

understanding



schizophrenia

Understanding schizophrenia

This booklet explains what schizophrenia is, including possible causes and how it is treated. It also offers practical suggestions for self-help, and information for friends and family.

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What is schizophrenia?

You could be diagnosed with schizophrenia if you experience some of the following symptoms:

- a lack of interest in things
- feeling disconnected from your feelings
- difficulty concentrating
- wanting to avoid people
- hallucinations, such as hearing voices or seeing things others don't
- delusions (which could include paranoid delusions) – strong beliefs that others don't share
- disorganised thinking and speech
- not wanting to look after yourself.

Delusions and hallucinations are types of psychosis. (See Mind's online resources on psychosis, paranoia and hearing voices for more information.)

●● *I have bizarre delusions which include psychic battles in which people around me can be perceived as either 'good' or 'evil'. Sometimes I am in a different time zone or move between periods of history in different lives.* ●●

What's it like to have schizophrenia?

Many experiences and behaviours can be part of schizophrenia. They can start suddenly for some people, while others find that they develop gradually over time.

●● *Sometimes I feel thoughts are being put in my head and that people are reading my thoughts.* ●●

Each person's experience of schizophrenia is unique to them, but you might find that you:

- aren't able to carry on with day-to-day activities, like going to work or taking care of yourself
- become upset, confused, distrusting or suspicious of other people or particular groups, like strangers or people in authority
- disagree with people who think something is wrong
- feel worried or afraid of seeking help.

👉👉 *More recently my symptoms have included voices outside my head, feelings that people are talking about me and spying on me.* 👉👉

What are positive and negative symptoms?

People sometimes describe the symptoms of schizophrenia as 'positive' symptoms or 'negative' symptoms. This doesn't mean they are good or bad.

Positive symptoms are experiences or behaviours that you start having as part of schizophrenia. They can include hearing voices, seeing things that others don't, believing something is real or true when it isn't, or believing your thoughts are being monitored or controlled.

Negative symptoms are experiences or behaviours that you stop having (or have less) as part of schizophrenia. You might find people or activities less interesting or enjoyable, that you move your body less, feel disconnected from your emotions or have less motivation to do things.

👉👉 *What was real and what was not? I couldn't tell the difference any longer and it was exhausting.* 👉👉

Misconceptions about schizophrenia

Many people have heard of schizophrenia, but this doesn't mean that they understand the diagnosis. You might find that some people have negative ideas about schizophrenia or have misconceptions about you.

A diagnosis of schizophrenia does not mean someone has a 'split personality', but many people wrongly think this. Some people think hearing voices means someone is dangerous, when voices are actually more likely to suggest that you harm yourself than someone else. It's also important to remember that people have a choice in whether they do what the voices say.

Schizophrenia in the media

Misconceptions about schizophrenia often come from the media, including newspapers and TV. There is more media misinformation about schizophrenia than about any other type of mental health problem.

Sensational stories in the press often wrongly present people with schizophrenia as being dangerous, even though most people with schizophrenia don't commit violent crimes.

What diagnoses are related to schizophrenia?

There are several diagnoses that share many of the same symptoms – such as schizoaffective disorder, schizotypal personality disorder and schizoid personality disorder. (See Mind's online resources on schizoaffective disorder and personality disorders for more information.)

Different views about diagnosis

Views on schizophrenia have changed over the years. Lots of people have questioned whether schizophrenia is actually one condition or a few different conditions that overlap.

Some people argue that because psychiatric experts cannot agree on the exact definition of schizophrenia, it shouldn't be used as a diagnosis at all. Others think the name of the condition doesn't matter and that it would be more useful to focus on what helps with specific symptoms and individual needs.

The reality is that many people are still given a diagnosis of schizophrenia. If you are one of them, it might be helpful to think of a diagnosis as a tool for treating what you're currently experiencing, rather than a definite condition or label that you will have to live with forever.

Some people find getting a diagnosis helpful and some don't. For more about diagnosis, see Mind's online resource *Seeking help for a mental health problem* and our legal advice pages.

How can I make people more aware of schizophrenia?

