

understanding



psychosis

Understanding psychosis

This booklet is for anyone who experiences or has experienced psychosis, and their friends and family. It explains what psychosis is, what may cause it and what might help.

Contents

What is psychosis?	4
What are the effects of psychosis?	5
How is psychosis diagnosed?	7
What causes psychosis?	8
What treatment and support is available?	9
How can I help myself?	15
What can friends and family do to help?	18
Useful contacts	21

What is psychosis?

Psychosis (also called a psychotic experience or episode) is when you perceive or interpret events differently from people around you. This could include experiencing hallucinations, delusions or flight of ideas.

Hallucinations

Hallucinations include:

- Seeing things that other people don't – such as people's faces, or other images or visions, like animals or religious figures. You may also see objects that appear distorted, or that move in ways they normally wouldn't.
- Experiencing tastes, smells and sensations that have no apparent cause – such as feeling insects crawling on your skin.
- Hearing voices that other people don't – these could be positive and helpful, or hostile and nasty. You may hear one voice or many different voices. They could be voices of people you know or be complete strangers. (See Mind's booklet *How to cope with hearing voices* for more information.)

●● *I was hearing people talk but hearing totally different words to what they were actually saying and voices when people weren't there. I even heard the voice of God. It was distressing and disorientating. I couldn't say what was real and what wasn't.* ●●

Delusions

A delusion is a belief that other people do not share. For example, you might believe that you are closely related to the Queen, although you don't share any relatives. You may also experience delusions of grandeur

(thinking you are a very important person) – for example, you may believe that you are very rich and powerful, or control the stock markets or weather.

Some delusions can be extremely frightening and make you feel mistrustful or threatened. For example, you may feel that something or someone is trying to control or kill you. These ideas are called paranoid delusions. (See Mind's booklet *Understanding paranoia* for more information).

Flight of ideas

Flight of ideas is when your thoughts move very quickly from idea to idea, making links between things that other people don't. Doctors may also call this word salad or thought disorder.

If you experience flight of ideas, you might:

- lose control of your words – speaking very quickly so that other people notice and find it difficult to follow what you're saying
- link words together because of the way they sound rather than what they mean – for example, if it starts to rain, you might start to talk about railway trains, then brains or photo frames.

What are the effects of psychosis?

Psychosis affects people in a range of ways. Many people experience psychosis only once in their lives. Other people experience fairly short episodes throughout their lives. Some people live with ongoing psychosis as a long-term problem.

Some people who experience psychosis do not find it distressing. For example, if you see the faces of loved ones who have died or hear their voices, you may find this comforting and not see it as a problem.

Understanding psychosis

Other people find psychotic experiences very distressing, and they have a significant impact on their day-to-day life.

Depending on your experience of psychosis, you may feel:

- anxious or stressed
- scared
- confused
- frustrated or angry
- mistrustful of other people and organisations
- victimised, persecuted or threatened
- disbelieved or misunderstood
- alone and isolated
- depressed
- tired – from worrying all the time.

Psychosis can be very disruptive and affect your ability to carry out day-to-day tasks, such as going to work, shopping or eating. It can also start to affect your behaviour.

For example, you may:

- find it hard to concentrate on tasks that require you to focus on doing one thing at a time
- find it hard to trust people and maintain relationships
- find it hard to sleep and not make time to eat or care for your appearance
- start to avoid certain situations, places or activities, or feel unable to go outside
- try to protect yourself in ways that other people do not understand – for example, covering your windows at all times or removing electrical devices from your home

- act in a way that may appear aggressive or threatening to others
- harm yourself, or behave in ways that put you or other people at risk – for example, if you feel you have to do something dangerous because of a voice or vision.

It can be particularly upsetting if people around you dismiss your experiences as untrue, as they seem very real to you.

●● *It's like the world you thought you knew has changed. You become unsure of what's real and what isn't. You question everything.* ●●

Psychosis can be very distressing and, over time, can lead to additional mental health problems such as anxiety and depression. (See Mind's booklets *Understanding anxiety and panic attacks* and *Understanding depression* for more information.)

How is psychosis diagnosed?

Psychosis isn't given as a diagnosis on its own. If you experience psychosis, you may be given one of the following diagnoses:

- schizophrenia
- bipolar disorder (manic depression)
- schizoaffective disorder
- paranoid disorder, delusional disorder or paranoid personality disorder
- puerperal psychosis (a severe form of postnatal depression)
- severe depression.

For more information about these diagnoses, see the relevant booklets in Mind's *Understanding* series.

