very real condition reflecting changes in the chemicals of the brain and that it is not a reflection of being weak. You cannot cheer the person up out of this state.
- ♥ Be aware of suicide risk. If you are concerned, do not be afraid to talk to the person about suicide – this will not make them act on possible thoughts of suicide. Talk with their treating team about this issue. This issue may be a reason for hospitalisation
- ♥ If the person seems unexpectedly happy and begins to give possessions away and organise their affairs, be aware that this is a risk factor for suicide and get help immediately
- ♥ Be aware that poor concentration from depression can cause safety issues e.g. if someone works with knives or drives.
- ♥ Be aware of whether the person is drinking enough water or eating properly. Again, these issues may need to be attended to in hospital.
- ♥ Connect with how the person is feeling rather than trying to change their mind eg 'It must be very hard feeling so low'
- ♥ Let the person know that you care about them.
- ♥ Try to sit beside and be in the person's space – often people who are depressed do not like to make demands on others but they appreciate company. Likewise, you will need to do the talking rather than expecting the person to do so
- ♥ Let the person know where you are going even if there is no response.



Mood and Psychosis

Signs & symptoms of psychosis for people with mood disorders



“Psychotic symptoms were some of the scariest parts of my mood disorder. At first, I didn’t talk about them, but I realized in order to get well I needed help with this too. Telling my doctor about the strange things I was experiencing was the best thing I did for my own health.”

Hearing voices and seeing things that other’s don’t.

Feeling suspicious and paranoid.

Feeling and behaving in ways that are not yourself.

Having difficulty thinking and organizing your thoughts

If you have depression or bipolar disorder and are experiencing some of these symptoms, it is important to tell your doctor about them. While not common, psychotic symptoms can be a part of a number of mental illnesses.

It is in the normal range of human experience to have symptoms such as hearing voices or having visual hallucinations very occasionally, especially on the edge of sleep or waking, or if you have not slept or eaten for a long time. However, if you have these types of symptoms often or persistently, then it’s time to talk to your doctor.

While schizophrenia is commonly thought of as the main mental illness that has psychotic symptoms, there are several mental illnesses that can have psychotic symptoms associated with them. This is not surprising, as these illnesses tend to be connected to similar types of problems in the brain.

Bipolar disorder—in bipolar disorder, psychotic symptoms tend to fit in with the person’s mood. For example a person who is depressed might hear voices telling them to kill themselves, or a person with mania might believe they have special supernatural powers.

Schizoaffective disorder—A person with this disorder has both a mood disorder and psychosis, and the voices, hallucinations or false beliefs are more independent of what is going on with their mood, and may be present even if their mood is stable.

Depression and Post Partum Depression—a person who is depressed may hear voices telling them things that go with the depression.

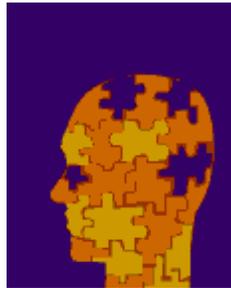
Mood and Psychosis

Signs & symptoms of psychosis for people with mood disorders

Continued...

What Causes Psychosis?

We don't completely understand what causes psychosis or the psychotic symptoms sometimes associated with mood disorders. Many medical researchers think some people are born with a vulnerability or tendency towards psychosis. This doesn't mean they'll automatically become ill, but that if they are exposed to enough stress it can trigger psychosis.



Vulnerabilities may be genetic (inherited through your genes from your parents) or caused by things that happen during pregnancy or to the baby while being born. Stresses might include difficult life events or situations or drug use. Psychosis is sometimes also the result of other medical problems.

Psychosis is a medical condition and it can be treated.

Almost always, psychosis improves with treatment. The sooner a person is treated the smoother their recovery will be.

How to Manage Symptoms

If you are already receiving treatment for your mood disorder, speaking to your doctor or care team about these experiences is a good place to start. Your medications may have to be adjusted to deal with these symptoms as well.



Cognitive behavioural therapy has been demonstrated to have good results with psychosis symptoms when combined with medication.

Many street drugs such as crystal meth (methamphetamine) and cannabis (marijuana) have been shown to increase psychotic symptoms. These drugs do no one's brain any good, but if you have experienced psychotic symptoms it is particularly important to avoid these drugs.

"You don't have to deal with this alone. Help is available."

Help is available. Treatment works.

For more information:

BC Schizophrenia Society—www.bcscs.org Information on psychosis and information for families.

Early Psychosis Intervention Information www.psychosissucks.ca

Other fact sheets in this BC Partners series on topics related to psychosis, including post partum depression & psychosis, and resources for families and children are available at www.heretohelp.bc.ca

WHAT CAN I DO?

Do's And Don'ts

Families coping with psychosis need to know:

- How to be *effective* in getting help for someone who is seriously ill
- What questions to ask
- Who to see and where to go
- How "the system" works and how best to interact with it

Do's

1. KEEP RECORDS

Try to keep a record of everything ---Nothing is unimportant!

- Keep a list of names, addresses, phone/fax numbers, etc.
- Start keeping a notebook or diary. The ability to be precise about *dates and times* of incidents, *who said what, and what subsequently happened*, is crucial. (Why? Because it helps professionals understand what/where the person is at.)
- Keep all notices and letters you receive
- Keep copies of everything you mail

2. COMMUNICATE EFFECTIVELY

When someone is ill with psychosis, patients and families are often so overwhelmed by the experience that vague information or jargon gets accepted as substantive. *Family members need honest, direct information.* They also need specific, practical suggestions about how to cope during acute and stable phases of the illness.

To get positive results:

- Be polite. Keep all conversations to the point. Ask for specific information and ***write it down.***
- Get the name of the early intervention clinician. Arrange for an appointment with this person. During the meeting, ask to review your relative's ***treatment plan.*** Ask to participate in the development of the Plan.
- Help keep meetings short---come prepared with a list of specific questions. Some sample questions might be: "What symptoms should we be most concerned about? What can we do to help your family member deal with these? What medications are being prescribed? How much? How often? How is medication monitored? Are there possible side-effects? (Also, if your family member is in hospital - "When can we meet to talk about discharge planning?")

- Keep your family member informed of everything you plan to do.
- Be polite but assertive. As a taxpayer, you are entitled to information, respect, and courtesy. Your taxes go to pay health care employees. You are not asking for gratuities. *You are simply trying to help get the job done.*
- You won't want to do this immediately, but sooner or later you will want to educate yourself about the mental health system. Learn about the departments involved, and about the chain of command in each department relevant to your relative's needs. Familiarize yourself with services and resources outside the mental health centre.
- Write letters of appreciation when warranted. Write letters of criticism when necessary. Send these to the head of Mental Health Services or to the hospital concerned.

Don'ts

REMEMBER:

1. Some actions are effective --- others are counter-productive
2. Most professionals want to do a good job
3. Many direct-service staff are over-scheduled

These points hold true throughout the system --- mental health centres, supervised housing facilities, hospitals, and forensic institutes. Direct staff (those who work directly with consumers --- social workers, therapists, nurses, doctors, continuing care workers) sometimes have unreasonably heavy caseloads. Knowing this can help you maintain some perspective on what to reasonably expect.

Always start by assuming that the staff care and want to help your relative recover. The following will help both you and the professionals:

- Do not be late for appointments
- Do not make excessive demands on staff, or harass them with special requests
- Do not call all the time, or have long phone conversations filled with elaborate details

Avoid things that DON'T WORK!

- Dealing with people just because they are accessible, but who actually have little or no power (i.e., secretaries, receptionists)
- Always criticizing and never acknowledging mental health professionals for their good intentions and hard work
- Only calling when there is a crisis, rather than establishing and maintaining a relationship with case workers, social workers, psychiatrists, etc.

- Always expecting immediate attention and blowing up if you don't get it.

Courtesy is something we all aim for. Do not, however, overlook the fact that professionals must also be accountable:

- Don't feel you *should* know the meaning of technical terms or phrases.
- Don't hesitate to ask for clarification in plain language, if you are unsure of specific issues.
- Don't accept vague answers or statements that are confusing. If someone says "*We are observing your daughter carefully---* they are providing you with no information!
- Don't be afraid to ask for an explanation of procedures. Try to understand who does the observing, exactly *what* is being observed, how this information is documented, if and *when* you can obtain a progress report, and so on.
- Don't allow yourself to be intimidated (and don't try to intimidate others.)

Finally, NEVER allow guilt or shame to play any part in these proceedings. Your goal is to help obtain proper medical care for someone who is suffering from a neurobiological disorder. Outdated notions of stigma have no place here.

How to Help People Recovering from Psychosis

What Family and Friends Need to Know



“My daughter didn’t know at first what she needed, but she did need us. It took some time, but now her good days are the norm rather than the exception.”

What to Expect

When your family member comes home from the hospital, many of their symptoms may be reduced or gone, but some may remain. You can help them recover by maintaining a calm, positive environment for them, and by educating yourself on their illness.

It is quite normal for a person who has just experienced psychosis to:

- Sleep much more than usual
- Need to have a lot of quiet, alone time.
- Be slower and not feel able to do much.

Slowing down and resting is part of allowing the brain to heal. Each person will recover at their own pace, and it could take up to a year of this type of rest for someone to recover. It is a good idea to gently encourage the person to do simple chores, hang out with family or go out to do activities they used to like when they feel up to it.

Your relative may seem emotionally distant during this time as well. This is part of the illness as well, and is not about their relationship with you. When around people, they may be very quiet and just sit and watch, which is quite normal.



Positive Factors in Promoting Recovery

These are some of the factors on a smooth road to recovery.

- Strong social support networks
- Stable living condition
- Safe and structured environment
- Sense of purpose or direction, feeling of contributing to society
- Someone to discuss experiences and feelings with and provide practical help
- A good understanding of what has happened
- Physical well-being
- Effective medication without distressing side-effects
- Sense of realistic expectation and hope about the future

How to Help People Recovering from Psychosis

What Family and Friends Need to Know

Continued...

Identifying relapse triggers

It is useful to think back on the signs your family member showed when they were becoming ill. Often, but not always, they will show similar signs if they are heading into a relapse or are under too much stress. Your relative may have signs that are particular to them. **The following are some common warning signs:** hallucinations / voices, suspiciousness, disorganized thoughts, speech that doesn't make sense, difficulty concentrating, bizarre behaviour, a belief they have special powers or feeling rested after almost no sleep for several days. Changes in sleeping habits, anxiety, agitation, depression, difficulties concentrating, isolating, and irritability may be signs of a relapse or they may be signs the person is under too much stress.

Supporting Health

- ♥ Calm, quiet environment.
- ♥ Gentle encouragement.
- ♥ Let the person recover at their own pace.
- ♥ Keep healthy foods around.
- ♥ Provide encouragement if the person needs help with daily chores and personal care.
- ♥ Give them their space to have quiet, rest and calm while they recover.



For More Information

Early Psychosis Intervention Program—Fraser South Health Authority www.psychosissucks.ca This site includes a lot of useful information including a booklet for families in the 'downloads' section. The booklet includes good information for families on coping with symptoms.

