

Understanding
psychotic
experiences



For better
mental health

Psychotic experiences

Understanding psychotic experiences

Psychotic experiences, such as hearing voices or experiencing delusions, are surprisingly common, but can also lead to diagnoses such as schizophrenia or bipolar disorder. This booklet explains what the experiences are like, what might cause them, available treatments and what family and friends can do to help.

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What does 'psychotic' mean?

The word 'psychotic' relates to 'psychosis', which is a psychiatric term, and describes experiences, such as hearing or seeing things or holding unusual beliefs, which other people don't experience or share. For many people, these experiences can be highly distressing and disruptive, interfering with everyday life, conversations, relationships, and finding or keeping a job.

One theory is that when you experience psychosis, your brain is in the same state as it is when you are dreaming. When we are dreaming, all sorts of strange and sometimes frightening things can happen to us, and while we are asleep we believe that they are really happening. Psychotic experiences can be just like 'waking dreams', feeling as real and intense.

Diagnoses

Psychiatrists regard these types of experiences as symptoms of a mental illness, and, depending on other factors, they will base a diagnosis on them. The diagnosis could be 'psychotic illness', or 'psychotic episode', or it could be:

- severe depression
- schizophrenia
- bipolar disorder (manic depression)
- paranoia
- schizoaffective disorder
- puerperal psychosis (a very severe form of postnatal depression).

(For more information about these diagnoses, see Mind's range of *Understanding* booklets.)

Apart from puerperal psychosis, these diagnoses are not straightforward, and people who have repeated episodes of psychosis may receive different diagnoses at different times and from different doctors.

One sign of psychosis, in the view of many psychiatrists, is that you lack insight into your own state of mind. In diagnosing you, they will want to know how you see and understand what is happening, and whether you are aware of being different from usual. Your view of the world will be influenced by your cultural background and personal experiences. If these are not understood or shared by your doctors, you may feel that they lack insight, too.

Alternative approaches

These types of experiences are not necessarily symptoms of a psychotic illness. **A large number of people have heard voices, or hold beliefs that others might consider unusual, but are not distressed by them.** This usually means that other people remain unaware of them and these people do not need help from mental health services.

The general view in Europe and North America is that psychotic experiences are caused by mental illness and must be treated by doctors. Other societies may have very different interpretations of these experiences and different ways of dealing with them, such as relating them to past lives, or ancestral spirits. They may help people through them using ceremonies and rituals.

What sort of experiences are they?

- **hallucinations** – hearing, seeing or smelling things that aren't there
- **delusions and disturbed thoughts** – a feeling of being watched, or monitored in some way or that thoughts are being put into your mind from outside, and that you have no control over them
- **flight of ideas** – making strange connections between words and ideas in your head.

Many people think these perceptions are not 'real', when actually they are very real to you if you are experiencing them and often very difficult to ignore.

Hallucinations

Hearing voices

👂👂 *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.* 👂👂

You may or may not recognise any voices you hear. There may be one or many of them talking to, or about, you. They might be present occasionally, or all the time, interfering with ordinary life, making concentration and conversation difficult. The voices may be positive and helpful, or hostile and nasty.

If you hear only positive voices, you may not regard them as a problem, but may even feel them to be a helpful, guiding light.

If you hear only negative voices, ridiculing you, or issuing threats and commands which you feel you must obey, you are likely to feel very threatened and fearful. This may make you very distrustful of other people and appear aggressive or threatening. You may harm yourself or behave in ways which put you or other people at risk of harm.

Other hallucinations

You may see things – images and visions – or the things you are looking at may appear distorted, or may appear to move when normally they would not. Or you may experience tastes, smells and sensations, which have no apparent cause, such as a sensation of insects crawling on your skin.

Delusions

A delusion means a belief that other people would regard as unfounded. For example, you might believe that you are closely related to the Queen, although you actually share no relatives. You may be quite untroubled by any apparent contradictions of your beliefs. You may see nothing unusual in a member of the royal family serving drinks in a pub, for instance.

