



A FAMILY'S GUIDE TO

early
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Canadian Mental
Health Association
Waterloo Wellington

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Waterloo Wellington

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We would like to thank all the families who have already made use of our program – for their stories and their wisdom and for the privilege of walking beside them on their journey with their family member. You have been the greatest of teachers, and we have admired your courage.

Special thanks also to Dr. Loys Ligate and Kathy Kruger, whose knowledge and passion fill these pages.

1st Step Team

Trellis Mental Health and Developmental Services

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the purpose of this booklet

It can be very distressing to understand that someone close to you is experiencing psychosis. Family members often feel shocked, confused, afraid, angry and guilty. There is no right or wrong way to feel.

Recognizing the problem is difficult for everyone. There are many questions that go through a family member's mind. Often, they don't really understand what psychosis is. Family and friends often wonder how they should behave and talk to the person who is psychotic. *How can they help?*

The first part of this booklet will provide some basic information about the symptoms and treatment of psychosis. The second part will discuss the role of families and friends in supporting the recovery of their loved one. The booklet will provide you with some tools to help you cope with the symptoms your family member is experiencing. It will address some of the common concerns that families have and suggest strategies to keep you and your family well and functioning.

Professionals often use language that most people are not familiar with. This booklet will explain commonly used terms in order to help you become more comfortable in your interactions with mental health professionals and the mental health care system. A glossary of these terms is provided at the end of the booklet (see page 24).

A family is made up of people who care. But families come in many shapes and sizes. Each individual is free to define family in the way that fits them and their life circumstances.

A MOM'S STORY

Hillary is a single mom whose son was just discharged from the hospital with a diagnosis of first episode psychosis.

At 13, her son had leukemia. People rallied around to provide all kinds of support for her and her son, including a trip to Disney World.

But when her son became psychotic at the age of 17, she was on her own. The psychiatric system used all kinds of acronyms such as ODSP and PRN that she didn't understand. Her friends asked, "What person is your son today?" A neighbour told her that she should "get her lazy boy a job." Hillary was left wondering, "How do I take care of my son?"

1. learning about psychosis

Families need to learn about psychosis to help them understand what their family member is experiencing. Learning about psychosis can help dispel myths that can be frightening. It can help families provide support that is helpful to their relative.

Many sources of information about psychosis are available. The **1st Step Program** and other early psychosis intervention programs have educational material, such as this booklet, to help families. The Canadian Mental Health Association, the Schizophrenia Society of Ontario and many hospital outpatient mental health departments and other community agencies provide seminars, lectures and discussion groups on mental health issues. Ask your family worker or your family member's clinician to suggest some educational resources.

WHAT IS PSYCHOSIS?

Understanding a bit about psychosis will help you know what to expect. Strategies for dealing with the symptoms are discussed later in this booklet. Psychosis is a real illness that is caused by a disturbance of chemicals in the brain called *neurotransmitters*. It results in experiences and thoughts that are out of touch with reality.

Psychosis affects about 3% of the population and is distributed equally across all ethnic groups. People in their late teens and early 20s are the most vulnerable. This illness affects males and females equally, although men tend to be a few years younger than women at the age of onset.

Psychosis is not a personality trait, it is not a character weakness, it is not laziness or a lifestyle choice. The person with psychosis cannot just pull up their socks, smarten up or get a grip.

You will hear professionals use unfamiliar terms to describe the symptoms and stages of psychotic illness. The symptoms are divided into four categories: positive, negative, cognitive and mood.

Positive Symptoms

Positive symptoms are the most noticeable part of psychosis. They are called positive symptoms because they are something extra, added on, that the individual experiences that others do not. Hallucinations are a common positive symptom. They can occur in any of the five senses,



but auditory hallucinations are the most common. The person sees or hears something that is not really there. Delusions are another positive symptom. These are false beliefs. People often believe that they are being followed or that they have a special mission. The individual might feel that people can read their mind or that TV or music has a special message for them. These symptoms respond very well to treatment.

