



For better
mental health

Understanding psychotic experiences



'When we dream, all sorts of strange things can happen to us, but we still believe that they're really happening to us. Hearing voices can be like that – a waking dream – but something that is experienced as real.'

'After a psychotic episode, one needs to re-learn how to perceive the world in a normal, ordinary, standard way, just like everybody else.'

'The problem is not so much the voices, as the inability to cope with them.'

'We should let people decide for themselves what helps or not.'

'My eyelids were bulging, my skin was greasy and grainy, my hair like rats' tails... I looked like everybody's image of a mental patient – but it was entirely a medication effect.'

'I needed someone who could just be there – non-judgmental, solid, not trying to force me to do this or that, just being with me and helping me to make sense of some very frightening, but also very beautiful and visionary experiences.'

Psychotic experiences, such as hearing voices, are surprisingly common, but can lead to diagnoses, such as schizophrenia or manic depression (bipolar disorder). This booklet is aimed at people who have such experiences, and for their families and friends. It explains what happens, and what the causes and effects might be. It also looks at the kinds of treatment available, and what people can do to help themselves.



What are psychotic experiences?

This is a psychiatric term, and describes experiences, such as hearing or seeing things or holding unusual beliefs, which other people don't see or share. During a psychotic experience, your thoughts may jump around very quickly, and so you may find it difficult to voice them in a way that others can understand. For many people, these experiences can be highly distressing and disruptive, interfering with everyday life, with making friends, having relationships, and finding or keeping a job.

Depending on other factors, psychiatrists will base a diagnosis on symptoms of this kind. The diagnosis could be severe depression, schizophrenia, manic depression (bipolar disorder), paranoia, psychotic illness, schizoaffective disorder, or puerperal psychosis (a very severe postnatal depression). These diagnoses are not clear-cut, and people may receive different diagnoses at different times.

One sign of psychosis, as far as psychiatrists are concerned, is if you lack insight into your own state of mind. They would want to know how you see and understand what is happening, and whether you are aware of being different from usual. If you are experiencing psychosis, you may find it hard to talk about your experiences and understanding of the world, because you feel no words can describe how you feel and think.

A large number of ordinary people have heard voices in the normal course of life, particularly during periods of stress or loss, such as a bereavement, divorce and separation. Many people also hold beliefs that others might consider unusual. Because the experiences don't distress them, or don't return, they are never in contact with mental health services.

There is a view that putting diagnostic labels on someone's experiences is questionable and not objective. Such labels may even be harmful, because the stigma attached, by society, to having mental health problems can worsen their situation and their symptoms.



What sort of experiences are they?

Everyone's experiences are unique. The majority hear voices, but others experience non-verbal thoughts, images and visions, tastes, smells and sensations, which have no apparent cause. For example, feeling as if insects were crawling under your skin, having a sensation like an electric shock, or smelling something that other people around you can't. These are called hallucinations, although many regard the term as misleading, because of the implication that the experiences are not real.

What seems to be important is how you react to these experiences. Some people take them in their stride; others feel overwhelmed by them. You may feel ashamed and afraid that you are going mad. You may not realise how common the experience is.

Hearing voices

The voices may be recognisable or unfamiliar. 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 benign and helpful, or hostile and nasty. Some people hear only positive voices, and may not regard them as a problem. They may even feel them to be a helpful, guiding light. Others hear only negative voices, ridiculing and belittling them, which cause them great distress and which they feel they have to fight. They may feel the voices are in control of their body and can hurt them. The voices might punish them, if they don't do as they're told. This may be responsible for them cutting themselves and other behaviour.

Unfounded beliefs

A delusion means holding an unshakeable belief that other people would regard as groundless. For example, the delusion could be the belief that they are closely related to the Queen, although they share no relatives. The person may be quite untroubled by any apparent contradictions. They may see nothing unusual in a member of the royal family serving drinks in a pub, for instance.

To qualify as a delusion, many people would argue that the belief has to be quite out of keeping with the person's culture and family background. So, if someone believes in curses and comes from a background that accepts witchcraft as a fact of life, their belief should not be regarded as a delusion. However, not all medical professionals would agree with this distinction.

Some delusional ideas can be extremely frightening; for example, someone might believe that other beings are placing thoughts in their head, or trying to control or kill them. These ideas are called paranoid delusions. The person may feel quite powerless in their grip. They may start avoiding certain situations, or try to protect themselves in some way. They may believe they deserve to be punished, or feel very angry and resentful. Sometimes, people also have delusions of grandeur, thinking they are very rich and powerful, perhaps controlling the stock markets or even the weather. This could be a way of coping with feelings of low self-esteem and powerlessness.

