



For better
mental health

Schizophrenia

Understanding schizophrenia

Exactly what is meant by a diagnosis of schizophrenia is the subject of a lively debate. This booklet introduces the different theories and ideas about the diagnosis, causes and treatment of schizophrenia. It also offers practical suggestions to anyone with this diagnosis, and to their family and friends.

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What is schizophrenia?

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

When a doctor describes schizophrenia as a psychotic disorder, they mean that, in their view, you can't tell your own intense thoughts, ideas, perceptions and imaginings from reality.

Views on schizophrenia have changed over the years. Questions have been asked about whether schizophrenia is one condition or more than one syndrome with related features. These questions drive both debate and research. Although there may be some discussion over the true nature of schizophrenia, most psychiatrists will diagnose and treat in the same way.

Many people argue that when considering a diagnosis of schizophrenia it is important to think about individual experience. In this way, each symptom of schizophrenia might then be seen as a logical or natural reaction to difficult life events or life experience.

Some people argue that because psychiatric experts can't agree about the definitions, causes, and suitable treatments for schizophrenia, it shouldn't be used as a diagnostic category at all.

How is schizophrenia diagnosed?

When you become unwell, you are likely to show significant changes in your behaviour. For some people this can happen quite suddenly, but for others these changes may 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.

In making a diagnosis, doctors will want to rule out other physical or mental health problems. They will look for various 'positive' symptoms and 'negative' symptoms, and make a diagnosis based on the presence and duration of some or all of these symptoms.

Positive symptoms

'Positive' symptoms are symptoms that most people do not normally experience. They include: strange thinking ('thought disorder'), hallucinations and delusions.

Strange thinking ('thought disorder')

Your thoughts and ideas may seem jumbled and make little sense to others. Conversation may be very difficult and this may contribute to a sense of loneliness and isolation.

Hallucinations

Hallucinations can affect any of your senses. You might:

- see things that others don't
- smell things that others don't
- hear voices or sounds that others don't.

Voices can be familiar or strange, friendly or critical and might discuss your thoughts or behaviour. The voices you hear might tell you to do things. People who are diagnosed with schizophrenia seem to hear mostly critical or unfriendly voices. You may have heard voices all your life, but a stressful life event might have made the voices harsher and more difficult to deal with.

👂👂 *I can ignore the voices most of the time but some days it's insistent and frightening.* 👂👂

According to some research, up to four per cent of the population hear voices. For most people, the voices they hear present no problem and are not associated with schizophrenia.

Delusions

Delusions are usually strongly held beliefs or experiences that are not in line with a generally accepted reality. Delusions associated with schizophrenia are

probably distressing for you, or those around you, as they may be unusual or extreme. For instance, you might believe secret agents are following you or that outside forces are controlling you or putting thoughts into your mind. For more information, see Mind's booklets, *Understanding paranoia and Understanding psychotic experiences*.

Negative symptoms

'Negative' symptoms are a lack of some emotional responses or thought processes. 'Negative' symptoms include: lack of interest, emotional flatness, inability to concentrate, wanting to avoid people or to be protected.

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

Being withdrawn, being apathetic, and being unable to concentrate are all described as 'negative' rather than 'positive', because they show a reduction in thought or function. It can be very difficult to tell whether negative symptoms are part of the schizophrenia, or whether they are present because you are reacting to other frightening or distressing symptoms. For example, a person with a mental health problem may be discriminated against or ignored which may cause them to feel isolated and depressed and so withdraw.

Different diagnoses

There are different types of schizophrenia. The most common one is paranoid schizophrenia. If you don't have all the symptoms used to diagnose schizophrenia, you may be given a diagnosis of 'borderline schizophrenia'.

If you have any doubts about the diagnosis you have been given, you can ask for a second opinion.

What causes schizophrenia?

There's no complete answer to why some people develop symptoms of schizophrenia when other people do not. And, because of differences of opinion about the definition of schizophrenia and its symptoms, it's not easy to identify what might cause it.

It's generally agreed that schizophrenia is probably caused by a combination of factors; someone's genetic make-up could make them more vulnerable, but stressful events or life experiences could trigger the onset of symptoms. It can be helpful to think about potential causes of schizophrenia in terms of how much evidence there is to support the idea that a particular trait, event or factor causes schizophrenia.

Dopamine

Dopamine is one of the chemicals that carry 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 p.8.)

Stressful life events

Studies and personal accounts suggest that very stressful or life-changing events may trigger schizophrenia. Social isolation has also been shown to be linked to schizophrenia and other mental health issues. Being homeless, living in poverty, having no job, losing someone close to you, or being physically or verbally abused or harassed may all also be factors. In one study, significantly more people who heard negative voices said that sexual or physical abuse was a cause.