Understanding psychosis

The diagnosis you are given will depend on how severe your psychosis is, how often you experience it, and whether you experience it on its own or with other symptoms. As psychosis can be a symptom of several different diagnoses, you may find that you are given different diagnoses at different times.

Before you are given a diagnosis, your doctor should rule out any physical causes for your psychosis. If the cause is physical – for example, if you are experiencing psychosis as the result of a physical illness – treatments such as psychiatric drugs or talking treatments are unlikely to help.

If you use street drugs or regularly drink large amounts of alcohol, doctors will usually ask you to stop doing this before they give you a diagnosis. (See Mind's booklet *Understanding the mental health effects of street drugs*.)

What causes psychosis?

There are many different explanations for why people experience psychosis. The following are all ideas about what might cause it:

- **Physical illness or injury** – you may see or hear things if you have a high fever, head injury, or lead or mercury poisoning.
- **Drugs** – you may hear or see things as a result of taking street drugs, or as a side effect of some prescribed drugs. This may also happen if you are coming off psychiatric drugs. (See Mind's booklet *Making sense of coming off psychiatric drugs*.)
- **Lack of sleep** – symptoms of psychosis, particularly hallucinations, can happen if you have a severe lack of sleep.

- **Hunger** – you may hear voices if you are very hungry, have very low blood sugar, or if you are not getting enough food.
- **Bereavement** – if you have recently lost someone very close, you may hear them talking to you. You may also feel that they are with you, even though you cannot see them.
- **Abuse or trauma** – if you have experienced abuse or a particularly traumatic event, you are more likely to experience psychosis.
- **Spiritual experiences** – some people experience voices or visions as part of a spiritual experience. This may be a positive experience for you. For example, it may make you feel special or help you to make sense of your life. Or it could be negative or upsetting. For example, you may feel that you are possessed by an evil spirit.
- **Family inheritance** – you are more likely to experience psychosis if a blood relative has also experienced this.

What treatment and support is available?

For many people, there is no quick and simple treatment to deal with psychosis. You may find that, as well as finding the right treatment, you need further support to help you cope. You may also need to make changes to your lifestyle (see 'How can I help myself?' on p.15).

However, with the right treatment and support, it is possible to manage the symptoms of psychosis and recover. This does not always mean that the symptoms of psychosis will go away entirely. You may find that they do go away, or you may still experience them, but learn ways of coping so they are less distressing and do not have such a negative impact on your life.

Understanding psychosis

Before you start any treatment, doctors, psychiatrists and other mental health workers should discuss all your options with you, and take your preferences into account when making decisions about your treatment. They should also look at all aspects of your problem, taking into account your environment, as well as any possible physical causes.

If you are finding it difficult to get the treatment or support you need, you may find it helpful to have an advocate to support you and help you put forward your views. (See Mind's booklet *The Mind guide to advocacy* for more information.)

Talking treatments

Talking treatments can help reduce any distress you are feeling because of your psychosis, and can reduce the intensity and frequency of episodes. They aim to help you understand your experiences and develop coping strategies to deal with them, and to improve your relationships and quality of life. A therapist may also be able to help you to challenge paranoid feelings, and deal with any anxiety and depression you have as a result of experiencing psychosis. (See Mind's booklet *Making sense of talking treatments*.)

The most commonly used talking treatments for psychosis are:

- **Counselling** – allows you to talk about your experiences and ways of coming to terms with them.
- **Cognitive behaviour therapy (CBT)** – aims to identify connections between thoughts, feelings and behaviour, and to help develop practical skills to manage them. (See Mind's booklet *Making sense of cognitive behaviour therapy*.)
- **Psychodynamic psychotherapy** – looks in more depth to try and identify unconscious and subconscious factors from your past that may have caused your experiences.

A talking treatment should be available to you on the NHS via your GP or psychiatrist. The choice will depend on what's available in your area, your own preferences and how severe your psychosis is.

Waiting times on the NHS for talking treatments can be long, so you may seek therapy or counselling privately if you are able to pay. Private therapists should be accredited by the British Association for Counselling and Psychotherapy (BACP) or the British Association for Behavioural and Cognitive Psychotherapies (BABCP) (see 'Useful contacts' on p.21). Some offer a reduced fee for people on a limited income.

Medication

Most people diagnosed with a psychotic illness will be offered antipsychotic drugs (also called neuroleptics or major tranquillisers). (See Mind's booklet *Making sense of antipsychotics* for more information.)

