



Understanding psychosis

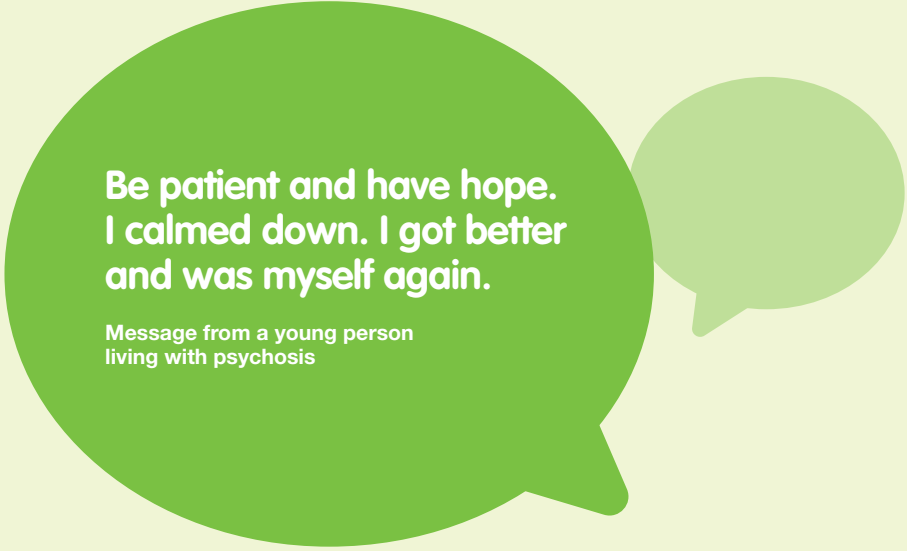
Ways to feel better
and help that is available



This booklet has been informed by young people who have experienced psychosis, as well as families and bilingual workers who have supported young people living with psychosis. You will find quotes from these young people and their families about managing their experiences of psychosis throughout the booklet.

This booklet is helpful for young people who are experiencing their first episode of psychosis. We hope that it helps you to understand what you are experiencing and that it gives you some information about finding help. We also hope that it allows your family, friends, community and workers to have useful conversations with you. You might like to use this booklet with your worker, family member or other support person to talk about what you are feeling at the moment.

Everyone's experiences are different and help and support is available from a range of people and services. Getting help as early as possible can mean that you feel better sooner.



**Be patient and have hope.
I calmed down. I got better
and was myself again.**

**Message from a young person
living with psychosis**

Disclaimer: This information is not medical advice. It is generic and does not take into account your personal circumstances, physical wellbeing, mental status or mental requirements. Do not use this information to treat or diagnose your own or another person's medical condition and never ignore medical advice or delay seeking it because of something in this information. Any medical questions should be referred to a qualified healthcare professional. If in doubt, please always seek medical advice.

What does psychosis mean?

Psychosis is a medical term that describes a group of experiences that include the following examples:

- Feeling confused about what is real and what is not real ('psychosis')
- Hearing voices when no one is there ('hallucinations')
- Seeing, tasting or smelling things that other people do not ('hallucinations')
- Believing things that others find strange ('delusions')
- Feeling that people are going to hurt you when this is not the case ('paranoia')
- Speaking in a way that others find hard to follow ('thought disorder')

It is helpful to understand medical terms as doctors use them to explain what is happening. A person with psychosis may have some or all of the above experiences. An 'episode of psychosis' is a medical term that describes a time when someone has stronger symptoms of psychosis that last for more than a week and negatively affects their day-to-day life. Some people will only have one episode of psychosis in their lifetime, while others will take longer to recover and have more than one episode.

Everyone's experience of psychosis is different. This experience can be very stressful. You might feel scared, sad, punished, special, or you may not be sure how you feel. There is no right or wrong way to feel. It is important to get help if you are finding any these experiences distressing or if you are at risk of hurting yourself or others.

“ Psychosis does not mean that you are psycho or crazy.”

“ I thought that I was going to die when I was told that I had psychosis. Then they explained that it was a bit like having a broken leg and I needed help. Now I feel better.”



There is more than one way to understand psychosis

Some cultures and languages have a different word to describe psychosis; other cultures and languages might not have a word to describe their experiences. Some people find it useful to think about psychosis in medical terms, others do not feel okay with that.

“ If it is a more medical term, people in my culture are more likely to take it seriously.”

Does your community encourage people to talk about their experiences of psychosis? Some cultures may encourage people to talk and other cultures may not feel free to talk about their experiences.