Sometimes, people also have delusions of grandeur, thinking they are very rich and powerful, perhaps controlling the stock markets or even the weather.

🔵🔵 *I withdraw into an alternate reality where I believe I can solve everybody's problems; then something changes and that reality becomes a nightmare in which I am going to be viciously punished.* 🔵🔵

Some delusional ideas can be extremely frightening. For example, you may feel that something or someone is trying to control or kill you. These ideas are called paranoid delusions. Separate episodes can also be connected and carry on from one another a bit like a soap opera – making it more believable. You may start avoiding certain situations, or try to protect yourself in some other way. You may come to believe you must deserve to be punished, or you may feel very angry and resentful.

Flight of ideas

You may see links between ideas that others don't, because these links are so personal. You may find that, in trying to express these ideas, you lose control of your words. You may link words together in ways that may have more to do with their sound than their meaning; and, although the connections may seem very clear to you, others will probably not follow your thoughts clearly. Doctors may call these experiences 'flight of ideas', or 'word salad', or even 'thought disorder'.

What causes psychotic experiences?

Almost anyone can have a brief psychotic episode. There are different ideas about why psychotic experiences develop. But it's generally thought that:

- some people are more vulnerable to them than others
- very stressful or traumatic events make them more likely to occur.

Your own attitude to the experience, as well as the attitude of those around you, also plays a part.

Psychotic experiences may be caused by:

- physical causes, such as illness
- drug use
- changes in brain chemistry
- inherited vulnerability
- traumatic events such as abuse.

Physical causes

Psychotic experiences may result from a lack of sleep (through severe jet lag, perhaps), through illnesses and high fevers (including malaria, pneumonia, other viral infections). They can also be a result of damage to the brain or dementia, lead and mercury poisoning, or changes in blood sugar levels.

Drug use

They may be caused by alcohol or drug use. Both street drugs and prescription medication (including steroids) can produce extraordinary sensations and/or side effects, and sometimes these may continue after the drug has worn off.

Changes in brain chemistry

Psychotic experiences may involve biological changes in brain structure or brain chemistry. It's not clear though whether these changes are the cause or the effect of the psychotic experience.

Inherited vulnerability

Research into whether there's an inherited vulnerability to psychotic experiences is inconclusive. If one member of your family is diagnosed with schizophrenia or bipolar disorder, then there seems to be more chance of another family member being similarly diagnosed. No single gene has been found to be responsible, though, and the majority of people who have these experiences have no known family history.

Traumatic experiences

Many people who have psychotic experiences have been physically, emotionally, or sexually abused, and feel a need to push their feelings and memories away, because they are so painful. Psychotic experiences may be an expression of these overwhelming feelings and forbidden thoughts, and a way of coping with trauma.

If you have been abused and then have a psychotic experience, it may be particularly frightening and disturbing. For instance, if you hear voices, you may think you are being bugged. You may become afraid that someone is persecuting you, and interpret everything you see as supporting this view. You may start to avoid certain places and activities, or refuse to go outside at all. Feeling threatened and on constant alert can be very frightening and tiring. It may interfere with sleep and daily life, and make it very hard to trust anyone.

Will I get over it?

Many people will have just one psychotic episode in their lives; others have fairly short episodes throughout their lives; some people live with ongoing psychosis as a long-term problem. People in these last two groups are more likely to be given a diagnosis of schizophrenia, bipolar disorder or schizoaffective disorder. (See Mind's booklets *Understanding schizophrenia*, *Understanding bipolar disorder*, and *Understanding schizoaffective disorder*.)

In some cases, you may be able to understand the causes of your psychotic experiences, through psychotherapy or arts therapies, and be able to put them behind you so that you are not troubled by them again (see p. 10).

However serious the difficulties, and whatever the diagnosis, there are treatments and coping strategies that reduce the disruption and enable you to lead a fulfilling life and to achieve your ambitions.

What sort of treatment can I get?

Mental health workers and other professionals should look at all aspects of your problem, taking into account your environment, and provide you with information and give you a choice about treatment.