Negative Symptoms

Negative symptoms are seen when, during a psychotic episode, part of a person's usual personality becomes less strong. Many people experiencing psychosis have trouble getting motivated to do even simple things that they used to enjoy. They may find it hard to maintain their personal hygiene. They just don't have much interest in anything. Negative symptoms may cause your relative to withdraw from family and friends and spend more time alone. These symptoms make it harder for your family member to be active and productive.

Negative symptoms usually appear before anyone knows the person is ill, and they take the longest to resolve.

Cognitive Symptoms

An individual experiencing psychosis may have difficulty getting their thoughts together. Their thoughts may be disorganized, and they may have trouble with concentration and memory. This can make your family member forgetful and easily overwhelmed.

Mood Symptoms

A person experiencing psychosis may have changes in their mood. Their mood may be too high or too low. Low is much more common. Mood disturbances are more than just being unusually happy or sad. People can be slowed down or sped up. People who are depressed often feel anxious and guilty about small things. They may have poor appetite, sleep too much, or too little, and have low energy. It is common for individuals to experience depression following a psychotic episode.

A person can also have an elevated mood. This is sometimes called hypomania if it is not too severe and mania if it is very pronounced. The individual may be full of unrealistic plans and ideas. They might spend too much money and take risks without worrying about the danger. They may take on grand projects and believe that they have unusual abilities.

Professionals sometimes call mood problems *affective disorders*.

PHASES OF PSYCHOSIS

Psychosis has three phases: the *prodromal*, the *acute* and the *recovery* phases.

Prodromal phase

During the prodromal phase, families do not usually know that their relative is ill. People often have subtle prodromal symptoms for months, even a year or more, before they become acutely ill. Prodromal symptoms are vague, and their significance is not clear until after positive symptoms emerge. During the prodromal phase, there is a gradual decrease in functioning. Something is not quite right, but there is nothing definite. The individual begins to show negative symptoms. They become more isolated and drop out of their usual activities. They may stop taking care of their hygiene. The person may develop unusual preoccupations that have a religious, political or science fiction flavour.

Most people who develop a full psychosis first have prodromal symptoms. However, many people who experience prodromal symptoms do not develop psychosis.

Acute phase

During the acute phase, the individual develops positive symptoms, and it becomes clear that they are ill. It is usually during this phase that medical help is sought. The sooner treatment begins, the quicker the recovery. Research shows that early intervention leads to better outcomes. Sometimes people are hospitalized, but often they can receive treatment and be cared for in their homes. Whether at home or in the hospital, family is an important part of an individual's recovery.

Recovery phase

During the recovery phase, the individual will experience a gradual decrease in symptoms and return to more normal functioning. Positive symptoms respond best to treatment, and many people become free of hallucinations and delusions. Negative and cognitive symptoms take longer to resolve and are more resistant to treatment. Depression is common following a psychotic episode.

The person who has suffered a psychotic episode has been through a frightening experience. Often they have become disconnected from friends, work and school. They have to come to terms with what has happened to them. Sometimes there is a grief reaction. Their confidence and self-esteem may be affected. The individual may lose



faith in their own judgement and perceptions and their ability to do things successfully.

Your family member will benefit from your support and the support of professionals throughout the recovery phase. There will be a period of psychosocial rehabilitation that will involve strengthening social and vocational skills that they did not use during their illness. As their symptoms improve, they will be able to resume productive activity and engagement with life.

1st Step and other early psychosis intervention programs have many activities designed to support this recovery process. The person will meet individually with their clinician and be invited to attend group meetings and activities. This will help recreate structure and meaning in their life as they move toward wellness.

DIAGNOSIS

People experiencing their first episode of psychosis are often diagnosed as having Psychosis Not Otherwise Specified, or NOS for short. A mental health diagnosis is a description of a picture that emerges over time. In the past, people have often had several different diagnoses over the years. However, treatment is based on the symptoms and not the diagnosis. We hope to provide early intervention and treatment to individuals before they have been sick long enough to qualify for a clear diagnosis.

Common diagnoses in early psychosis include Psychosis NOS, Schizophrenia, Bipolar Disorder, Schizoaffective Disorder, Psychotic Depression, Substance Induced Psychosis and Delusional Disorder. With your relative's permission, their doctor will talk to you about the diagnosis.