Experiences such as hearing voices may be understood as communication from ancestors, spirits or a God. Some people do not find the experience of hearing voices distressing but a lot of people do. For example, some people hear voices that might say good things or they are neutral (not good or bad), so this is not necessarily a problem.

In some communities hearing voices or seeing things that other people do not see is a religious experience or part of grieving after a person close to you has died. It might be helpful to talk with your worker about how your culture understands what you are experiencing.

Whichever way psychosis is understood, if your experiences are distressing to you or stopping you doing the things that you enjoy, you need to get some help. As with any illness, when someone becomes unwell they need help to get better.

Why do some young people experience psychosis?

There is no one single reason why someone will experience psychosis. It can be a mix of how a person is made (their biology) and things in life they have seen, heard or lived that can make them more likely to experience psychosis.

Some possible reasons for experiencing psychosis include:

- Experience of trauma or abuse; for example, being physically hurt by someone or seeing someone else get injured
- Extremely stressful events
- Use of street drugs and some prescription drugs
- A physical illness or injury; for example, a high fever or head injury
- Family history or other people in the family experiencing psychosis

Talking with your worker about your life experiences before the psychotic episode can help you to understand what is happening and find the most useful ways to help you.



What treatment and support is available from early psychosis services?

A good place to start is with a local doctor (also called a 'GP'), your local community mental health service or youth mental health service (for example **headspace** Youth Early Psychosis Program). These services know about early psychosis and will help with the next step of finding the right care.

“**The staff are kind and supportive.**”

“**Even if they are not the same race as you, they help you; they give your family hope.**”

headspace Youth Early Psychosis Program (hYEPP)

This service offers support to young people experiencing or at risk of a first episode of psychosis. hYEPP has a team of workers who can work with you to help you feel well. There are different workers like doctors, nurses, social workers, counsellors, psychiatrists, occupational therapists, and psychologists. There are also peer workers, who are people who have had similar experiences as you with mental health difficulties.

“**They helped me get into the Certificate 1 of General Education so that I can get a job.**”

What will happen when I go to a service?

The first thing that services will do is work with you to manage any bad experiences. Services will also:

- Talk with you to help understand what is happening for you. They may ask a range of questions to help them understand and build a picture of what your psychotic symptoms are like and how they may be affecting you.
- Help you to make sense of your experiences of psychosis and deal with any shock you might be feeling.
- Assist with any other things you may be experiencing, such as not wanting to be around friends, family and community; not feeling motivated; or trouble with thinking or showing your feelings.
- Give medication and information about medication if needed.
- Provide education and support for your family members.
- Help you with any difficulties at work, school or other parts of your life including friendships, family or your community.
- Work with any other health issues.
- Help you to find ways to reduce the possibility of psychosis happening again.
- Help you to identify goals and work on them.

“**People often worry that psychiatrists and medicines cost a lot of money but this is not the case.**”

What treatments will the early psychosis service offer?

If you are not sure what would help, that is ok; you can take your time and ask your workers for the options available. For example, you might have more than one worker to help with different areas of your life. You can also ask for a peer worker to help you.

How someone gets better or learns to manage their experiences of psychosis can involve a number of treatments.

“ They listen to you.”

Talking therapy

Having someone to talk to is an important part of treatment and getting better. Talking therapy can help you to understand your experiences and come up with strategies of how to deal with them. The exact method of talking therapy may vary to suit your needs.

Practical support

Practical support involves working with you to find out what's important to you in getting better or well. This is different for different people. It might mean returning to school, getting a job, finding a place to live, getting help with money problems or meeting new people and making new friends. One-to-one counselling, group activities and activity based therapies can help to achieve these things.

Medication

Medication can be an important treatment for psychosis. There are a number of different medicines that help to reduce the experiences of psychosis and the anxiety and upset that these experiences can cause. A doctor will help work out the details about how much medication you may need to take and when to take it. Medication should be monitored and if side-effects develop the kind of medication or the amount taken may need to be changed.

Will medication help me?

Many people find medication improves their well-being; some people even call it a “life-saver”. Other people don't experience much or any benefit from medication. Your doctor might try different ones to find the best one for you. Doctors recommend taking the exact amount prescribed. Taking more or less medication or suddenly stopping medication can make your symptoms stronger. You can always talk with your doctor if you have any concerns or experience any difficulty with your medication.

Useful questions to ask:

- Why are you recommending this particular medication?
- Are there any side effects?
- How long will it take before I will feel any benefit or know if this is the best medication for me?
- How long will I need to take this medication— will I need to take it forever?