BC Schizophrenia Society—Also offers resources on psychosis for families. www.bcscs.org

"How You Can Help—A Toolkit for Families" - at the BC Partners for Mental Health & Addictions Information site at www.heretohelp.bc.ca



Early Psychosis Intervention Program

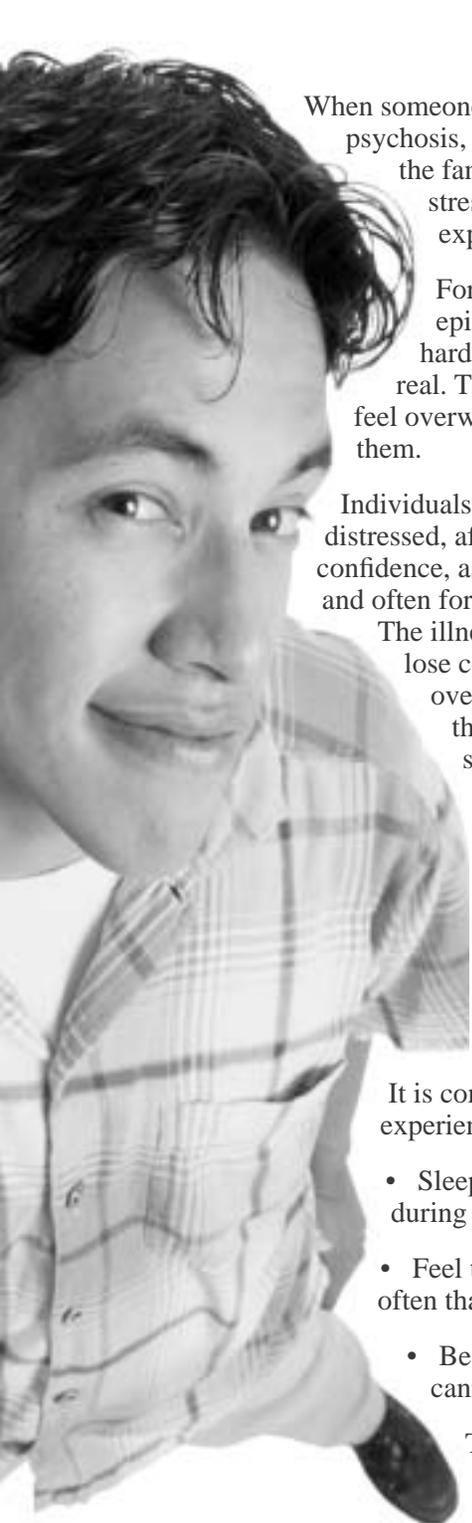
Coping

when someone in
your family has
Psychosis



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When someone in the family has symptoms of psychosis, it is confusing and distressing for the family and friends. In this time of stress it can be helpful to learn what to expect and what to do.

For a person dealing with a first episode psychosis, the illness makes it hard to tell what is real from what is not real. This illness also makes the person feel overwhelmed by things going on around them.

Individuals are likely to feel confused, distressed, afraid, and lacking in self-confidence, as they become ill, in hospital and often for some time after a hospital stay.

The illness may have caused them to lose control of their thoughts and feel overwhelmed by the world around them. They may have ideas that someone is persecuting them or talking about them, or they may also hear voices or feel depressed.

The person has had a serious shock. The body and brain need rest to be able to cope, just as we need rest to get over the flu. With a psychotic illness, however, recovery usually takes longer.

It is common for individuals who have just experienced psychosis to:

- Sleep longer hours every night (or even during the day) for many months.
- Feel the need to be quiet and alone more often than other people.
- Be less active and feel that they cannot or do not want to do much.

These behaviours are natural ways of slowing down in order to help the body and brain recover.

It is best to let the person recover at his or her own pace instead of expecting them to get back to their previous functioning. For many people, it may take several months or a year to recover. Putting too much pressure on the person to get up or go out and do things can slow recovery.

On the other hand, this DOES NOT MEAN the person needs to lie down all day, have everything done for them, or never do any household chores. It is a good idea to gently encourage the individual to help with simple chores, chat with the family, or ask if they would like to go out on some outing they used to like. If the person says no at this stage you should leave him or her alone, saying “Okay, but you are welcome to come when you want to”.

It is not a good idea to do everything for your relative, or to do so much that you feel worn out. For example, some family members may feel they have to tidy up after their relative or do all their cooking for them. It is important to encourage your relative to take responsibility for such tasks, but perhaps offer to help if necessary. You may need to supervise them while they are trying to make a meal, as their memory and thinking abilities are slowed. It is important to let your relative know they will recover and you will support them in this process.

It is important for your recovering relative to have a quiet place to go. This can be quite helpful for the person to cope with symptoms they are experiencing. It is NOT a personal rejection of you or the family if the person withdraws to his or her bedroom quite frequently. It is only if your relative stays there all the time that you need to be concerned. If the withdrawal is excessive, it can mean that some symptoms may be reoccurring.

For the same reason (the need for calm, quiet and simplicity) you may find your relative being emotionally distant, not very affectionate, or expressing very little feeling. This is part of the disorder, and is NOT a personal reflection of anyone. In the same way as the need for quiet withdrawal, this emotional distance is simply the need to cut down on all the confusing stimulation.

Often the person may like to just sit in company and watch or listen to people. It is good to accept these behaviours and not be worried by your relative saying nothing when in the company of others.

You may find the person likes to listen to music or play video games a lot of the time. The music or videos may be a way of drowning out the distressing ‘voices’ or thoughts. Earphones or a discman may be helpful.

Your relative may sometimes talk in a strange way which you may find hard to follow. The talk may seem unconnected or irrelevant to the conversation at times. Or your relative may make unexpected remarks that do not make sense. This 'odd' conversation may happen because of difficulties in thinking clearly or because the person is hearing voices that seem very real, although they are not there.

It is important to remember that the person with psychosis often acts and speaks quite normally. Symptoms often get better and may re-appear only under stress. It is important to learn about your relative's symptoms and the course psychosis typically takes. Do not forget, your relative has many successful coping skills. It may be difficult for them to recall these skills when they are trying to recover.

There are also ways of making yourself feel better about the difficult behaviour, even if you cannot change the other person's behaviour. It is important to watch your own health. You cannot help your relative if you become ill. Setting limits and monitoring your own stress levels are important for your relative and everyone in the family.

It is important to encourage the other person to control his or her own behaviour. Before working out the best thing to do, try to understand what is happening to your mentally ill relative. Your relative may not be able to help doing some things because these behaviours may be a part of the illness itself, however, much behaviour can be changed with good management. With your help, the individual may be able to improve his or her sense of control. Ask your relative's permission to discuss the situation with their EPI Clinician/Psychiatrist.

The following suggestions are made to help you cope with certain behaviours associated with psychosis. If these suggestions do not work for you, make sure you consult with your EPI Clinician or Psychiatrist to find other strategies that may work instead. Perhaps the particular suggestion needs to be used differently in your situation or maybe a different method will work better. Psychosis is treatable. Recovery is expected.

SYMPTOMS and What you can do

Hallucinations - when your relative hears, or sees things that you do not hear or see. The person may talk to him or herself or otherwise seem to be responding to things that aren't there. Remember the experiences are real to the person having them and can be quite frightening and distressful. Hallucinations can involve any of the five senses.

Helpful

- Staying calm.
- Do distract the person if you can by: involving the person in something interesting; offering something to look at (e.g., newspaper article).
- Asking the person to help you find something (e.g., to find the newspaper); or to focus on some other activity.
- Do engage the person in pleasant conversation. You may ask about the experience if the person wants to talk about what they are seeing or hearing.
- Encourage the person to be with other positive and supportive people he or she knows well.

Not Helpful

- Blaming yourself or another family member.
- Panicking or getting angry.
- Don't try and figure out what he or she is talking about or to whom he or she is talking.
- Laughing about these hallucinations or strange talk.
- Don't ask him or her to try to *force* the voices to stop.
- Trying to minimize the experience for your relative. Remember it is real to them.

Sleeping or Withdrawing a lot of the Time, or **Sleeping at Odd Times**

Helpful

- Do leave the person alone but make regular contact whenever he or she comes out.
- Letting your relative know you are there if needed.
- Remember that he or she may need sleep while recovering.
- Gently encourage other activities which are not too demanding (e.g., watching TV, washing dishes, pet care, etc).
- Do go out and enjoy yourself with other people.
- Do occasionally offer a cup of tea, coffee or juice.
- Ask what would be helpful.
- Do offer to help the person set up a schedule for sleeping and times to wake up.
- Involving the person in family activities if they are willing.

Not Helpful

- Taking it personally or blaming yourself.
- Trying to coax the person out of his or her room.
- Worrying or fussing too much over your relative.
- Avoiding or isolating your relative.
- Inviting a lot of visitors home - it may be too overwhelming.
- Trying to force him or her to talk to people.

As your Relative Recovers

Helpful

- Slowly ask the person to get up earlier in the day and to do more things.
- Offer something to enjoy when he or she gets up, like a tempting breakfast or pleasant music.
- Do praise your relative for getting up, for being more social and for their effort.
- Help them with a plan for good personal hygiene, a healthy balanced diet and some physical activity.

Not Helpful

- Don't think you always have to be protective.
- Expecting your relative to stay ill or incapable of daily routine activities.

Note

If your relative has been well for some time and develops sleeping difficulties or begins to withdraw again, discuss this with your relative. This may be a sign that your relative is relapsing.

Inactivity and Not Feeling Like Doing Anything

Helpful

- If your relative says they are bored, offer or suggest some simple activities such as watching TV, listening to music, going for a walk, gardening, etc.
- Experiment with different activities to find out what the person will enjoy. At first try activities that are passive (e.g., listening to or watching something).
- Try to have a regular daily routine so that things are predictable.
- Encourage him or her to join in or follow a daily routine.
- Encourage other members of the family to assist the relative. Everyone needs to help out.
- As your relative starts getting better, give simple daily chores to do. Break chores into small steps if they are difficult, as they are likely to be experiencing some difficulties with their memory. Give one instruction at a time.
- Try to make allowances for him or her if they need to do things like eating at unusual times (you can leave healthy snacks in the fridge).
- Offer incentives and praise for the times when your relative does the chores, even if the chores are not done perfectly. It's the effort which is more important than outcome.
- Remember that your relative may be distractible and may make mistakes or find it hard to finish long jobs.
- With your relative's permission, do talk with your relative's EPI Clinician or Psychiatrist about future plans. Get advice about when they are ready to do various things and how to encourage them to do these things.
- Remember to focus on the process rather than the outcome, as it will make everyone feel better.
- Find out about side effects of any medication as they can interfere with your relative's motivation or recovery.

Not Helpful

- Don't insist on your relative doing too much or going out.
- Don't overwhelm him or her with too many suggestions at once. Your relative's thinking is usually slowed during recovery so short steps are more likely to be achieved.
- Suggesting activities or chores that are too complicated (e.g., a game of Scrabble or grocery shopping, and reading a technical book).
- Criticizing.
- Don't expect your relative to do things he or she is afraid of doing (e.g., going out to a party) or which he finds too confusing (e.g., writing letters).
- Do not argue with your relative.
- Don't give too many instructions at one time.
- Labeling your relative as 'lazy' - this label doesn't help either of you.
- Don't wear yourself out doing everything for your relative.

Challenging Behaviour

If your relative feels helpless, left out, or suspicious and threatened, he or she may start to use challenging behaviour. For example, the person may try to get the members of the family to do everything for them. Remember these behaviours and situations also happen in all families at some time.

If your relative tries to get you to do things you don't want to do, or tries to get you to do things that are unreasonable:

Helpful

- Be firm by saying, "No, this is something you can do for yourself".
- Clearly saying, "I don't like this behaviour. Please stop".

Not Helpful

- Don't do things for your relative that they can do for themselves, or which you feel are too much for you. Doing everything for your relative makes them feel helpless.
- Don't let yourself give in through feelings of guilt.
- Setting no limits. Your relative needs to learn to relate to others. They need the security of knowing where they stand.

If your relative seems to do inappropriate things to get attention

Helpful

- Say you want him or her to stop the behaviour.
- Pay attention and give praise when your relative does something nice and helpful.
- Try to avoid paying attention to the inappropriate behaviour.
- Make it part of the routine to spend time doing something positive with your relative (e.g., chatting over coffee, walking, gardening, pet care, etc).

If your relative tells you negative things about other people

Helpful

- Check out any negative 'stories' your relative tells you about others (in the family or outside).
- Do ask why he or she feels/thinks that way.
- Remember your relative may be confused and may misinterpret what people say.
- Have open family problem solving discussions if behaviours bother the family.
- Discuss your relative's concerns with the EPI Clinician to sort out any misunderstandings or to see whether your relative may need to change his or her treatment in some way.
- Seek another opinion if you are not happy with your relative's treatment.

Not Helpful

- Don't make accusations against other family members or friends. Check out the facts.
- Don't jump to conclusions if your relative says negative things about others (including family, clinicians, doctors, friends, workplace staff, teachers, etc).
- Withdrawing from your relative until they get better. This makes the situation worse.