It's increasingly recognised that many people are experts in their own condition, and learn the ways of coping with it which work best for them. **The more involved you can be in your own treatment and in looking after yourself, the better.**

The treatment you are offered is likely to be a combination of medication, a talking treatment, and other social support. You should be able to decide for yourself what forms of treatment are most helpful for you.

Talking treatments

Talking treatments, such as counselling, cognitive behavioural therapy (CBT), and psychodynamic psychotherapy can reduce distress, and the intensity and frequency of psychotic experiences. They aim to help you understand your experiences, to develop coping strategies, and to improve your relationships and quality of life. Talking treatments can also help to tackle depression and anxiety that may result from having psychotic experiences.

- **Counselling** allows you to talk about your experiences and ways of coming to terms with them.
- **CBT** aims to put your experiences in context, help you to understand them, and test your beliefs about them. You may be asked to keep a diary of your experiences and try out different strategies for dealing with them.
- **Psychodynamic psychotherapy** looks in more depth to try and identify unconscious and subconscious reasons behind your experiences.

If you can relate your present experiences to events that have occurred in your past, this may help you make sense of them and help make them less troubling. You may then feel able to take control of them rather than feeling

that you must let them control you. Once you feel more in control, these symptoms may diminish in intensity and frequency.

Similarly, a therapist may help you to challenge paranoid feelings, such as the belief that people are looking at you, or controlling your thoughts.

(See Mind's booklets, *Understanding talking treatments* and *Making sense of cognitive behaviour therapy (CBT)*).

Arts therapies

Art and music therapies may help you to express how you are feeling, especially if you are having difficulty talking about this. Drama therapy may help you to come to terms with traumatic events that you may have experienced in the past and which may contribute to your psychotic experiences. Some people have been able to make a complete recovery through such therapies. (See Mind's online factsheet *Arts therapies*.)

Medication

At least initially, most people diagnosed with a psychotic illness will be offered antipsychotic medication (also called neuroleptics or major tranquillisers). In all circumstances, the aim of drug treatment should be to help reduce psychotic symptoms by using the lowest possible dose for the shortest possible time.

Medication may not stop you experiencing the symptoms of psychosis, but it may make you feel calmer and less troubled by them. If this is the case, you may find the medication helpful at times, but as you learn more about your condition, you may find other ways of coping. Even if you do not wish or need to take it continuously, if you find a drug that is helpful you may want to keep some with you to use if the symptoms recur.

You may find that taking a drug continuously is the best way of keeping your symptoms under control. If you have been very disturbed during a psychotic episode, possibly endangering yourself and others, and have been admitted to hospital under the Mental Health Act 1983 (see p. 13), 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.

If your psychosis is associated with severe depression, you are likely to be treated with antidepressants, and if your diagnosis is bipolar disorder you may be given a mood stabilising drug. Both of these types of medication may be combined with an antipsychotic.

There is some evidence that using psychological and social treatments without medication in the early stages of psychosis produces better long-term outcomes than using medication first, and that once you have started on medication it may be difficult for your doctors to let you stop, because they are afraid you will relapse.

Some things to consider

Antipsychotic medication can often have unwelcome side effects including lethargy, weight gain, uncontrollable movements, and sexual problems. Some of these can be reduced with the help of other medication. Medical staff should discuss the intended benefits and the possible harms of these drugs with you, before you start to take them, to help you decide whether to try them.

If you do decide to try medication, you should also have the chance to talk about:

- whether it is helpful
- whether you would like to try a different drug
- how much to take
- how to manage withdrawal
- whether to take it regularly, as a preventive, or only under certain circumstances.

For more information about medication, see Mind's booklets, *Making sense of antipsychotics*, *Making sense of antidepressants*, *Making sense of lithium and other mood stabilisers* and *Making sense of coming off psychiatric drugs*.