If you find that people don't understand or know about schizophrenia, you could:

- **Show them this information.** This can help them understand more about your diagnosis.
- **Get more involved in your treatment.** Our online resource *Seeking help for a mental health problem* explains more about having a say in your treatment, getting your voice heard and steps you can take if you're not happy with your care.
- **Know your rights.** Our online pages on legal rights have more information.
- **Take action with Mind.** See our online campaigning page for details of how you can get involved. For more about campaigning, visit the Time to Change website (time-to-change.org.uk).

What causes schizophrenia?

The cause of schizophrenia is not yet known, and research into it is happening all the time. But it is generally agreed that schizophrenia is caused by a combination of factors rather than a single one. This section has information about possible causes of schizophrenia.

Stressful life events

Highly stressful or life-changing events may sometimes trigger schizophrenia. These can include:

- feeling lonely or isolated
- being out of work
- having money problems
- becoming homeless
- losing someone close to you
- being abused or harassed.

 *The onset of schizophrenia for me was sudden and dramatic, though it followed a period of depression and acute stress. A really compelling and powerful voice started to try to control me.* 

Cannabis and other recreational drugs

Some people may develop symptoms of schizophrenia after using cannabis or other recreational drugs. Researchers still aren't sure whether using recreational drugs directly causes schizophrenia, or if people who develop schizophrenia are also more likely to use recreational drugs.

If you already have schizophrenia, research has shown that using recreational drugs may make the symptoms worse. Some studies suggest that people who use high-potency cannabis ('skunk') during a period of recovery are more likely to have a relapse of their symptoms.

Drinking alcohol and smoking may also stop medication from effectively

treating your symptoms. (See Mind's online resource on recreational drugs and alcohol for further information.)

Does schizophrenia run in families?

You are more likely to develop psychosis such as schizophrenia if you have a parent or sibling who has experienced psychosis, but researchers aren't sure why this happens. It is thought that certain genes might make some people more vulnerable to developing schizophrenia, which could explain why people in the same family may be affected.

Some possible causes of schizophrenia are also more likely to affect people living in the same household. For example, some studies suggest that living in cities increases the risk of developing schizophrenia – but researchers don't yet know why.

Chemicals in the brain

Some chemicals seem to behave differently in the brains of people who experience schizophrenia. These chemicals are thought to include dopamine, which helps to carry messages between brain cells.

One theory is that people with schizophrenia have more dopamine in their brains, or that dopamine has different effects for them. Some research suggests that other chemicals are involved too.

Antipsychotics, which are sometimes used to treat schizophrenia, can help to lower dopamine levels. (See Mind's online resources on antipsychotics for further information.)

Other possible causes of schizophrenia

Some studies suggest that physical differences in the brain, or injury to the brain, may be linked to schizophrenia. Other physical causes have also been suggested.

Research into a wide range of other possible causes is ongoing.

●● *More recently my physical health has deteriorated... I have become more agoraphobic and find group settings harder than before.* ●●

Are some people more likely to be diagnosed than others?

About one in every 100 people is diagnosed with schizophrenia. It seems to affect roughly the same number of men and women. Most people diagnosed with schizophrenia are aged between 18 and 35, with men tending to be diagnosed at a slightly younger age than women.

African-Caribbean men in the UK are particularly likely to be diagnosed with schizophrenia, despite there being no evidence that they are biologically more vulnerable to it. It has been suggested that this is caused by difficult life events, such as migration, racism, environment and cultural differences that affect mental health.

It may also be that psychiatrists with very different cultural, religious or social experiences to their patients mistakenly diagnose schizophrenia.

What treatments can help?

The National Institute for Health and Care Excellence (NICE) – the organisation that produces guidelines on best practice in health care – recommends treating schizophrenia and psychosis with a combination of talking treatments and antipsychotic medication while you are unwell.

You can read the full guidelines on the NICE website (nice.org.uk), including a list of questions you might want to ask about your diagnosis and treatment.

●● A lot of people want help with understanding why they are experiencing their symptoms and want help to live their lives without distress. The goal isn't always to eradicate symptoms but to understand them, tolerate distress and address any deeper problems. ●●

What treatments can help with schizophrenia?

