For better
mental health

Understanding schizophrenia

There’s considerable disagreement about the diagnosis of schizophrenia. This booklet introduces the different theories and ideas about causes 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. Doctors may describe 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.

Many people prefer to look at schizophrenia 'holistically', and argue that these symptoms are logical or natural reactions to adverse life events. In other words, an extreme form of distress. They emphasise 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 doctors diagnose schizophrenia?

When someone becomes unwell, they are likely to show drastic changes in their behaviour. They may be upset, anxious, confused and suspicious of other people, particularly anyone who doesn't agree with their perceptions. They may be reluctant to believe they need help. Doctors will want to rule out other physical or mental health problems. They will look for various 'positive' symptoms (strange thinking, hallucinations and delusions) and 'negative' symptoms (apathy, emotional flatness, inability to concentrate, wanting to avoid people or to be protected).

Strange thinking ('Thought Disorder')

A person may be unable to follow a logical sequence of thought; their 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

Some people hear voices that others around them don't hear. (Some people hear other sounds.) The voices may be familiar, friendly or critical. They might discuss the hearer's thoughts or behaviour, or they might issue orders. Up to four per cent of the population hears voices, according to some research, and for most, they present no 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 harsher and more difficult to deal with.

Delusions

Delusions are usually beliefs or experiences that are not in line with a generally accepted reality. For instance, someone might believe secret agents are following them or that outside forces are controlling them or putting thoughts into their mind. (See Mind's booklets, *Understanding paranoia* and *Understanding psychotic experiences*, details under *Further reading*, on p. 14.)

Negative symptoms

Other symptoms, such as being withdrawn, apathetic, and unable 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 and depressed.

Are some people more likely to be diagnosed than others?

About one in every hundred people is diagnosed with schizophrenia, usually as a young adult between 15 and 35 years old. It seems to affect roughly the same number of men and women, but men tend to be slightly younger on diagnosis. Someone may be more likely to have schizophrenia if a member of their family already has the diagnosis.

It's been suggested that the number of African-Caribbean men diagnosed with schizophrenia is out of all proportion, and even that the entire theory of schizophrenia is based on racist ideas. When a psychiatrist has very different cultural, religious or social experiences to their patient's, there is a risk of mistaken diagnosis. If you have any doubts about the diagnosis you have been given, you can ask for a second opinion. 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.

What causes schizophrenia?

Because of differences of opinion about schizophrenia, it's not easy to identify what might cause it.

Inheritance

Some families seem to be prone to schizophrenia, suggesting that there must be some sort of genetic component to its development, but researchers have looked for a particular 'schizophrenia gene' without success. It's now thought that combinations of certain genes might make some people more vulnerable to the condition, but this doesn't mean they will necessarily develop the symptoms. And although there is evidence to show that people who have a parent with schizophrenia are more likely to develop it themselves, this is not necessarily the case, and the majority of people with the diagnosis have no family history.

Dopamine

Biochemical research has been centred on dopamine, which is one of the chemicals that carry messages between brain cells. The theory is that an excess of dopamine may be involved in the development of schizophrenia, but it's still not clear. Neuroleptic drugs (antipsychotics) sometimes used to treat schizophrenia, however, do target the dopamine system. (See p. 6.)

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.

Stressful life events

Studies and personal accounts suggest that very stressful or life-changing events may trigger schizophrenia. Being homeless, living in poverty, having no job, losing someone close to you, or being physically, emotionally, sexually or racially abused or harassed may be factors. According to one study, over half the people who heard negative voices said that sexual or physical abuse was a cause of their problem. Nearly a quarter of them thought that guilt at their own actions had triggered the negative voices.

Drug abuse

Studies have revealed that some people may develop symptoms of schizophrenia as a result of using cannabis or other street drugs. It's already been established that using cannabis, cocaine and amphetamines makes the problem worse, if you already have schizophrenia. (See Mind's factsheet *Cannabis* and booklet *Understanding the psychological effects of street drugs*.)

Other causes

There is evidence that injury to, or physical differences in the brain may be linked to schizophrenia. But this could be either a cause or an effect. Research into other possible causes, including viruses, hormonal activity (particularly in women), diet, allergic reaction or infection, is either contradictory, inconclusive or applicable only in a few cases.

