

understanding



schizophrenia

Understanding schizophrenia

This booklet explains what schizophrenia is, its 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?

Schizophrenia is a diagnosis you may be given 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
- hearing voices
- delusions
- feeling like you need to be protected.

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

●● *For me, the paranoia is the worst. It is very real and frightening.* ●●

For some people these experiences or beliefs can start happening quite suddenly, but for others they can occur more gradually. You may become upset, anxious, confused and suspicious of other people, particularly anyone who doesn't agree with your perceptions. You may be unaware or reluctant to believe that you need help.

●● *I was finding it difficult to talk. The words in my mind just would not come out.* ●●

Delusions, hearing voices and hallucinations are all types of psychosis. See Mind's booklets *Understanding psychosis* (online), *Understanding paranoia* and *How to cope with hearing voices* for more information.

Positive and negative symptoms

You may hear professionals talk about positive or negative symptoms. This is just a way that people group the symptoms of schizophrenia.

- **Positive symptoms** – things that most people do not normally experience, for example strange thinking, hallucinations and delusions.
- **Negative symptoms** – when you lack some emotional responses or thought processes that most people normally experience, for example lack of motivation.

Impact on day-to-day life

The symptoms of schizophrenia can be disruptive and have an impact on your ability to carry on with day-to-day tasks, such as going to work, maintaining relationships with other people, caring for yourself or for others.

Cognitive behaviour therapy (CBT) can help you to deal with this added stress and to develop ways of managing your symptoms (see p.9). You might also find it helpful to talk and share coping tips with other people in the same situation. See 'Use peer support' on p.16 or 'Useful contacts' on p.21 for organisations that can help you find groups like this in your area.

Schizophrenia and stigma

There is more media misinformation about schizophrenia than about any other type of mental health problem. A diagnosis of schizophrenia does not mean 'split personality', or indicate that someone will swing wildly from being calm to being out of control.

Sensational stories in the press tend to present people with schizophrenia as dangerous, even though most people diagnosed with schizophrenia don't commit violent crimes. We often think that people who hear voices are dangerous, but actually voices are more likely to suggest that you harm yourself than someone else. It's important to remember that people also have a choice in whether they do what the voices say.

Diagnoses related to schizophrenia

There are several diagnoses that share many of the same symptoms. For more information on schizoaffective disorder, see Mind's booklet *Understanding schizoaffective disorder*. For information on schizotypal personality disorder or schizoid personality disorder, see *Understanding personality disorders*.

Different views about diagnosis

Views on schizophrenia have changed over the years. Lots of people have questioned whether schizophrenia is actually one condition or if it might actually be a few different conditions that overlap. Some people say that what the condition is called doesn't matter and that it would be more helpful to focus on relieving specific symptoms and individual needs.

Other people argue that because psychiatric experts can't agree on the definition, causes or suitable treatments for schizophrenia, it shouldn't be used as a diagnostic category at all.

The reality is that many people are still diagnosed with schizophrenia. If you are one of them, it might be helpful to think of a diagnosis more 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.

What causes schizophrenia?

It is generally agreed that schizophrenia is caused by a combination of factors rather than a single one.

Dopamine

Dopamine is one of the chemicals that carries messages between brain cells. There is evidence that too much dopamine may be involved in the development of schizophrenia, but it's still not clear how, or whether everyone diagnosed with schizophrenia has too much dopamine.

Neuroleptic drugs (antipsychotics), which are sometimes used to treat schizophrenia, target the dopamine system (see 'Medication' on p.10).

Stressful life events

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

- social isolation
- being out of work
- living in poverty
- being homeless
- losing someone close to you
- being physically or verbally abused, or harassed.

Drug abuse

Some people may develop symptoms of schizophrenia as a result of using cannabis or other street drugs such as cocaine and amphetamines. If you already have schizophrenia, using street drugs can make the symptoms worse. Drinking alcohol and smoking may also limit how effectively medicines treat the symptoms of schizophrenia. (See Mind's booklet *Understanding the mental health effects of street drugs* for more information.)

Inheritance

Some families seem to be prone to schizophrenia, which suggests a genetic link. Rather than there being a specific gene for schizophrenia however, it is thought that certain genes might make some people more vulnerable to the condition.