Community care

Everyone who has been referred to psychiatric services in England should have their needs assessed through the Care Programme Approach. These services aim to support recovery by treating existing problems, and by working on strategies to help prevent problems from coming back. You

may be referred to the service by your GP or by a community mental health team if you have been in contact with services before. You may be seen by a variety of health professionals, including psychiatrists, mental health nurses and psychologists. You should be allocated a named care coordinator, and have a written care plan, which should be regularly reviewed. A similar system applies in Wales. For more information, see Mind's 'Community care' pages at www.mind.org.uk

Early intervention in psychosis services

Early intervention services have been set up in some areas for people aged 14-35 who are showing signs of experiencing a first psychotic episode. There is some evidence that treating symptoms as soon as possible can prevent psychotic illness from developing. Early treatment may also help to prevent some of the worse consequences of psychosis, such as periods of unemployment, misuse of drugs or alcohol, getting into trouble with the police or becoming depressed.

Hospital admission

If you become very distressed during an episode of psychosis, you may be admitted to hospital, either as a voluntary patient or under the terms of the Mental Health Act 1983, often known as being 'sectioned'. If you are admitted to hospital, this gives medical staff a chance to assess your needs and decide how to help.

A psychiatric ward can be a distressing environment, with not much to do and little privacy, but meeting other patients with similar problems, in similar circumstances, can also be very helpful and comforting.

For more information, see Mind's booklets *How to cope with hospital admission* and *Rights guide 1: civil admission to hospital*.

Crisis services

Crisis services exist in some areas as an alternative to hospital. They may offer accommodation, or support in your own home. For more information on crisis services, contact the Mind infoline (see p. 18).

Family work

Family work recognises that when you are having psychotic experiences, the rest of the household may also need support. The aim of family work is to help the whole family to understand what you are going through, and to identify what is helpful and unhelpful for you.

The work does not just focus on what is happening to you, but explores how your experience of psychosis affects the rest of the household, and the ways that their responses may help or make matters worse for each other as well as for you. For example, if you are unwell and your family members are very worried about you, they may unintentionally focus too much attention on you, making you feel more distressed. (Also see p. 17)

Therapeutic communities

Therapeutic communities provide a supportive, live-in environment for people with mental health problems. They usually hold regular meetings with all residents. You may benefit from the insights that others with similar problems may offer, and learn to live successfully in a group. The length of stay is usually limited to a set period of time.

Advocacy

Advocacy is a process of supporting and enabling people to:

- express their views and concerns
- access information and services
- defend and promote their rights and responsibilities
- explore choices and options.

Medical professionals in contact with you while you are in a crisis may not take what you have to say seriously. They may say you lack insight into your condition, without appreciating that perhaps they do, too. It can be very helpful to have the services of an advocate to help put forward your views, and to negotiate treatment and care that you can accept. For more information, see *The Mind guide to advocacy*.

How can I help myself?

66... a support network has helped me... learning to trust people who want to help, and accepting that help... determination to lead a normal life, keeping busy and knowing when things go wrong, or change dramatically, that I need to be particularly careful and, most importantly, to get a good night's sleep. ●●

Share your experience

Talking to other people who also have psychotic experiences can provide reassurance and hope, increase self-esteem and reduce isolation. Various organisations run self-help groups, which encourage members to share their experiences and help them to come to terms with them.

Self-help groups can help you:

- recognise underlying patterns in your experiences
- develop and discuss strategies
- identify early signs of crisis
- take active steps to manage your situation.

People who are experienced at this often train others.

For organisations that can put you in touch with self-help groups, see 'Useful contacts' on p. 18. You might be able to get similar support from self-help books containing the same information.

Relax

Relaxation is important to maintaining your good mental health. Relaxation exercises, yoga, and other physical activity can help. For some people, massage, aromatherapy or reflexology can be a benefit; for others, touch can bring on powerful or intense feelings that may cause distress.

Doing practical things, like gardening, cooking, or making things may also be relaxing, and, may help you stay connected to reality in a purposeful way.

You may also find it relaxing to have and maintain a structured daily routine for yourself.

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. You may be able to spot patterns which help you to identify triggers, situations or even particular foods or drinks to avoid and those which have been helpful. It is also important to share these things with your close family or friends so they can help.

If the voices you hear are of people you know, you could consider talking to those people at times when you are well, to find out if what you have heard is true. This can help you to challenge the voice if it comes again.