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. However, there's no complete answer to why some people develop the symptoms, when other people do not.

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 provided in hospital and in the community. The guidelines aim to maximise people's recovery, freedom from relapse, quality of life, independence, work prospects and social integration. NICE suggests that people should get help as quickly as possible. (See *Useful organisations*, on p. 13.)

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.

Medication

Doctors usually prescribe neuroleptic drugs (also known as antipsychotic drugs or major tranquillisers) to control the 'positive' symptoms. 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 and dizziness), and sexual side effects. 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.

Current guidelines suggest that, whenever possible, people should use the newer 'atypical' neuroleptics, such as risperidone,

olanzapine, quetiapine, amisulpride and zotepine, which have been developed to have fewer neuromuscular side effects, and may also improve ‘negative’ symptoms, which are much more difficult to treat and control. However, these drugs are more likely to cause a range of side effects which are grouped into the 'metabolic syndrome' and includes 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. 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. For these people, staying on the lowest effective dose of the drug may be the best way of dealing with symptoms, as well as lessening any 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. It may take trial and error to find the best form of medication for you. It may make a big difference to symptoms, or none at all. Some people stop taking it because of the side effects, others find they don’t need it. (For more information, see *Making sense of antipsychotics (major tranquillisers)* and *Making sense of coming off psychiatric drugs*, details on p. 14.)

Rapid tranquillisation

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

Talking treatments

Talking therapies, such as psychotherapy, counselling and cognitive behaviour therapy (CBT), can help people to overcome 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 defeat them.

NICE guidelines underline the importance of making CBT (increasingly available on the NHS) and family therapy 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. 13 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, and has also had some success in treating voices.

Community care

Everyone referred to psychiatric services should have a thorough assessment of their health and social care needs, a care plan and ongoing reviews of their progress. A care coordinator should be in charge of each 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 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 administer injections, and may provide other practical help. An occupational therapist may also be on the team and can help you develop new skills. The assessment may include your need for any community care services. This covers everything from day-care to housing.

You can ask Social Services, separately, to assess your needs, if you're not assessed by psychiatric services. If you need careworkers, any charges for this 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 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.

Crisis services

CMHTs, home treatment teams, early intervention teams and acute day hospitals may help people in a crisis to avoid going into hospital. Some of these offer accommodation, others aim to send support into people's own homes. However, they are not yet available all over the country.

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 (see *Further reading*, on p. 14). You can also ask Mind's Legal Unit for advice. Before leaving hospital, you should discuss the kind of services that would enable you to live independently (see *Community care,* opposite).

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 to help you access community care services.

Supported accommodation

Social Services and mental health projects, including some local Mind associations, may provide local supported housing. This allows people to live independently, but with help at hand from staff or other tenants, if necessary. Levels of support will vary from place to place. (See Mind's factsheet *Housing*.)

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.

What can I do to improve my life?

Most people who are diagnosed with schizophrenia recover. A third of people diagnosed only ever have one experience of it and a further third have occasional episodes. Others have to live with schizophrenia as an ongoing problem.

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. 13.)

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. (See the *Mind guide to relaxation*.)

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. 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. It's not true that schizophrenia means 'split personality' or that someone with this problem will swing wildly from being calm to being out of control. Sensational stories tend to depict 'schizophrenics' 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.

People are often very frightened of those who hear voices. They need to remember that people who hear voices make choices about whether to act on them, just as anyone else would do 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 have to make the conscious choice to stay alive every day, despite their voices.

What can partners, friends or relatives do to help?

Families can have a vital role in helping recovery and reducing the likelihood of relapse. You may be unsure what you should do. But your friend or relative 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'.

Find out about the reality of schizophrenia. 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.

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. One of the recommendations that NICE has made is that families should be offered psychological support or family therapy, if possible.

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.

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, can request a mental health assessment from an Approved Social Worker (this will change to Approved Mental Health Professional when the MHA 2007 comes into force), to look at treatment options and

decide whether someone should be detained. (See the *Mind rights guide* series, under *Further reading*, on p. 14.)