Other causes

Research is happening all the time into what might cause schizophrenia. For example there is evidence that physical differences in, or injury to the brain may be linked to schizophrenia, and that some of this process might

happen before someone is born. Research into other possible causes, including viruses, hormonal activity (particularly in women), diet, allergic reaction or infection is ongoing.

Are some people more likely to be diagnosed than others?

About one in every hundred 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. Some studies suggest that living in cities increases the risk of developing schizophrenia.

African-Caribbean men in the UK are much more likely to be diagnosed with schizophrenia than their white counterparts. This is despite no evidence that they are biologically more vulnerable to it. Suggestions have been made 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 are available?

If you think you need professional help, the first step is to visit your GP. If you are experiencing symptoms related to schizophrenia, your GP will probably refer you to psychiatric services for an assessment, treatment and care. However, before you have any treatment, all possible treatment options should be discussed with you, and your views and wishes should be taken into account.

The National Institute for Health and Care Excellence (NICE) has produced guidelines for treating and managing schizophrenia. If you receive treatment from the NHS, it should follow these guidelines. NICE recommends that you be treated with a combination of talking treatments and antipsychotic medication while you are unwell.

They also recommend that you get help as quickly as possible. For more information, you can read the full guidelines on the NICE website (see 'Useful contacts' on page 21).

Different things work for different people so you may need to try a few types of treatment before you find what works best for you. If you have difficulty getting the treatments you would like, you may find it helpful to use an advocate. (See 'Advocacy' on p.13 and Mind's booklet *The Mind guide to advocacy* for more information.)

Talking treatments

Talking treatments provide a regular time and space for you to talk about your troubles and explore difficult feelings with a trained professional. You have the right to ask for talking treatments from your GP. These treatments are free on the NHS but they are not available in all parts of England and Wales. Waiting times can be long too so you might choose to pay for a private therapist. Private therapists should be appropriately trained and accredited. (See 'Useful contacts' on p.21 for details of where to find accredited therapists.)

Cognitive behaviour therapy (CBT)

Cognitive behaviour therapy (CBT) is a talking treatment which aims to identify connections between thoughts, feelings and behaviour, and to help develop practical skills to manage any negative patterns of thinking or behaviour that may be causing you difficulties.

CBT can be helpful for people with schizophrenia because it can:

- help you develop coping strategies to deal with the symptoms of psychosis such as hearing voices or delusions
- ease stress so that your symptoms don't get worse
- suggest ways of managing the side effects of medication, such as weight gain
- help you to manage things like social anxiety and depression, which are often associated with schizophrenia.

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CBT for psychosis is a bit more complex than regular CBT, because it has to take into account the unusual beliefs and experiences people with schizophrenia might have. However, you should still be able to access CBT on the NHS, so ask your doctor if it is available in your area. (See Mind's booklet *Making sense of cognitive behaviour therapy* for more information.)

Family intervention therapy

If you live with or have regular contact with your family, family intervention therapy can help. The aim of this type of therapy is to help family members develop communication, problem solving, information sharing and coping skills together. The whole family will be able to have a say in how this works, for example it might be done as a group or one-to-one.

Other types of talking treatment

We know that some people find talking treatments other than CBT and family intervention therapy, such as counselling, supportive psychotherapy and social skills training useful. There is not as much evidence to support these types of therapy for schizophrenia. However, your personal preference should always be taken into account, especially when the other treatments are not available in your area.

Medication

Doctors usually prescribe antipsychotic drugs (also known as neuroleptic drugs or major tranquillisers) to control the 'positive' symptoms of schizophrenia (see p.5).

Not everybody finds antipsychotics helpful and they can cause unpleasant side effects. If you find the medication helps your symptoms, you may feel it is worth putting up with the side effects, but some people find them harder to cope with than their symptoms and decide to come off them. (See Mind's booklet *Making sense of coming off psychiatric drugs* for more information.)

Different drugs may affect you in different ways, so you might need to try one or two types before you find the one that suits you best.

How long will I need to take medication?