It may be useful to keep a diary about your experience taking medication so you can talk to your doctor about how it is going. If you have any concerns, remember that you can ask questions and have the right to see another doctor for a second opinion about your medical treatment. Keep asking questions until you understand. You can take someone you trust to your appointments.

“ At first I did not agree with the diagnosis and did not want to take medicines but now I see they are helping me.”

Confidentiality

You have the right to have your privacy protected, which means that all professionals working in mental health services must keep your information private. For example, if a family member wants to know information about you, workers need your permission to give it to them (except when you are at risk of hurting yourself or others).

If you are 16 or over, you can get help from a service without a parent's or guardian's permission. You can also get your own Medicare card which means your treatment will be free or a very small cost.

What might help me to feel more comfortable with early psychosis services?

Asking for help takes courage; congratulations on taking the first step!

You might feel more comfortable if you talk about:

- Things that helped you in the past to feel comfortable talking about difficult times.
- What you like and do not like when workers offer help. For example, you might like your worker to use another word instead of psychosis.
- What is important for you when receiving support? For example, feeling like your worker understands how you feel and respects your ideas.
- How you would like your family, friends or community leaders to be part of you feeling better. If you would like some of them to go with you to the sessions you can ask your worker to help arrange this.
- Let your worker know if you prefer to express yourself in ways other than talking, for example: painting or writing.
- Let workers know what you like and what you don't like. For example, you might not like eye contact.
- Let the workers know when you feel like talking and when you prefer to be quiet.

“ Lots of people come here, it is a common problem.”

“ At the beginning I preferred painting; the colours helped me to feel better. I did not want to talk.”

“ My worker listens to me. I immediately connected with my case manager, I loved the way she talked.”

“ Think about the personality that you like and things that you like to feel safe.”

“ It helped me to talk about the type of worker that I might like.”

What role do my culture and traditions play in my treatment?

Some cultures find it helpful to have a combination of mental health and other types of support such as: healers, shamans, community leaders, elders or faith or religious leaders. There may be differences of opinion within age groups in a culture. For example, young people might feel more comfortable with mental health workers and their parents might feel more comfortable with traditional healers or community leaders.

It is also common for people within a family to have different opinions about the causes of psychosis, what should be done to get better and what is going to happen in the future. You might find it helpful to talk about any differences between you, your family or your community with your mental health workers.



How can I help myself?

There are different things that you can do to manage your experience of psychosis. Every person is different and some things will work for some people and not for others. Learn what works for you and take control. Remember you are not alone, other young people have experienced psychosis and have found ways to get better with the support of services and family and friends.

“ Don’t blame yourself. It is something that you need help with.”

Ask for help early

Asking for help as early as possible can help you to feel better sooner. Many young people have become better from their first time of psychosis and can get back to school or work and their usual activities. If the voices you hear are negative and are saying bad things about you or telling you to hurt yourself or others, you are in a crisis and you need to find help urgently.

Let family, friends, community and mental health services know what might help you. You might need different support at different times and that is okay.

“ Get help early. You can feel better. Persevere, keep going and you will eventually get there.”

Know your triggers; what makes you feel unwell?

Understanding what makes you feel more confused or distressed can help you to develop helpful strategies. Ask yourself: are there specific places, situations or people that make me feel more stressed? What can I do to help myself with these situations? You might want to talk about these things with someone you trust.

“ I understood the things that were making me feel sad. Now I don’t take drugs and I play instruments.”



Look after yourself; what is important to you and helps you feel well?

- What gives you a feeling of pleasure, fun, relaxation or purpose? Do you enjoy gardening, listening to music, playing sports, or watching movies? You might enjoy volunteering or helping someone in your community.
- Spend time with your community.
- Connect to culture and traditions.
- Looking after your physical health. Eating good food, exercising regularly and getting enough sleep can make a difference to your mood and energy levels.
- Spend time with friends and family and other people that make you feel good about yourself.
- Look after your spiritual health. Do you have particular spiritual or religious beliefs that help you feel stronger?
- Remind yourself of your strengths. What has helped you in past difficult situations?

“Dancing helps, it makes me most happy.”

“Tell yourself: You are beautiful because it is easy to forget that.”



Create a wellness plan

A wellness plan can help you during difficult times. It will remind you of things that you can do to feel better. A plan could include things that you can do regularly to stay well. It might be useful to list people you can contact for help (family/friends and community services). Developing your wellness plan is something you can do on your own or with your worker.

Some people find it useful to have different sections in your plan to stay well:

- What I can do when I am feeling well, to maintain my wellness.
- What I can do when I am becoming unwell.
- What I can do when I am very unwell.
- People and services I can go to for help.