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 may include anger, guilt, fear or frustration. A number of voluntary organisations provide help for carers (see *Useful organisations*, below). You are entitled to have your own needs for practical and emotional support assessed by Social Services.

Useful organisations

Mind
Mind is the leading mental health organisation in England and Wales, providing a unique range of services through its local associations, to enable people with experience of mental distress to have a better quality of life. For more information about any mental health issues, including details of your nearest local Mind association, contact the Mind website: www.mind.org.uk or Mind*info*Line on 0845 766 0163

The Arbours Association
6 Church Lane, London N8 7BU
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
List accredited private therapists

Carers UK
32-36 Loman St, London SE1 0EE
tel. 020 7922 8000 web: www.carersuk.org
Information and advice on all aspects of caring

Hearing Voices Network
tel. 0845 122 8641 web: www.hearing-voices.org
User network. Information about strategies and support groups

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

United Kingdom Council for Psychotherapy
tel. 020 7014 9955 web: www.psychotherapy.org.uk
Can provide a list of registered members

Useful websites

www.foodforthebrain.org/schizophrenia

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

www.rcpsych.ac.uk/mentalhealthinformation.aspx

Further reading

- ☐ *Accepting voices* eds Prof M. Romme, S. Escher (Mind 1993) £13.99
- ☐ *Coming off psychiatric drugs* ed. P. Lehmann (Peter Lehmann Publishing 2004) £14.99
- ☐ *Healing schizophrenia: using medication wisely* J. Watkins (Michelle Anderson Publishing 2006) £14.99
- ☐ *Hearing voices: working out a positive approach* S. File (Mind 2005) £4.95
- ☐ *How to cope as a carer* (Mind 2006) £1
- ☐ *How to cope with hospital admission* (Mind 2004) £1
- ☐ *How to look after yourself* (Mind 2006) £1
- ☐ *How to rebuild your life after breakdown* (Mind 2004) £1
- ☐ *How to recognise the early signs of mental distress* (Mind 2006) £1
- ☐ *Living with schizophrenia: an holistic approach to understanding, preventing and recovering from negative symptoms* J. Watkins (Hill of Content 1996) £10.99
- ☐ *Madness explained: psychosis and human nature* R.P. Bentall (Penguin 2004) £11.99

☐ *Making sense of antipsychotics (major tranquillisers)* (Mind 2007) £2.50
☐ *Making sense of cognitive behaviour therapy* (Mind 2007) £2.50
☐ *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 2006) £1
☐ *The Mind guide to food and mood* (Mind 2006) £1
☐ *The Mind guide to physical activity* (Mind 2006) £1
☐ *The Mind guide to relaxation* (Mind 2006) £1
☐ *Mind rights guide 1: civil admission to hospital* (Mind 2007) £1
☐ *Mind rights guide 2: mental health and the police* (Mind 2006) £1
☐ *Mind rights guide 3: consent to medical treatment* (Mind 2007) £1
☐ *Mind rights guide 4: discharge from hospital* (Mind 2007) £1
☐ *Mind rights guide 5: mental health and the courts* (Mind 2007) £1
☐ *Mind rights guide 6: community care and aftercare* (Mind 2005) £1
☐ *Models of madness: psychological, social and biological approaches to schizophrenia* J. Read, L.R. Mosher, R.P. Bentall (Brunner Routledge 2004) £19.99
☐ *Overcoming childhood trauma: a self help guide using cognitive behavioural techniques* H. Kennerly (Robinson 2000) £9.99
☐ *Understanding paranoia* (Mind 2007) £1
☐ *Understanding the psychological effects of street drugs* (Mind 2007) £1
☐ *Understanding psychotic experiences* (Mind 2004) £1
☐ *Understanding talking treatments* (Mind 2005) £1

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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.

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. 028 9032 8474

The development of this publication has been made possible by the kindness of the late Mrs Flora Maud Lawrence of Southampton, who left a legacy to Mind in her will.

This booklet was written by Fiona Hill and revised by Mind
First published by Mind 1995. Revised edition © Mind 2008

ISBN 9781874690771
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