Treatments that are recommended for schizophrenia include:

What the treatment is called	How it might help
<p>Cognitive behavioural therapy (CBT) A type of talking treatment that helps with patterns of thinking or behaviour that may be causing you difficulties.</p>	<p>CBT for schizophrenia can help you to:</p> <ul style="list-style-type: none">• cope with symptoms of psychosis such as delusions or hearing voices• ease stress so your symptoms don't get worse• manage any side effects from medication• cope with other problems like social anxiety and depression, which people with schizophrenia may also experience. <p>Talking treatment for schizophrenia should focus on helping you cope with your symptoms, rather than trying to convince you that your beliefs or experiences are wrong.</p> <p>See Mind's online resource on CBT for more information.</p>

What the treatment is called	How it might help
<p>Medication</p> <p>Doctors usually prescribe antipsychotic drugs (also known as neuroleptic drugs or major tranquilisers) to help with schizophrenia.</p>	<p>Medication for schizophrenia:</p> <ul style="list-style-type: none">• could help with symptoms of psychosis• affects different people in different ways• is helpful for some people but not others• can have side effects – it’s best to tell your doctor about these• can involve trying more than one type of medication before you find what works for you• should be something you have a say in – your doctor should explain the risks and benefits of any medication• might be something you take for a short time, or you might need to stay on it long-term. <p>See Mind’s online resources on antipsychotics for more information.</p>
<p>Family intervention</p> <p>A type of talking treatment for relatives or carers of people who are diagnosed with schizophrenia.</p>	<p>Family intervention for schizophrenia can:</p> <ul style="list-style-type: none">• help relatives or carers work out how best to support you• help family members find ways of coping and solving problems together• involve you if possible, depending on how you feel and what you would prefer• be with other families or just yours, depending on what’s available and what you and your family prefer.

What the treatment is called	How it might help
<p>Arts therapies A way of using creative arts – music, painting, dance, voice or drama – to express yourself in a therapeutic environment with a trained therapist.</p>	<p>Arts therapies for schizophrenia:</p> <ul style="list-style-type: none">• may be helpful if you feel distanced from your feelings or find it hard to talk• should be considered for everyone with a diagnosis of schizophrenia and related problems like schizoaffective disorder and psychosis, according to National Institute for Health and Care Excellence (NICE) guidelines.

●● *I am on mood stabilisers as I also get hyper and very depressed. Also angry sometimes.* ●●

Can I recover from schizophrenia?

There isn't currently a cure for schizophrenia, but many of the symptoms can get better with treatment. Some people find their symptoms stop altogether, or stop for long periods of time.

However, for many people schizophrenia is something that they live with long-term.

●● *I have had one major and three minor episodes of the illness but am able to lead a pretty normal life. I have made some good friends through my experience but am more distant with others. I would say to others that you can get through the worse times and [to] always have hope.* ●●

If you want to stop taking medication

Some people find antipsychotics unhelpful or want to stop taking medication because they feel better. It's important not to stop suddenly as this can cause withdrawal symptoms.

It's best to speak to your doctor or care team if you want to stop taking medication, even if you don't think you need it any more. See Mind's online resource *Coming off psychiatric drugs* for more information.

It's also a good idea to talk to your care team about any over-the-counter medicines or complementary therapies you want to try, in case they are likely to interfere with your medication.

How can I help myself?

Many people who are diagnosed with schizophrenia are able to live happy and fulfilling lives, even if they continue to experience symptoms.

It can help to:

- look after your physical health
- try to cut down on stress
- do things you enjoy
- maintain relationships
- use peer support
- look out for warning signs
- plan for more difficult times.

●● *My recovery has been gradual and in stages... No matter how bad I feel, I can now manage my worst days until I get to a better place mentally.* ●●

Look after your physical health

- Try to get enough sleep. Sleeping well can make you feel calmer and more able to cope. If you feel tired, you are more likely to feel stressed or worried and find it difficult to manage your symptoms. (See Mind's online information on sleep problems.)
- Try to eat a balanced diet. Following a healthy diet with plenty of fresh fruit and vegetables can help your wellbeing. Eating regularly can also help avoid psychosis being brought on by changes to your blood sugar levels. (See Mind's online resource *Food and mood*.)

