

Important Information for Parents and Friends of Young People Experiencing Psychosis

Lessons Learned from Young Adult Graduates of EASA

April 2019



What is psychosis?

It's important for family and friends to understand what psychosis is and what it may look like. That understanding is the first step that parents or friends can take so they may provide support on the journey towards recovery. As a parent or friend of someone with psychosis, it may be hard at first to understand what someone with psychosis is experiencing. Psychosis is a mental health word that describes a significant change in how a person experiences reality, which can make it harder for them to understand the world around them, or themselves. As a close friend or family member, you may notice symptoms of psychosis which include:

- » Perceiving things other people don't perceive (for example, hearing voices),
- » Having a harder time than usual staying on topic or communicating,
- » Believing that you can achieve things that aren't real or possible.

How do I support a person who is experiencing psychosis?

Maintaining contact with family and friends is an essential part of recovery from psychosis. However, the changes the person is experiencing can make it difficult. A group of young adults who experienced psychosis put together these recommendations for families and other supporters:

- » Consider yourself an important part of the team. Help the professionals get to know your family and work with them actively.
- » Give me space. My senses may be overwhelmed and having space helps me sort things.
- » Encourage me and don't put me down.
- » Listen to me when I talk and understand I am saying what I really experience.
- » Just because I may be spending time alone doesn't mean I'm not making progress.
- » Encourage me to do a little more, one step at a time.
- » Keep everybody safe and respected by setting healthy limits.
- » Don't discourage me from trying things that may seem hard.
- » Keep things calm and peaceful.
- » Educate yourself about my condition and what helps.
- » Psychosis symptoms can cause people to act differently. Keep sight of the person you know; symptoms of psychosis do not change who the person is.
- » Help me meet other people who have had similar experiences. They can help me understand I'm not alone and there is real hope for my future.
- » Never give up, no matter what.
- » Take care of yourself and keep having fun.

Tips for communicating

It can be hard to put yourself in the shoes of someone with psychosis, and miscommunications might occur. Also, it may take the person longer to understand what you are saying, or to speak. Sometimes the individual may not be able to stay in the same room as you or carry out a conversation for longer than a few minutes. Whatever they can do should be encouraged without judgment. Here are tips from young people who have been there:

- » Please slow down and give me as much time to speak as I need.
- » Don't tell me I'm wrong. Listen to me and try to understand what I'm saying, what I'm experiencing, and how I feel.
- » Only ask me one question at a time, and give me time to answer.
- » Try to keep things simple and concrete.
- » Break things into simple steps.
- » Write things down to help me remember.



Seek connection without trying to decide who is right and who is wrong. Xaviar Amador, in his book *I'm Not Sick I Don't Need Help*, suggests using the acronym LEAP:

- » **L**istening so the person feels genuinely heard
- » **E**mpathizing with the person's feelings even if their beliefs and experiences don't make sense to you
- » Finding something you can **A**gree on
- » **P**artnering to work together

Help the person reconnect to their strengths and interests

In the early stage of recovery from psychosis, simple things can be much more difficult than they used to be. The person in recovery may lose confidence and get stuck, not knowing how to move forward. Families and friends can help by:

- » Assisting the person to identify their strengths and interests, and to understand that those strengths don't go away just because things are hard.
- » Helping them to set small, step-by step goals to move forward and overcome challenges.
- » Recognizing that even small steps can involve great effort for a person in early recovery.
- » Sticking by the person and supporting them to move forward at their own pace.
- » Helping them to understand that many challenges they face are just the normal challenges other people their age deal with. For example, not getting a job the first time you apply doesn't mean no one will employ you.
- » Finding activities you can do on your own and with each other. All activities small and large count, and help you stay connected to a sense of strength.

While a friend or family member may be able to provide support and guidance, evaluating strengths, goals, and challenges is an introspective experience for the person close to you, and may, at times, be overwhelming for them. You can offer resources and ideas regarding their strengths, goals, and challenges, as well as providing support in overwhelming situations.



Be hopeful for the future



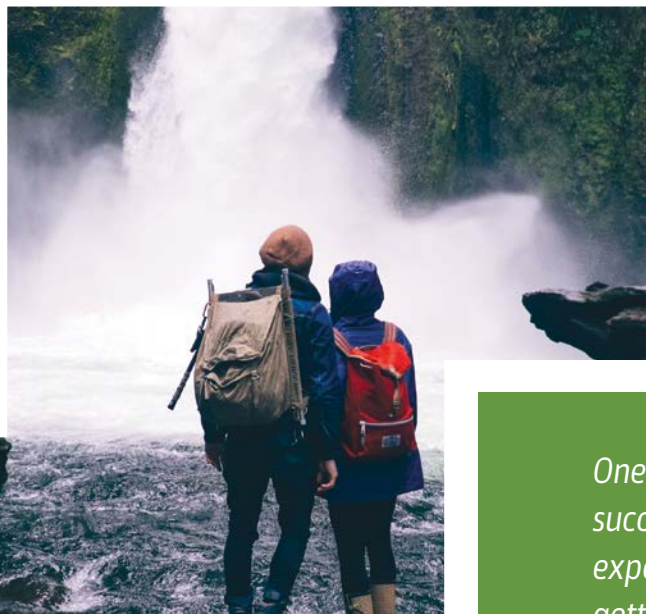
Hopefulness is a feeling that the future can happen, challenges can be met successfully, and one can take positive action toward the future. Hopefulness is important because without it, it's hard to act. If you and the person you care about believe success is possible, then taking action is more likely. Hopefulness makes it easier to move toward recovery goals.