Antipsychotics are not a cure for psychosis, but they can help control your symptoms and stop you feeling distressed by them. For example, they can:

- control anxiety and serious agitation, so that you feel less threatened
- reduce incoherent speech and muddled thinking
- reduce confusion
- lessen delusions and hallucinations
- reduce violent or disruptive behaviour
- reduce mania.

👤👤 *I was assessed and prescribed a variety of drugs, including olanzapine and various benzodiazepines... Over a few days, the medication took effect, and that coupled with the kind behaviour of the staff began to calm me.* 👤👤

However, antipsychotics can also have unwelcome side effects, and some of these can be quite serious.

Understanding psychosis

These include:

- lethargy
- weight gain
- uncontrollable movements
- sexual problems.

You may be offered other drugs as well if you experience psychosis along with other symptoms. For example:

- antidepressants – if your psychosis is associated with severe depression (see Mind's booklet *Making sense of antidepressants*)
- mood stabilisers – if you have a diagnosis of bipolar disorder (manic depression) or experience mania (see Mind's booklet *Making sense of lithium and other mood stabilisers*)
- drugs to help reduce side effects caused by the antipsychotics.

Before you start to take any drugs, doctors should discuss the possible benefits and risks with you, so you can decide whether you want to try taking them. If you take medication, you should have the chance to talk regularly about how your treatment is going and your options for the future. The dosage you are taking should be reviewed regularly, and you should be given the option to take a different antipsychotic if the one you are taking isn't working for you.

If you have been admitted to hospital under the Mental Health Act (see 'Hospital admission' on p.14), you may find that you have no choice about taking medication. In these circumstances, you may be expected to continue to taking medication when you are discharged from hospital too. (See Mind's booklet *The Mind guide to the Mental Health Act 1983* for more information.)

Once you have started medication, you may find it difficult to stop. Doctors may also be reluctant to take you off antipsychotics in case your symptoms return. If you do decide that you would like to stop taking medication, make sure you discuss it with your doctor and have all the

information and support you need to do so safely. (See Mind's booklet *Making sense of coming off psychiatric drugs.*)

Arts therapies

Arts therapies, such as art, music and drama therapy, are recommended by NICE (the National Institute for Health and Care Excellence) for schizophrenia and related disorders (see 'Useful Contacts' on p.21). They may help you to express how you are feeling, especially if you are having difficulty talking about this. (See Mind's booklet *Making sense of arts therapies.*)

Community care

If you have repeated or long-lasting psychosis, you may be referred to community care services to help you cope. (See Mind's online booklet *The Mind guide to community-based mental health and social care* for more information.)

You may be able to access the following services:

- **Community mental health team (CMHT)** – This is a team of mental health professionals, including psychiatrists, nurses and occupational therapists. They can provide treatment, support and information, and refer you to local services.
- **Care Programme Approach (CPA)** – If you have complex needs, you may be treated on the Care Programme Approach (CPA). On the CPA, you should have a care coordinator and a care plan. This should include a crisis plan, and should be reviewed regularly.
- **Social care services** – Social care can help you carry out day-to-day tasks if you find these difficult. This could include a range of different things – for example, help with managing money or improving relationships, help with transport to attend appointments or services, or help with benefits and housing applications. You can ask your GP or

CMHT to refer you to social services, or contact them directly to ask for an assessment.

- **Early intervention team (EIT)** – This is a team that exists in some areas and works with anyone aged 14–35 who is experiencing a first episode of psychosis or at significant risk of doing so. An EIT aims to help you understand the symptoms that occur just before a psychotic episode, in order to help you seek appropriate treatment as early as possible. The aim is to reduce the length of your psychotic episodes and help you recover from them more quickly.
- **Crisis services** – Crisis services exist in some areas as an alternative to hospital. They offer services, available at short notice, to help you resolve a mental health crisis. These differ from area to area but can include a telephone helpline, crisis resolution and home treatment teams (CRHTTs) to assist you at home, or acute inpatient wards if you need a short stay in a safe place. (See Mind’s booklet *The Mind guide to crisis services* for more information).

Hospital admission

If you become very distressed during an episode of psychosis, you may need to be cared for in hospital as an inpatient. Hospital can provide a safe and supportive environment if you are distressed, and it may be comforting to have other people around you and to know that you are being cared for. However, it can be upsetting to be around others who are distressed, and the lack of privacy and support can also be difficult to cope with.

If hospital admission is thought to be necessary for your own health or safety or the protection of others, you may be compulsorily detained under the Mental Health Act. (See Mind’s booklets *Rights guide: civil admission to hospital* and *The Mind guide to the Mental Health Act 1983* for more information.)

