Psychotic experiences, such as hearing voices, are surprisingly common, but can lead to diagnoses such as schizophrenia or bipolar disorder (manic depression).

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?
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What are psychotic experiences?

Psychosis 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 normal conversations, with having ordinary relationships, and finding or keeping a job.

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.

Psychiatrists regard these types of experiences as symptoms, and, depending on other factors, they will base a diagnosis on them. The diagnosis could be severe depression, schizophrenia, bipolar disorder (manic depression), paranoia, psychotic illness, schizoaffective disorder, or puerperal psychosis (a very severe form of 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 are short-lived, they are never in contact with mental health services.

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

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 or punish them if they don’t do as they’re told. This may cause them to cut themselves or carry out other harmful types of 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.
Many people would argue that, to qualify as a delusion, 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.

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

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 (both 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 develop. 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 may involve biological changes in brain structure or brain chemistry, but its not clear whether these are the cause or the effect of the psychotic experience. Research into whether there’s an inherited vulnerability is inconclusive. If one member of a family is diagnosed with schizophrenia or bipolar disorder, 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 overcritical or over-protective families make people more vulnerable.

All our experiences affect 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 someone is persecuting them, and interpret everything they see as supporting this view. They may start to avoid certain places and activities because of this, 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, they 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 cultural misunderstanding.

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. People in these latter two groups are more likely to be given a diagnosis of schizophrenia or bipolar disorder. However serious the difficulties, and whatever the diagnosis, 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 Rethink campaign against discrimination and stigma. In the Time to Change initiative these organisations, together with the Institute of Psychiatry, are working together to change attitudes in society (see Useful organisations). Joining a local group can also be a way of meeting other people who may share similar experiences and views.
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.

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

Medication

Most people diagnosed with a psychotic illness will be offered antipsychotic medication (major tranquillisers or neuroleptics). These drugs can often have very 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 help people explore whether medication is helpful and, if so, which drug, at which dose, whether to take it regularly, as a preventive, or only under certain circumstances. The aim of drug treatment should be to help reduce psychotic symptoms by using the lowest possible dose for the shortest possible time. (For more information, see Further reading.)

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 an experienced and well qualified therapist takes it slowly, with only gentle challenging (See Useful organisations and Further reading).

Arts therapies

Art and music therapies may help people to express how they are feeling, especially if they are having difficulty putting things into words. Drama therapy may help people to come to terms with traumatic events that they may have experienced in the past and which may contribute to their psychotic experiences. Some people have been able to make a complete recovery though such therapies.

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. They 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.

**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 (See Mind's booklet *How to cope with hospital admission*).

**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.

**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. Different people may have many different explanations for the experience – psychological, spiritual or mystical or relating them to less conventional ideas such as out-of-body experiences or past lives. 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.

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.
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 and Further reading).

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 decisions

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 may like to make out an advance decision (also known as a living will), which states this in writing (See Mind rights guide 3: consent to medical treatment).

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).

If you feel their mental health is deteriorating rapidly, and there is no crisis provision (including an advance decision) 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 (See Mind rights guide 1: civil admission to hospital).