WHAT CAUSES PSYCHOSIS?

Most family members wonder what caused their relative to become psychotic. Usually, a combination of factors contributes to developing psychosis. These factors are described as *vulnerability* and *stress*. Vulnerability is made up of characteristics that are part of the person. These include genetics, premature birth, head injury and the effects of drug use on the brain. Stressors are things that happen to a person – including trauma (such as an accident or assault), immigration, school, work and relationships. Everyone has stressors in their life. Sometimes, when vulnerability is combined with stressors, psychosis occurs.

WHAT DOES NOT CAUSE PSYCHOSIS?

Family members sometimes blame themselves, or each other, for their relative's psychosis. Extended family, neighbours and friends may imply that the family somehow did something wrong that caused this illness. *This is not true.* Psychosis is not caused by parenting style (such as by being too strict or spoiling). It is not caused by laziness or weak character. It is not caused by poverty or socioeconomic status. *Please do not blame yourself or your family member.*

TREATMENT

An individual experiencing their first episode of psychosis needs comprehensive treatment to make the best possible recovery. The illness must be treated. The person needs support to maintain their roles in life such as student, friend, brother/sister, girlfriend/boyfriend, athlete or musician. They need help to deal with the experience of psychosis.

Medication

Psychosis is a real medical illness, and it requires medical treatment. Medication is the cornerstone of recovery because it helps bring the brain chemicals back into balance. It helps protect the brain and helps it heal. Scientists used to think that the brain could not heal, but recent research shows that the brain does heal and develop new pathways.

It is usually necessary for the individual to take medication for at least one year after symptoms resolve. Many people will need to take medication for longer than one year in order to stay well.

It is helpful for you to know a little about the medication your relative is taking. There are a few different types of medications.

Antipsychotic medications treat the unusual thoughts and experiences the individual is having. Hallucinations and delusions, for example, are treated with antipsychotic medications. These medications have some effect on negative symptoms, but psychosocial rehabilitation is also necessary. Some antipsychotic medications also have an antidepressant effect.

Medications can have side effects. The most common side effect of antipsychotic medication is increased appetite and weight gain. This leaves the individual at risk for the health problems associated with increased weight, such as diabetes and high cholesterol. Some people find that medication makes them feel tired. This often wears off as people get used to their medication. Sexual side effects can also occur.

Women may develop menstrual irregularities, and men may have difficulty with sexual functioning.

If your family member is having problems with their medication, please encourage them to talk to their doctor. We will describe this more later in this booklet (see page 19).

Antidepressant medications balance the chemicals in the brain that affect mood. They take between two and six weeks to be effective. Side effects are rarely a problem. Occasionally, some people experience hand tremors, nausea or sleep disturbances. When the time comes to stop antidepressant medication, it is best to do it slowly, with the supervision of a doctor.

Mood stabilizers help make mood swings less intense. It is important to maintain a therapeutic blood level. So people taking mood stabilizing medications usually need to get their blood tested regularly. Antipsychotic, antidepressant and mood stabilizing medications are not addicting in the way that pain medication can be. Your family member will not become addicted. They may need medication to stay well, but they will not become tolerant or experience withdrawal or cravings.

Psychosocial Rehabilitation

Medication is important, but there is much more to recovering from psychosis. Many things about getting better after psychosis are similar to recovering from a medical illness or an accident. As the individual improves, they need to gradually increase their level of activity. Their clinician will help them set goals and develop a plan to work toward those goals. At first, they may not feel much interest or motivation and may not enjoy things they used to like. Getting better takes hard work.

1st Step groups are a good way to start. They provide an opportunity to participate in a safe, non-threatening environment. Different groups cater to different interests. Some groups are about socialization and recreation, and others are devoted to skill development and therapy.

As people improve, it is helpful to get back into a routine. Volunteer work is one good way to ease back into productive activity. Most people find it best to return to work or school part time at first. It is better to start small and be successful than to try to do too much and get discouraged.

A healthy lifestyle is also important for recovery. Exercise helps relieve stress and also helps the brain heal. Weight gain is often a problem. Sensible eating and regular exercise really do help.