Some people get short-term help from medication, then come off it and remain well. Others may benefit from longer-term treatment. If you do stay on medication long term, staying on the lowest effective dose of the drug may be the best way of dealing with symptoms whilst at the same time reducing side effects.

Arts therapies

Arts therapies are a way of using the arts – music, painting, dance, voice or drama – to express and understand yourself in a therapeutic environment with a trained therapist. They can be helpful if you feel distanced from your feelings or find it too upsetting to talk about painful experiences, and would therefore find it difficult to benefit from talking treatments. (See Mind’s online booklet *Making sense of arts therapies* for more information.)

What support services are available?

As well as receiving treatment, you may find that you need additional support to help you live your day-to-day life. The following range of services is available.

Community care

Care in the community is normally split into two categories:

- **Health care** generally means any care you need to manage your mental or physical health such as medication, therapy or crisis care.
- **Social care** generally means any care or support you need to manage your day-to-day life as a result of your mental health needs, for example transport, money or employment.

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You will usually need to be assessed before you receive community-based support. During an assessment, trained professionals ask you questions to find out more about your needs, decide whether or not you are eligible for a service and if so, which service(s) you should have.

Your care may be coordinated under the Care Programme Approach (CPA). This means that you have:

- A **care coordinator** who is responsible for coordinating all your mental health and social care services.
- A **care plan** put together with your and your family's input. This should include a plan for what to do in a crisis. Both of these should be reviewed regularly.

Some services, including voluntary services, allow self-referral, which means you can access them without an assessment and you contact them directly yourself. For more information on community services, see Mind's online booklet *The Mind guide to community based-mental health and social care in England*. Services are similar in Wales but not identical.

Crisis services

Community mental health teams (CMHTs), home treatment teams, early intervention teams and acute day hospitals may be able to help you avoid going into hospital in a crisis. Some CMHTs offer accommodation while others send support into your home. The services CMHTs provide may vary across the UK. (See Mind's online booklet *The Mind guide to crisis services* for more information.)

Hospital admission

There might be times when you feel you need to go into hospital for more intensive treatment. Some people find this helpful as it means they can get the support and care they need to feel better. However, other people find going into a hospital environment upsetting or difficult to cope with.

If your care team feel that you need to go into hospital, but you are unwilling to, you might be compulsorily admitted under the Mental Health Act (see Mind's Rights guides for information about your rights under this Act). You can also ask Mind's Legal Advice Line for advice (see 'Useful contacts' on p.21). Before leaving hospital, you should discuss the kind of services that would enable you to live independently. (See Mind's booklet *The Mind guide to community-based mental health and social care in England* for more information.)

Supported accommodation

Social services and mental health projects, including some local Minds, may provide local supported housing. This might allow you to live independently, but with help at hand from staff or other tenants. Levels of support will vary from place to place. (See Mind's online booklet *The Mind guide to housing* for more information.)

Advocacy

An advocate is someone who can both listen to you and speak for you in times of need. They might help you to access the information you need or go with you to meetings or interviews. You might also want them to write letters on your behalf, or speak for you in situations where you don't feel able to speak for yourself. There are lots of different types of advocate. (See Mind's booklet *The Mind guide to advocacy* for more information.)

Physical health checks

The physical health of people with mental health problems such as schizophrenia is often a lot worse than the rest of the population. They show higher rates of problems like diabetes, high blood pressure, obesity and cardiovascular disease.

This is thought to be due to a combination of factors:

- the side effects of medication (such as weight gain)
- lifestyle factors caused by social isolation and low motivation associated with schizophrenia
- a lower rate of treatment for physical conditions by medical professionals who are focused on the mental rather than physical health of their patients.

Because of this, you should receive annual physical health check-ups from your GP or another medical professional. You should also be able to ask for help with things like giving up smoking or changes to your diet.

How can I help myself?

Most people who are diagnosed with schizophrenia are able to live normal and happy lives, even if they continue experiencing symptoms.

👉👉 *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.* 👉👉

Below are some suggestions for self-help techniques that you might find useful. You can find more ideas in Mind's booklet *How to improve and maintain your mental wellbeing*.

Look after your physical health

- Making sure you get enough sleep 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 booklet *How to cope with sleep problems* for more information.)

