mind

For better
mental health

Understanding schizophrenia

There's much disagreement about the psychiatric diagnosis of schizophrenia. This booklet introduces the various different theories and ideas about its diagnosis, cause and treatment. It also offers practical advice to anyone told they have this problem, and to their family and friends.

What is schizophrenia?

The term schizophrenia is widely used in the mental health system. Psychiatrists classify it as a psychosis. They mean that, in their view, a person can't distinguish their own intense thoughts, ideas, perceptions and imaginings from reality (the shared perceptions, sets of ideas and values that other people in that culture hold to be real). Among other symptoms, a person might be hearing voices, or may believe that other people can read their mind and control their thoughts.

Most psychiatrists regard such symptoms as a psychiatric disorder. They would usually prescribe major tranquillisers to treat it. Not everyone shares this view of these psychological episodes, however. An alternative idea is that they are logical or natural reactions to adverse life events, in other words an extreme form of distress. Many people prefer to look at schizophrenia 'holistically'. They stress the need to think about individual experience, and the importance of understanding what the experiences mean to the individual. Hearing voices, for instance, holds a different significance within different cultures and spiritual belief systems.

How do psychiatrists make a diagnosis?

Problems of this kind often start with confusing, or even drastic changes in behaviour. It's important to rule out other possible causes. These symptoms may be similar to other mental health problems, such as bipolar disorder and schizoaffective disorder, or they could be the result of underlying physical problems. (See *Further reading*, on p. 14, for details of relevant Mind publications.)

Psychiatrists make a diagnosis of schizophrenia on the grounds of various 'positive' and 'negative' symptoms.

'Positive' symptoms include:
- disordered thinking
- hallucinations, such as hearing voices or other sounds
- delusions.

'Negative' symptoms may include:
- feeling apathetic or emotionally flat
- being unable to concentrate
- wanting to avoid people
- feeling a need to be protected.

Thought disruption

A person is said to be experiencing thought disruption if he or she seems unable to follow a logical sequence of thought, and if their ideas appear jumbled and make little sense to others. This can make conversation very difficult and may contribute to the person's sense of loneliness and isolation.

Hallucinations

Some people hear voices that others around don't hear. The voices may be familiar, friendly or critical. They might discuss the hearer's thoughts or behaviour, or they might tell them what to do. Hearing voices doesn't inevitably mean a label of schizophrenia. Up to four per cent of the population hears voices, according to some research, and for most, the voices are not a problem. But people who are diagnosed with schizophrenia seem to hear mostly critical or unfriendly voices. They may have heard voices all their lives, but a stressful life event might have made the voices more severe and harder to deal with. People sometimes hear other sounds as well as, or instead of, voices.

Delusions

Delusions are defined as beliefs or experiences that are not shared by others. Someone might believe, for instance, that they are being pursued by secret agents or controlled by external forces that are putting thoughts into their mind. (See Mind's booklet *Understanding Paranoia,* details under *Further reading*, on p. 14.)

Negative symptoms

Other symptoms, such as social withdrawal, apathy, and inability to concentrate, are described as 'negative' rather than 'positive', because they are less clear-cut. It can be very difficult to tell whether they are part of the schizophrenia, or whether the person is reacting to other symptoms they find frightening and distressing. For instance, depending on what kind of experience they are having, someone might be quiet and immobile for hours, or move about constantly. Such symptoms could also be a response to other people's behaviour towards them. It's all too often the case that someone with a mental health problem is discriminated against or ignored, causing them to feel isolated, depressed or hopeless.

Are some people more likely to be diagnosed than others?

About one in a hundred people is diagnosed with schizophrenia at some point in their life – usually as a young adult. This figure is roughly the same for both sexes, but men tend to be younger when the diagnosis is made. You may be more likely to be told you have schizophrenia if a member of your family has already been given the same diagnosis. It's been estimated that around one third of people diagnosed with schizophrenia only experience one episode. Another third may have occasional episodes, while the last third may have to live with schizophrenia as an ongoing problem.