Aggressive Behaviour

People with psychosis are often withdrawn. However, aggression may sometimes occur and you should know what to do if your relative becomes aggressive, so that you feel more able to cope in these situations.

Helpful

- Do develop a plan as to what to do in the event your relative's behaviour becomes difficult. Discuss with your EPI Clinician, supportive relatives and friends what role each of them will play in helping with the situation should it arise.
- Give clear direction such as "stop please".
- If he or she doesn't stop, leave the room or the house quickly.
- Do leave the person alone until they've calmed down. If you've left the house, a phone call may tell you if he or she is calmer.
- Do take any threats or warnings seriously and contact your EPI Clinician or Psychiatrist, particularly if your relative has ideas of being persecuted and talks about "Getting them before they get me", etc.
- Afterwards you can say, "I know you were upset but we won't put up with aggressive behaviours or threats - EVER" or "You can tell us what you're angry about, but cannot threaten anybody".
- Discuss any threats and aggression openly in the family and with your EPI Clinician and Psychiatrist. Everyone needs to work together to help your relative manage these behaviours.
- Try to see what triggers the aggression and try to avoid the behaviour/situation (e.g., overcrowding in the house, criticism, doing too much for the person, etc).
- If all else fails, it's OK to call emergency personnel (e.g. the police/ambulance) if you or your family needs help.

Not Helpful

- Saying angry, critical things, which may upset your relative.
- Arguing.
- Don't stay around if the person doesn't calm down.
- Ignoring verbal threats or warnings of aggression made to you or about others.
- Don't tolerate aggression to you or your family or others.
- Don't try to reason it out on your own - ask for help.
- Don't let yourself or the family become the only ones your relative depends on - this can create resentment, anger and isolation.



Strange Talk or Beliefs

Helpful

- Gently and matter-of-factly identify that the strange ideas are not common or real.
- Show some understanding of the person's feelings (e.g., fear of the voices). Do encourage the person to talk openly.
- Do change the subject to something routine, simple, or pleasant in real life (e.g., what you're making for dinner).
- Do say when you think something is not real (e.g., 'the voices'), while acknowledging that they seem real to your relative.
- Help your relative to tell the difference between reality and fantasy by saying you think "It's your brain chemistry which is making something appear- it's not really out there".
- It may be appropriate to help the relative check out the facts about their beliefs. (e.g. getting a brain scan to show there is no implant in their head).
- Tell your relative that if he or she feels they must talk about the strange ideas, to do this only with certain people who are not worried by these ideas (e.g., EPI Clinician or other mental health professionals).

Not Helpful

- To allow other family members to make jokes or criticize the person.
- Don't argue about the strange ideas - arguing never changes the ideas and only upsets both of you.
- Spending much time listening to talk that makes no sense to you.
- Pretending to agree with strange ideas or talk you can't understand.
- Don't keep looking at the person or nodding your head if they are speaking strangely.
- Trying to enter his or her world and follow everything said.
- Don't keep up a conversation that you feel is distressing, or annoying, or too confusing for you. It's OK to say, "I'll talk to you later".
- Looking upset or embarrassed by strange talk. It's better to say clearly that you don't like or understand the strange talk.

Not Taking Prescribed Medication

Helpful

- If the problem is a result of forgetting, gently remind the person when it is time to take the medicine.
- Use a dosette container to keep meds organized.
- Find a daily routine (e.g., breakfast, tooth brushing) when tablet taking can become a habit.
- Do remind him or her calmly that medication helps to keep/make him or her well.
- Do ask if he or she is having any side effects. Your relative may want to consider ways of helping with side effects: change of diet, water bottle, more exercise.
- Do talk to your EPI Clinician or Psychiatrist about your relative's difficulty with remembering to take medication and ask about the types of side effects, which may be expected.
- Informing your general practitioner about information on early psychosis, medication and your relative's side effects.
- If your relative refuses to take medication, let your EPI Clinician and Psychiatrist know if symptoms get worse or reappear.
- Calmly remind your relative that medication may be crucial to their recovery.

Not Helpful

- Nagging or threatening the person. This causes a loss of rapport and trust in you.
- Altering the prescribed dosage without psychiatrist's knowledge.
- Attributing every problem to not taking medication.
- Tricking the person by sneaking it into their food. They will notice the effects of medication and stop trusting you. This could put their health at risk if they decide to take the medication or are using street drugs.
- Supplementing the medication with herbs, vitamins or other medications without talking it over with the clinical team.
- Avoiding discussions about medication and side effects. Your relative may be on a number of medications and needs to be able to talk about them.

Fears of Suicide

Helpful

- Listen to all your relative's feelings of depression but also point out that help is available.
- Do show appreciation of your relative's feelings and the fact that he or she confided in you.
- Contact your EPI Clinician or Psychiatrist if suicidal ideas persist.
- Discuss suicide and how to respond with your EPI Clinician. It's best to talk about your concerns and the available resources to support your relative and your family.
- Encourage your relative to be involved in pleasant, low key activities.
- Help the person to be with someone who accepts them so they don't feel isolated.
- It is important to let the person know you accept and care about him or her to reduce their sense of isolation.
- Consider whether any stressors can be removed which might be depressing your relative (e.g., too much pressure to go back to work, too many classes/courses at school, etc).

Not Helpful

- Don't panic if your relative talks about suicide, but do take his or her feelings seriously.
- Telling the person things like, "Pull yourself together".
- Not talking about this with a mental health professional.
- Keeping this a secret.

Odd or Embarrassing Behaviour

Helpful

- Do remember that you are not responsible for this behaviour.
- Ignore this behaviour if you can, especially if the behaviour is not serious.
- If you can't ignore the behaviour, ask the person clearly and pleasantly not to do that particular behaviour.
- If the person can't help the behaviour, ask him or her to do it only in their room.
- Do state clearly that the behaviour is not acceptable to others.
- If you can, change the environment so as to lessen the behaviour (e.g., turn the TV off if it's upsetting).
- Find times to praise the person for acting more appropriately.
- If the behaviour seems to be set off by stress (e.g., too many visitors, being criticized, upsetting events, etc.) see if the stress can be reduced or lessened.

Not Helpful

- Telling yourself that the behaviour is a reflection on you or your family.
- Acting upset.
- Getting into long discussions.
- Letting other family members and friends pay attention to the behaviours or laugh at the behaviours.
- Nagging the person about the behaviour.

Alcohol or Street Drugs

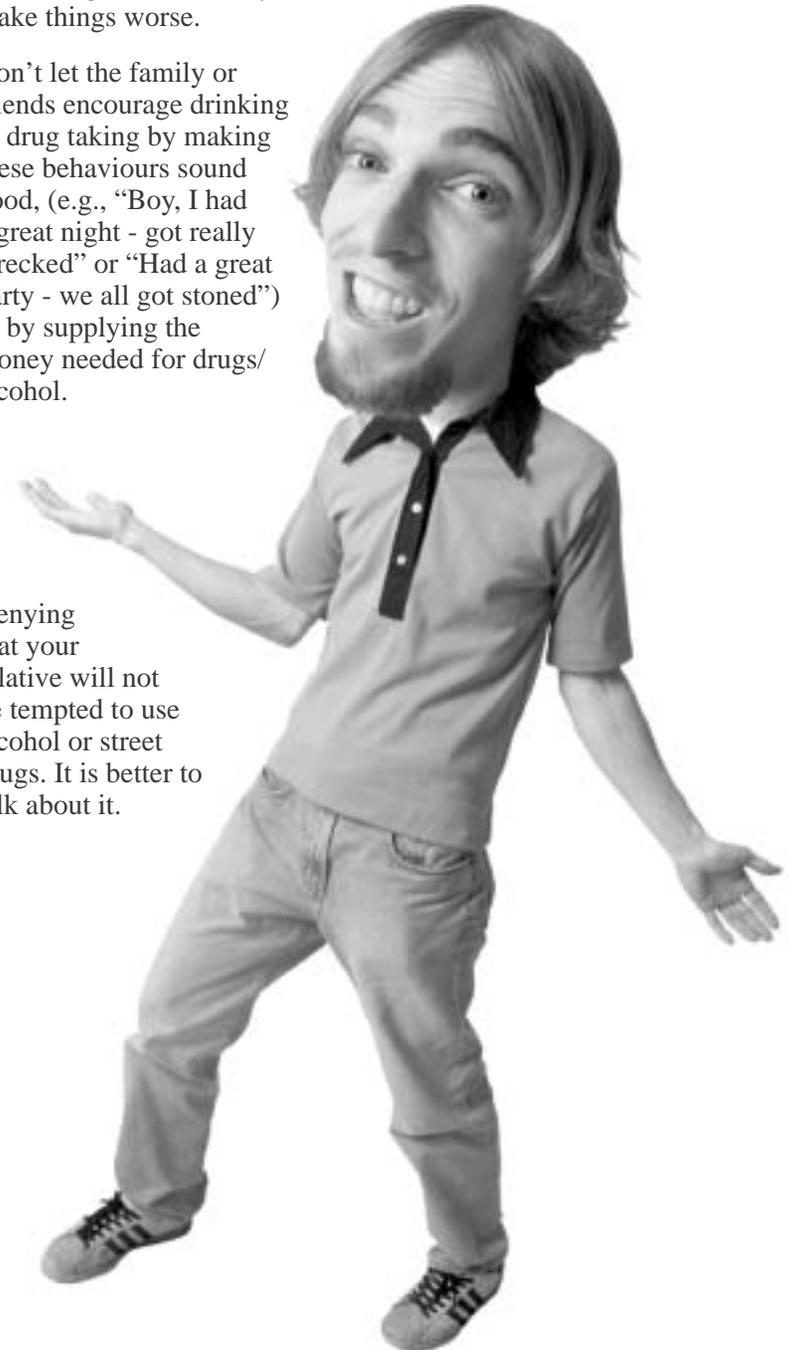
Depending on the medication your relative is taking, the effects of drinking or taking other kinds of drugs (over the counter or street) can vary widely. Young people with mental disorders sometimes use marijuana to help with their symptoms such as sleeping difficulties or social anxiety. However, drugs such as marijuana, crystal meth., amphetamines ('speed') and ecstasy can make symptoms worse and can trigger a relapse. If your relative takes these drugs or too much alcohol:

Helpful

- Remind him or her that the drugs are harmful.
- Do remind your relative about how alcohol may effect them.
- Assist your relative with developing ways (ideas) on how to say 'no' to offers of drugs or alcohol (e.g. I am on medication right now and I don't want to mix my drugs: I don't need drugs/alcohol to have a good time).
- Discuss how to cope with any stressors other than drinking or drug taking (e.g., fights with family, job pressures). Problem solving and developing plans for dealing with the stressors makes the relative feel more in control.
- Let your relative know that it's okay to let friends know that drugs/alcohol are not helpful when recovering from a chemical imbalance in the brain.
- Do discuss alternative ways of being social or being with friends without using drugs or alcohol. Assisting your relative to find other ways to enjoy themselves or to gain energy is really important. Your relative may need to learn new things (e.g., socializing with people who don't drink or take drugs, a new satisfying hobby, or doing volunteer work to gain a sense of achievement).

Not Helpful

- Criticizing since this may make things worse.
- Don't let the family or friends encourage drinking or drug taking by making these behaviours sound good, (e.g., "Boy, I had a great night - got really wrecked" or "Had a great party - we all got stoned") or by supplying the money needed for drugs/alcohol.
- Denying that your relative will not be tempted to use alcohol or street drugs. It is better to talk about it.





Early Psychosis Intervention Program

**Fraser South EPI Program
15521 Russell Avenue
White Rock, BC. V4B 2R4
Phone: 604-538-4278; Fax: 604-538-4277**

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WHY EARLY INTERVENTION?

Why is it important to get help early?

Problems in thinking and perceiving the world can have a big effect on a person's life, relationships, school and career. The longer problems go on, the more serious the effects will be and the more they will affect that person's future. Whether problems are caused by psychosis or not, getting help is important. Early, effective medical treatment can make a big difference in how quickly a person recovers and can reduce the chances of having more episodes. Each psychotic episode damages the brain, so that it takes longer to recover from a second or third episode and recovery is less complete. Treatment almost always involves medication. Usually, the person must continue to take the medication as prescribed even when they feel well to avoid getting sick again. This is similar to other illnesses like diabetes. It often takes a while for the doctor to work out what the right drug and dosage is for each person to keep them well with the fewest side effects. Letting the doctor know about any side effects will help. If they get proper treatment, many people recover fully from their first episode and never have another one.