Relapse Recognition and Prevention

Relapses can occur. These happen when a person's symptoms improve significantly and then come back. If there are future episodes, they will look very much like the first episode. The very same troubling thoughts and experiences will return. Relapses can often be prevented by seeking intervention at the first sign of symptoms recurring. This approach will be discussed in more detail in the second part of this booklet, which deals with strategies for families.

MENTAL HEALTH AND THE LAW

Privacy

The privacy of individuals receiving mental health care is protected by law. Before health care professionals can share information about a person, that individual must give their consent. Usually, consent is obtained to share information within what is called The Circle of Care within the health care system. This includes family physicians, labs and hospitals. Information cannot be shared with anyone else (such as schools or employers) without the individual's specific written consent.

This situation can often be frustrating for family members. Clinicians working with your family member cannot share information with you without their consent. However, we can always listen. Your observations are important to the recovery of your family member. Please talk to us.

The Mental Health Act

Under very specific conditions, a person can be hospitalized without their consent. However, for this to happen, their own safety or the safety of others must be in jeopardy. To have an individual hospitalized, a physician can fill out a Certificate of Involuntary Assessment, known as a Form 1. The period of involuntary hospitalization can be extended using a Form 3.

If family members think their relative should be hospitalized, they can go to a Justice of the Peace and request a Form 2. This is also a Certificate of Involuntary Assessment. If the individual wants to appeal any of these certificates, they can request a review board.

Participation in 1st Step is entirely voluntary. Unlike the case for hospitalization, an individual can never be required to participate in 1st Step.

STIGMA

Although much progress has been made, stigma can still be associated with mental health problems. Friends and neighbours may have false negative beliefs about mental illness and give unhelpful, even hurtful, advice. Families can be isolated because they don't want anyone to find out about their family member's illness.

Discrimination against people with mental illness is wrong. Myths associated with mental illness are false. People with psychosis are not psycho. They do not have multiple personalities, and they are not more dangerous than other people.

Even more destructive, the individual experiencing psychosis might think badly of himself or herself for being ill.

Psychosis is an illness. People experiencing psychosis are ill, not bad or weak. Health care workers, schools, government agencies and many others recognize this. Individuals experiencing psychosis and their families are entitled to all the help and support that people with other illnesses receive.

So far, this booklet has provided a basic summary of information about psychosis to help families understand what their family member is experiencing. If you have any questions about the nature of this illness, please ask your relative's clinician.

In the second part of this booklet, we will discuss simple strategies to help you help your family member and keep your whole family functioning.



2. how families can best respond to early psychosis

Now that you understand a bit about psychosis, we can describe how families can help. In this second part of the booklet, we'll first indicate how the symptoms of psychosis might affect your family member's behaviour and interactions. We'll then discuss strategies and tips for managing symptoms.

WORKING TOGETHER

Families, whether intact, separated, blended or extended, need to work together, as they are all part of the team. When a member of the team is sick, it puts a strain on the resources – physical, financial and emotional – of the whole team. For a while, the individual who is sick might not be able to contribute in the way that they did when they were well. They might need more time and attention. They might need a bigger share of a limited amount of space. Families need to work together so that the family as a whole, and each individual member, still gets what they need to continue to function and be well.

Here are a couple of examples of how families responded to a family member experiencing psychosis.

Jeremy's parents are divorced and each has remarried. Neither parent wants to be in the same room with the other. This causes stress to Jeremy, who is put in the middle. Parents may not like each other, but they need to put aside their differences to be able to help their child.

Jason's immediate family is large, busy and noisy. Since he got sick, Jason finds it overwhelming. His grandparents offered to let him stay with them in order to reduce his stress. Jason finds it easier to cope with his symptoms in the quiet environment of his grandparents' home.

John's parents are divorced, and each one has remarried. John can stay with either parent. His parents communicate with each other and spell each other off. John gets the support he needs, and his parents are able to keep up with the other important things they need to do.

Try to avoid being the only person your family member relies on. This may lead to them resenting you, and it is too heavy a burden for you. Try to involve other family members and friends, so that there are a few people your family member is comfortable with.