When a psychiatrist has very different cultural, religious or social experiences to their patient's, there is a risk of mistaken diagnosis. For example, there is considerable concern in Britain about the disproportionately high number of young African-Caribbean men given this diagnosis, which has led some experts to ask whether the entire theory of schizophrenia is based on racist ideas. 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.

Are people diagnosed with schizophrenia dangerous?

There is more media misinformation about schizophrenia than about any other psychiatric diagnosis. One popular myth is that schizophrenia means 'split personality' and that someone with schizophrenia swings from being calm to being out of control. There are often sensational stories in the newspapers or on TV about 'schizophrenics' who are depicted as being dangerous unless drugged and kept in institutions. In fact, the number of homicides committed by people with any mental illness diagnosis remained at the same low level for ten years, during which time the total number of homicides committed in Britain considerably increased.

Most people diagnosed with schizophrenia don't commit violent crimes, and most violent crimes are not committed by people with schizophrenia. Research has found that people with drug or alcohol problems are twice as likely to commit a violent crime as someone diagnosed with schizophrenia. Evidence of a relationship between schizophrenia and serious crime is so uncertain that predictions about violence are considered virtually impossible.

People are often very frightened of those who hear voices. It's important to remember that people who hear voices make choices about whether to act on them, just as anyone else would if told to do something. It seems to be most common for voices to urge the people to kill themselves rather than to kill somebody else. Many make the conscious choice to stay alive every day, despite their voices.

What causes schizophrenia?

Because of differences of opinion about schizophrenia, it's not easy to identify what might cause it, but there are various different ideas.

Inheritance

Researchers looking for a particular 'schizophrenia gene' haven't found one. However, it's thought that particular genes might make some people more vulnerable to the symptoms, although this doesn't necessarily mean they will develop them.

People's physical development, their upbringing and the environment they grow up in probably all play a part, as well as other psychological factors. (See *Keyfacts on Genetics and Mental Health*, details on p. 14.)

Body chemistry

Biochemical research has been centred on the neurotransmitter dopamine, which is one of the chemicals that carry messages between brain cells. The theory is that an excess of dopamine may be involved, but it's still not clear whether it has a role in the development of schizophrenia. Nevertheless, major tranquillisers are designed to work on the dopamine system.

Family experiences

It's generally accepted that early experiences of family life affect the development of personality. There have been theories put forward about whether there is a particular type of family that might contribute to causing schizophrenia, but this has not been proved.

Stressful life events

Studies and personal accounts suggest that very stressful events may trigger schizophrenia. This could include such life-changing events as losing someone close to you, or the strain of having to change jobs. Other ongoing pressures, such as homelessness, poverty, and sexual or racial harassment, may also contribute to the problem.

Over half the people who heard negative voices said that sexual or physical abuse was a cause of the problem, according to one study. Nearly a quarter felt that guilt at their own actions had triggered the negative voices.

Substance abuse

No-one has established whether the development of schizophrenia is linked to substance abuse. Most researchers don't believe it is, but there is anecdotal evidence that makes this connection. It's possible that people who are diagnosed with schizophrenia may have particularly bad reactions to certain drugs.

Overall, most experts think that schizophrenia is caused by a combination of factors; someone's genetic make-up could make them more vulnerable, but stressful events or particular family or life experiences could trigger the onset of symptoms.

What help will I be offered?

If you go to your GP, he or she is likely to prescribe medication and may be able to offer you some form of talking treatment. He or she may refer you to a psychiatrist and to a community mental health team for further assessment, treatment and care, if you require it. Most people with schizophrenia live in the community, but if your symptoms appear very suddenly, and are very severe, you may need to go into hospital.

Medication

Antipsychotics, also known as major tranquillisers or neuroleptics, are usually prescribed to control the positive symptoms. They can have unpleasant side effects, particularly if taken in high doses, and may have a sedative action, which can make it more difficult to cope with side effects or to benefit from talking treatments. The side effects include, among other things, neuromuscular effects (trembling hands, stiffening of muscles) and antimuscarinic effects (blurred vision, rapid heart beat, constipation and dizziness).