Remember, psychosis is a medical disease, and early treatment is effective.

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From: BC Schizophrenia Society

http://www.bcscs.org/Get_Information/Schizophrenia/early_intervention.html#Why

Why Early Intervention?

Psychosis is very upsetting to both the person who is experiencing it, and to their family and friends. It can cause a lot of longstanding problems if it is left untreated. These problems include problems with the person's sense of self-identity, delays and problems with getting a good education or career, and having a hard time getting by socially and personally. We also know that the longer psychosis continues without medical treatment, the greater the risk of personal or legal harm. Psychosis has been linked to a variety of other problems including drug/substance misuse, depression and suicide.

Early intervention is when professionals try to find people experiencing psychosis and get them medical treatment as soon as possible, ideally in their first episode or soon after.

When psychosis is caught and treated early, people recover more easily and do better in the long run as well. However, the longer they are ill without treatment, the longer it takes for them to stop having symptoms, the less completely they recover, and the more likely they will get sick again. Because of this, early psychosis intervention (EPI) programs try to catch and treat psychosis early, ideally the first time a person has it. They do this so they can help people be sick for a shorter period of time, and be less severely sick as well. When psychosis is treated early, the person will have fewer related problems.

Because of what we know about the value of early psychosis treatment, it is important to make sure professionals, youth and the general public are aware of what psychosis is and how important it is to get treatment early, so everyone can help.

Early *Intervention*



Early Psychosis Intervention Program

Early intervention of psychosis involves:

- Early detection and treatment of the first-episode of psychosis
- Sustained treatment during the “critical period”
- Early detection and treatment of any psychotic relapses

1. Early detection and treatment of the first-episode of psychosis

Numerous studies have shown that there is often a major delay in initiating treatment for people affected by a psychotic disorder.

These delays vary widely from person to person, but the interval between onset of psychotic symptoms and commencement of appropriate treatment is often *more than one year*.

A long duration of untreated psychosis before first treatment has been shown to involve significant distress, disruption and development of secondary problems for individuals and their relatives.

Some evidence shows that long delays in obtaining treatment may also cause the illness to become less responsive to treatment.

It has been found that delays in receiving treatment are associated with slower and less

complete recovery and that long duration of psychotic symptoms before treatment appears to contribute to poorer prognosis and a greater chance of early relapse.

2. Sustained treatment during the “critical period”

The ‘critical period’ is considered to be the first few years after the onset of psychosis.

It is during this time that social and personal disability is most likely to develop.

Depression, unemployment, homelessness, decreased social supports, drug abuse, and loss of self-esteem can develop aggressively during the critical period.

The longer these needs are not dealt with, the more difficult they are to treat or deal with.

By actively treating the psychosis and secondary problems during the first few years after onset of illness, better long-term outcomes can be achieved.

For this reason, early intervention is not just treating the first episode. It also consists of sustained treatment to prevent the development of disability and enhance quality of life.

3. Early detection and treatment of any psychotic relapses

Individuals experiencing a first episode of psychosis are at risk for relapse.

Through sustained treatment during the critical period, the risk of relapse will be reduced but not eliminated.

It is therefore necessary to be alert to any signs of impending relapse and intervene as early as possible to either prevent the relapse or reduce its severity.

By reducing the duration of untreated psychosis (both the initial episode and any relapses), the likelihood of good prognosis is increased.

Benefits of Early Intervention:

Some of the potential benefits of early intervention include:

- Reduced secondary problems and work/school disruption
- Retention of social skills and support
- Decreased need for hospitalization
- More rapid recovery and better prognosis
- Reduced family disruption and distress
- Less treatment resistance and lower risk of relapse

IMPORTANT ISSUES

Medication



Early Psychosis Intervention Program

Summary of medication for early psychosis:

1. Treatment usually begins with an atypical antipsychotic medication
2. The goal is to relieve symptoms and prevent relapse
3. The lowest possible dose will be used to help avoid side effects

Antipsychotic Medication

Medication is essential in the treatment of psychosis. It relieves symptoms of psychosis and is critical in preventing relapses.

There are many different medications available to treat psychosis. These medications are called *antipsychotics* (or sometimes neuroleptics).

The antipsychotic medications are usually divided into two categories:

1. Typical antipsychotics
- includes haloperidol, loxapine and many others
2. Atypical antipsychotics
- includes risperidone, olanzapine, quetiapine, ziprasidone and clozapine

Side Effects of Antipsychotics

Atypical antipsychotics are usually tried first because they have fewer side effects.

The antipsychotics differ in terms of side effects.

Many side effects diminish over time and some people do not experience any side effects.

Some common side effects of the atypical antipsychotics include:

- tiredness
- dry mouth
- blurred vision
- weight gain

Your EPI psychiatrist and clinician will closely monitor for side effects.

If bothersome side effects develop, it may be recommended to lower the dose, add a medication to reduce side effects or try a different medication.

Response to Antipsychotic Medication

Treatment begins with a low dose of medication that may gradually be increased over time - this will help prevent side effects.

It may take several weeks or even months for the medication to have its full effect.

If the first antipsychotic medication does not produce satisfactory results, then usually a different antipsychotic will be tried.

Clozapine is often effective for people who have not responded to other antipsychotics.

Duration of Antipsychotic Treatment

It is recommended that you continue taking medication even after symptoms of psychosis are gone.

There is very high risk of relapse if medication is discontinued too soon.

Talk with your EPI psychiatrist to find out how long you should remain on medication.

Other Medications

There are other medications that might be used, along with an antipsychotic, depending on the symptoms you have experienced.

For example, antidepressants or mood stabilizers might be used for problems with mood.

Whenever you are prescribed a medication, be sure to find out what symptoms it is meant to help with and what side effects are associated with it.

Remembering to take Medication

Remembering to take medications every day can be difficult.

Some people find that keeping their medication next to something they use the same time every day is helpful (e.g., keeping medication next to toothbrush). Other people find that using a pill container that organizes medications by the day of the week is useful.

If you are having problems remembering to take your medication, talk to your EPI psychiatrist or clinician who can help you find memory strategies that work for you.

Persistent Symptoms



Early Psychosis Intervention Program

Some individuals with early psychosis continue to experience symptoms of psychosis even after they have been on medication for a while. If this is your experience, it may be that adjustments to your medication are needed or that these symptoms are slower to respond to treatment.

Open communication with your EPI Clinician and Psychiatrist is extremely important. If they do not know that you are still experience symptoms, they will be limited in how much they can help. If they know about these ongoing symptoms, they can adjust your treatment and also work with you to help you find effective strategies to manage these symptoms.

It is especially important to let your EPI Clinician and Psychiatrist know if you begin to experience an increase in these symptoms in case this is a warning sign of relapse. Prompt initiation of treatment can help to prevent a relapse from occurring.

If you are experiencing persistent symptoms, ask yourself the following questions:

Are there things that help me cope with these symptoms?

- Determine if these are good or bad coping strategies.
- Good strategies are those that don't have any short or long-term risks (most of the stress management strategies are good coping strategies).

- Bad strategies are those that have either short or long-term risks (an example of a bad strategy would be doing street drugs – although this may help you cope with current symptoms - it significantly increases the risk of relapse).
- If you aren't certain whether your current coping strategies are good or bad, talk with your EPI Clinician about them.

Are there certain things or situations that tend to make these symptoms worse?

- Consider whether there are certain tasks, activities, places or people that are associated with an increase your symptoms.

Understanding these symptoms can guide you in controlling them by:

- Increasing your use of good coping strategies that work
- Decreasing your exposure to situations that make your symptoms worse

Many people who have persistent symptoms of psychosis have reported that there are things they can do to help reduce these symptoms or help them cope. Many people with early psychosis find that stress increases symptoms. Often stress management strategies can be helpful in decreasing persistent symptoms or by making these symptoms easier to cope with.

In addition to stress management strategies, here are some

strategies that others with persistent psychotic symptoms have found useful.

- Either increasing (going for a walk or exercising) or decreasing (relaxing) level of activity may help with hallucinations or feelings of disorganization.
- Changing posture (sitting down or lying down) helps some people with hallucinations.
- Distracting oneself with some other activity (reading, watching television or listening to music) may help with hallucinations or delusions.
- Using organization strategies or memory aids for problems with disorganized thoughts or memory difficulties.
- Changing auditory input by using earplugs, listening to music through headphones, humming, or talking with other people may be helpful for auditory hallucinations.
- Engaging in reality testing (asking trusted others about thoughts or perceptions to determine whether or not they experience them as well) may be helpful for hallucinations or delusions.

These are just some of the possible strategies that might help you deal with any ongoing symptoms. Every individual is unique in terms of what is the best way to manage persistent symptoms. So it's best to try out a range of different strategies to find ways that work well for you.

Stress Management



Early Psychosis Intervention Program

Part I

What is stress?

Stress can be defined as a strain on your abilities to cope with demands.

Stress results from things such as:

- Many life events that result in change (for example moving to a different city or changing jobs). These can be sources of stress even when they are positive changes.
- Work and/or school can create stress by presenting challenges, difficult tasks and deadlines.
- Conflicts with friends, family or coworkers.
- Ongoing concerns about money and housing.
- Your own thoughts – for example, by setting impossibly high standards for oneself or worrying excessively about things you can create stress for yourself.
- Daily hassles, such as getting stuck in traffic, missing the bus, or misplacing your keys.
- Other things such as - drug abuse, poor nutrition, bad sleep habits, and physical health problems.

In response to prolonged stress, the body and brain chemistry change in a way that can result in numerous negative physical and mental responses.

Research has shown that chronic stress can increase the risk of developing depression, anxiety, other mental disorders and physical health problems. For a person who has experienced psychosis, the experience of too much stress increases the possibility of a relapse.

How to Manage Your Stress

First, you must learn to recognize stress:

Stress symptoms include many mental, social, and physical changes.

Common symptoms of stress include:

- Feelings of exhaustion and fatigue
- Irritability or anxiety
- Changes in appetite or sleep patterns
- Headaches and/or muscle tension in the back and neck
- Increased use of alcohol and/or drugs may also be an indication of stress

Each person's response to stress is unique.

Make a note of what symptoms you experience when under stress. Be on the lookout for these symptoms. When you notice you are experiencing these symptoms – attempt to decrease your stress level by trying out one or more of the following strategies.

Strategies for Managing Stress

Anticipating Stress - Managing Stress by Preparing For It

By anticipating stress you can prepare for it and work out how to control it when it happens.

You can do this in a number of ways:

a) Rehearsal:

This is useful strategy for any upcoming event that you are worried about. This might be a job interview or a certain social situation where you won't know anybody. Go over the event in your mind and rehearse things to say or behaviours to engage in that will prepare for you the event.

b) Problem-Solving and Planning:

By analyzing the likely causes of stress, you will be able to plan your responses to likely forms of stress. These might be actions to alleviate the situation or may be stress management techniques that you will use.

It is important that you formally plan for this - it is little use just worrying in an undisciplined way - this will be counterproductive. Your EPI Clinician will review the structured method of problem-solving with you during one of your visits.

c) Avoidance:

Where a situation is likely to be unpleasant, and will not yield any benefit to you, it may be one you can just avoid. You should be certain in your own mind,

however, that this is the case, and that you are not running away from problems or making things worse by delaying the inevitable.

Relaxation – Adjusting Your Mental and Physical Response to Stress

Through relaxation you can calm your body and mind and decrease the stress response. There are different ways in which you can engage in relaxation.

a) Taking Time-Out:

Allow yourself to engage in calming activities that you enjoy. Some examples include going for an unrushed walk, reading a book for pleasure, or taking a warm bath.