- Eating a 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. (See Mind's booklet *The Mind guide to food and mood* for more information.)

Be involved in your treatment

If you have a mental health problem, being involved in your treatment can help you stay well. Some ways you can do this are by:

- finding out more about your diagnosis and the different treatments available
- asking your doctor to be involved in decisions about your treatment
- making sure you understand any treatment or medication you are prescribed.

You have a right to be given information that you can understand and that is appropriate to your culture and reading ability. If this isn't happening or is proving difficult, an advocate might be helpful (see p.13 and Mind's booklet *The Mind guide to advocacy*).

Manage your medication

If you are on medication, it is important to learn to manage this in a way that works for you. For example, if your medication makes you feel drowsy, you may want to ask your doctor if you could take it in the evening or you may find that you feel better if you avoid alcohol or certain foods.

If you experience side effects because of your medication, you should discuss this with your GP or psychiatrist. They can help you decide whether to continue taking the medication or change to something else. They should also be able to give you advice about how to manage side effects.

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If you want to come off medication, make sure you know all the pros and cons of doing so and how best to do it carefully. Get as much information and support as possible. (See Mind's booklet *Making sense of coming off psychiatric drugs* for more information.)

Talk to your employer

If you have a job, you may be able to work shorter hours, or to work in a more flexible way. Under the Equality Act 2010, all employers must make 'reasonable adjustments' to facilitate the employment of disabled people, including those with a diagnosis of a mental health problem. (See Mind's booklet *How to be mentally healthy at work* for more information.)

Try to minimise stress

Too much stress can make symptoms of schizophrenia worse and increase the chances of you becoming unwell. You may need to reduce the number of responsibilities you have. Or you could try to be aware when things are getting too much so you can ask for help. You may also find it helpful to learn a relaxation technique to help you cope at times of stress. (See Mind's booklet *How to manage stress* for more information.)

Do something you enjoy

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

Staying involved in the things you enjoy is important. They can improve your confidence and help you stay well – whether it's cooking, seeing your friends or doing DIY. Some people find that doing something creative, such as drama, drawing or sewing, helps them to express themselves positively and deal with any difficult emotions in a positive way.

Use peer support

Talking to people who have had a similar experience or share similar feelings can be a massive support. Self-help groups provide this opportunity, along with ways of coping and campaigning for better

services. For details of organisations that can help you find self-help groups in your area, see 'Useful contacts', on p.21.

You can also access support on the internet via an online community such as Mind's Elefriends, or by reading about other people's experiences on Mind's blog or the National Perceptions Forum website. (See 'Useful contacts' on p.21 and Mind's online booklet *How to stay safe online* for more information.)

Maintain your social life

Feeling connected to other people is an important part of staying well. It can help you to feel valued and confident about yourself, and more able to face difficult times. Think about the interactions you have every day with family, friends, colleagues and neighbours. Spending a little more time on relationships you're interested in can really give you a boost. In return, if you are caring and supportive to other people, you are more likely to get a positive response from them.

●● *I've found the thing that helps me is being around other people, no matter how tiring it is. It forces me to interact and interpret the unpredictability of others in the flesh, instead of listening to people's thoughts.* ●●

If you do not have the social contact you feel you need, or experience feelings of loneliness for whatever reason, this can also have a negative impact on your mental wellbeing. (See Mind's booklet *How to cope with loneliness* for more information.)

Learn some mindfulness techniques

Some people also find mindfulness techniques helpful to manage unwanted or intrusive thoughts and reduce anxiety. Mindfulness is a way of paying attention to the present moment, using techniques like meditation, breathing exercises and yoga. Be Mindful (see 'Useful contacts' on p.21) has details of local mindfulness classes around the UK.

Plan for a crisis

You may want to make a crisis plan or advance statement to tell people what you want to happen if you are in crisis. This can help reduce stress and address any worries about what will happen to you or your family if you become ill. (See Mind's booklet *The Mind guide to crisis services* for more information.)

Complementary and alternative therapies

Some people who are diagnosed with schizophrenia find complementary therapies help them keep on top of their problems. These might include homeopathy and acupuncture. Tai chi, yoga and relaxation techniques can also be of benefit, although it might be a good idea to discuss the possibilities beforehand with a qualified teacher.