Someone in a psychotic crisis may not feel they can trust, understand or relate to other points of view. They may not accept that other people find their beliefs strange. They may see links between ideas that others don't, because these links are so personal. After a crisis has passed, people may begin to question their own experiences. It may gradually become clear that there is a meaningful connection to explore between their personal history and the delusional idea or what the voices say.

What causes them?

Almost anyone can have a brief psychotic episode. It may result from a lack of sleep (through severe jet lag, perhaps), through illnesses and high fevers (including malaria, pneumonia, 'flu and other viral infections) or abusing alcohol or drugs (street drugs, and prescription medication, including steroids). There is considerable evidence that psychotic experiences are connected to using cannabis in some vulnerable people. Experiences of this kind can also be a result of damage to the brain or dementia, of lead and mercury poisoning, or changes in blood sugar levels.



There are different ideas about why psychotic experiences become a problem. But it's generally thought that some people are more vulnerable to them, and that very stressful or traumatic events make them more likely to occur. A person's own attitude to their experience, as well as the attitude of those around them, also plays a part.

The experiences involve biological changes in brain structure or brain chemistry, but whether these are the cause or the effect of the psychotic experience is impossible to say. Research into whether there's an inherited vulnerability is inconclusive. If one member of a family is diagnosed with schizophrenia or manic depression, then there seems to be more chance of another family member being similarly diagnosed. But no single gene has been found to be responsible. Early experiences in life may be important in helping to prevent, or contributing to, problems. One theory suggests that over-critical or over-protective families make people more vulnerable.

All our experiences colour the way we interpret what happens to us in life. Many people who have psychotic experiences seem to have been physically, emotionally or sexually abused. Their experience of life can make them anxious and suspicious about other people, as well as lowering their self-esteem. So, if they have a psychotic experience, it may be particularly frightening and disturbing to them. This sets up a vicious, negative circle. For instance, someone who hears voices may think they are being bugged. They may become afraid that the secret service is persecuting them and interpret everything they see as supporting this view. They may start to avoid all streets with white vans in them, or refuse to go outside at all. Feeling threatened and on constant alert can be very frightening, tiring, and preoccupying. It may interfere with sleep and daily life, and make it very hard to trust anyone.

People who have been through very difficult or unhappy events may need to push their feelings and memories away, because they are so painful. Some therapists suggest that psychotic experiences are an expression of these overwhelming feelings and forbidden thoughts. In other words, these are a way of coping with life events, such as abuse.

It's also been suggested that they are traits we all share, to varying degrees, but which are interpreted differently, according to our culture or social standing. Someone regarded as 'charmingly eccentric' in an artistic community, may be condemned as 'abnormal' elsewhere. It's been pointed out that a very high proportion of disadvantaged young men are likely to receive a diagnosis of schizophrenia, many of them from the Black community. Misdiagnosis may come from misunderstanding. Some people suggest that it is evidence of underlying racism.

Will I get over it?

The majority of those who have one psychotic episode never have another one. Others may be prone to fairly short-lived episodes throughout their lives. Some may live with ongoing psychosis as a long-term problem. However serious the difficulties, there are treatments and coping strategies that reduce the disruption and enable people to lead fulfilling lives and to achieve their ambitions.

Campaigning against stereotypes

One of the biggest problems people encounter is social exclusion and poverty, because of the prejudice and discrimination they face. Media misinformation tends to reinforce negative stereotypes and myths, for instance, that people with mental health problems are violent. On the contrary, they are much more likely to be the victim of violence, or to harm themselves

People often feel unable to be open about their problems, in particular when applying for jobs. This means they don't have the chance to change people's misconceptions and challenge the taboos. Having to conceal their problems also reinforces a sense of shame.

Organisations such as Mind and Mad Pride campaign against discrimination and stigma. By people working together in this way, these pressure groups are gradually changing attitudes in society. Joining a local group can also be a way of meeting other people who may share similar experiences and views (see p. 10).



What sort of treatment can I get?

Many mental health workers and other professionals now look at people's problems as a whole, within their environment, and give them information and choice about treatment. It's increasingly recognised that many people are experts in their own condition.

Medication

Most people diagnosed with a psychotic illness will be offered antipsychotic medication (major tranquillisers or neuroleptics). Some can have very unwelcome side effects (lethargy, a shuffling walk and uncontrollable movements), which can be reduced with the help of other medication. Newer 'atypical' antipsychotics, which should be offered by doctors in preference to older drugs, have fewer side effects. Medical staff should help people explore whether medication is helpful and, if so, which drug, at which dose, and whether to take it regularly, as a preventive, or only under certain circumstances. (For more information, see *Further reading*, on p. 14.)