You may need different strategies at different times. When you are unwell you might need more support than when you are well. You might want to include people, places and activities that are helpful in your wellness plan, including what to do if you are very unwell.

Some questions to ask yourself might include:

- How is this experience affecting my daily life?
- What do I think or fear is going to happen?
- Are there things happening with family, friends, school or work that are contributing to me feeling unwell?
- What helps me to feel better?
- Who has helped me when I have had difficulties in the past?
- What gives me hope?

Think about small goals that can lead to bigger goals.

How can family, friends and community help?

Families, friends and community are very important in helping a young person to get well. Being there, listening, giving love and support, offering assistance with finding help and letting the young person know that things will be ok are all important things that you can do. It can be upsetting to see someone experiencing psychosis. As family and friends you may feel all many different things, such as shock, confusion, guilt, fear or anger. The good news is that many people do get better. The earlier someone gets help the more likely they will get better.

“ I got better, I started feeling happy again. My parents understood I was ill and I got better.”

“ Another really really really important thing is that family and friends say that you are a good person. It helps when they remind you that life can be better because sometimes it is difficult to stay positive.”

How should I talk to the young person when they are unwell?

When someone is experiencing psychosis they may behave in ways that seem strange or frightening. It is important to remember that they are still your son, daughter, brother, sister, wife, husband, partner or friend.

- Be yourself. Behave as you would normally.
- Try not to be upset if the person says hurtful things to you when they are unwell.
- Believe that the person will get better; understand that this will take time.
- Help the person to feel safe and loved.
- When someone is very unwell with psychosis they may have strong beliefs and ideas about something which may not be true or happening; try not to argue with them, listen and try to understand why they are feeling that way.
- Keep showing your care and respect; remember their strengths and abilities.

“ See the person as a normal person – know about the symptoms.”

How can I offer support?

Families and friends are very important in helping a person to become well again. There are many practical things that family and friends can do. Gaining as much knowledge as you can about psychosis is important.

It can be useful to:

- Find out who is looking after the person (the treating team). Ask for their names, what their role is in the treatment, and how to contact them by phone.
- Ask who the best person is to keep in contact with and keep that information with you.
- Ask for a meeting with the key people in the team and prepare a list of questions to take with you. Write down the answers at the meeting; if you don't understand what you are being told, ask for clearer explanations.
- Ask where you can get any other information that you need. For example, are there information sessions you can attend about psychosis? Or are there websites or factsheets you can look at?
- Often early psychosis services have family peer workers who have gone through the experience of having a family member experiencing psychosis. Ask if there is a family peer worker in the service who you could speak with.

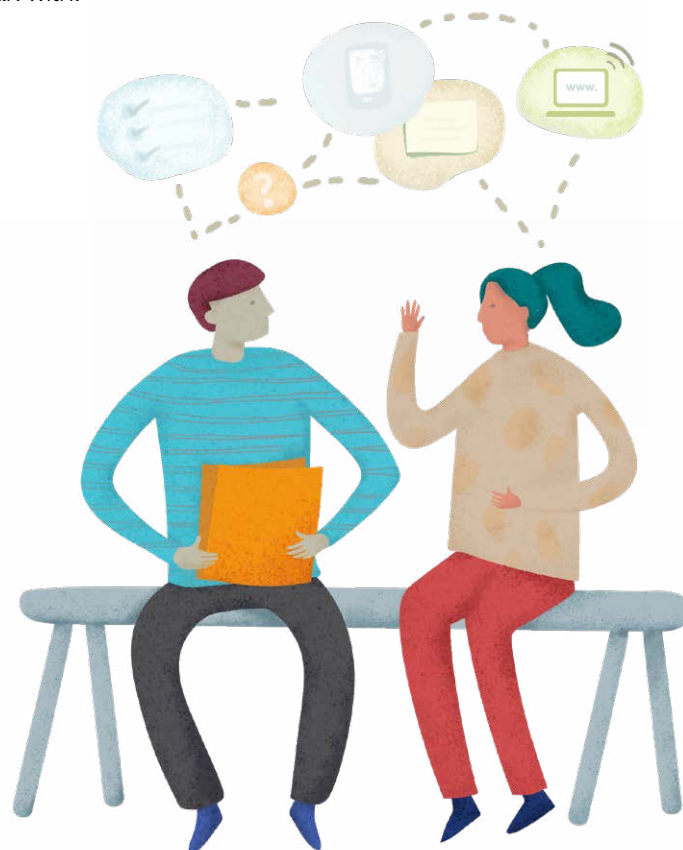
What if they don't want to get help?