Create a crisis plan

During a crisis, you may not be able to tell people what helps you. While you are well, it may be a good idea to discuss with someone you trust what you would like to happen, or not to happen, when you are in a crisis.

You can also make what is known as an 'advance decision' (or 'living will'), which states this in writing and is legally binding as long as it meets certain conditions. (For more information, see the booklet *Mind rights guide 3: consent to medical treatment* and the online *Mind legal briefing 1: overview and key provisions of the Mental Capacity Act 2005*.)

What can family and friends do to help?

This section is for friends and family who want to support someone they know who has psychotic experiences.

It may be difficult to communicate with a friend or relative who is having a psychotic experience, and to understand their behaviour or what they are saying. But you may be able to understand and sympathise with feelings, such as anxiety, that they are going through. This doesn't mean you have to confirm or deny their delusions. However, **if you can accept their experiences, you can be more supportive, which can make their life easier, and improve their confidence in social situations.**

Acknowledge it when you can see truth in what they say. For instance, someone who feels that people are talking about them behind their back may be quite correct: worried friends and family may be doing just that.

If you feel your friend or relative's health is deteriorating rapidly, you might suggest that they:

- use their crisis plan
- seek help from their GP
- seek help from the duty psychiatrist in a hospital Accident and Emergency unit.

If the person 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 [MHA]) can ask for a mental health assessment to be carried out. Under the MHA, they can be compulsorily 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 rights guide 1: civil admission to hospital*).

Seeing someone you care about experiencing a psychotic episode 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 (see 'Useful contacts').

Useful contacts

Mind

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

Association of Therapeutic Communities

www.therapeuticcommunities.org
Online directory available

British Association for Behavioural and Cognitive Psychotherapies (BABCP)

tel: 0161 704 4304
web: www.babcp.com
Online directory of psychotherapists

British Association for Counselling and Psychotherapy (BACP)

tel: 01455 883 300
web: www.bacp.co.uk
Online list of accredited counsellors and psychotherapists

Complementary and Natural Healthcare Council

Tel: 020 3178 2199
web: www.cnhc.org.uk
Lists registered therapists

Depression Alliance UK

www.depressionalliance.org
Information and support

Hearing Voices Network

tel: 0114 271 8210
web: www.hearing-voices.org
National user network and local support group.

MDF The Bipolar Organisation

tel: 020 7931 6480
web: www.mdf.org.uk
Runs self-management courses.

Rethink

tel: 0845 456 0455 or 020 7840 3188
web: www.rethink.org
Aims to help everyone affected by severe mental illness recover a better quality of life.

Samaritans

PO Box 9090, Stirling FK8 2SA
24-hour helpline: 08457 90 90 90
email: jo@samaritans.org
web: www.samaritans.org

Thyromind

web: www.thyromind.info
Effects of thyroid disorders on mental health, including psychosis, depression and bipolar disorder.

Further information

Mind offers a range of mental health information, covering:

- diagnoses
- treatments
- wellbeing

Mind's information is ideal for anyone looking for further information on any of these topics.

For more details, contact us on:

tel. 0844 448 4448

email: publications@mind.org.uk

web: www.mind.org.uk/shop

fax: 020 8534 6399

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tel. 020 8215 2243

email: dons@mind.org.uk

web: www.mind.org.uk/donate

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Mind
(National Association for Mental Health)

15-19 Broadway
London E15 4BQ
tel. 020 8519 2122
fax: 020 8522 1725
web: www.mind.org.uk

Mind's mission

- Our vision is of a society that promotes and protects good mental health for all, and that treats people with experience of mental distress fairly, positively, and with respect.
- The needs and experiences of people with mental distress drive our work and we make sure their voice is heard by those who influence change.
- Our independence gives us the freedom to stand up and speak out on the real issues that affect daily lives.
- We provide information and support, campaign to improve policy and attitudes and, in partnership with independent local Mind associations, develop local services.
- We do all this to make it possible for people who experience mental distress to live full lives, and play their full part in society.



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mental health