Before you leave hospital, you should be given the opportunity to discuss the kind of services that would help you cope better at home.

How can I help myself?

Most people find that they need professional help to deal with psychosis (see 'What treatment and support is available?' on p.9). However, there are also some things you can also try yourself that might help you cope with your symptoms better, either on their own or alongside treatment.

Go to a support group

In a support group, people with similar experiences meet to discuss these and share tips for coping. This can be helpful because it:

- gives you a safe space to talk with others who have similar experiences
- helps you understand your own experiences better – others may see things you may have not seen yourself, and help you to come to terms with it
- helps you feel accepted and listened to, and less alone
- helps increase your self-esteem
- encourages you to make your own choices and decisions about how you want to live, and get the most out of your life.

👩👧 *A support network has helped me learn to trust people who want to help, and [to] accept that help.* 👩👧

Various organisations, such as the Hearing Voices Network, the National Paranoia Network, and Bipolar UK, run support groups that may be helpful if you experience psychosis. Search online or contact the Mind Infoline to find out about what is available in your area. (See 'Useful contacts' on p.21.)

You can also access support online, via an online community, such as Mind's Elefriends, or by reading about other people's experiences on

Understanding psychosis

Mind's blog or the National Perceptions Forum website. (See 'Useful contacts' on p.21 and Mind's booklet *How to stay safe online* for more information.)

Look after yourself

Whatever your diagnosis, it's important to look after your mental and physical wellbeing. (See Mind's booklet *How to improve and maintain your mental wellbeing*.)

You might find these things helpful:

- Relaxation exercises or yoga can help reduce stress. Some people also find massage, aromatherapy or reflexology helpful. (See *Mind tips for better mental health: relaxation*.)
- Doing practical things, like gardening, cooking, or making things, can boost your self-esteem and help you feel more connected to the world around you by having activities to focus on.
- Being outside in a green space can also make you feel more in touch with your surroundings. (See Mind's booklet *Making sense of ecotherapy* for more information.)
- Making sure you get enough sleep can make you feel calmer and more able to cope. If you feel tired, you are more likely to feel stressed or worried and find it difficult to manage your symptoms. (See Mind's booklet *How to cope with sleep problems* for more information.)
- Eating a healthy, balanced diet with plenty of fresh fruit and vegetables can help you feel healthier. Eating regularly can also avoid psychosis brought on by significant changes to blood sugar levels. (See Mind's *Food and Mood* poster for more information.)

- Maintaining a structured daily routine can help to make day-to-day tasks seem more manageable.

👉👉 *Breaking up the day with tasks and giving myself time to acknowledge what's happening is really important to me.* 👉👉

Recognise your triggers

If you have repeated episodes of psychosis, it may be helpful to keep a diary, recording life events, your mood, your diet and sleep. This can help you recognise patterns in your moods and psychosis, and identify what might trigger it or make it worse. It can also help you identify things that have been helpful, and recognise warning signs that tell you when you are becoming unwell.

Once you have a better understanding of your triggers, you can try to take positive steps to avoid them. If you learn to recognise your warning signs, you can take positive action early if you are becoming unwell and prevent your psychosis becoming worse.

👉👉 *I string the day together in a series of 15 minute chunks... if I can recognise the signs of an episode.* 👉👉

If you let your close family or friends know what your warning signs are, they may also be able to help you spot when you are becoming ill.

Create a crisis plan

During a crisis, you may not be able to tell people what helps you. While you are well, it is a good idea to discuss with someone you trust what you would like to happen, or not to happen, when you are in crisis. You can also make an advance statement. This is a document that states your preferences in writing, and in some cases, this can be legally binding. (See Mind's booklet *The Mind guide to crisis services* for more information.)

What can friends and family do to help?

This section is for friends and family who would like to support someone they know who experiences psychosis.

As a friend, relative or partner, you can have an important role in helping someone learn to manage their psychosis and reduce the likelihood of them becoming unwell. However, it can be difficult to know how best to help. These are some ideas that may be helpful.

Listen and try to be sympathetic

Most people want to feel cared about and not to feel alone, so it's important your friend or family member feels they can discuss their feelings and options with you. Try to listen sympathetically, and avoid blaming them for their problems or telling them to 'pull yourself together'. Spending positive time with them that is not just about their illness can also be helpful.

👂👂 *Friends and family can help by lending an ear to talk to, especially between visits from mental health nurses, support workers, psychologists and psychiatrists.* 👂👂

Focus on feelings rather than experiences

It can be difficult for you to know how to respond when someone sees something or believes something that you don't. Rather than confirming or denying their experience, it may help if you say something like, 'I accept that you hear voices or see things in that way, but it's not like that for me'. It's usually more constructive if you can focus on how the person is feeling, rather than what they are experiencing.