You can support the person you care about in following these tips to increase hopefulness. You can also use these tips to increase your own hopefulness:

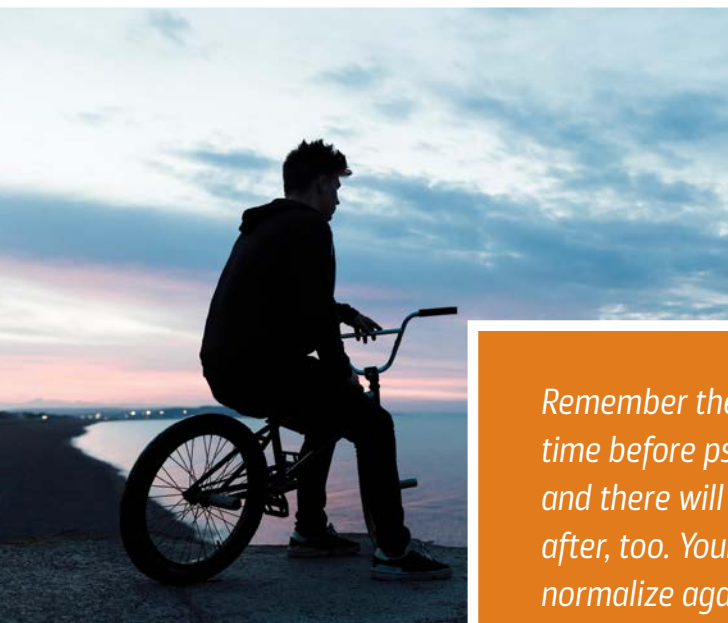
- » Take time to refresh and care for yourself, whether it's brushing your teeth, doing something to pamper yourself, or finding a space of quiet or meditation.
- » Do things that make you happy, and that make you laugh.
- » Acknowledge the people, places, and things in your life that you are grateful for.
- » Seek out others who have had similar experiences to you for encouragement and a sense of connection.

There is every reason to be hopeful. Young people have been successful in their own recoveries. Here are some of their stories and advice:

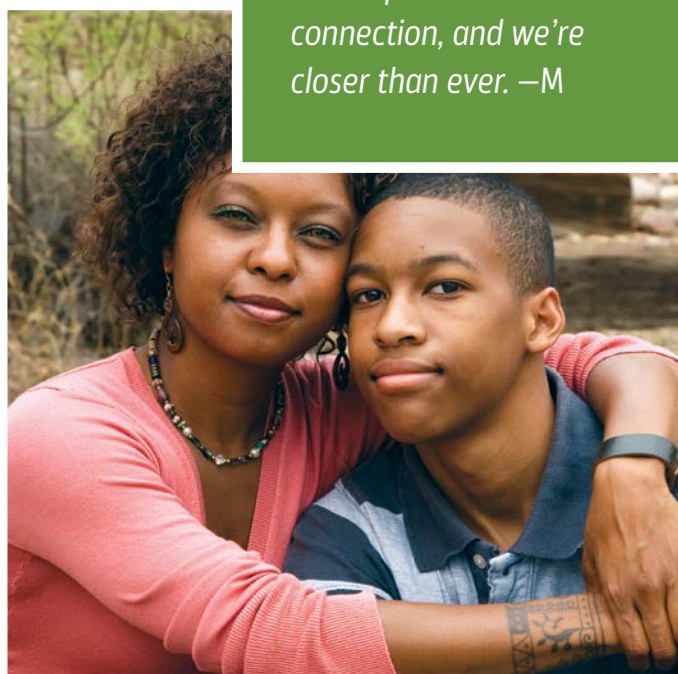
When I first started [recovery] I was having trouble staying in school, making connections with friends, finding a job, and I really wanted a girlfriend. Now, not only have I finished school, got a great job, got great friends [laughs] I even have a girlfriend. —NB



One of my biggest successes I didn't even expect... I found myself getting closer to my family. Now I have a deeper, more satisfying relationship with my family than before I experienced psychosis. My mom and I have a more open and honest connection, and we're closer than ever. —M



Remember there was a time before psychosis and there will be a time after, too. Your life will normalize again. This, too, shall pass. —P



Take care of yourself and your family

Managing stress and keeping communication open means slowing down and focusing on what matters most. Don't try to get through this alone. Reach out to trusted family, friends and professionals. Most early psychosis programs have guidelines for families and friends. Here are some important ones:

- » Seek education and support.
- » Take it one step at a time, and keep it calm. Time outs are allowed; communicate when composed and ready to listen.
- » Give each other space. Let anyone – including yourself – walk away if they need to, without making a fuss.
- » Set a few simple limits. For example, yelling or name calling may be off-limits, and if it starts to happen, it's allowed for the other person to leave the room.
- » Find a place to sort through your own difficult thoughts and feelings.
- » Ignore what you can't change. On certain things, you can't change everyone's mind, and neither can others necessarily change yours. Focus communication where it can accomplish something. It's okay to disagree with them.
- » Treat the mental health team as partners.
- » Work with your team to plan ahead for relapse and crisis.
- » Keep a balanced perspective. Understand what they are saying even if you disagree, and honestly consider if there is any value to what they've said, even if the value is simply just to understand them better.



Thanks for being there! You matter! Even if it's just being quiet, your persistent caring will be noticed and will matter.



This booklet was adapted from EASA Connections, a multi-year research project in which young adult graduates of EASA worked with scientists and clinicians to develop a website for young people new to EASA.

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