The older antipsychotics, such as chlorpromazine (brand name Largactil) and haloperidol (Serenace and Haldol) have been associated with severe and long-term side effects, including permanent damage to the central nervous system (known as tardive dyskinesia). Current guidelines suggest that people should only use antipsychotics at the lowest possible dose. They should start, whenever possible, with the newer 'atypical' antipsychotics, such as risperidone, olanzapine, quetiapine, amisulpiride and zotepine. These were developed with the aim of reducing the neuromuscular side effects. They are not only safer, but may also improve the negative symptoms. Antipsychotics may come in tablet, syrup or injectable form, and may be taken daily, weekly, fortnightly or monthly.

Medication can't prevent relapses altogether, but there is evidence to show that it reduces their number and severity. Staying on low doses of the drug may be the best way of dealing with symptoms, as well as lessening 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.

Individuals respond differently to medication, and it may take some trial and error to arrive at the best one. Many people find it can make a big difference to their symptoms, but some patients don't find it at all helpful, others stop taking it because of the side effects, and a few don't need it at all. (See *Making Sense of Antipsychotics*, details on p. 14, for more information.)

Community care

Everyone referred to psychiatric services in England should have their needs assessed and care planned within the Care Programme Approach (CPA). This should provide you with a thorough assessment of your social and health care needs, a care plan and ongoing reviews. A care coordinator should be in charge of your case. You are entitled to say what your needs are, and have the right to have an advocate present (see p. 9). The assessment might also include carers and relatives. (The same system applies in Wales, in effect.)

Community mental health teams usually make the care assessments. Their aim is to enable you to live independently. They can help with practical issues, such as sorting out welfare benefits and housing, and other services, such as day centres or drop-in centres. They can also arrange for a community psychiatric nurse (CPN) to visit you at home. CPNs administer injections, and may provide other practical help. There may be other resources you can access, such as an occupational therapist, who can help you develop the skills to do the activities you want to do.

As part of the CPA, or separately, you can request social services to make an assessment of your needs for community care services. This covers everything, from daycare services to your housing needs, with the aim of providing services in your own home or appropriate supported accommodation.

You might need careworkers and, since many areas now charge for these services, the cost of services should be included in the needs' assessment. Once your need for care has been established, you may be able to claim Direct Payments to employ your own careworker 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 your GP, or the social services department, a local Mind association, your community mental health team, the community health council or the council for voluntary services. Details should be in local telephone directories.

Hospital admission

If you are feeling particularly distressed, you may want to go somewhere that feels safe and undemanding. At present, this usually means going into hospital. In 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. Before leaving hospital, you should have your needs assessed to enable you to live independently (see *Community care*).

If you are unwilling to go into hospital, you might be compulsorily admitted under the Mental Health Act 1983. Mind's series of *Rights Guides* gives information about your rights under this Act (see *Further reading*, on p. 14). You can also ask Mind's legal unit for advice.

Crisis services

In some areas, crisis services have been developed as alternatives to hospital. Some of these offer crisis accommodation, others aim to support people in their own homes. Most aim to try and avoid the need for hospital admission. These services rely less on drug treatments and offer more in the way of talking treatments and informal support. (See *Further reading*, on p. 14.)

Advocacy

Advocates are trained and experienced workers whose role is to assist people to communicate their needs or wishes, to access impartial information, and to represent their views to other people.

Advocates based in your hospital, or local mental health groups, including Mind, can offer support and advice about coping with drugs and treatments and how to get alternatives to them. They may also be able help you access community care services.

Supported accommodation

Supported housing is an arrangement whereby help is at hand, if it's necessary, both from staff and other tenants. Levels of support vary from place to place, but the role of all supported housing staff is to enable you to live as independently as possible. Supported housing is provided, locally, by social services and mental health projects, including some local Mind associations. (See *Further reading*, on p. 14.)

Social and vocational training

Training can help people to find work, manage money, use public transport, solve problems and cope with social situations. Ask your care coordinator for information about this.

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What else can I do to improve my life?