Talking treatments

There is good evidence that talking treatments, including counselling, psychodynamic psychotherapy and, especially, cognitive behavioural therapy, can reduce distress and the intensity and frequency of the experiences. They provide a calm, supportive and non-judgmental atmosphere, with the aim of helping people to understand their experiences, to develop coping strategies, and to improve their relationships and quality of life. They can help to tackle depression and anxiety that may result from having psychotic experiences. Some approaches may suit some people more than others.

However, some experts believe that psychotherapy for someone experiencing a psychotic episode makes things worse. Others believe it can help complement other treatments, if a well experienced and qualified therapist takes it slowly, with only gentle challenging. (See *Useful organisations*, on p. 12, and *Further reading*, on p. 14.)

Family therapy

Family therapy can strengthen the family and enable them to identify what is helpful and what is unhelpful for individual members. This helps people with a psychotic condition to maintain their mental health, as well as providing support for all family members in a crisis.

Therapeutic communities

Therapeutic communities provide a supportive, live-in environment for people with mental health problems. The length of stay is usually limited to a set period of time.

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. This gives medical staff a chance to assess your needs and decide how to help. A psychiatric ward can be a distressing environment, with little to occupy you and little privacy. But meeting other patients with similar problems, in similar circumstances, can also be very helpful and comforting.

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 *MindinfoLine*.)

Community care

Everyone who has been referred to psychiatric services in England should have their needs assessed through the Care Programme Approach. 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.

Advocacy

Medical professionals in contact with you while you are in a crisis may not take seriously what you have to say. 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. (See p. 12.)



How can I help myself?

Being given a diagnosis can be a great relief if you have been feeling overwhelmed by your experiences. One expert, Prof Marius Romme, suggests that people's own personal perspective can be as valid as a medical view of psychosis, which sees psychotic experience as an illness to be treated. They may include many different explanations for the experience – parapsychological, psychodynamic, psychological, spiritual or mystical. These allow people a framework for developing their own coping strategies. (See *Further reading*.) The more involved you can be in your own treatment and in looking after yourself, the better.

Self-help groups and coping strategies

Talking to other people who also hear voices 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. They can help people to recognise underlying patterns in their experiences, develop and discuss strategies, identify early signs of crisis, and take active steps to manage the situation. People who are experienced at this often train others. Books and booklets containing the same information are also helpful. (See *Useful organisations*, on p. 12, and *Further reading*, on p. 14.)

Relaxation

Taking steps to increase relaxation is important. Relaxation exercises, yoga, and other physical activity can help. For some people, massage, aromatherapy or reflexology can be a benefit. For others, touch can evoke unexpectedly powerful or intense feelings that may cause distress.

Advance directives

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 happen, when you are in a crisis. You may like to make out an advance directive (also known as a living will), which states this in writing.

What can family and friends do to help?

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 well be able to understand and sympathise with feelings, such as anxiety, that your friend or relative is 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 sense of 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.

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. (See *Useful organisations*, on p. 12.)

If you feel their mental health is deteriorating rapidly, and there is no crisis provision (including an advance directive) or other resources available, then you can suggest that your friend or relative seeks medical help from their GP, or the duty psychiatrist in a hospital Accident and Emergency unit. If the person doesn't seek help, and you believe they, or others are, at risk, the person's nearest relative can ask for a mental health assessment to be carried out. Under the Mental Health Act 1983, it's possible to 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.



References

'The stream of psychotic consciousness' P. Chadwick *Openmind* 124, Nov/Dec 2003

The voice inside: a practical guide to coping with hearing voices
P. Baker (Handsell Publishing/Mind 1997)

Understanding mental illness: recent advances in understanding mental illness and psychotic experience (British Psychological Society 2000)



Useful organisations

Mind

Mind is the leading mental health organisation in England and Wales, providing a unique range of services through its local associations, to enable people with experience of mental distress to have a better quality of life. For more information about any mental health issues, including details of your nearest local Mind association, contact the Mind website: www.mind.org.uk or MindinfoLine on 0845 766 0163.