Drug abuse

Studies have shown that some people may develop symptoms of schizophrenia as a result of using cannabis or other street drugs. Studies also indicate that, if you have schizophrenia, using drugs like cannabis, cocaine and amphetamines can make the symptoms worse.

Alcohol and nicotine may also limit how effectively medicines can treat the symptoms of schizophrenia. For more information, see Mind's resources on the mental health effects of street drugs at www.mind.org.uk

Inheritance

Some families seem to be prone to schizophrenia, suggesting some sort of genetic component to its development. Rather than a 'schizophrenia gene' it is thought that certain genes might make some people more vulnerable to the condition. This does not mean they will necessarily develop schizophrenia. There is evidence to show that people who have a parent with schizophrenia are more likely to develop it themselves; however, most people with the diagnosis have no family history.

Family experiences and personality

Parents of people with schizophrenia sometimes blame themselves, unnecessarily. Early experiences may affect the development of personality, but the idea that a particular type of family contributes to the development of schizophrenia is generally dismissed.

Other causes

There is evidence that physical differences in, or injury to the brain may be linked to schizophrenia. It's unclear though, whether this is a cause or an effect. 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 and **everyone diagnosed with schizophrenia will have a different experience of the symptoms.**

Schizophrenia 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. It's been suggested that the number of African-Caribbean men in the UK

diagnosed with schizophrenia is out of proportion. The reasons for this are still unclear. Suggestions have been made that migration, racism, and environment and cultural differences could play a part. When a psychiatrist has very different cultural, religious or social experiences to their patient, there may be a risk of mistaken diagnosis.

What help will I be offered?

The National Institute for Health and Clinical Excellence (NICE) has produced guidelines for treating and managing schizophrenia. It covers psychological treatments, medication and the services that should be made available in hospital and in the community. The guidelines also state that, in addition to medical treatment, help should be offered for social issues that may be affecting your mental health. NICE recommends that you should get help as quickly as possible. (Visit www.nice.org.uk)

If you decide to see your GP, he or she will probably refer you to psychiatric services for initial assessment, treatment and care. However, once treatment is established, your GP can be responsible for your ongoing care.

Help may be different whether you have just been diagnosed or if you need more long-term support.

| <i>Staying well and recovering</i> <i>(See p.8)</i> | <i>In a crisis or when things are difficult</i> <i>(See p.10)</i> | <i>Moving on and day to day challenges</i> <i>(See p.10)</i> |
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| <i>Talking treatments</i> | <i>Crisis services</i> | <i>Advocacy</i> |
| <i>Transcranial magnetic stimulation (TMS)</i> | <i>Hospital admission</i> | <i>Supported accommodation</i> |
| | | <i>Social and vocational training</i> |

Staying well and recovering

Medication

Doctors usually prescribe neuroleptic drugs (also known as antipsychotic drugs or major tranquillisers) to control the 'positive' symptoms (see p.3). They have a sedative action, which can make it more difficult to cope with side effects or to benefit from talking treatments. They have unpleasant side effects, particularly in high doses. These include:

- neuromuscular effects (shaking and muscle stiffness)
- antimuscarinic effects (blurred vision, rapid heart beat, constipation)
- sexual side effects (breast development, loss of sexual desire, loss of periods).

Older neuroleptics, such as chlorpromazine (Largactil) and haloperidol (Serenace, Haldol) have been associated with severe and long-term side effects including involuntary movements and muscle spasms (known as tardive dyskinesia) which may be permanent.

The newer neuroleptics, such as:

- risperidone
- olanzapine
- quetiapine
- amisulpride
- zotepine

have been developed to have fewer neuromuscular side effects. These drugs are, however, more likely than the older drugs to cause metabolic symptoms which include: weight gain; high blood sugar, with diabetes in some cases; high cholesterol; and high blood pressure. People taking any neuroleptics should have their weight, blood pressure and blood sugar checked regularly. They may also improve 'negative' symptoms (see p.4), which are much more difficult to treat and control. Neuroleptics come in tablet, syrup or injectable form, and may be taken daily, weekly, fortnightly or monthly.

Some people get short-term help from medication, then come off it and remain well. Others may benefit from more long-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 and at the same time reducing side effects. If you are taking these drugs, you should have the

dosage reviewed regularly, with the aim of keeping it as low as possible. You may have to try more than one drug to find the best one for you. This may not make too much difference to your symptoms but it could reduce the side effects. Some people stop taking medication because of the side effects, others find they can manage without medication. For more information, see Mind's booklets *Making sense of antipsychotics (major tranquillisers)* and *Making sense of coming off psychiatric drugs*.