Talking treatments

Talking therapies, such as psychotherapy, counselling and cognitive behaviour therapy (CBT) can help people to live with schizophrenia, by recognising their problems, dealing with its consequences, developing coping strategies and learning how to prevent crisis situations developing. It can allow them to explore the significance of their symptoms, and so to overcome them.

Ask your doctor about getting individual or family therapy. 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. 12).

Self-help

Self-help groups provide an important opportunity for individuals and families to share experiences and ways of coping, to campaign for better services, or simply to support each other. (For details of self-help groups in your area, see *Useful organisations*, on p. 12.)

Work

You may want to try to avoid situations you find particularly stressful. If you have a job, you may be able to work shorter hours, or work in a flexible way to avoid stress. Under the Disability Discrimination Act 1995, employers with more than 20 employees 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. T'ai 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.

Diet

Recent studies have looked at the possible advantages of improved nutrition for those diagnosed with schizophrenia. Some studies have suggested the benefits of EPA-rich fish oils that can be found in sardines, pilchards and supplements.

What can partners, friends or relatives do to help?

It can be very shocking when someone you are close to experiences the symptoms of schizophrenia. You may be unsure what you should do. Finding out about the reality of schizophrenia may help. This could include learning about the different coping strategies, which you could encourage your partner, friend or relative to try.

It may be helpful to discuss with the person, when they are feeling OK, what it is they want from you when, and if, they do experience a crisis. It can also be useful to state clearly what you feel you can and can't deal with. A person experiencing the symptoms of schizophrenia wants the same things we all do: to feel cared about, not to feel alone, and to have someone they can discuss feelings and options with. It's very important to avoid either blaming the person or telling them 'to pull themselves together'.

Coping with caring

It's important to get support in coping with your own feelings, which may include anger, guilt, fear or frustration. There are a number of voluntary organisations that provide help for carers, and social services are also obliged to assess your needs for practical and emotional support, if the person you care for has had, or is having, a community care assessment (see *Useful organisations*, on p. 12).

Responding to delusions

It can be difficult to know how to respond when your friend or relative sees something or believes something 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 to focus on how the person is feeling, which may make it easier for you both to communicate constructively.

Independent representation

You might need to provide practical help. If you do act on the person's behalf, it's important to consult them and not take over. It may also be possible to find an independent advocate to act on their behalf. (see p. 9). Local mental health projects, including local Mind associations, may be able to help.

Compulsory hospital admission

If you feel there's a serious risk that harm may come to the person, or to anyone else, it may be necessary to think about compulsory hospital admission, as a last resort. The 'nearest relative', as defined under the Mental Health Act 1983, can request a mental health assessment from an approved social worker, to look at treatment options and decide whether someone should be detained. (See *Mind's Rights Guides*, under *Further reading*, on p. 14.)

Useful organisations

Arbours Association
6 Church Lane, London N8 7BU
tel. 020 8340 7646, fax: 020 8342 5822
crisis centre: 020 8340 8125
e-mail: coordinator@arboursassociation.org
web: arboursassociation.org
Offers alternatives to traditional mental hospital treatment, in the form of intensive psychotherapy and residential services

Carers UK
20–25 Glasshouse Yard, London EC1A 4JT
tel. 020 7490 8818, carers line: 0808 808 7777
fax: 020 7490 8824, minicom: 020 7251 8969
e-mail: info@ukcarers.org web: www.carersonline.org.uk
Information and advice on all aspects of caring

Hearing Voices Network
91 Oldham Street, Manchester M4 1LW
tel./fax: 0161 834 5768, helpline: 0161 834 3033
e-mail: hearingvoices@care4free.net web: www.hearing-voices.org
User network. Information about strategies and support groups

Rethink Severe Mental Illness
(formerly the National Schizophrenia Fellowship)
28 Castle Street, Kingston-upon-Thames, Surrey KT1 1SS
tel. 0845 456 0455, advice line: 020 8974 6814
e-mail: advice@rethink.org web: www.rethink.org
Working to help everyone affected by severe mental illness, including schizophrenia, to recover a better quality of life