It can be difficult making the decision to get help for lots of reasons. The person experiencing psychosis might not wish to get help or even admit that they are unwell. Getting help supports the person to find out exactly what is happening and what type of care is needed. Encourage them to ask for help and let them know you will be there to support them for as long as they need it. You can help them to find the type of support that they would like to receive. For example, a person might feel comfortable talking with a spiritual leader.

Remember to look after yourself

Remember that mental ill-health is very common and it is not the person's fault. Learning about psychosis can help you to understand what is happening when others are unwell. You do not need to have all the answers!

Caring for someone with psychosis can be difficult. It is important that you ask for support for yourself too! You can start with your general practitioner (GP) or a trusted community leader.



Useful contacts

There are a number of hYEPP services around Australia. They operate during normal business hours but have a MATT team that work during the day and after hours. MATT stands for Mobile Assessment Treatment Team. MATT is a team of workers such as nurses, social workers, occupational therapists, psychologists and doctors who often see the young person for the first time to understand what they are experiencing and how they can best be helped. MATT will see a young person wherever the young person would prefer to be seen.

New South Wales

hYEPP Mt Drutt

Phone 02 881 2500

Hours Mon–Fri 9am–5pm
After hours sessions are available by appointment

headspace Parramatta

Phone 1300 737 616

Hours Mon–Fri 9am–5pm
After hours sessions are available by appointment

headspace Penrith

Phone 02 4720 8800

Hours Mon–Fri 9am–5pm

MATT team

Phone 0437 802 035

Hours Mon–Fri 8am–10pm
Sat–Sun 10am–6pm

Northern Territory

hYEPP Darwin

Phone 08 8931 5999

Queensland

hYEPP Meadowbrook

Phone 07 3804 4200

hYEPP Southport

Phone 07 5509 5900

Hours Mon–Fri 9am–5pm

MATT team

Phone 04 2361 4781

Hours Mon–Fri 8am–10pm
Sat–Sun 10am–6pm

South Australia

hYEPP Adelaide

Phone 1800 063 267

Hours Mon–Fri 9am–5pm

MATT team

Phone 0475 989 619

Hours Mon–Fri 8:30am–9pm
Public holidays 9am–5pm

Victoria

hYEPP Bentleigh

Phone 03 9076 9400

Hours Mon–Fri 9am–5pm
Wed 9am–7pm

hYEPP Dandenong

Phone 1800 367 968

hYEPP Frankston

Phone 03 9769 6419

Hours Mon–Fri 9am–5pm

hYEPP Narre Warren

Phone 1800 367 968

MATT team

Phone 03 9076 9400

Hours Mon–Fri 8.30am–9.30pm
Sat–Sun 10am–5.30pm

Western Australia

hYEPP Joondalup

Phone 08 9301 8900

Hours Mon–Wed & Fri
8:30am–4:30pm
Thur 8:30am–7pm

hYEPP Midland

Phone 08 9274 8860

Hours Mon–Wed & Fri
8:30am–4:30pm
Thur 8:30am–7pm

hYEPP Osborne Park

Phone 08 9208 9555

Hours Mon–Fri 8:30am–4:30pm

MATT team

Phone 08 9301 8999

Hours Mon–Fri 8am–10pm
Sat–Sun, public holidays
10am–6pm

Other supports

Orygen, The National Centre of Excellence in Youth Mental Health
Website www.orygen.org.au

Hearing Voices Network
Website www.hearing-voices.org

Independent Mental Health Advocacy
Phone 1300 947 820
Website www.imha.vic.gov.au

SANE Australia
Phone 13 11 14
Website www.sane.org

Reach Out
Phone 02 8029 7777
Website www.reachout.com

MIND Australia
Phone 1300 286 463
Website www.mindaustralia.org.au

Lifeline
Phone 13 11 14
Website www.lifeline.org.au

Suicide Call Back Service
Phone 1300 659 467
Website www.suicidecallbackservice.org.au

Police
Phone 000 in an emergency or life-threatening situation, when urgent police help is needed; call 131 444 for police assistance.

If you require an interpreter to help you get in touch with any of the above services you can call the Translating and Interpreting Service on **131 450**

Other local support



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Acknowledgements

Orygen, The National Centre of Excellence in Youth Mental Health, The Centre for Multicultural Youth, and Victorian Transcultural Mental Health worked together to produce this booklet that supports conversations about self-help, ways to feel better and assistance that is available. We would like to thank the young people, family members and bilingual workers who participated in consultation sessions.