



talking about
schizophrenia

This booklet reflects many discussions, suggestions and comments made by health professionals, professional bodies, lay and voluntary organisations, people with schizophrenia and their friends and family.

Health Scotland would like to thank all of those who contributed in any way to the development of this booklet, for so willingly giving their time, and sharing their expertise and experience.

All the quotes in this booklet are from real people.

Disclaimer

Every effort has been made to ensure that this publication is as up-to-date and accurate as possible. However, new research can sometimes mean that information and recommendations change very quickly. Changes and alterations will be made at the next reprint to reflect any new information.

While the booklet represents the consensus of good practice, please remember that different circumstances and clinical judgement may mean that you have slightly different experiences.

If you have any doubts, worries or fears, then do not hesitate to contact your doctor for reassurance and further explanations.

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introduction

This booklet is for people with schizophrenia. It is also for families and friends, and for people who would like to know more about how schizophrenia affects people. It provides basic information about schizophrenia and suggests some sources of further help. It also contains references to other reading material and to organisations which can provide further information for those who want to find out more. A selection of useful sites on the internet has also been included.

Schizophrenia affects the way someone thinks and, because of that, it affects how they feel and behave, and how they relate to other people.

There are many myths and misunderstandings about schizophrenia that arouse fear and anxiety even though there is little or no truth in them. For example, schizophrenia is *not* split personality and it is *not* Jekyll & Hyde and, contrary to popular folklore, most people with schizophrenia are not violent and in fact are far more likely to be withdrawn, preferring to be left alone. A significant number of people actually recover from schizophrenia, and many of those who do not make a full recovery can nevertheless, with support, enjoy a fulfilling life.

what is schizophrenia?

"I feel like I'm locked in my head."

"I know they're watching me all the time... through a tiny hole in the wall. And if I go out, I can see them. They stand in the shops, watching when I go past."

Schizophrenia is a mental illness. Around 1 person in 100 will experience schizophrenia at some point in their lives. It affects men and women equally. It can affect people from all walks of life and the first symptoms often develop in early adulthood.

Schizophrenia affects different people in different ways. For some, the illness starts suddenly, with the person becoming quickly and severely unwell, and possibly experiencing muddled thoughts or hallucinations. For others, it may be more gradual. They may find they are uninterested in anything around them or may neglect themselves, display mixed emotions and turn away from family and friends. These changes in behaviour can be difficult to understand especially when the illness has not been diagnosed.

Not everyone experiences all of the symptoms associated with schizophrenia, but some people will have:

- Hallucinations, where they can see, hear, feel, smell or taste something that does not exist. Hearing voices is very common.
- Delusions, where they hold false and often unusual beliefs with unshakeable conviction like a fear of being watched or followed by someone who wants to control them or do them harm.

- Emotional incongruity, where feelings are expressed out of context, or emotional blunting where feelings are flattened or dulled so that you feel flat and empty of emotion.

"It can be a very miserable experience, not being able to do things as you could before."

- Apathy, becoming withdrawn, avoiding friends and family and staying in their rooms.

"I felt in a daze a lot of the time."

- Speech difficulties, where they barely speak but when they do, it can often be muddled and illogical, and makes little sense.
- Thought disorder and strange behaviour that prevents them being easily understood or where they may become hostile to members of the family.

"It really knocks your confidence. You're young and are expected to be going out with boys, settling down and all that. That just didn't happen for me. It wasn't possible."

It can be hard for those around to recognise that these are symptoms of an illness but it is important to remember that this behaviour is not deliberate. It has not happened because of something the individual involved or the people who care about them, might have done.

understanding schizophrenia

No one really knows for sure what causes schizophrenia. It is an illness caused by several factors including genetic vulnerability, exposure to certain kinds of prenatal or perinatal medical problems, stress and emotional development through childhood and the teenage years, drug misuse and stress as an adult.

Schizophrenia can be inherited but that does not mean that because someone in a family has it, everyone else will get it too. The risk is approximately 1 in 10 for those people with a close relative like a parent or brother or sister who has been diagnosed with schizophrenia – about 10 times higher than in the general population – but hereditary factors alone do not determine that a person will go on to develop schizophrenia.

People with schizophrenia may have an imbalance of certain chemicals in the brain, like dopamine for example, and that can affect the way the brain reacts to sounds, smells and sights.