Offer practical help

Ask your friend or family member if they would like practical support and what you can do to help. For example, they might like your help to find

better accommodation or access a particular service. They may also want you to act as an advocate, to help them express their opinions and access the help they need. You could also find an independent advocate. (See Mind's booklet *The Mind guide to advocacy* for more information.)

Whatever help you offer, it's important that you respect their wishes, and don't try to take over or make decisions without them.

Plan for a crisis

When your friend or family member is feeling well, it is useful to discuss how you can help if and when a crisis occurs. As well as planning practical things like treatment options and hospital visits, it can be helpful for you to state clearly what you feel you can and can't deal with during a crisis. (See Mind's booklet *The Mind guide to crisis services* for more information.)

Help in an emergency

If you are worried that your friend or relative is becoming very unwell, you could suggest that they:

- use their crisis plan if they have one (see p.17)
- seek help from their GP
- seek help from the duty psychiatrist in a hospital Accident and Emergency unit (A&E).

If your friend or family member doesn't seek help, and you think they are putting themselves or others at risk, their nearest relative (as defined under the Mental Health Act 1983) can ask for a mental health assessment to be carried out. Under the Mental Health Act, they can be detained in hospital for further assessment and treatment if necessary. You may wish to discuss the consequences of taking this action with other family members first. (See Mind's booklet *Rights guide: civil admission to hospital* for more information.)

Family work

If you are caring for a family member, you might want to ask your GP or social services if you can try a course of family work. However, what is available varies from area to area. The aim of family work is to help the whole family understand what the person with psychosis is going through, and to identify what is helpful and unhelpful for both them and you. For example, if you are very worried about your family member, you may unintentionally focus too much attention on them, making them feel worse.

Get support for yourself

Seeing someone you care about experiencing psychosis can be distressing and even frightening. You may find it helpful to discuss your feelings and concerns with someone else, such as a counsellor, or to join a support group, such as those provided by local Minds or Rethink Mental Illness. (See Mind's booklet *How to cope as a carer* and 'Useful contacts' on p.21.)

Useful contacts

Mind

Mind Infoline: 0300 123 3393
(Monday to Friday, 9am to 6pm)
email: info@mind.org.uk

web: mind.org.uk

Details of local Minds and other local services, and Mind's Legal Advice Line. Language Line is available for talking in a language other than English.

Bipolar UK

tel: 020 7931 6480

web: bipolaruk.org.uk

Support for people with bipolar disorder (including hypomania) and their families and friends.

British Association for Behavioural and Cognitive Psychotherapies (BABCP)

tel: 0161 705 4304

web: babcp.com

Maintains a list of accredited CBT practitioners.

British Association for Counselling and Psychotherapy (BACP)

tel: 01455 883 300

web: itsgoodtotalk.org.uk

Information about talking treatments and details of local practitioners.

Elefriends

web: elefriends.org.uk

A safe, supportive online community where you can listen, be heard and share your experiences with others.

Hearing Voices Network

tel: 0114 271 8210

web: hearing-voices.org

Information and support for people who hear voices and local support groups.

Intervoice

web: intervoiceonline.org

International community for people who hear voices.

National Institute for Health and Care Excellence

tel: 0845 003 7780

web: nice.org.uk

Provides guidance on health and social care.

National Paranoia Network

tel: 0114 271 8210

web: nationalparanoianetwork.org

Information and support for people who experience paranoid thoughts.

National Perceptions Forum

web: voicesforum.org.uk

Forum for people who experience psychosis.

Rethink Mental Illness

advice line: 0300 5000 927

web: rethink.org

Information and support for people affected by severe mental illness.

Samaritans

Freepost RSRB-KKBY-CYJK

Chris, PO Box 90 90

Stirling FK8 2SA

24-hour helpline: 08457 90 90 90

email: jo@samaritans.org

web: samaritans.org

24-hour support for anyone feeling down, experiencing distress or struggling to cope.

Further information

Mind offers a range of mental health information on:

- diagnoses
- treatments
- practical help for wellbeing
- mental health legislation
- where to get help

To read or print Mind's information booklets for free, visit mind.org.uk or contact Mind Infoline on 0300 123 3393 or at info@mind.org.uk

To buy copies of Mind's information booklets, visit mind.org.uk/shop or phone 0844 448 4448 or email publications@mind.org.uk

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Mind

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