

UNDERSTANDING PSYCHOSIS

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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.

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WHAT IS PSYCHOSIS?

Psychosis (also called a psychotic experience or episode) is when you perceive or interpret events differently from those around you. This includes experiencing hallucinations, delusions and flight of ideas (see below).

Many people will 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.

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.

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. You might believe that you are closely related to the Queen, although you actually share no 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. For example, you may feel that something or someone is trying to control or kill you. These ideas are called paranoid delusions.

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. Some people experience psychosis, but 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.

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

Depending on your experience of psychosis, they can bring up a wide range of emotions. You may feel:

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

Psychosis can be very difficult to deal with, and can be very disruptive. It can start to affect your ability to carry out day-to-day tasks, such as going to work, shopping or eating, and 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 – for example, if voices are telling you things about them or if you are worried about what they think of you.
- 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 in response to 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.

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

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.

HOW IS PSYCHOSIS DIAGNOSED?

WHAT CAUSES PSYCHOSIS?

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 SAMH booklets.

The diagnosis you are given will depend on how severe your experiences are, how often you experience them and whether you experience them 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 an 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 taking drugs or alcohol before they give you a diagnosis.



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

- Physical illness or injury you may see or hear things if you have a high fever, head injury, or have 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.
- 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. This experience is very common, and can be comforting, especially in the early days of bereavement.
- 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 very special experience for you, and you may feel that it helps you to make sense of your life. Or you may feel that you are possessed by an evil spirit, which is why you are experiencing these things.
- Genetic inheritance you are more likely to experience psychosis if a blood relative has also experienced this.

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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 to help you deal with your psychosis, 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 may not always mean that the symptoms of psychosis will go away entirely – 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.

Before you start any treatment, doctors, psychiatrists and other mental health workers 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.

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 *Useful Contacts* p.20).

Talking treatments

Talking treatments can help reduce the 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 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.

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 behaviourial therapy
 (CBT) aims to identify connections
 between thoughts, feelings and behaviour, and to help develop practical skills to manage them.
- Psychodynamic psychotherapy looks in more depth to try and identify unconscious and subconscious factors from relationships in your past that lie behind 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.

The Scottish Government has set a target that nobody should wait longer than 18 weeks between being referred for a talking treatment and starting treatment. However, in some areas waiting times are still long, so you may wish to 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.20). 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).

Antipsychotics are not a cure for psychosis, but they can help control your symptoms and stop you feeling distressed by them. 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, 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. 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.
- Mood stabilisers if you have a diagnosis of bipolar disorder or experience mania.
- 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 do decide to try medication, you should have the chance to talk regularly about how your treatment with them 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.

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.

Arts therapies

Arts therapies, such as art, music and drama therapy, are recommended by NICE for schizophrenia and related disorders. They may help you to express how you are feeling, especially if you are having difficulty talking about this.

Community care

If you have repeated or long-lasting psychosis, you may be referred to a community mental health service to help you cope.

You may be able to access the following services if you experience psychosis:

- Community mental health team

 (CMHT) This is a team of mental health professionals, including psychiatrists, nurses and occupational therapists, who 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 you can 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. This is intended 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.



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. Before leaving hospital, you should discuss the kind of services that would enable you to live independently.

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. For further information and advice about your rights you can contact the Mental Welfare Commission for Scotland (see 'Useful Contacts' p.20)

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.10).

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 accept that help.

Various organisations, such as the Hearing Voices Network, the Paranoia Network, and Bipolar Scotland, run support groups that may be helpful if you experience psychosis. Search online or contact SAMH to find out about what is available in your area (see 'Useful Contacts' on p.20).



Look after yourself

Whatever your diagnosis, it's important to look after your mental and physical wellbeing (see SAMHs booklets Five ways to better mental health & wellbeing and Get Active)

The following things might be helpful:

- Relaxation exercises or yoga can help reduce stress. Some people also find complemetary therapies like massage, aromatherapy or reflexology helpful. (see SAMH's booklet A guide to Complementary Therapies for more information)
- 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 grounded.
- Maintaining a structured daily routine can make day-to-day tasks seem more manageable.
- Making sure you get sufficient sleep can make you feel calmer and more able to cope. If you feel tired, it is more likely that you will feel stressed or worried and find it more difficult to manage your symptoms.

 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.

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 you are becoming unwell.

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

Once you have a better understanding of your triggers, you can try to take positive steps to avoid these. Similarly, 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. 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.