Smoking and antipsychotics

Smoking can change the effects of antipsychotic drugs. If you smoke and are prescribed antipsychotics, it's particularly recommended that you try to give up.

It's best to talk to a doctor first because:

- they can help you with giving up smoking
- they might need to adjust your prescription.

Alcohol and recreational drugs can also affect the way your medication works. (See Mind's online information on recreational drugs and alcohol.)

Try to cut down on stress

Too much stress can make the symptoms of schizophrenia worse and increase the chances of you becoming unwell. It could help to spend time outside in green space or try doing some exercise like walking, swimming or yoga.

You might need to cut down on the number of responsibilities you have – it could help to explore support services in your area. For more suggestions, see Mind's booklet *How to manage stress*.

Do things you enjoy

It's important to stay involved in doing things you enjoy. They can boost your confidence and help you stay well, whether it's cooking, listening to music or doing DIY.

Some people find that doing something creative like drama, drawing or sewing can help them to express themselves and deal with difficult emotions. (See Mind's online information on arts therapies.)

●● Focus on something practical [like] an allotment. It calms the mind. ●●

Maintain relationships

Feeling connected to other people is an important part of staying well. It can help you to feel valued, confident and more able to face difficult times.

Feeling lonely or isolated could make your symptoms worse. If you don't feel you have strong connections with people or you'd like to make more, it could help to explore support services and peer support.

Use peer support

Peer support brings together people who have had similar experiences. Some people find this very helpful.

There are lots of ways to find peer support. You could:

- see our list of useful contacts on p.21
- see Mind's online peer support directory
- ask your local Mind about peer support
- try an online peer support community like Elefriends: elefriends.org.uk (also see the Mind website resource *How to stay safe online*).

Look out for warning signs

If you are becoming unwell, there might be signs you could spot early on. These will be different for everyone, but they could include:

- feeling anxious or stressed
- sleeping less well
- feeling suspicious or fearful
- hearing quiet voices
- finding it hard to concentrate
- avoiding other people.

Noticing when you are becoming unwell

You might find you can learn to recognise signs that you are feeling less well. It could help to:

- **Pay attention to what triggers your symptoms.** Some activities, situations or people might seem to have a particular effect.
- **Ask other people to help.** You could ask someone you trust to let you know if they notice changes in your moods or behaviour.
- **Keep going to appointments.** It's best to carry on going to any appointments for treatment, support or check-ups, even if you're feeling better.

Plan for more difficult times

If you're feeling less well you might not be able to tell people what help you want, so it could be helpful to plan ahead. It can also help to talk to someone you trust about how you would like to be helped. (See Mind's online information on crisis services for more about planning ahead.)

For more ideas on how you can help yourself, see Mind's online information on helping yourself with paranoia, living with voices and improving your mental wellbeing.

What can friends or family do to help?

If someone close to you has schizophrenia, it can be hard to know how to help – but there are lots of things you can try. You could:

- ask how you and others can help
- focus on feelings, not experiences
- notice what's going well
- find out more about schizophrenia
- plan ahead for more difficult times
- look after yourself.

Ask how you and others can help

Ask what help they would find useful. This might include helping with everyday things like shopping or housework, taking them to appointments or reminding them to take their medication.

If someone doesn't want help

People who experience schizophrenia may not realise they are unwell until they get treatment. It can be hard to persuade someone to see a doctor if they don't want to, or if they don't think anything is wrong.

Mind's online information *Seeking help for a mental health problem – Supporting someone else* has some suggestions on what to do.

Focus on feelings, not experiences

You might feel unsure what to say or do when someone sees or believes something you don't – but it's important to remember that their experiences feel real to them.

It can help if you focus on how they are feeling, rather than talking about what is real or true.

●● *If someone turns 'round and says to you: 'It's not real,' it just makes you feel more alone than ever.* ●●

Notice what's going well

It can be hard seeing someone close to you experience schizophrenia. They might find it hard to think clearly, have problems understanding what is real, stop taking care of themselves or avoid seeing people.