What can friends or family do to help?

This section is for friends and family who want to support someone they know with a diagnosis of schizophrenia.

As a friend, relative or partner, you can have a vital role in helping someone recover and reducing the likelihood of them having a relapse. However, it can be difficult for you to know how to help sometimes.

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

Most people want to feel cared about, not to feel alone, and to have someone they can discuss their feelings and options with. It's very important to avoid either blaming them or saying things like "pull yourself together".

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.

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

Find out about schizophrenia

This could include learning about the different coping strategies, which your friend or relative might find useful. You may also find it helpful to learn about other people's experiences by reading personal stories, joining support groups or speaking to others in the same situation as you. (See 'Useful contacts' on p.21.)

When the person is feeling well, it's useful to discuss how friends and family can be supportive when and if a crisis occurs. In having this conversation, it can be helpful for friends and family to state clearly what they feel they can and can't deal with.

Ask how you and others can help

Ask the person if they would like practical support. This might include helping them find accommodation or access particular services. However if you're acting on their behalf, it's important that you consult them and don't take over. Alternatively, it may be possible to find an independent advocate to help them. (See 'Advocacy' on p.13 and Mind's booklet *The Mind guide to advocacy* for more information.)

Help in an emergency

If you think your friend or family member could be at risk of hurting themselves or others, it might be necessary to consider a mental health assessment for them. The 'nearest relative', as defined under the Mental Health Act, can request that the person at risk be given a mental health assessment by an approved mental health professional. This assessment involves considering treatment options and deciding whether or not the person should be detained (admitted to hospital).

Referring someone for an assessment can be a difficult decision to make, as it can result in someone being detained in hospital against their will. In this situation, there are no right answers. It can help to make sure you are fully informed about the law and what could happen, and perhaps consider talking to other family members before you take this step. (See Mind's Rights guides for more information.)

Get support for yourself

It can be distressing when someone you are close to experiences the symptoms of schizophrenia. It's important to get support in coping with your own feelings, which you may find include anger, guilt, fear or frustration.

The National Institute for Health and Care Excellence (NICE) recommends that families of people with a diagnosis of schizophrenia should be offered psychological support or family therapy, if possible. Carers are also entitled to have their own needs for practical and emotional support assessed by Social Services as part of a carer's assessment. A number of voluntary organisations provide help and information for carers around these topics. (See 'Useful contacts' on the following pages or Mind's booklet *How to cope as a carer* 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.

Be Mindful

web: bemindful.co.uk
 Raises awareness of the benefits of mindfulness-based therapies as a treatment to improve mental and physical health.

British Association for Behavioural and Cognitive Psychotherapies (BABCP)

tel: 0161 705 4304
 web: babcp.com
 Lists accredited private therapists.

British Association for Counselling and Psychotherapy (BACP)

tel: 01455 883 300
 web: bacp.co.uk
 Information about counselling and therapy. See sister website, itsgoodtotalk.org.uk for details of local practitioners.

Carers UK

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

Elefriends

web: elefriends.org.uk
 Mind's safe, supportive online community where you can listen, be heard and share your experiences with others.

Hearing Voices Network

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

National Perceptions Forum

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

National Institute for Health and Care Excellence (NICE)

tel: 0845 003 7780
 web: www.nice.org.uk
 Provides guidance on health and social care.

Rethink Mental Illness

advice line: 0300 5000 927

web: www.rethink.org

Provides services and support groups for people affected by mental illness and their carers.

Samaritans

Freepost RSRB-KKBY-CYJK

Chris PO Box 90 90

Stirling FK8 2SA

24-hour helpline: 0845 790 9090

email: jo@samaritans.org

web: samaritans.org

24-hour emotional support for anyone struggling to cope.

Royal College of Psychiatrists

web: rcpsych.ac.uk/

mentalhealthinformation.aspx

For information, including podcasts, about mental health.

Further information

Mind offers a range of mental health information on:

- diagnoses
- treatments
- practical help for wellbeing
- mental health legislation
- where to get help

To read or print Mind's information booklets for free, visit mind.org.uk or contact Mind Infoline on 0300 123 3393 or at info@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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