Find activities that are quiet and calming that you enjoy and put time aside to engage in them regularly. Allowing yourself the time to unwind can be very helpful in reducing stress.

b) Imagery:

The principle behind the use of imagery in stress reduction is that you can use your imagination to recreate a place or scene that is very relaxing.

Scenes can involve images such as lying on a beach in a deserted cove. You may ‘see’ cliffs, sea and sand around you, ‘hear’ the waves crashing against rocks, ‘smell’ the salt in the air, and feel the warmth of the sun and a gentle breeze on your body. Other images might include looking at a mountain view, swimming in a tropical pool, or whatever - you will be able to come up with the most effective images for yourself.

With imagery you substitute actual experience with scenes from your imagination. Your body reacts to these imagined scenes almost as if they were real. Use the imagined place as a retreat from stress and pressure.

c) Progressive Muscle Relaxation:

This is a physical technique for relaxing your body when

muscles are tense. This can help reduce your feeling of stress.

The idea behind progressive muscle relaxation is that you tense up a group of muscles so that they are as tightly contracted as possible. Hold them in a state of extreme tension for a few seconds. Then relax the muscles to their previous state. Finally you consciously relax them again as much as you can.

You can apply this technique to any or all of the muscle groups in your body depending on whether you want to relax just a single area or your whole body.

Experiment with progressive muscle relaxation by forming a fist, and clenching your hand for a few seconds. Then relax your hand to its previous tension, and then consciously relax it again so that it is as loose as possible. You should feel deep relaxation in the muscles.

Part 2 describes some additional strategies for managing stress.

Stress Management



Early Psychosis Intervention Program

Part 2

This handout describes some additional strategies that people often find useful for reducing stress.

Rational Thinking

Controlling Internally-Generated Stress

Negative thinking causes stress because it damages your confidence that you are equal to the task you face.

You are thinking negatively when you put yourself down, criticize yourself for errors, doubt your abilities or expect failure.

The following two steps can help you combat negative thinking.

a) Thought Awareness:

Thought awareness is the process by which you observe your thoughts for a time, perhaps when under stress, and become aware of what is going through your head. It is best not to suppress any thoughts - just let them run their course while you observe them and watch for negative thoughts.

Examples of common negative thoughts include: worries about how you appear to other people, dwelling on consequences of poor performance, self-criticism and feelings of inadequacy. Make a note of any negative thoughts you encounter.

Thought awareness is the first step in the process of eliminating negative thoughts - you cannot counter thoughts you do not know you think.

b) Rational Thinking:

Once you are aware of your negative thoughts, write them down and review them rationally. See whether the thoughts have any basis in reality. Often you find that when you properly challenge negative thoughts they are obviously wrong. Often they persist only because they escape notice.

With rational thinking you look at the basis of these negative thoughts, and challenge them rationally. Where the thoughts are obviously wrong, you can eliminate them. Where the thoughts may be fair, you can work on the problem to eliminate or neutralize it.

Reducing Daily Hassles

Preventing Stress by Streamlining Your Life

We all experience frustrations on a regular basis.

Things such as misplacing ones keys, being stuck in a long line-up at the grocery store, getting stuck in traffic or missing the bus may seem like minor annoyances. However, these types of daily hassles can add up to create a significant source of stress.

Many of these daily hassles can be easily avoided or managed through the use of two simple strategies.

a) Time Management:

Analyze how you currently spend your time and revise this so that the use of your time is more effective. For example, if you always go to the grocery

store at 5pm when it is most crowded, consider going at a different time of day to avoid long waits in line. Alternatively, by pre-planning your meals for a week could allow you to do shopping just once/week. In planning how you will spend your time, it is important to use a daily schedule to help remind you of the things you are to do at specific times.

b) Increased Organization:

A cluttered environment and/or frequently misplacing things such as keys can increase stress. You can help reduce your stress simply by reducing clutter and developing a system for storing or placing important items (e.g., a hook for a key by the front door, using a filing system for important documents, etc.).

Reducing Responsibilities

Managing Stress by Decreasing Workload

Recognize when stress gets to be too much and the other stress management strategies are not helping to eliminate your feelings of stress. When this happens, it is time to consider reducing your responsibilities and obligations in order to reduce your stress level. These could be responsibilities such as work, school, volunteering, household duties, or social clubs.

The following steps may help guide you in reducing your responsibilities.

a) List all responsibilities:

Think of all the different things that you are currently doing and are responsible for. Make a list of these responsibilities.

b) Evaluate your responsibilities:

For each of the responsibilities on your list, consider how stressful you find each, how easily they can be delegated to others, and what the consequences would be for no longer engaging in them.

c) Decide which responsibilities to reduce:

Your decision should be based on your evaluation.

d) Develop and carry out a plan for reducing these responsibilities:

This might involve informing others of your decision or delegating work to someone else

Summary

You now have an overview of some of the approaches that you can use to effectively manage your stress. Some other strategies include regular exercise, eating and sleeping well, and goal-setting.

The best approach to stress management is individualized – experiment with different strategies to find ways of reducing stress that work for you.

Social Supports



Early Psychosis Intervention Program

Your social relationships play an influential role in promoting recovery from psychosis and maintaining health and well-being.

Unfortunately, individuals affected by psychosis often withdraw socially and become socially isolated. It is not uncommon for the family to also become socially isolated.

A number of factors may contribute to lowered levels of social relationships and supports. Avoiding people, not being able to socialize as well as before, the problems caused by symptoms and worries about stigma may all lower social supports.

It is important to try to maintain your current social relationships.

If you have experienced a loss of contact with friends and relatives, it is important for your recovery to try and build new social relationships and find sources of social support.

Research has shown that individuals with large social networks tend to have fewer psychotic flare-ups and hospitalizations than those with smaller social networks,

presumably because a larger social network is more likely to fulfill social needs (such as the needs for communication, company and receiving feedback and support from others). It may be that loneliness and social isolation increase stress which can lead to relapse.

Good social supports may help promote recovery in many different ways.

Some of the positive aspects of social supports are that they can:

- Provide opportunities for you to express your emotions openly without fear of criticism
- Allow you to obtain practical feedback from others about any day-to-day problems you might be experiencing
- Provide motivation and encouragement for you to achieve your goals
- Assist you with symptom monitoring – letting you know when they are concerned that there are early warning signs of relapse

- Provide you with opportunities to do things you enjoy with others – and have more fun by sharing the experience.

Maintaining or developing a good social network requires you to be proactive - keeping in touch with old friends, making new friends by joining leisure groups or taking educational classes.

Joining a support group is one way of finding other supportive individuals who are going through a similar experience.

Some people who have experienced early psychosis find that certain social situations (that they once handled with ease) have suddenly become difficult or awkward.

Problems with social skills and social interactions are not uncommon in early psychosis.

If you have any concerns about your social functioning, communicate these to your EPI Clinician. Effective strategies can help you regain your ability to function well socially. Treatment for problems with social functioning is most effective when started as early as possible.

Problem Solving



Early Psychosis Intervention Program

We all face problems

– occasionally we are faced with a problem that seems overwhelming and we may try to cope with the problem by avoiding it or by worrying excessively about it. These strategies are usually not very helpful – doing little to resolve the problem and sometimes just making it worse.

One strategy that clearly is helpful is the method of structured problem solving. This is a method that can help guide you in finding solutions to a problem you are faced with. With just a little bit of practice, you'll find that the method is easy to use and can help you better deal with any problems.

There are six steps to structured problem solving.

1. Identify and define the problem – Identifying that there is a problem is usually not too difficult - often we know that there is a problem because we feel stressed or find ourselves worrying. What can be a bit more difficult is defining exactly what the problem is. By spending some time thinking about all the different elements of the situation, you can usually figure out what the problem is. If you've spent some time thinking about it, but still don't have a clear definition of the problem, it is often useful to talk through the problem with someone you trust.

2. Brainstorm around possible solutions to the problem

– In brainstorming, you come up with as many solutions as you possible can and write them all down. You do not reject any ideas or try to think of just the best idea. You should use your imagination and think of all possibilities. Even ideas that are clearly impractical or not possible may have elements that are useful.

3. Examine these solutions

– Consider the pros and cons of each solution you have thought of. For each solution ask yourself the following questions. Are there any potential negative consequences (both right away or in the near future)? How much time will it take to carry this out? Is this going to require much money? Do I have the skills to carry this out? Do I have the necessary resources? Does this require the cooperation of other people and if yes, are they likely to cooperate? Am I likely to be faced with difficulties when carrying out this solution?

4. Decide which solution you will try – Which solution you decide upon will depend on the urgency of the problem and the difficulties you anticipate in implementing the different solutions. In a situation where the problem needs to be dealt with quickly, you may choose a solution that you can apply right away (even though this might not be the ideal solution).

5. Plan how you will carry out this solution – In order for your solution to impact your problem, you need to put it into practice. Many solutions will have several steps to them. Break your chosen solution down into these steps and determine how and when you will carry out each step.

6. Review your progress

– Problem solving is an ongoing process and requires you to regularly review your progress and revise your solution. You can't think of all potential difficulties you might be faced with when carrying out your solution. The review of your progress can help you identify any problems. Steps may need to be revised or new steps added. You may need to consider a different solution if the current one you have been working with is not helping.

7. Congratulate yourself

– Solving problems takes patience and persistence. Always remember to congratulate yourself on both your efforts and your progress.

The problem solving method is a tool to help you with many of the problems you are faced with. It will not make all your problems go away nor will it help with all of your problems. However, with time and practice using this method, you will find that you are better able to cope and experience less stress when difficulties present themselves.

Lifestyle habits are an essential part of maintaining good mental health.

Good lifestyle choices will improve your physical and mental health, decrease your stress levels, and help you get more out of life.

Recreation

Recreation is the activities that you engage in for enjoyment. There are many different types of recreation, including sports, games, movies, hobbies, and crafts.

It's important to take time to do the things that you enjoy – this helps keep your stress level down and allows you to feel good and have fun.

Many of the different recreational activities involve being with other people doing the same thing (such as many sports). Even if the activity does not require other people, it is often more fun to engage in recreation with others who also enjoy the activity.

You may find that with certain recreational activities, you prefer to be by yourself when doing them and this is good too because it will allow you to unwind and provides you with valuable time to yourself - just remember that it's important to maintain your social contacts and not become isolated.

Many people who have experienced early psychosis find that they have dropped many of the recreational activities they used to enjoy. If this has been

your experience, you may want to try to pick up some activities that you used to do, or you may want to try something new.

The main thing is to find something that you enjoy and that you have fun doing. If something you once enjoyed, no longer brings you pleasure – don't feel that you have to continue doing it. Try out new forms of recreation until you find something that you like.

Diet and Exercise

The more balanced and healthful your diet, the more healthy your body will be. A well-balanced diet also will give you more energy.

If you are eating an unbalanced diet, you may be causing your body to be under extra stress by depriving it of essential nutrients. If you eat a good, well-balanced diet then your body will be receiving all the nutrients it requires to function effectively.

Daily exercise, from walking to more vigorous aerobic activities, is good for your physical health. Exercise releases the body's natural endorphins, which provide you with a sense of well-being. Exercise will also provide you with more energy and help provide you with better sleep.

Getting regular exercise is probably one of the best physical stress-reduction techniques available. Exercise not only improves your health, it also relaxes tense muscles and reduces your feelings of stress.

An important thing to remember is that exercise should be fun - if you do not enjoy it, then you will probably not keep doing it. Think of creative ways of getting exercise. For example, make exercise part of your recreation by playing sports or learning how to rock-climb, or team-up with a friend for exercise at the gym or for walking or jogging.

Sometimes certain medications may cause weight gain as a side effect. If you are having difficulties maintaining a healthy weight or are concerned about your weight, talk to your EPI Clinician and Psychiatrist about this. They can help you by coming up with a weight management plan or they may suggest a different type of medication.

Both a balanced diet and regular exercise will help you achieve and maintain a healthy weight.

There is a lot of inaccurate and even harmful information about diet and exercise on the Internet and in many magazines and books.

The best place to get information is from your EPI Clinician or Psychiatrist, your family physician or someone who has specialized training in these areas, such as nutritionist. These professionals can provide you with accurate information and also help you come up with an individualized plan for making changes.