REALISTIC EXPECTATIONS

During a first episode of psychosis, it is often difficult for family members to know what to expect. Families wonder, “Can I expect him or her to do the things I expect the other family members to do?”

It is appropriate for you to have expectations of your family member. They can take some responsibility in the home. They can, to some extent, control their behaviour. But when they are experiencing psychosis, they do not feel the same as they usually do. Simple tasks may seem overwhelming. Symptoms interfere with concentration and organization. Many people experiencing psychosis find it difficult to be around others or to accomplish anything. Your family member may avoid people and activities.

Recovery is a long-distance run, not a sprint. The other members of the family must carry on with their lives during the individual's recovery. It may take a year or more for a person to recover from an episode of psychosis. (Each individual will recover at their own pace.) For family and friends, there is a delicate balance between expecting too much or too little. It's important to have realistic expectations, so your family member will do as much as they are able to do without feeling too pressured. If they are under too much stress, they cannot be successful and will therefore lose confidence. Your relative will not be the same as they were before, and they will not be able to do the same things as their friends. They may not be able to do things that used to interest them. Your family member may be afraid to contact old friends because they don't know how to explain what has happened to them.

During a first episode of psychosis, your relative may not be able to tell the difference between what is real and what is not. They often feel overwhelmed by the world around them because they are not in control of their thoughts. They may feel confused and frightened. They may have lost confidence in themselves. It is common for people to be withdrawn, to lose interest in life and to be unable to initiate anything.

COPING WITH NEGATIVE SYMPTOMS

Negative Symptoms

Negative symptoms, such as withdrawing from social interaction and having no motivation or energy, are often the hardest for families to cope with. These symptoms look a lot like laziness and lack of effort. Families often feel hurt and rejected when their relative does not want to spend time with them or talk to them. During this part of an individual's recovery, they need to begin to engage in activities even

though they still don't feel like doing anything.

Families play an important role in supporting their family member in re-engaging with life. However, your relative's recovery is their responsibility. You cannot make them do things you know would be good for them. Here are a few suggestions for helping your relative:

- Provide support.
- Let your family member know that you are there if they need you.
- Encourage them to participate in activities that are not stressful.
- Praise their successes.
- Ask them what would be helpful.
- Encourage them to participate in activities they enjoy. Start small and build on successes.
- Help them make a schedule of daily activities.
- Be honest. If you can't do something, say so.
- If something bothers you, say so.
- Continue to be involved in your own life.
- Don't bribe or blackmail your relative.
- Don't feel guilty or blame yourself.
- Choose your battles. Let the little things go.

Social Withdrawal

People experiencing psychosis are often socially withdrawn. They may not want to go anywhere, and they may spend a lot of time alone in their room. It may be difficult to engage your family member in a conversation. Your relative may not be as affectionate as they were before. Please don't take this personally, as it is part of the illness. Try to engage your family member in conversations that require more than yes or no answers. For example, instead of saying, "Did you like the movie?" try saying, "Tell me about the part of the movie you liked best."

Although your family member may find it difficult to interact with others, this does not mean that it is alright for them to stay in bed all day. There should be some expectation that the individual will participate in household activities such as chores or joining the family in social events. For example, if they are not able to sit through a whole baseball game, invite them to watch the last inning with you. If the person refuses, say, "You're welcome to join us when you feel ready."

Often, special events such as family birthdays and weddings are particularly stressful. Your relative may feel overwhelmed. They may be anxious that they will have nothing to say. They may be concerned that people will ask them what they've been doing. This could be especially difficult for them if they feel they might have to talk with people who

are not aware of their situation. Sometimes arrangements can be made for your relative to have “time outs” in a quiet room. This will allow them to join the family for as much time as they can tolerate and withdraw when they’ve had enough.

Communication

Your family member may have difficulty processing information. It’s helpful to keep conversations simple and clear. For example, instead of saying, “Please get ready to go to your grandmother’s,” try to be more specific about what they need to do. Try asking, “Please take a shower and get dressed in your brown pants by 6 pm to go to your grandmother’s.”

Your family member may have difficulty picking up on social cues. Communication like this (which is implied, rather than being obvious) may be missed by your relative – even when it is apparent to others. For example, instead of looking at your watch to signal that it’s time to go, you may have to tell them.