Stress caused by early childhood trauma e.g. childhood sexual abuse, bereavement, leaving home, a car accident, or perhaps by pressure of work, can all contribute to an episode of schizophrenia.

People with schizophrenia may also experience depression, anxiety, stress or perhaps a personality disorder. It may be helpful to read some of the other books in the *Talking About* series (see *Talking about Depression*, *Talking about Anxiety*, *Talking about Stress* and *Talking about Personality Disorders*).

Drug and alcohol misuse may be a contributory factor. Drugs like cannabis and those with hallucinogenic properties such as LSD, amphetamine or speed, have been shown to bring on schizophrenia in a small number of their users and to make it worse for some people who already have the illness.

Early symptoms involving behaviours and emotions that are common in late adolescence or early adulthood may suggest schizophrenia, but many young people will have some of these symptoms without developing the illness. With schizophrenia, the symptoms are more likely to persist, and last longer.

getting help

Help is available from different sources. It is worth contacting one or more of the organisations listed at the back of this booklet to find out about different sources of help and support. The doctor, and clinical and counselling psychologists, can also be major sources of help, providing information, advice and support.

medical treatment

The first step in getting treatment for schizophrenia is getting a correct diagnosis. This can be difficult if there are other symptoms present (see *Talking about Depression*, *Talking about Anxiety*, *Talking about Stress* and *Talking about Personality Disorders*).

"I was told I had borderline personality disorder then schizoaffective disorder and I'm just totally fed up with constantly changing diagnoses."

“Schizophrenia is a really scary thing to face, but it’s much more scary not to face it.”

It is important to see a psychiatrist experienced in the treatment or diagnosis of this illness. Your doctor is also a good place to start. Although the doctor may not be an

expert on schizophrenia, he or she will be able to put you at ease and refer you to someone who knows how to offer the best help.

If going to the doctor or psychiatrist is a problem to begin with, contacting a local support group can help.

Starting treatment as soon as possible after the illness begins is important. In the first year of treatment, people experiencing schizophrenia will see a consultant psychiatrist, who can offer expert help. It may be that they will need to stay in hospital for a short time for assessment and treatment. Most help and treatment after that can be given at home.

Medication is a vital first step in treatment and is very effective when it is combined with other types of help, including support from family and friends, and social services. While it is not a cure in itself the medication, mainly ‘typical’ and ‘atypical’ antipsychotic drugs, can ease or take away some severe symptoms like delusions and hallucinations and prevent the symptoms getting any worse, which in turn enables the recovery process as people regain control of their lives. The medication is usually given in the form of pills and syrup, and sometimes as an injection.

The effects of the drugs vary considerably. While older style drugs are more likely to have caused unpleasant side effects like trembling hands, blurred vision and difficulty in concentrating, people currently presenting with a new episode of psychosis at the moment are likely to be prescribed atypical antipsychotic drugs which do not carry such problems. The newer atypical drugs however do have the potential to cause weight gain which can be distressing, especially for younger people. Some people using atypical drugs report stiffness or a difficulty in waking up in the morning. However, the newer drugs are designed to improve concentration, not weaken it. Some people do not experience any side effects at all but for those who do, there is no doubt that the benefits of taking the drugs far outweigh the potential side effects. Given the wide range of antipsychotic drugs available, it is worth discussing with your psychiatrist which one is likely to suit you best.

Schizophrenia, like most other mental illnesses, can be treated best by a combination of medicine and the various other forms of help, particularly 'talking treatments' like counselling and psychotherapy.

counselling and psychotherapy

People sometimes find it hard to talk about their difficulties but it is important to seek help and support. Counselling and psychotherapy give people the chance to talk through their problems. Both focus on present day feelings and difficulties, which may be current or rooted in the past, and enable us to take more control of our life and to cope in the longer-term.

Cognitive and behavioural therapies (CBT), social skills training and family therapy can help people feel better about themselves, learn new ways of solving their problems, and help control and make sense of hallucinations or delusions. CBT is known to reduce stress by altering behaviour and thinking patterns, by undoing prior learning that may have adverse consequences and replacing it with new, more adaptive learning. There is evidence to show that even previously unresponsive and medication-resistant psychotic symptoms can be modified. Studies of CBT in chronic schizophrenia show that the therapy has a significant effect on positive symptoms and can be effective when used in conjunction with drug treatment.

support groups

It can be very comforting to meet other people in similar circumstances and finding out how they cope with the same kind of difficulties. Support groups often provide that kind of reinforcement and they can also be a very important source of practical advice and information.