United Kingdom Council for Psychotherapy
167–169 Great Portland Street, London W1W 5PF
tel. 020 7436 3002, fax: 020 7436 3013
e-mail: ukcp@psychotherapy.org.uk web: www.psychotherapy.org.uk
An umbrella organisation of all psychotherapies, with a list of registered members

Further reading

☐ *Accepting Voices* eds. Prof M. Romme, S. Escher (Mind 1993) £13.99
☐ *Breaking the Circles of Fear: A review of the relationship between mental health services and African and Caribbean communities* S. Hannell, C. Kinsella (The Sainsbury Centre for Mental Health 2002) £15
☐ *A Can of Madness* J. Pegler (Chipmunka Publishing 2002) £9.99
☐ *Drugs used in the Treatment of Mental Health Disorders*: FAQs (3rd ed.) S. Bazire (Academic Publishing Services 2002) £8.95
☐ *Factsheet: Community Care 2* (Mind 2002) £1
☐ *Factsheet: Crisis Services* (Mind 2002) £1
☐ *Factsheet: List of Crisis Services* (Mind 2000) 50p
☐ *Forbidden Drugs* P. Robson (Oxford University Press 1999) £13.99
☐ *Hearing Voices J. Watkins* (Hill of Content 1998) £10.99
☐ *How to Cope as a Carer* (Mind 2001) £1
☐ *How to Rebuild Your Life After Breakdown* (Mind 2000) £1
☐ *How to Recognise the Early Signs of Mental Distress* (Mind 2002) £1
☐ *Keyfacts: Genetics and Mental Health* (Mind 2001) £5.50
☐ *Living with schizophrenia: A holistic approach to understanding, preventing and recovering from negative symptoms* J. Watkins (Hill of Content 1996) £9.99
☐ *Making Sense of Antipsychotics (Major Tranquillisers)* (Mind 2003) £3.50
☐ *Making Sense of Cognitive Behaviour Therapy* (Mind 2001) £3.50
☐ *Making Sense of Voices* Prof. M. Romme, S. Escher (Mind 2000) £25
☐ *Mental Illness: A handbook for Carers* eds. R. Ramsay, C. Gerada, S.Mars, G. Szmukler (JKP 2001) £15.95
☐ *The Mind Guide to Advocacy* (Mind 2000) £1
☐ *The Mind Guide to Food and Mood* (Mind 2000) £1
☐ *The Mind Guide to Relaxation* (Mind 2001) £1
☐ *The Mind Guide to Yoga* (Mind 2001) £1
☐ *Mind Rights Guide 1: Civil Admission to Hospital* (Mind 2003) £1
☐ *Mind Rights Guide 3: Consent to Medical Treatment* (Mind 2003) £1
☐ *Outsiders Coming In?* L. Sayce, D. Morris (Mind 1999) £4
☐ *Schizophrenia: the facts* M. Tsuang. S. Faraone (Oxford University Press 1997) £9.99
☐ *Toxic Psychiatry* P. Breggin (HarperCollins 1993) £9.99
☐ *Understanding Mental Illness* (British Psychological Society 2000) £15
☐ *Understanding Paranoia* (Mind 2002) £1
☐ *Understanding Talking Treatments* (Mind 2002) £1

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Mind does this by:

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- promoting inclusion through challenging discrimination
- influencing policy through campaigning and education
- inspiring the development of quality services which reflect expressed need and diversity
- achieving equal civil and legal rights through campaigning and education.

The values and principles which underpin Mind's work are:
autonomy, equality, knowledge, participation and respect.

For details of your nearest Mind association and of local services contact Mind's helpline, Mind*info*Line: 0845 766 0163 Monday to Friday 9.15am to 5.15pm. Speech-impaired or Deaf enquirers can contact us on the same number (if you are using BT Textdirect, add the prefix 18001). For interpretation, Mind*info*line has access to 100 languages via Language Line.

Scottish Association for Mental Health tel. 0141 568 7000

Northern Ireland Association for Mental Health tel. 0289 032 8474

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Mind (National Association for Mental Health)
15-19 Broadway
London E15 4BQ
tel: 020 8519 2122
fax: 020 8522 1725
web: www.mind.org.uk

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