Try to avoid having a sensitive conversation when you or your family member is upset or angry.

Set reasonable limits and be clear about them.

Sleeping Too Much or Sleeping at Odd Times

Your family member may spend a lot of time in bed. Sleep helps them heal. Medication can also be sedating. Or they may retreat to their bed because activity is overwhelming for them. The world is quieter at night, and your relative may find it easier to cope with being awake then. They may feel that they have no reason to get up in the morning.

It is very common for people who have had their first episode of psychosis to sleep almost all day. Sometimes they stay up all night. As they move forward in their recovery, it will be helpful for them to re-establish some routine and structure in their lives.

COPING WITH POSITIVE SYMPTOMS

Hallucinations

Hallucinations seem very real to the person experiencing them. Your family member may find them distressing and frightening. As people start to get better, hallucinations become less frequent and intense. They usually do not go away all at once, however. Instead, they fade away gradually. People begin to be able to distinguish these experiences from reality. If your family member believes that the voices or other

hallucinations are real, you will not be able to reason them out of their belief. *Please do not try.* It will only upset both you and your family member.

You can help by being sympathetic and understanding. There is no need to ask about the details of the hallucinations, but you can listen if they want to talk about them. Some people are able to reduce the voices by distracting themselves. Ask your family member if it would be helpful to listen to music or go for a walk with you.

Delusions

The most important thing to remember about delusions is that they are completely real to your family member. You will not be able to reason them out of their delusions no matter how much proof you have. *Please do not try.* Don't argue with your family member. Try not to get angry.

But you should not pretend that you agree with a delusion. You can say something like "I understand that you believe these things, but I do not see it that way" or if the delusion is supernatural or magical, you can say, "I don't know anything about things like that."

Your family member may find it comforting to be able to share their thoughts with you. Acknowledge how these thoughts must make them feel. For example, you could say, "It must be scary to think that cameras are watching you." When you become worn out from listening, it is okay to say, "I can't talk about this any more right now."

Encourage your relative to talk about their unusual ideas only with people who understand, such as close friends and family and their clinician.

NEGATIVE FEELINGS

Your family member may misinterpret things that others say and do. They may have a short fuse and be impulsive. Have open discussions in the family to solve issues that are troublesome. Allow yourself and your family member to calm down before trying to resolve conflict.

Your family member may be angry and sad about what has happened to them. They may experience grief. Please do not force them to look on the bright side. Allow them to express their true feelings. Say things like "I'm listening. You've had a hard time. You're brave and strong to cope the way you have."

Depression is common after a psychotic episode. If your family member seems depressed, please let their clinician know.



SUICIDAL THOUGHTS

Your family member may have suicidal thoughts, especially if they are depressed. Suicidal thoughts are quite common among people with psychosis. Most people do not act on these thoughts. However, about 10% of individuals with psychosis take their own lives. Talking about suicidal feelings makes it *less* likely to happen – not more likely. It is also helpful for you to be aware of changes in your family member’s mood and activities. Here are some tips for supporting a family member who has suicidal thoughts:

- Ask your family member how they are feeling.
- Ask them if they feel safe and in control of their actions.
- Ask your family member what would help them feel safe.
- Acknowledge their feelings, but tell them that help is available.
- Stay with your family member and engage them in pleasant, non-stressful conversation.
- Offer the person your support. Let them know that you accept and care for them.
- Give them positive feedback for confiding in you.
- Do not promise to keep your family member’s suicidal thoughts a secret.
- Look at your family member’s crisis plan. This should already have been made up with their mental health worker. It should include resources to call and strategies for the reduction of stress.
- Call their mental health professional.
- Call crisis services. Most communities have a crisis service that is available 24/7. Keep the number handy. Call them if you need them.

MEDICATIONS

Many individuals, and their families, do not like the idea of taking medication. They are worried about side effects and concerned about the risk of addiction. Taking medication is serious and deserves to be given careful thought. However, medication is necessary to recover from psychosis. The chance of relapse without medication is 80% to 90% within the first two years.