"It's been good to get to know others who have been through it too. The group was a chance to make new relationships."

practical services

Practical support is very important to people with schizophrenia. Local community mental health workers, community psychiatric nurses who will listen and sort out any medication problems, social workers who can advise on benefits, supported housing and employment, and occupational therapists can all help to make the situation feel less frightening. Day hospitals and day centres can give people somewhere to go during the day, and usually offer various physical, creative, educational and vocational activities. Projects that offer supported employment and training programmes are also available.

user groups and advocacy groups

Many non-profit organisations run local user and advocacy groups, drop-in centres and resource centres. Sometimes it can seem that decisions are being made by other people but user and advocacy groups can help give those with schizophrenia the confidence, support and encouragement they need to have a say in matters that directly affect them. Advocacy will have a much stronger role in future, and legislation is in place to make sure that independent advocacy support is available to anyone who wants it.

Service users have the right to make advance statements enabling them to appoint a representative and set out how they would wish to be treated in the event of becoming unwell and being unable to express their views at some point in the future.

The Scottish Executive (Health Department) has funded the Advocacy Safeguards Agency (ASA) to ensure that good quality independent advocacy is available and accessible at local level to everyone in Scotland who needs it.

what you can do

Schizophrenia can be frightening, but with the right kind of professional help, people with schizophrenia will begin to feel more calm and can start to put their lives in order again. That may mean changing a few things to avoid stressful situations.

Some people have made the following suggestions, based on their own personal experiences:

“Having a routine to stick to is good.”

“I find it helps to have things to do, but nothing too vigorous. I need to be able to go at my own pace.”

“I need to push myself gently to get involved and keep occupied, otherwise I just lapse into total inactivity.”

Like everyone else, people experiencing schizophrenia need to look after themselves. That means eating healthily, drinking in moderation and being physically active. The ‘feel good’ factor can also be helped by learning new skills, taking time to relax, enjoying different creative activities and keeping in touch with friends or making new ones by joining a club or volunteering.

the role of partners, family and friends

Before schizophrenia has been diagnosed it is important for partners, family and friends to offer support and to encourage the seeking of a diagnosis and professional help.

Being close to those with schizophrenia can sometimes be disturbing and upsetting. Trying to talk to them can be difficult and frustrating, but rather than getting into arguments partners, friends and relatives should try to encourage them to talk about their feelings, try not to criticise, and reassure them that they are not alone. All of that requires a great deal of patience.

"We're all trying to support my sister but she refuses to see a doctor and her condition's getting worse."

Do not argue with a person about their delusions and hallucinations. Accept that they are real for them. However, do not pretend that these hallucinations or delusions are real to you. Do not try to humour the person or agree with them.

"Since I was diagnosed with schizophrenia, I feel like my dad wants to control my life. I don't think he trusts me to take my medication. I know he's doing it because he loves me but it's making me want to get out."

Partners, family and friends need support too though, to know that that they are not alone in their feelings and that they are not to blame if a crisis occurs. It is important for them to meet other people like themselves, perhaps through support groups,

who can understand and share their feelings of anger and resentment at the disruption and pain that has been caused, as well as their hopes for the future. And it is important that they take some time for themselves.

the future

For those who will continue to be affected in some way by schizophrenia, it is possible to find ways of limiting its impact and adapting their lives to make them as fulfilling as possible.

About one-third of people who develop schizophrenia have only one episode and fully recover, another one-third have multiple episodes but are well in between, and one-third has a lifelong illness. About 1 in 10 people with schizophrenia end their lives by suicide.

We are starting to develop a better understanding about what helps people stay well and recover from long-term mental health problems. Research evidence shows that many people recover from even the most severe mental health problems. Other people may continue to experience ongoing symptoms for many years but this does not mean that they are not able to live a satisfying and fulfilling life given the right opportunities and supports. It is important to recognise that there is no overnight cure. Receiving treatment and working towards recovery is an ongoing process that takes time.

The Scottish Recovery Network has been set up to promote and support recovery in the various areas of mental health, including schizophrenia. The Scottish Recovery Network has three main aims:

- To raise awareness of recovery and what it means for individuals, families, public services and policy.
- To help build the infrastructure of values and principles required to promote recovery among individuals, families, service providers and decision makers.
- To build capacity by sharing information, experience and evidence.