Sleep

Getting adequate sleep every night has a positive impact

on your mood and energy throughout your days. Poor sleep habits can lead to difficulties falling asleep or a poor night's sleep.

Significant problems with sleep can lead to problems with your ability to regulate your mood.

If you have experienced problems with your mood (either a depressed or manic episode), it is especially important for you to get adequate sleep every night and have good sleep habits.

Here are a few suggestions around how to develop good sleep habits:

- Try to keep a regular bedtime and establish a regular rising time in the morning, even on weekends and other days off from work.
- Avoid coffee, cola, tea, chocolate, alcohol, and tobacco after supper.
- Wind down for a period before sleep time. Quiet activities such as reading or relaxing in a hot bath help promote sleep.
- Avoid using the bed as a place for reading, watching television, doing paper work, eating, or other activities.
- If sleep does not occur after 30 minutes in bed, get up and engage in a quiet activity until sleepy again. Do not watch TV.

- Avoid taking naps during the day, especially in the evening. If you must nap, do so in the early afternoon for no longer than 30 minutes.
- Try to keep the room dark, quiet and at a comfortable temperature. Make sure that your mattress and pillows are comfortable.
- Heavy exercise should be avoided after dinner because it will delay sleep. However, engaging in gentle exercise after dinner or before bed (such as a slow walk) helps to produce fatigue before sleep.

If you have problems sleeping that are not helped by these suggestions, talk to your EPI Clinician and Psychiatrist. There are many available and effective treatments for significant sleep problems.

Sexuality

Regardless of whether you are sexually active with others or not, it is important that you feel good about your sexual life. It's also important that you are engaging in safe sexual practices to protect you from sexually-transmitted diseases, unwanted pregnancy, or other risks associated with unsafe practices.

Many people experience problems with sexual functioning at some point and most people have at least a few

unanswered questions about sex that they would like professional answers to.

Unfortunately, many people never get the help or answers they could use, simply because they are hesitant to discuss these issues with their health care professionals. It's perfectly normal to feel this way, as this is a very personal topic that you don't usually discuss with others. However, if you are experiencing sexual problems or have questions, it is important to get past any embarrassment you may feel and talk to your EPI Clinician, Psychiatrist or family physician.

If you have noticed recent problems with your sexual function, this may be a side effect of your medication. There are a number of effective strategies that can help restore your sexual function to normal.

Most problems with sexual functioning can be treated and most of your questions answered. But only by openly communicating with a health care professional can you get the answers and help you need.

Remember, health care professionals hear about sexual difficulties and other sexual issues all the time and are usually very comfortable talking openly about this.

Goal Setting



Early Psychosis Intervention Program

Goal setting is a technique that helps people achieve their goals. It is used by all sorts of people (such as successful business-people, students and athletes) and provides them with long-term vision and short-term motivation.

The use of a structured goal setting method can greatly increase your chances of attaining your goals.

By setting goals on a routine basis you decide what you want to achieve, and then step-by-step move towards the achievement of these goals.

The process of setting goals allows you to choose where you want to go in life. By knowing precisely what you want to achieve, you know what you have to concentrate on to do it.

By setting clear goals, you can measure and take pride in the achievement of those goals. You can see forward progress in what might previously have seemed a long pointless grind.

By setting goals, you will also raise your self-confidence, as you recognize your ability and competence in achieving the goals that you have set. The process of achieving goals and seeing this achievement gives you confidence that you will be able to achieve higher and more difficult goals.

The Goal Setting Method

1) List your goals and select one or two to work towards

Think of all the goals you have over the next year or two. Ask

yourself “What is it that I want to accomplish?” and “Where would I like to be one year from now?”

Your goals might relate to work or school, recreation or hobbies, getting more exercise or having more social contacts.

If you initially have difficulties coming up with goals, think about whether there is anything about your life that you would like to change or anything you are not happy with. For example, you may be unhappy with your current job or would like to socialize more often. It can become your goal to change things that you are not happy with.

Write down these goals as you come up with them. Try to write your goals down so that they are positive: “I will pass this course” rather than “I will not fail this course”.

After thinking about your goals for a while, you may find that you have many different goals that you want to achieve – and if you do - this is great! However, working on all these goals at once would leave you with less time and effort available to focus on each and will likely make you feel overwhelmed. Take a closer look at your list and prioritize your goals. Try to really focus on just one or two for now.

When thinking about goals and selecting ones to work on, it is important to be realistic. In order for goal setting to work, the goals have to be possible and achievable. Some goals are clearly not realistic – for example, many people would

love find a job where they earn \$1 million dollars this year but for most people this clearly isn't a realistic goal! With other goals it may be much more difficult to determine whether or not they are not realistic.

Talking about goals openly with your EPI Clinician or a trusted friend will often help you decide if these are goals you can attain.

Setting your goals at the right level involves making sure that they are not too difficult or too easy to achieve.

It is ideal to have goals set so that they are slightly out of your immediate grasp, but not so far that there is no hope of achieving them.

It often takes practice to find what the right level of goal is – and often goals may have to be revised if they begin to appear too easy or too difficult.

Don't be disheartened if you have to revise your goals – this is all part of the goal setting process and is to be expected.

2) Define your goals clearly and break them down into small steps

Once you have selected one or two realistic and achievable goals, you will then need to clearly define these. Be precise in defining your goals - putting in dates, times and amounts so that you can measure achievement.

Divide each goal up into small steps that are also precise. These steps should be ones that you can attain in a short period of time - over days or weeks.

If possible, try to make these steps enjoyable – there are often many different ways to attain the same goal – choose the more enjoyable way when you can.

3) Review your progress and revise

You should regularly review your progress towards achieving your goal. Identify and write down any problems or obstacles you have encountered.

Engage in problem solving to determine if there are methods of fixing these problems so that you continue working towards your goal as planned. In some cases, the problem may not have an apparent solution and either the steps towards the goal or the goal itself will have to be revised.

Do not be disappointed if you have to revise your goals – this is actually to be expected and indicates that you are correctly using the goal setting method.

In reviewing your progress, note whether you are achieving the goal too easily or if progress is slow, difficult, or non-existent. All this means is that the goal wasn't set at the right level and that you need to make adjustments to the goal.

There are no failures in goal setting – just adjustments to the process or to the level of goal.

Also, remember that your goals may change simply with the passage of time. Just because something was your goal six months ago, doesn't mean that it has to be today.

If goals do not hold any attraction any longer, then simply change them or let them go. Goal setting is a tool to help you achieve the goal *you want to achieve*.

4) Take satisfaction in your efforts and achievements

Of course you should enjoy your success in achieving one of your goals. Congratulate yourself – you have worked hard and deserve to feel good about your success!

But success could not be possible without your efforts and without achieving the individual steps towards your goal. Along the way towards a goal, whenever you achieve a step or have made a significant effort, always take time to enjoy the satisfaction of having done so.

WHAT ABOUT ME?

Loss & Grief - A family response to mental illness

Grief is an essential and normal response to loss in one's life. Having a relative or friend diagnosed with a mental illness is often associated with a number of losses and corresponding grief. Some of these losses are:

- Loss of normal life expectancies e.g. inability to work full time.
- Change in family roles e.g. having to "parent" adult child again.
- Change in lifestyle e.g. participating in less social activities due to stigma
- Loss of self esteem e.g. due to inability to protect child.
- Loss of identity e.g. because of major changes in loved one.

The Grief Response

The grieving response varies from person to person to person, and is influenced by a number of factors - e.g. extent of the loss, personality, cultural background and religious beliefs. It is quite common for members of the same family to grieve very differently (e.g. husband and wife), or to be at different stages of grieving. Despite the fact that people react to grief in an individual manner, there still appears to be a series of commonly experienced stages in the grieving process, and these are:

- Shock e.g. "This can't be happening"
- Denial e.g. "The doctors don't know what they are talking about"
- Anger i.e. at self, ill relative and/or treating team.
- Bargaining - to gain time or to push back the inevitable
- Depression e.g. tired, withdrawn, apathetic. Different to clinical depression.
- Acceptance i.e. coming to terms with loss; learning to live with it.

Ways of Coping with Loss & Grief

There are no simple answers to coping with such painful losses as those associated with mental illness, but there are certain steps/ideas that can be helpful in easing the pain:

- Reach out for support e.g. friends, support groups, professional counsellors.
- Be patient with yourself - it takes time to adjust to significant changes.
- Be good to yourself e.g. listen to music, read a book, catch up with friends.
- Don't let others burden you with their expectations e.g. "you should be more lenient with him. He is sick after all."
- Try journal writing to help release pent up feelings and gain perspective.
- Get informed about mental illness and services e.g. read books, speak to people in the field of mental health.
- Maintain a healthy, balanced lifestyle e.g. exercise, eat well.

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<http://www.arafmi.asn.au/arafmi/lossgrief.asp>

Taking Care of Yourself

Dealing with a mental or substance use disorder in a family member—whether temporary or long-term—brings on challenges and stresses for the family. In order to be of help to the person you love, you need to first take care of yourself.

When we don't take care of our own needs, we're more likely to become irritable, short-tempered, judgmental, resentful—which can have a negative impact on the ill family member.

Self-care involves taking steps to preserve one's mental health. Recognize when you are feeling stressed. Problem-solve ways to reduce your stress. Keep your own life and don't let the illness consume the family.

Establishing a social support system is a necessity. Mental or substance use disorders are not something that anyone should have to deal with by themselves. Find supportive friends, co-workers, anyone you feel comfortable talking to about your family member. Join a support group for families—either in your community or an online support group.

Decide what level of support and care you are *realistically* able to provide. Let others involved in the care of your family member know what your limits are. This will help in making arrangements for care. It is also wise to plan for future care for when you are no longer able to provide support and care.

Don't let the illness take over everyone's life. Yes, it undoubtedly plays a part, but maintain as much of your life as possible.

Be aware of your health. If you're run down, you won't be able to provide the support your family member needs. Eat nutritiously and exercise as often as possible. Find activities you enjoy.

Let your doctor know that you are caring for a family member with a mental illness.

Find a place that you can retreat to when you need a break. We all need to replenish our strength from time to time.

If you can't care for yourself, you can't care for another.

Flight attendants always give the following instructions before the plane takes off:

“In the event the cabin depressurizes, oxygen masks will automatically drop from the ceiling. Make sure you put your own mask on before attempting to help others.”

Similarly, your attempt to help your family member will only succeed if you help yourself first.

It makes sense to put yourself in a position where you can be most helpful before you try to render help.

Be a hero—not a martyr. Sacrificing everything for your family member will only exhaust you. Encourage your family member to take responsibility and be as independent as possible.

Try and separate the mental illness from the person you are caring for. Try and separate your emotions from the problems of caring. This may help you to focus on problem-solving without negative emotions getting in the way.

Remember there is only so much you can do to help your family member. Recognize the limits of what you are able to do.

Continue to plan and pursue things that you enjoy. Give yourself permission to go off and maintain your normal routines. This will help reduce the stress for you and your family members.



Get as much help as you can from professionals and mental health organizations. Join a support group so you can network with other families and learn from their experiences.

Use the experience and the expertise you have built up caring for your family member to guide you when new problems arise. Get as much practical help as possible from other family members, friends, other relatives.

Talk over your problems with someone you trust. Problems are rarely solved on the first attempt. Don't get discouraged. Try out a number of solutions until you find the ones that work for you.

Don't lose hope. Focus on the successes, no matter how small.

One of the hardest things you will do while supporting your family member is to gradually let go and not take responsibility for their behaviour.

Ways to Take Care of Yourself

- Go for a walk or run**
- Practice meditation**
- Keep in touch with friends**
- Take a break; ask another family member or hire someone to provide care**
- Read a good book**
- Enjoy a pet**
- Go for a massage**
- Accept help**
- Let go of the need for everything to go right**
- Delegate chores**
- Stay with a routine**
- Enjoy nature**
- Take up a hobby**
- Maintain a good diet**
- Set limits and keep time for yourself**
- Celebrate the good times**

~Family-to-Family, British Columbia Schizophrenia Society



Family members confronted with the reality of mental illness quickly learn that without constructing appropriate boundaries they risk becoming engulfed and potentially consumed by the other's illness.