Encourage your relative to speak with their doctor about any concerns or side effects they might have. Antipsychotic and antidepressant medications are not addictive. There are several different medications in each category, and each is somewhat different. Medication regimes often need to be tinkered with before they’re just right for the individual.

It is important that medication be taken as prescribed. The dose should not be changed without checking with the doctor. If your relative has trouble remembering to take their medication and is willing to accept your help, you can help them build their medication into their daily routine. It can be helpful to keep medication beside their toothbrush or in another place where they won't forget it. Dosettes organize medications into day and time slots. Do not become the medication police. You may know your family member needs medication, but if they do not want to take it, you cannot force them.

Do not trick them by putting medication into their ice cream or other food.

If you think your family member is not taking their medication, please share this information with their clinician.

Herbal and over-the-counter medications can interfere with the effectiveness of prescribed medication. Encourage your family member to talk to their doctor about all the herbal and over-the-counter medications they take.

ALCOHOL, STREET DRUGS, CIGARETTES AND CAFFEINE

Many individuals with mental health issues use alcohol and street drugs. Mental health professionals call this a *concurrent disorder*, meaning two problems at once – a mental health problem and a substance use problem.

Individuals sometimes use drugs and alcohol to help them control their symptoms, such as anxiety. Cigarettes and caffeine can also be used to stimulate cognitive functioning.

Alcohol and street drugs are harmful and can increase symptoms and bring on a relapse.

Many young people believe that cannabis is safe. They know many people who use it and do not seem to be having problems. However, people who experience psychosis are especially vulnerable to the effects of cannabis. For these people, cannabis contributes to the development of psychosis and interferes with recovery.

Encourage your family member to stop using. If they are not willing to stop, encourage them to reduce their risk. Suggest that they talk to their clinician about their substance use. Their clinician can connect them with the support they need to become free of drugs and alcohol.

Sometimes, when a person stops using drugs and alcohol, they no longer feel comfortable with their social group. Help your family member find ways to socialize without using drugs and alcohol.

Encourage them to avoid situations where they will be tempted to use. Help them find ways to say no and to explain why they do not want to use anymore.

ANGRY AND IRRITABLE BEHAVIOUR

A person experiencing a psychotic episode may be less easygoing and tolerant than usual. They may be especially sensitive about their room and their possessions. They may get angry and become irritable when things are expected of them. Families often try so hard to accommodate their relative that they become uncomfortable in their own homes.

While it is important to try to keep the peace, it is also necessary to avoid becoming intimidated. Try to have an honest conversation with your family member about what upsets them. Whenever possible, avoid the things that create conflict. For example, if your relative doesn't like people in his or her room, you could help by asking their younger siblings to stay out.

Be honest and firm about the things you need your family member to do so that the rest of the family can carry on with their lives during the individual's recovery. For example, if your family member sleeps during the day, you can insist that they sleep in their room and not on the living room sofa.

It might help your family member to have a safe way to express their anger. Physical activity, such as going for a run or using a punching bag, can help relieve stress. If controlling anger is a problem for your family member, please encourage them to talk to their clinician. Talk therapy, anger management and sometimes medication can help your relative get control over their emotions.

AGGRESSIVE BEHAVIOUR

Sometimes psychotic thoughts can lead to aggressive behaviour. The individual may find it hard to control their emotions or to express themselves in a calm way. If your family member is becoming upset and you are concerned about aggression, here are a few suggestions to try to calm the situation down:

- Remain calm yourself. If you are becoming upset, cool down before you approach your relative.
- Don't insist on resolving things when you and/or your family member are upset. Allow your relative to leave the room and have some space and time on their own to settle down.