There is no doubt that there has been tremendous progress in the treatment of schizophrenia over the past few years and the future does look much brighter. A better understanding of the illness, improved research techniques, and the development of new treatments are all helping to improve the quality of life for those with schizophrenia.

useful addresses

The national organisations listed below can put you in touch with local sources of help in your area.

National Schizophrenia Fellowship (Scotland)

Claremont House
130 East Claremont Street
Edinburgh EH7 4LB
Tel: 0131 557 8969
www.nsfscot.org.uk

The National Schizophrenia Fellowship works to improve the wellbeing and quality of life of those affected by schizophrenia and other mental illness.

NHS Quality Improvement Scotland

Elliot House
8–10 Hillside Crescent
Edinburgh EH7 5EA
Tel: 0131 623 4300

Delta House
50 West Nile Street
Glasgow G1 2NP
Tel: 0141 225 6999
www.nhshealthquality.org

NHS Quality Improvement Scotland (NHS QIS) was set up to take the lead in improving the quality of care and treatment delivered by NHSScotland.

Penumbra

Norton Park
57 Albion Road
Edinburgh EH7 5QY
Tel: 0131 475 2380
www.penumbra.org.uk

Penumbra is a Scottish mental health organisation that provides a wide range of support services for adults and young people.

Scottish Association for Mental Health

Cumrae House
15 Carlton Court
Glasgow G5 9JP
Tel: 0141 568 7000
www.samh.org.uk

Scottish Association for Mental Health (SAMH) is the major voluntary organisation in Scotland working to promote mental health.

Advocacy Safeguards Agency

1-2 St Andrew Square
Edinburgh EH2 2BD
Tel: 0131 524 9380
Email: info@advocacysafeguards.org
www.advocacysafeguards.org

The Advocacy Safeguards Agency has been funded by Scottish Executive (Health Department) to ensure that good quality independent advocacy is available to everyone who needs it.

NHS 24

Delta House
50 West Nile Street
Glasgow G1 2NP
Tel: 08454 24 24 24
www.nhs24.com

NHS 24 is a 24-hour health service for Scotland.

Breathing Space Scotland

Tel: 0800 83 85 87

www.breathingspacescotland.co.uk

Breathing Space is a free, confidential phone-line you can call when you are feeling down. The phone-line is open from early evening right up until two in the morning. Advisors will listen, and try to help prevent problems getting worse, offer advice and suggest local people who can help with specific problems.

useful websites

www.schizophrenia.com

schizophrenia.com

www.mentalhealthcare.org.uk

Mental Health Care

www.rcpsych.ac.uk/info/schiz.htm

The Royal College of Psychiatrists

www.library.nhs.uk/mentalhealth

National electronic library of health

suggestions for reading

There are many publications about schizophrenia and your doctor or local library will be able to suggest some for you. Here are a few that might help.

Surviving Schizophrenia: A Family Manual

by E Fuller Torrey.

Published by HarperCollins, 2001.

ISBN 006-095919-3

Diagnosis – Schizophrenia: A Comprehensive Resource for Patients, Families and Helping Professionals

by Rachel Miller and Susan Mason.

Published by Columbia University Press, 2002.

ISBN 023-112625-5

Schizophrenia: A Very Short Introduction

by Chris Frith and Eve Johnstone.

Published by Oxford University Press, 2003.

ISBN 019-280221-6

The Day the Voices Stopped: A Schizophrenic's Journey from Madness to Hope

by Ken Steele and Claire Berman.

Published by Basic Books, 2001.

ISBN 046-508227-0

Working with Voices (Victim to Victor S)

by Ron Coleman and Mike Smith.

Handsell Publishing, 1997.

ISBN 190-319901-8

Accepting Voices

by Marius Romme and Sandra Escher.

MIND, 1993.

ISBN 187-469013-8

Other topics covered by the *Talking about...* series are:

- Attention Deficit Hyperactivity Disorder (ADHD)
- Anxiety
- Bereavement
- Depression
- Eating Disorders
- Manic depression
- Personality disorders
- Phobias
- Postnatal depression
- Self-harm
- Stress

Contact your local health promotion resource service for copies. You can access their details via www.show.nhs.uk

Our publications are available in other formats and languages. For further information please contact Health Scotland.