The inevitable task that family members face is to honor the obligation and commitment they feel towards their sick spouse, parent, child, or sibling without losing their own health and self.

~Bearing Responsibility: How caregivers to the mentally ill assess their obligations, D.A. Karp and D. Watts-Roy

Setting Boundaries and Limits

Let your family member be who they are—you cannot do everything for them or always protect them. They are more than just someone who has a mental illness. After making any necessary allowances, treat your family member day to day like anybody else.

Setting limits is about accepting and respecting your own feelings, and taking your own personal needs seriously. Families have a right to be comfortable in their home. Clear statements about what members of the family need, want, or expect will help everyone understand how they can help.

Everyone has the right and the duty to take responsibility for how we allow others to treat us.

Violence or aggressive behaviour is never acceptable.

As a family, you will need to make decisions as to the extent of the support you can provide and the conditions under which you can provide that support.

The truth is that you can't force someone to seek treatment or change their behaviours, but you can set standards and boundaries for what *you* can and will live with when a family member has a mental or substance use disorder.

When we are placed in a caregiving role, we often want to do as much as possible to help the person. In doing this, we run the risk of overextending ourselves and responding to the needs of others at the expense of our own needs. We may feel obligated to help out of guilt, sincere desire, fear of hurting the person or our own need for approval by others. Understanding your own needs is not selfish; it is healthy.

In order to best help your family, find some time to sit down and evaluate what you and other family members can realistically do. Communicate the limits of the support you can provide and the expectations you have of your family member.

Keep in mind that establishing boundaries is a process. Take your time and look for small ways to begin.

It's OK to expect basic rules of conduct and cooperation. We all require these to get along with each other. Be aware that feelings of guilt may prevent families from effectively setting limits and realistic expectations for their family member.

If, as a family, you decide that your family member will be living with you, it may be necessary to set reasonable limits on what behaviours will be tolerated. Some of these rules may be for the benefit of the person with the mental or substance use disorder; others may be for the benefit of others living in the household.

The following are some guidelines that may be helpful in setting limits when your family member lives with you.

- As a family, decide on the rules or conditions under which the person can live in the home. For example, staying up late at night may be tolerated but use of alcohol is not.
- Communicate these limits clearly. It may be helpful to write them into your illness management plan (see Module 2).
- Anticipate that these limits will be tested.
- Be prepared to take action to enforce limits if necessary.



PERSONAL STORIES

Permission to reprint from:
<http://www.gethelppearly.ca/stories.htm>

J's Story: A Mother's Story
Ontario

A Mother's Story

My daughter was diagnosed with schizophrenia in 2002 and it was like stepping into a nightmare for our whole family. Our prior experiences with mental illness with other family members held many painful and negative associations.

Through the hospital where she was first treated my daughter was referred to an early treatment program for psychosis. She almost missed out on the opportunity to be accepted by this program because she was prescribed medication for psychosis in the community before her hospitalization. Because the early intervention program in our community is research based, to qualify for admission, patients could not have taken medication for psychosis prior to admission to the program. My daughter had not complied with the medication she was prescribed and we could provide proof, therefore she was admitted to the program. Within the program there were many treatments and supports available for the patient and family.

I question why general practitioners or psychiatrists in our community would treat, rather than refer patients to a program where a patient would receive so many treatments and supports. A person with psychosis can have a very difficult time accessing services and supports that are not coordinated. I saw for myself how she could have lost her apartment because she did not fill out forms or did not fill out forms properly and I saw she needed assistance until she was able to deal with the stresses of daily living.

As I mentioned many of our associations with mental illness were painful and negative. We found ourselves seeking out someone with schizophrenia who was living successfully with the illness rather than being a victim of the illness. We hoped to find a person who was going to school or working and dealing with issues such as acceptance, disclosure, medication, sexuality, substance abuse, finances, fitness, pregnancy, careers and any issues adolescent and young adults' need to address.

The early intervention program offered peer support and counseling and we sought out and found young people who were willing to meet and encourage my daughter and this has helped immeasurably.

My daughter experienced psychosis and was commanded by visions and voices to harm herself. She was cutting herself and was commanded to jump from moving cars and off buildings. During her stay in hospital we had discovered she could draw her illness and experiences and we found we could then discuss her thoughts and feelings through the art and we were able to talk in greater detail and with more understanding than with words alone. Being told she had mental illness filled her with pain and fear of the future and there was no way except through the art she could express what she was feeling in a unique way that held meaning for her.

When she came home she was still harming herself and we discovered that through art

she was able to express herself and relieve herself of these harmful thoughts on paper and move away from self harm. In our experience art has played a very important role. We have journals and pictures of my daughter's journey through mental illness.

My daughter is now going to university part time and working part time in the art business. She is called upon to speak with individuals with schizophrenia and with community and mental health groups about her illness and recovery. Her struggle with psychosis takes a lot of courage, faith and belief in herself and in the mental health system. Thanks to early intervention my daughter is able to have hope in the return to a normal and productive life.

T.L.'s Story: Coping
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Ontario

Family Coping with First-Episode Psychosis

When my daughter was diagnosed with her first episode of psychosis nine years ago at the PEPP clinic, our whole family began a journey to live better. I still can't believe it, but I managed to quit smoking, stick to a routine at the gym, and eat healthy over the years. I am the last person you'd expect to make significant lifestyle changes. I was a 4-5 cup of coffee a day and junk food junkie from way back! There was nothing I liked more than drinking coffee in the afternoons at the computer and eating handfuls of candy while watching movies on the weekend!!

My partner made several changes in his life as well. He's learned to manage his time and prioritize responsibilities to keep stress levels low. He continues to learn not to get too caught up in work to offset financial demands caused by psychosis. He's figured out how to balance work and play in an effort to stay healthy. My boyfriend makes time for himself to enjoy outdoor activities whenever as he can to maintain his energy.

say reevaluating our lives was inevitable during my daughters' recovery from first episode psychosis. It was impossible not to be affected by sound advice I found on-line for my daughter to reduce stress, eat nutritiously, and engage in positive relationships with others. A healthier approach to living didn't happen overnight, but over time our family made incremental changes we're still benefiting from.

It was especially important for my partner and me to be fit early in my daughter's recovery. For the first few years my daughter leaned on us a lot for emotional and financial support. We had to make sure we had the wherewithal to cope any additional demands caused by psychosis. We wouldn't be too much help if we were both burnt out!

For our family any burdens caused by first episode psychosis evolved over time. My daughter's needs and abilities changed and my boyfriend and I made a point of adapting to new levels of health and independence. The first two years coping with psychosis were the hardest. "Everything is new - there's so much to learn and everyone in the family is trying to find their footing." After the first year things got easier for me. My daughter tells me for her it took about a year for the 'fog of psychosis' to lift. In the second year coping was a bit more straight forward it seems.

In no uncertain terms coping with psychosis had been in a team effort in our family. Brian disease forced lifestyle changes that weren't always easy, but by embracing health we're all better off. My daughter is getting set to move onto a new phase in her life and I'm thinking my boyfriend and I might enjoy a canoe trip together this year. I think after all the healthy living I'll be able to paddle the canoe without getting too tired soon after launching from shore!

- A Mom

*The names in this article have been changed.

Published 01/05/2003

From:

<http://www.abc.net.au/health/yourstories/stories/2003/05/01/1884225.htm#c>

When a previously happy and well-adjusted son started acting strangely, his desperate mother didn't know where to turn. Jennifer tells her story of her Australian family's struggle with psychosis.

Some people said it was just a normal teenage phase. But I knew in my heart there was something wrong with Stephen. His work was going downhill: he was turning up late, not concentrating. He just wasn't himself. He was staying in his room constantly, not coming near us, not even saying good morning. He was going out and getting into fights and he's a passive person. He was going missing for days. We didn't know where he was and he'd come home with bruises and he wouldn't remember what had happened.

He was acting quite strangely and saying he had super powers and things like that. He thought I was dead. He thought someone had killed me and chopped my head off. But he'd been drinking a lot and when people drink they act pretty strangely.

We ended up taking him to our GP and Stephen opened up a little bit. The GP said: "Well, why not be admitted to hospital for a while?" I was hoping Stephen would agree but he wouldn't go. He just thought that he was OK, because he was OK maybe 15 per cent of the time, but mostly he wasn't. The doctor put him on antidepressants. But he was just getting worse and worse.

We ended up getting him referred to a psychiatrist. But he didn't get better. I spent a month running around trying to get people to diagnose him. He was screaming and acting irrationally. Then one day we got a phone call. He was in a police station. I told them I thought something was wrong and I wanted him to go to hospital. I couldn't handle him. He would get very, very upset. He was like a toddler having a tantrum. So the police took him to hospital.

A psychiatrist assessed him and said he was depressed. But if the person acts quite normally, they just don't know what's really the problem. By that time, you see, Stephen was very calm. He really was scared of going into hospital. I think he thought "I'm going nuts, they'll lock me away," all those sorts of fears. Also I'm sure he didn't want people to know. That's a very big thing with young men. The stigma.

A turning point

Things were pretty bad at home around that time. I just could not find anyone to help me. My husband was getting angry because I was getting upset, depressed, and

crying a lot. He couldn't understand why Stephen was acting that way. He just thought he was being a naughty boy. It was taking up all my time. I couldn't work, I couldn't do anything. I felt really bad about putting him into hospital but if I hadn't, I don't know what would have happened. Because I was almost in giving-up mode.

The hospital put us on to early intervention centre. Stephen was released, he had an appointment and I came in with him for an interview. He wasn't living at home at this stage. He just couldn't live with people. He couldn't stand us, not even his sister who he absolutely adores. He just couldn't cope with any interaction. The moment I walked in to the centre, I started to feel better. There's some sort of specialness about the place.

He was assessed and diagnosed almost immediately as having psychosis. They got him on the right drugs – antipsychotic medication. The hospital had given him antipsychotics but they weren't the right ones. The centre staff knew what he needed, because this problem is all they deal with. When he first came in, he was very sick. The staff saw him every day and it was quite intense. They kept in contact on the weekends. It takes a while for the drug to work, so you still have to keep an eye on the patient. They gave a course for everyone – family and friends – about the drugs, about psychosis, about treatment. When you go to the hospital and the doctors are in white coats, it's intimidating. It wasn't like that at the centre. It was a cosy, family-friendly atmosphere.

I didn't find out until later what Stephen was really experiencing because he wouldn't talk to us. Then when he started going to the centre and the medication started working, he was able to talk. It was surprising that I couldn't see it. When I did the course at the centre, they talked about hallucinations and voices and I thought: "Yes, Stephen had that; I remember that". But you really have to know what you're looking for. There's not a lot of education out there I guess.

Hope returns

Family support is critical because psychosis is a family problem and everyone's in pain. I thought that Stephen would die. They said later he probably would have died, without help. And since then I know two people whose sons had psychosis and then went on to develop schizophrenia. One took his life. Stephen didn't know what he needed, but he did need us.

When I did the course there were families coming in who had been where I'd been and weren't smiling. They were sitting there stony-faced like they hadn't slept in nights worrying whether their child was dead. And I'd think, in a week or two you'll be smiling because there's just so much hope here. It saved my son's life and saved my family – so how much more could you ask for?

Now I find it hard to think back to the bad times. Things have just been good for so long. Stephen still has his bad days but that's probably one day a week. The rest of the time, he's going for jobs and socialising. We had an engagement party a couple of

weeks ago and he came along. He's back to how he was. It's just amazing. It's a miracle.

RESOURCES

I AM NOT SICK I DON'T NEED HELP!

ed & Updated



How to Help Someone with
Mental Illness Accept Treatment
Xavier Amador

Foreword
by Pete Earley

"How would you feel Dad, if someone you loved killed himself?"

I was rushing my college age son, Mike, to an emergency room when he asked me that question. He was seeing secret messages in bumper stickers and experiencing rapid mood swings. When we reached the hospital, I felt a tremendous sense of relief. The doctors there would know what to do!

Four hours later, a doctor finally appeared and after briefly questioning Mike declared there was nothing he could do to help him. Mike was convinced that he wasn't sick and he refused to take anti-psychotic medication.