Depression Alliance

35 Westminster Bridge Road, London SE1 7JB

tel. 0845 123 2320, fax: 020 7633 0559

email: information@depressionalliance.org

web: www.depressionalliance.org

National charity providing information, support and understanding

Hearing Voices Network

91 Oldham Street, Manchester M4 1LW

tel./fax: 0161 834 5768, email: info@hearing-voices.org

web: www.hearing-voices.org

National user network and local support group

The Manic Depression Fellowship (MDF)

Castle Works, 21 St Georges Road, London SE1 6ES

tel. 020 7793 2600, fax: 020 7793 2639

email: mdf@mdf.org.uk web: www.mdf.org.uk

Works to help people affected by manic depression

Rethink Severe Mental Illness (formerly NSF)

28 Castle Street, Kingston upon Thames KT1 1SS
tel. 0845 456 0455, advice line: 020 8974 6814
fax: 020 8547 3862, email: info@rethink.org
web: www.rethink.org

Aims to improve the lives of everyone affected by severe mental illness

Samaritans

The Upper Mill, Kingston Road, Ewell, Surrey KT17 2AF
For correspondence: PO Box 9090, Stirling, FK8 2SA
helpline: 08457 90 90 90, fax: 020 8394 8301
textphone: 08457 90 91 92, email: jo@samaritans.org
web: www.samaritans.org
24-hour telephone helpline

UK Advocacy Network (UKAN)

Volserve House, 14–18 West Bar Green, Sheffield S1 2DA
tel. 0114 272 8171, fax: 0114 272 7786
email: office@u-kan.co.uk
UKAN can assist you to locate a local advocacy service.

United Kingdom Council for Psychotherapy (UKCP)

167–169 Great Portland Street, London W1W 5PF
tel. 020 7436 3002, fax: 020 7436 3013
email: ukcp@psychotherapy.org.uk
web: www.psychotherapy.org.uk
Umbrella organisation for psychotherapy in UK

United Kingdom Psychiatric Pharmacy Group

tel. 020 7919 2999
Helpline run by pharmacists to answer queries on psychiatric drugs

Useful websites

web: www.madpride.org.uk
Mad Pride

Further reading

- Accepting voices* eds Prof M. Romme, S. Escher (Mind 1993) £13.99
- A can of madness* J. Pegler (Chipmunka Publishing 2002) £9.99
- Coping with bipolar disorder* S. Jones, P. Hayward, D. Lam (Oneworld 2002) £10.99
- Coping with depression and elation* Dr P. Mckeon (Sheldon Press 1997) £7.99
- The day the voices stopped* K. Steele, C. Berman (Basic Books 2002) £11.99
- How to cope as a carer* (Mind 2003) £1
- How to rebuild your life after breakdown* (Mind 2000) £1
- How to recognise the early signs of mental distress* (Mind 2004) £1
- Living with schizophrenia* J. Watkins (Hill of Content 1996) £9.99
- Making sense of antidepressants* (Mind 2004) £3.50
- Making sense of antipsychotics (major tranquillisers)* (Mind 2003) £3.50
- Making sense of cognitive behaviour therapy* (Mind 2004) £3.50
- Making sense of lithium* (Mind 2004) £3.50
- Making sense of voices: a guide for mental health professionals working with voice-hearers* Prof M. Romme, S. Escher (Mind 2000) £25
- Outsiders coming in? Achieving social inclusion for people with mental health problems* L. Sayce, D. Morris (Mind 1999) £4
- Overcoming mood swings: a self-help guide using cognitive behavioural techniques* J. Scott (Robinson 2001) £7.99
- Relaxation: exercises and inspirations for wellbeing* Dr S. Brewer (DBP 2003) £4.99
- Schizophrenia: the facts* M. Tsuang, S. Faraone (Oxford University Press 1997) £12.99
- Sheila's book: a shared journey through madness* S. Harvey (Somerset Virtual College/Mind Taunton 2003) £9.99
- Understanding anxiety* (Mind 2003) £1
- Understanding depression* (Mind 2004) £1
- Understanding manic depression* (Mind 2003) £1
- Understanding paranoia* (Mind 2004) £1
- Understanding schizoaffective disorder* (Mind 2003)
- Understanding schizophrenia* (Mind 2003) £1
- Your drug may be your problem: how and why to stop taking psychiatric medication* P. Breggin, D. Cohen (Persus 2000) £13.99

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Mind does this by:

- advancing the views, needs and ambitions of people with experience of mental distress
- promoting inclusion through challenging discrimination
- influencing policy through campaigning and education
- inspiring the development of quality services which reflect expressed need and diversity
- achieving equal civil and legal rights through campaigning and education.

The values and principles which underpin Mind's work are:
autonomy, equality, knowledge, participation and respect.

For details of your nearest Mind association and of local services contact Mind's helpline, *MindinfoLine*: **0845 766 0163** Monday to Friday 9.15am to 5.15pm. Speech-impaired or Deaf enquirers can contact us on the same number (if you are using BT Textdirect, add the prefix 18001). For interpretation, *MindinfoLine* has access to 100 languages via Language Line.

Scottish Association for Mental Health tel. 0141 568 7000

Northern Ireland Association for Mental Health tel. 028 9032 8474

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