- Acknowledge your family member's feelings and ask if there is anything that would help them calm down.
- Try to identify the things that trigger aggression and reduce them.
- After the situation has resolved, ask your relative what they were upset about. Encourage them to talk, in a calm way, about what makes them upset and angry.
- Tell your family member's mental health worker about their aggressive behaviour.
- Develop a plan with your family member's mental health worker about what to do if he or she becomes aggressive or talks about hurting others.
- Take warnings and threats seriously.
- Ensure your own safety and that of others by getting out of harm's way.
- **If all of the above fails, call the police. Tell the police operator that it is a mental health emergency.**

MANAGING STRESS

Your family member may be more vulnerable to being overwhelmed by stress when they are experiencing psychosis. Both positive and negative events can create stress – for example, birthdays, vacations, financial problems and loss. You can help your relative identify the things that cause stress for them. Help them develop strategies to manage small stresses and to avoid too much stress whenever possible. For example, in one case, when the extended family came over for dinner, Donald found all the activity stressful. He took breaks from socializing by going to his room when he felt overwhelmed.

RELAPSE RECOGNITION AND PREVENTION

Relapses can occur and usually look very much like the first episode. The individual will have the same unusual thoughts and behaviours. For example, when John had his first episode, he believed he was being followed. A year later, he was doing well and returned to university. The feeling of being followed returned. He told his clinician and met with his doctor. Together, they worked out ways to reduce his stress, and his medication was adjusted. He returned to university on a part-time basis and did not go through a full relapse.

Families are often the first to notice that a relapse has begun. You may realize that your family member is behaving in the same way that

they did when they were beginning to get sick the first time. Their sleep may be altered and their symptoms may begin to come back.

Relapses can be controlled, and full relapse can usually be prevented by getting help early.

As soon as you notice signs of relapse, please contact your family member's clinician.

STAYING WELL

As your family member improves, they should gradually return to having an active and productive life. Usually, they will resume activities gradually. For example, when Jennifer returned to work after her psychotic episode, she started with four-hour shifts instead of eight.

Volunteer work can be a good preparation for returning to employment. Volunteering helps individuals get used to a schedule and to responsibility. It also helps them practise their social and vocational skills.

Joining a **1st Step** group is a good way to build and practise skills for a successful return to productive activity. You can encourage your family member to choose activities that interest them.

Remember that your relative's recovery is their responsibility. You cannot do it for them.

TAKING CARE OF YOURSELF

Do not neglect your own health and well-being. It is not good for you and does not help your family member. It is important that your life and your other family members' lives are not just about your relative's illness. Do not let the need for secrecy isolate you. Continue to function in the other roles of your life, such as spouse, child, sister/brother, parent, worker and friend.

Take time with your partner, your other children, the extended family and your friends. Take a break from care giving. Let other family members and friends help out. Respite can be arranged. Please talk to your relative's mental health worker.

There are other people facing similar challenges. You can meet with the **1st Step** family worker to talk about things specific to your family. You can also attend groups with other families of individuals who have had a psychotic episode – to share experiences and strategies.

You have a very important, but difficult, role in your family member's recovery. You may need someone to talk to.

Please call.

glossary

Affective disorders: mood disorders

Auditory: refers to things you hear with your ears

Cognitive symptoms: the difficulty an individual experiencing psychosis has with memory, concentration and organizing their thoughts

Concurrent disorder: a substance abuse problem and a mental health problem occurring at the same time

Delusions: fixed false beliefs; they are often grandiose or persecutory and often have a religious or science fiction flavour

Hallucinations: sensory experiences that come from inside the brain. The individual hears, sees, smells or feels something that is not really there. Auditory (hearing) hallucinations are the most common.

Mood symptoms: a person with psychosis can have changes in their mood; their mood can be either too high or too low; a too-low mood is more common

Negative symptoms: this describes the spark that is missing when an individual has psychosis – the lack of interest, motivation and social engagement

Neurotransmitters: chemicals in the brain that are not properly regulated in psychosis

ODSP: Ontario Disability Support Program, an Ontario Government program that provides financial support, drug and dental benefits and employment support to individuals who have disabilities

Positive symptoms: these are things that are added on, things the individual experiences that others do not (such as hallucinations and delusions)

PRN: a medical term used for medication that is to be taken as needed rather than at a set time

Prodromal: the first phase of psychosis, before anyone knows the person is ill; negative symptoms begin to appear, and something is not quite right

Relapse: a recurrence of symptoms after they have resolved

Sedation: sleepiness caused by medication

Stigma: false negative ideas attached to a particular characteristic; the untrue negative beliefs and myths surrounding mental health problems