Because the doctor did not believe Mike was an "imminent danger" either to himself or others, my son was turned away even though he was clearly delusional.

During the next forty-eight hours, Mike decompensated. Only another parent can really understand how agonizing it is to stand by and watch your child slip further and further into a mental abyss. I tried, of course, to intervene. I told Mike that his anti-psychotic medicine would help him think more clearly. But he told me there wasn't anything wrong with the way he was thinking. I tried to show him that he was having delusions, but he disagreed. Finally, I begged him to take his pills. "Please, please, just do it for me!" But he wouldn't. "I'm not sick," he kept repeating. After hours-and-hours of exhausting conversations, I demanded that he take his medication or leave the house. That threat only made the situation worse. Afraid of what might happen to him on the street, I backed down. The next morning, when Mike caught me spiking his breakfast cereal with his medicine, he became enraged.

Forty-eight hours later, Mike was in police custody. He had slipped outside one morning and broken into a house to take a bubble bath because he felt dirty. Luckily, the homeowners were out-of-town. It took six officers to subdue him. Mike was charged with two felony crimes.

Uncertain what to do, I contacted the National Alliance on Mental Illness (NAMI), the nation's largest grassroots mental health organization, and a volunteer there urged me to read Dr. Xavier Amador's book, *I am Not Sick, I Don't Need Help!*

When I did, I was amazed. Just about everything I had done to help Mike had been wrong. Rather than calming the situation, my actions had driven a wedge between Mike and me. I had not Listened to him, not Empathized with him, certainly not Agreed with him and finally had not formed a Partnership with him. Those are the four guiding principles behind LEAP, an acronym Dr. Amador has coined to help teach parents and others how to better communicate with their mentally ill loved ones. When I was arguing with Mike, I had felt frustrated and overwhelmed. In Dr. Amador's book, I found a simple to understand blueprint for parents, siblings, children, and friends to follow. While I was reading Dr. Amador's book, I also realized I was not alone. Others had faced the very same situation I had encountered with Mike.

I discovered that Dr. Amador's advice came from years of experience as a clinical psychologist. His academic and professional credentials were impressive. He had served as a professor of psychiatry at Columbia University, as director of Research at NAMI, and director of psychology at the New York State Psychiatric Institute. He had worked as an NBC News consultant, appeared on countless television news shows, been quoted regularly in the media, and had been called on by the National Institute of Mental Health, Veteran's Administration, and U.S. Justice Department for advice. Dr. Amador also had served as an expert witness in high-profile cases, including the Theodore Kaczynski "Unabomber" trial, the Elizabeth Smart kidnapping, and the Zacarias Moussaoui "Twentieth Hijacker" case.

But it was another tidbit from Dr. Amador's background that really caught my eye. His brother Enrique has schizophrenia. This was important to me, because it meant Dr. Amador had not only professional experience, but also a personal stake in his research. One of the reasons he had developed LEAP was to help him find ways to better understand his own brother.

Eventually, my son was sentenced to two years of probation and during that period, Mike followed the rules. He attended therapy, participated in group sessions and took his medication. But several months after Mike's court imposed sanctions ended, signs of his illness began to resurface. I was stunned when I discovered that Mike had stopped taking his medication. Despite everything we had gone through, he had, once again, quit taking his pills. My first impulse was to confront him. How could you do this again? Haven't you learned anything? But my wife reminded me of Dr. Amador's

book. Using LEAP, she was able to work out an agreement that soon had him back on his medication and into treatment.

In this new edition, Dr. Amador updates his groundbreaking book. He explains how "unawareness" of a mental illness is a symptom brought on by the disease. It is not a choice that an ill person makes. He gives practical advice about how families and doctors can bridge the gap created by the federal Health Insurance Portability and Accountability Act (HIPAA) that frequently prevents loved ones from being informed and involved in treatment. He summarizes state commitment laws, using simple to understand terms to explain the legal complexities. Since releasing his first book, Dr. Amador has delivered more than more than 300 lectures and conducted hundreds of LEAP workshops. He has taken information from those sessions and added it to this edition. This new information includes model scripts that suggest specific phrases to use and NOT to use. Being able to refer to these passages is much like having Dr. Amador in your hip pocket.

The needs of each individual who has a mental illness are unique. But regardless of that person's specific problems, the basics that Dr. Amador teaches help readers improve their communication skills, help develop trust, and help turn combative situations into cooperative ones.

One night while Dr. Amador was autographing books, a man approached him empty handed. He had left his dog-eared copy at home, he explained, but had stood in line anyway because he wanted to shake the hand of the doctor who had, as he put it, "given me my son back."

I feel the same way.

Pete Earley is the author of *Crazy: A Father's Search through America's Mental Health Madness*. He is a former investigative journalist for *The Washington Post* and the author of several *New York Times* best-selling books.

Working together

Communication and consideration

By Xavier Amador, PhD

An important lesson I have learned time and time again is this: when a consumer and his or her therapist and family work together, treatment and recovery are optimized. When there is no team—or when there is poor communication between team members—bad things happen. (For our purposes, the term “therapist” includes doctor and/or any other provider.) I won’t tell you my horror stories because we all have them—whether you are a consumer, a relative, or a therapist (or all three).

Communication between the consumer and his/her therapist and loved ones has been studied and written about a great deal. But why don’t therapists and family members talk to each other more? Let’s look at it from different perspectives.

What is the therapist’s view? I can tell you from personal experience and from countless remarks I have heard from colleagues that fear plays a role. But it’s more than just the fear of getting into trouble, of being sued, or of breaking confidentiality regulations. We also fear betraying our patient’s trust. In fact, I think it’s fair to say this is the biggest fear of all. We worry that talking with family will weaken the alliance and leave us powerless to help.

With relatives—and again, I can speak from personal experience—the barrier is not only the therapist’s reluctance to talk with us, but also our own prejudice. Too often, we assume that providers just don’t care. Or we assume nothing will be gained

because we don’t think the therapist is right for our loved one.

All of these barriers are surmountable—quite easily, in fact—if we understand each other’s perspectives and take them all into account when building our team.

The road to hell is paved with good intentions; I can think of few better examples of this than mental health laws that are designed to put up a wall between mental health professionals and their patients’ families. And yet, one of the most important things a family member can do is to stay in touch with their loved one’s mental health care providers. This is true whether your loved one is in the hospital or is an outpatient seeing his therapist weekly or, more commonly, only once a month.

I remember my brother Henry’s first hospitalization for schizophrenia. During one meeting with Henry’s doctor and social worker, my



mother and I should have asked about the discharge plan and shared our observations about what we thought would and would not work. The most important observation we could have shared was that Henry did not think he was sick. We should have helped the professionals come up with a more realistic plan than the one they had. We could have asked: "Given that he does not believe he's ill, what good will your prescription and outpatient appointment slip do?" But we didn't, because we were new to it all.

With my brother's future therapists, I did eventually try to ask more questions and provide what I felt certain would be useful information—like the fact that he continued to think he wasn't sick. But I encountered the same problem most loved ones do: no one would talk to me. Strict privacy regulations make it difficult for mental health professionals to share information; often they cannot even confirm whether or not an individual is a patient. It's enough to make you want to scream. And yet, this obstacle is not coming from an evil place, nor is it unmovable.

If you're a therapist, you have to overcome your preconceived belief that family members may distract you from your work or have nothing to share. Family members usually have a wide range of vital information ... but there are times when they don't.

Relatives who call their loved one's therapist to vent—and, basically, get free therapy—are tapping an inappropriate resource. I often think about that at the end of a very long day when a family member wants to talk to me about how hard their relative's illness has been on them. Of course I understand and sympathize, but that's not the point. If you have more than one patient, it's impossible to be available to all of your patients' involved family members in this way.

Tips for sharing information without violating the doctor-patient relationship

- If the consumer knows certain types of communication will occur between therapist and family, confidentiality is not being violated.
- Clarify the limits of confidentiality with your patient up front.
- Tell him/her you would like to hear from his/her family from time to time "to get a feel for how they think you're doing."

What I have learned, however, is that if I explain my limitations and suggest to the stressed relative that he or she get help for him- or herself, it helps to refocus the conversation on what we should be talking about. If the family member is unwilling to get professional help—or even if they are—I strongly suggest that he or she go to a National Alliance on Mental Illness (NAMI) meeting to gain support from other people who are in the same situation.

If you're a family member, you may make the mistake of thinking an unresponsive therapist (one who doesn't return phone calls or who won't talk to you) doesn't care. I can't say you'd be wrong in every instance, but I can say that, in my experience, this assumption is much more often wrong than right. Most therapists get into this line of work because they care. They chose the career because, like me, it has personal meaning for them and they want to help. So if that's the case, why do they sometimes appear so uncaring?

Often the reason is, in a word, burnout. That being said, family members can help by being focused on specific issues when they call. For example: "I want to tell you about

■ There are no regulations prohibiting a therapist from listening. Try saying: "I know you can't talk to me about my loved one, and that's not what I'm asking you to do. I am not even asking you to verify that my loved one is your patient. All I am asking is that you let me share some observations and concerns about my loved one, and that you listen for a minute."

■ To get a therapist to talk with you about your loved one, try saying: "I know you cannot confirm my relative is your patient, I understand and respect that. But, hypothetically, if the person I just described were your patient, what would you say about ... ?"

■ Assume your loved one's therapist cares, and communicate that assumption. Say, "I know you are trying to help my relative," and it will usually open doors.

some warning signs of relapse I am seeing," or "I am concerned about the discharge plan because ..."

Don't call to vent. For that kind of support, call a friend, relative, or your own therapist.

I am reminded of an old anti-stigma campaign slogan that read: "Mental illness is not a flaw in character, it is a flaw in brain chemistry." When talking to relatives about therapists who seem to not care, I sometimes say, "Therapists did not get into the field because of a flaw in character; they did it because they care." **SZ**

Xavier Amador, PhD, an adjunct professor at Columbia University and the author of numerous scholarly and trade publications, is a regular columnist for Schizophrenia Digest.

RESOURCES FOR FAMILIES

Early Intervention Websites:

www.beatpsychosis.ca The Regional Early Intervention in Psychosis program's website

www.gethelpearly.ca An early psychosis intervention website developed by first-episode youth and families.

www.pepp.ca The Prevention and Early Intervention Program for Psychoses (PEPP) London, Ontario.

www.lynxtracks.ca LYNX Early Psychosis Intervention Program- Ontario.

www.psychosissupport.com Peer Support for Parents of Psychosis Suffers.

www.psychosissucks.ca Early Psychosis Intervention Program- Fraser Health Authority- British Columbia.

www.thesoonerthebetter.ca Early Psychosis Treatment Service Calgary, Alberta.

www.eppic.org.au Early Psychosis Intervention and Prevention Centre- Melbourne, Australia.

Mental Health Websites:

www.cmha.ca Canadian Mental Health Association.

www.schizophrenia.ca Schizophrenia Society of Canada.

www.heretohelp.bc.ca BC Partners for Mental Health and Addictions Information

www.bcscs.org BC Schizophrenia Society

www.rethink.org RETHINK- United Kingdom

www.mooddorderscanada.ca Mood Disorders Society of Canada.

www.getontop.org A Guide to Mental Health-The Compass Strategy, Australia.

Videos

<http://www.youtube.com/watch?v=TXO4Civ0eUU&feature=related> - *Transforming lives award recipient 2009*

<http://www.youtube.com/watch?v=b69pOQYve4Q> – *virtual reality of what it is like to experience a hallucination*

<http://www.youtube.com/watch?v=b69pOQYve4Q> – *Kim mik “That’s Crazy Talk”*

<http://www.youtube.com/watch?v=b69pOQYve4Q> *Transforming lives award recipient 2010*

<http://video.google.com/videoplay?docid=9016369953011097217#> *Early intervention – what you and your family should know*

<http://www.thejackproject.org> *Watch “The Jack Project Video”*

Website to help with memory and concentration

www.lumosity.com *Games to help people with cognitive dysfunction – note that there is a limited number of times a person can use this site before needing to pay for the site*