Try to notice positive things too. It can help to set small, realistic goals rather than focusing on what they can't do. It's also important to remember that losing interest and motivation are part of having schizophrenia and not something the person is choosing.

Find out more about schizophrenia

It could help to learn about the symptoms your friend or relative might experience and the coping strategies they might find useful. Some people find it helpful to read personal stories or speak to others in the same situation (see 'Useful contacts' on p.21).

Getting advice from professionals

If you are caring for someone with schizophrenia, you should be able to talk to their doctor, care team or other professionals involved in their care.

Even if someone doesn't want medical details to be shared with you, it should still be possible for you to ask for advice and information. They should also talk to you about your needs as a carer.

You might find it helpful to think about what questions you particularly want to ask. Some organisations have suggested ideas for questions:

- see 'questions for family members and carers to ask' on the National Institute for Health and Care Excellence (NICE) website: nice.org.uk
- see 'questions to ask the doctor' on the Royal College of Psychiatrists website: rcpsych.ac.uk

Plan ahead for more difficult times

When someone with schizophrenia is feeling well, it can be useful to discuss how friends and family can be supportive if or when things get more difficult. (See Mind's online information on crisis plans and advance decisions for more information.)

While having this conversation, it's important for friends and family to think about what they feel they can and can't cope with.

👉👉 *Lonely, confused, isolated, scared, prejudiced against... [In my experience] that's how family members feel.* 👉👉

Look after yourself

It can be distressing when someone you are close to experiences the symptoms of schizophrenia. It's important to invest time and energy into looking after yourself too.

See Mind's online resources *How to cope when supporting someone else* and *How to improve your mental wellbeing* for more information.

Useful contacts

Mind

Mind Infoline: 0300 123 3393
 (Monday to Friday 9am to 6pm)
 email: info@mind.org.uk
 web: mind.org.uk
 Details of local Minds and other local services, and Mind's Legal Advice Line. Language Line is available for talking in a language other than English.

Carers UK

helpline: 0808 808 7777
 email: advice@carersuk.org
 web: carersuk.org
 Information and advice on all aspects of caring.

Elefriends

web: elefriends.org.uk
 Elefriends is Mind's friendly, supportive online community for people experiencing a mental health problem.

Hearing Voices Network

tel: 0114 271 8210
 web: hearing-voices.org
 Information about strategies to cope with hearing voices and local support groups.

National Paranoia Network

tel: 0114 271 8210
 email: enquiries@nationalparanoianetwork.org
 web: nationalparanoianetwork.org
 Information and support for people who experience paranoid thoughts.

National Perceptions Forum

web: voicesforum.org.uk
 A forum for individuals with mental health problems to share experiences.

Rethink Mental Illness

tel: 0300 5000 927
 web: rethink.org
 Services and support groups for people affected by mental illness and their carers.

Royal College of Psychiatrists

web: rcpsych.ac.uk
 For information, including podcasts, about mental health.

Useful contacts

Samaritans

Freepost RSRB-KKBY-CYJK

Chris PO Box 90 90

Stirling FK8 2SA

24-hour helpline: 116 123

(freephone)

email: jo@samaritans.org

web: samaritans.org

24-hour emotional support for
anyone struggling to cope.

Time to Change

web: time-to-change.org.uk

(England)

web: timetochangewales.org.uk

(Wales)

Campaigning organisation with
information and blogs about
schizophrenia.

Support Mind

Providing information costs money. We really value donations, which enable us to get our information to more people who need it. Just £5 could help another 15 people in need receive essential practical information. If you would like to support our work with a donation, please contact us on:

tel: 0300 999 1946

email: supportercare@mind.org.uk

web: mind.org.uk/donate

This information was written by Annie Crabtree.

We welcome feedback on our publications.
To give feedback on this booklet, email us at
mindinfoteam@mind.org.uk

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Mind

We're Mind, the mental health charity for England and Wales. We believe no one should have to face a mental health problem alone. We're here for you. Today. Now. We're on your doorstep, on the end of a phone or online. Whether you're stressed, depressed or in crisis. We'll listen, give you advice, support and fight your corner. And we'll push for a better deal and respect for everyone experiencing a mental health problem.

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info@mind.org.uk
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