Anyone with the following should use these drugs with caution:

- liver or kidney disease
- cardiovascular (heart and circulation) disease – or a family history of these diseases
- family history of diabetes
- Parkinson's disease
- epilepsy
- depression
- myasthenia gravis (a disease affecting nerves and muscles)
- an enlarged prostate
- a history of glaucoma, an eye disease
- lung disease with breathing problems
- some blood disorders.

Talking treatments

Talking therapies, such as psychotherapy, counselling and cognitive behaviour therapy (CBT), can help to manage and treat schizophrenia. Talking treatments help you to identify the things you have issues with, explore them and discuss strategies or solutions. They can allow you to explore the significance of your symptoms, and so to defeat them.

NICE guidelines recommend CBT is offered (increasingly available on the NHS) and family therapy made available, so ask your doctor about this. Otherwise, accessing talking treatments can be difficult if you can't afford to pay. Some local voluntary projects, including local Mind associations, offer free services. (See p.16 for organisations listing registered practitioners.)

Transcranial magnetic stimulation (TMS)

TMS is a fairly new treatment, which is still only used in research studies. Although still on trial, it's non-invasive and seems to be quite safe. It uses magnetic impulses to stimulate the frontal regions of the brain. This may be helpful for people who have mainly 'negative' symptoms (see p.4), and has also had some success in treating auditory hallucinations.

In a crisis or when things are difficult

Crisis will most likely be treated in one of the following ways:

Rapid tranquillisation

On rare occasions, when other methods haven't worked, it may be necessary to use drugs to calm someone down in a hurry. This is known as rapid tranquillisation. It should never be used routinely because it carries risks and is traumatic. After rapid tranquillisation, people should receive a full explanation and support, and an opportunity to discuss what happened.

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 and some aim to send support into your home but services CMHTs provide may be different across the UK.

Hospital admission

If you are feeling particularly distressed, you may prefer to go somewhere that feels safe and undemanding. At present, this usually means going into hospital. 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. However, service user or patient groups based in the hospital can be very useful and supportive.

If you are unwilling to go into hospital, you might be compulsorily admitted under the Mental Health Act. The *Mind rights guide* series gives information about your rights under this Act. You can also ask Mind's Legal Advice Line for advice (see 'Useful contacts', p.16). Before leaving hospital, you should discuss the kind of services that would enable you to live independently (see 'Community care', opposite).

Moving on and day-to-day challenges

There are several support options as you move on to face day-to-day challenges. These are typically:

- community care
- advocacy
- supported accommodation
- social and vocational training.

Community care

If you are referred to specialised mental health services you should:

- get a thorough assessment of your health and social care needs to establish a care plan
- have your care plan reviewed on an ongoing basis
- be appointed a care coordinator or key worker to oversee your care.

You are entitled to say what your needs are, and have the right to have an advocate present (see below). The assessment might also include carers and relatives. This is called the care plan approach (CPA). (The systems in Wales and England are similar but not identical.)

Your local Community Mental Health Teams (CMHT) may make the care assessment. CMHTs are made up of a number of specialist workers, including a psychiatrist. Their job is to enable you to live independently, and to help with practical issues, such as sorting out welfare benefits and housing. They can also organise access to day centres or drop-in centres. A community psychiatric nurse (CPN) may visit you at home. CPNs can give medicines, and may provide other practical help. An occupational therapist may also be on the team and can help you develop new skills. The care assessment may include your need for any community care services. This covers everything from day care to housing.

If you're not assessed by psychiatric services you can ask Social Services to assess your needs. If you need care workers, any charges for this should be included in the needs assessment. Once your need for care has been established, you may be able to request direct payments to employ your own care worker or pay for a chosen day centre, rather than having the care provided by Social Services. You should be able to get information about local mental health services from the CMHT, your GP, Social Services, Patient Advice and Liaison Services (PALS) or local Mind association, which should be listed in your local phone directory and on the internet.

Advocacy

Advocates are trained and experienced workers who can assist you to communicate your needs or wishes, to access impartial information, and to represent your views to others. Advocates may also be able to help you

access community care services and represent you at Tribunals. See *The Mind guide to advocacy*.

Supported accommodation

Social Services and mental health projects, including some local Mind associations, 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 resources on housing at www.mind.org.uk

Social and vocational training

Training may be available to help you in a variety of ways, from learning how to use public transport, to finding work, managing money, coping with social situations and solving problems. Ask your care coordinator for information about training.

What can I do to help myself?

●● *My recovery has been gradual and in stages.* ●●

Most people who are diagnosed with schizophrenia recover.

A third of people diagnosed only ever have one experience of schizophrenia and a further third have occasional episodes. Others live with schizophrenia to varying degrees throughout their life.