Advance Statements were introduced under the Mental Health (Care and Treatment) (Scotland) Act 2003.

An advance statement includes any statement that you make while you are well, explaining what you would like to happen if you are in crisis and become unable ('lose capacity') to make decisions about your treatment. If someone else needs to decide things in your best interests, your advance statement should always be taken into account.

Advance statements must be witnessed and signed by a health or social care professional.

The Mental Health Act does gives psychiatrists power to override your decisions if you are detained and they believe that treatment is needed. However, if they do this, they must send a written record to the Mental Welfare Commission setting out why they believe this was necessary.

You can also attach a personal statement, setting out what you would like to happen in other areas of your life, if you become too unwell to make a decision. For example, you might want to say who should look after your children or ask for your employer to be notified. Personal statements do not have the same standing in law as an advance statement.

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 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.



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 accommodation or access particular services.

They may also want you to act as an advocate, to help them express their opinions and access the help they need. Or you find an independent advocate to help them. (See 'Useful Contacts' p.20) Whatever help you offer, it's important that you respect their wishes, and don't try to take over or make decisions without them.

Help in an emergency

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



- Use their crisis plan if they have one.
- Seek help from their GP.
- Seek help from the duty psychiatrist in a hospital Accident and Emergency unit (A&E).

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

Family work

If you are caring for a member of your family, you might want to ask your GP or social services if you can try a course of family work, although what is available varies from area to area. Family work recognises that when someone is experiencing psychosis, the rest of the household may also need support. The aim of family work is to help the whole family understand what the person is going through, and to identify what is helpful and unhelpful for both them and you.

The work does not just focus on what is happening to the person with psychosis, but explores how their experiences affect the rest of the household, and the ways that their responses may help or make matters worse for everyone in the family. 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. For further information about what is available in your area contact SAMH (see 'Useful contacts' on p.20).

USEFUL CONTACTS

Scottish Association for Mental Health

t: 0141 530 1000

email: enquire@samh.org.uk

w: samh.org.uk

Details of local SAMH services and information and sign-posting for people concerned about mental health. Office hours 9am to 5pm, Monday to Friday.

Bipolar Scotland

t: 0141 560 2050

w: bipolarscotland.org.uk

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

British Association for Behavioural and Cognitive Psychotherapies (BABCP)

t: 0161 705 4304

w: babcp.com

 $\label{lem:condition} Information and a register of accredited $$CBT$ therapists.$

British Association for Counselling and Psychotherapy (BACP)

t: 01455 883 300

Main w: bacp.co.uk

Sister w: itsgoodtotalk.org.uk

Information on counselling and psychotherapy, and a register of accredited practitioners.

Hearing Voices Network t: 0114 271 8210

w: hearing-voices.org

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

Intervoice

w: intervoiceonline.org

International community for people who hear voices.

National Perceptions Forum

w: voicesforum.org.uk

Forum for people who experience psychosis.

National Paranoia Network t: 0114 271 8210

w: nationalparanoianetwork.org

Information, support and understanding for people who experience paranoid thoughts.

Mental Welfare Commission for Scotland

Service Users & Carers Advice Line: 0800 389 6809

w: mwcscot.org.uk

They protect and promote the human rights of people with mental health problems, learning disabilities, dementia and related conditions.

Scottish Independent Advocacy Alliance

t: 0131 524 1975

w: siaa.org.uk

Provide assistance to access independent advocacy support.

Samaritans

Freepost RSRB-KKBY-CYJK

Chris, PO Box 90 90

Stirling

FK8 2SA

24-hour helpline:

116 123

email: jo@samaritans.org

w: samaritans.org

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

Carers Trust Scotland

t: 0300 123 2008

w: carers.org/country/carers-trust-

scotland

Information, support and advice on all aspects of caring.

NHS24

t: 111

w: nhs24.com

NHS24 is a 24-hour health service for Scotland.

Breathing Space

t: 0800 83 85 87

w: breathingspace.scot

Confidential out of office hours telephone line for people experiencing low mood, anxiety or depression.

See Me

t: 0141 530 1111

w: seemescotland.org

National programme to tackle mental health stigma and discrimination.

Further information

To read or print SAMH's information booklets, visit **samh.org.uk**;

to order copies contact SAMH on 0141 530 1000 or at enquire@samh.org.uk



SAMH is Scotland's largest mental health charity and is dedicated to mental health and well-being for all. We are here to provide help, information and support to people affected by mental health problems.

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