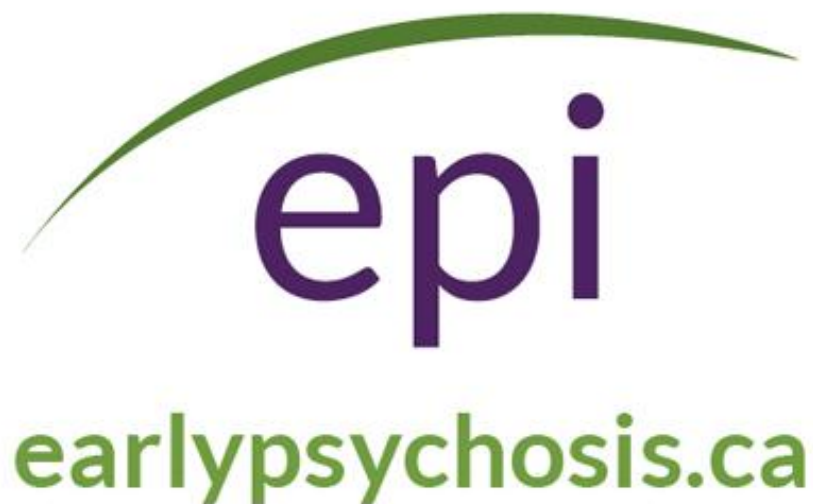


Coping:

When someone in your family has
Psychosis



Fraser Early Psychosis Intervention Program

English



Coping: When someone in your family has psychosis

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Introduction

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 of 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 iPod 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 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 is 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., over crowding 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 their 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 alcohol/drugs 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 behaviors 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.

EPI Family Services

EPI stands for Early Psychosis Intervention. The EPI program is an outpatient health care service that provides assistance to young people who have recently developed psychosis. Once accepted into the program, ongoing case management, psychiatric follow up, psychological/family interventions, and groups will be offered. The EPI program offers group and individual support/education for families.

Family Education Groups

Having the support of groups can be very beneficial. Groups provide a safe environment to meet with others who have been through similar experiences. Education about psychosis through videos, presentations, written material and discussion is offered in groups; and, they are also a great way to learn and be positive about recovery. Topics covered in the family group include:

- Description of the EPI program
- Symptoms and causes of psychosis
- Current treatments and resources
- Medications and side effects
- Recovery process
- Relapse prevention strategies
- Stress management
- Substance use issues
- Support and help available for families

Family Support

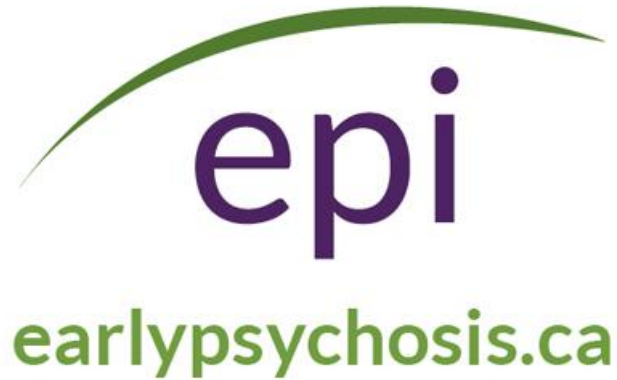
Each family is unique, and as such, the support offered is tailored specifically to meet the needs identified at the time of referral. Family support and interventions include:

- Assessment of the family situation
- Short-term family therapy
- Assistance with engaging and connecting ill family member to the program
- Referral to other service providers as needed

Family work may also involve education about psychosis, relationship work, and liaising between the family and the rest of the treatment team.

Family therapy is based on various theoretical frameworks centering on family systems theory which assists family members in establishing treatment goals aimed at a change process of enhancing relationships and communication in the family.

To learn more about Early Psychosis in English and other languages
See our website at: www.earlypsychosis.ca



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