Self-help

Self-help groups provide an important opportunity for you and your family to share experiences and ways of coping, to campaign for better services, or simply to support each other. For details of organisations that can help you find self-help groups in your area, see 'Useful contacts', on p.16.

Work

It may be important that you avoid too much stress. If you have a job, you may be able to work shorter hours, or to work in a more flexible way. Under the Disability Discrimination Act 1995, all employers must make 'reasonable

adjustments' to facilitate the employment of disabled people, including those with a diagnosis of mental ill-health.

Alternative therapies

Some people diagnosed with schizophrenia find complementary therapies help them to keep on top of their problems. These might include homeopathy and creative therapies focused on art and poetry. 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.

Looking after yourself

Recent studies have looked at the possible advantages of improved nutrition for those diagnosed with schizophrenia. Some studies have suggested there are benefits in EPA-rich fish oils that can be found in sardines, pilchards and supplements. [Due to the high risk to physical health posed by antipsychotic medication, a generally healthy life style is likely to be beneficial.](#) This might include avoiding too much stress, eating well, and getting sufficient exercise and sleep.

Are people diagnosed with schizophrenia dangerous?

There is more media misinformation about schizophrenia than about any other psychiatric diagnosis. 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 tend to depict those affected by schizophrenia as dangerous unless drugged and kept in institutions. The facts speak otherwise. The number of homicides committed by people with any mental illness diagnosis is very low. [Most people diagnosed with schizophrenia don't commit violent crimes.](#) People with drug or alcohol problems are twice as likely to commit a violent crime as someone diagnosed with schizophrenia.

It's a commonly held belief that people who hear voices are dangerous to others. This is largely untrue. Voices are more likely to suggest that you harm

yourself than someone else. What's more, those who hear voices make decisions about whether or not to act on any suggestions.

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; though it can be difficult for you to know how.

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 telling them '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.

Find out about the reality of 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.

Ask how you and others can help

Ask the person if you they would like practical support. This might include helping them find accommodation or accessing particular services. If you are acting on their behalf, though, it's important that you consult them and don't take over. Alternatively, it may also be possible to find an independent advocate to help them (see p.11).

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.

Help in an emergency

If you think your friend or family member may be at risk of hurting themselves or others, it may 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). (See the *Mind rights guide* series for more information.)

Get emotional support for yourself

It can be very shocking 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.

One of the recommendations that NICE has made is 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', overleaf.)

Useful contacts

Mind

web: www.mind.org.uk
Mind Infoline: 0300 123 3393
(Monday to Friday 9am to 5pm)
email: info@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.

The Arbours Association

tel. 020 8348 6466
web: www.arboursassociation.org
Intensive psychotherapy and residential services

British Association of Behavioural and Cognitive Psychotherapies (BABCP)

tel. 0161 797 4484
web: www.babcp.com
Lists accredited private therapists

British Association for Counselling and Psychotherapy (BACP)

tel. 01455 883 300
web: www.bacp.co.uk
Can provide advice on therapies and details of local therapists

Carers UK

tel. 0808 808 7777
web: www.carersuk.org
Information and advice on all aspects of caring

UK Council for Psychotherapy

tel. 020 7014 9955
web: www.psychotherapy.org.uk
Can provide a list of registered members

Hearing Voices Network

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

National perceptions forum

web: www.voicesforum.org.uk
Forum for individuals to share experiences

NICE

web: www.nice.org.uk
Publishes guidelines for good practice

Rethink

tel. 0845 456 0455
web: www.rethink.org
For anyone affected by severe mental illness

Royal College of Psychiatrists

web: www.rcpsych.ac.uk/mentalhealthinformation.aspx

Further information

Mind offers a range of mental health information, covering:

- diagnoses
- treatments
- wellbeing

Mind's information is ideal for anyone looking for further information on any of these topics.

For more details, contact us on:

tel. 0844 448 4448

email: publications@mind.org.uk

web: www.mind.org.uk/shop

fax: 020 8534 6399

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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 booklets.

If you would like to support our work with a donation, please contact us on:

tel. 020 8215 2243

email: dons@mind.org.uk

web: www.mind.org.uk/donate

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Mind's mission

- Our vision is of a society that promotes and protects good mental health for all, and that treats people with experience of mental distress fairly, positively, and with respect.
- The needs and experiences of people with mental distress drive our work and we make sure their voice is heard by those who influence change.
- Our independence gives us the freedom to stand up and speak out on the real issues that affect daily lives.
- We provide information and support, campaign to improve policy and attitudes and, in partnership with independent local Mind associations, develop local services.
- We do all this to make it possible for people who experience mental distress to live full lives, and play their full part in society.



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mental health

