

Understanding NICE guidance

Information for people who use NHS services

Schizophrenia

NICE 'clinical guidelines' advise the NHS on caring for people with specific conditions or diseases and the treatments they should receive.

This booklet is about the care and treatment of people with schizophrenia in the NHS in England and Wales. It explains guidance (advice) from NICE (the National Institute for Health and Clinical Excellence). It is written for people with schizophrenia but it may also be useful for their families or carers or for anyone with an interest in the condition.

The booklet is to help you understand the care and treatment options that should be available in the NHS. It does not describe schizophrenia or the treatments for it in detail. A member of your healthcare team should discuss these with you. There are examples of questions you could ask throughout this booklet to help you with this. You can get more information from the organisations listed on page 19. Medical terms printed in **bold** type are explained on pages 17 and 18.

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The advice in the NICE guideline covers:

- the care, treatment and support that adults (aged 18 and older) with schizophrenia should be offered. This includes people who develop schizophrenia before they are 60 and continue to require treatment after this age.

It does not specifically look at:

- the care and treatment of people who develop schizophrenia after they are 60
- the care provided for people younger than 18 except those who are receiving treatment from **early intervention services**
- the treatment of other conditions that people with schizophrenia may often have, such as depression, anxiety or **personality disorder**. NICE has produced separate guidance about these and about **post-traumatic stress disorder** and drug and alcohol problems. See the NICE website (www.nice.org.uk) for more information.

This is an update of advice on schizophrenia that NICE produced in 2002.

Your care

Your treatment and care should take into account your personal needs and preferences, and you have the right to be fully informed and to make decisions in partnership with your healthcare team. To help with this, your healthcare team should give you information you can understand and that is relevant to your circumstances. All healthcare professionals should treat you with respect, sensitivity and understanding and explain schizophrenia and the treatments for it simply and clearly.

The information you get from your healthcare team should include details of the possible benefits and risks of particular treatments, as well as details of other treatments and therapies. You can ask any questions you want to and can always change your mind as your treatment progresses or your condition or circumstances change. Your own preference for a particular treatment is important and your healthcare team should try to respect and support your choice of treatment wherever possible. This is the case even if you are being treated under the **Mental Health Act**.

Your treatment and care, and the information you are given about it, should take account of any religious, ethnic or cultural needs you may have. It should also take into account any additional factors, such as physical or learning disabilities, sight or hearing problems, or difficulties with reading or speaking English. Your healthcare team should be able to arrange an interpreter or an advocate (someone who supports you in putting across your views) if needed.

If you agree, your family and **carers** should have the chance to be involved in decisions about your care. Family members and carers also have the right to the information and support they need in their roles as carers.

If you are unable to understand a particular issue or are not able to make decisions for yourself, your healthcare professionals should follow the advice that the Department of Health has produced about this. You can find this by going to the Department of Health website (www.dh.gov.uk/consent). Your healthcare professional should also follow the code of practice for the Mental Capacity Act. For more information about this, visit www.publicguardian.gov.uk

Schizophrenia

Schizophrenia is a condition that affects a person's mental state, including their thoughts, mood and behaviour. The condition varies from person to person but the main symptoms are called 'psychotic' symptoms.

These are:

- hearing voices and sometimes seeing things that are not really there (called hallucinations)
- having fixed beliefs that are false but which the person believes in completely (called delusions).

Because of these symptoms the person may not be able to think clearly or concentrate. They may lose interest in things, lack motivation and become withdrawn from other people. The symptoms can be distressing for the person and can also be upsetting for families and friends (see page 16 for information for families and carers). It may take a while for a person with these symptoms to accept that they are ill or to ask for help or treatment. Some people do not accept the term schizophrenia to describe their symptoms.

About 1% of people have schizophrenia at some point in their lives. For most people the symptoms start when they are young adults, but they can occur at any age. Some people may only have symptoms for a short time, but others may have them for months or years. Some people will recover completely from their symptoms; others will improve but may become ill again. In this booklet, an increase in distressing symptoms, including hallucinations and delusions, is called an '**acute episode**'.

Some people with schizophrenia may also have other conditions such as depression, anxiety, post-traumatic stress disorder, personality disorder, and drug and alcohol problems.

What should happen when I first see a healthcare professional?

If you think you have symptoms of schizophrenia, it is important to get help as early as possible. Because hallucinations and delusions can feel real, you may not realise there is anything wrong even when the symptoms are quite severe. People around you may suggest you get help. Most people see a professional in a mental health services team after seeing their GP. Other people may have contact with other teams such as accident and emergency staff in a hospital first. Some people will be referred to mental health services through the criminal justice system or because they have been detained under the Mental Health Act if they are thought to be at risk to themselves or others.

If you have been referred to a mental health services team you will be offered an **assessment**. This should usually take place at your local mental health service (this might be an early intervention service, a **crisis resolution and home treatment team** or a **community mental health team**). If you are in hospital, this will be carried out by the hospital mental health service. If you have been detained under the Mental Health Act this process may take place without your consent.

During the assessment the healthcare professional will ask you about different aspects of your life. This should include your thoughts, feelings and behaviour, your physical health, any other mental health problems, your relationships, living arrangements and background. It is likely that you will be assessed by more than one healthcare professional, including a psychiatrist.

You may then be referred to a healthcare team who should develop a care plan with you so you can get the treatment and support that is most appropriate for you. You and the professional who referred you for assessment should be given a copy of your care plan. The plan should include information about what should happen if you have a **crisis**, and identify the healthcare professionals who should be involved in your care at this time.

All people first experiencing symptoms of schizophrenia or with psychotic symptoms should be offered treatment and support at an early intervention service. This service should provide a range of treatments, including medication and **psychological treatment**.

If you want to ask for a second opinion from another healthcare professional about being diagnosed with schizophrenia or whether you need treatment, this decision should be supported by your healthcare team.

Questions you might like to ask your healthcare team

- Why am I being offered an assessment?
- What could have caused my symptoms?
- Who can I contact if I have a crisis or if my symptoms get worse?
- Are there any support organisations in my local area?
- Can you provide any information for my family or carers?

What treatment should I be offered when I first become ill?

You should first be offered ‘**antipsychotic** medication’ in a form that you can swallow (tablets or liquid).

Your healthcare professional should give you detailed information about the medications available, how they can help you and their side effects. They should involve you (and, if you agree, your family or carers) in the decision about which medication to take, even if you are being treated under the Mental Health Act. They should discuss with you which side effects you would most like to avoid.

If your medication seems to cause distressing side effects, tell your healthcare professional so that they can lower the dose or offer you another medication which may suit you better. It may take a while to find the right medication for you, but your healthcare professional should guide you through this process. Your healthcare professional should not offer you more than one antipsychotic for schizophrenia at the same time, except for short periods if your medication is changed.

Your healthcare professional may check your heart (by taking an **electrocardiogram**) before you start taking antipsychotic medication.

Your healthcare professional should see you regularly while you are taking antipsychotic medication, especially when you first start taking it. They should check whether the medication is helping you and whether you are having any side effects. They should also check if you are having problems taking the medication as prescribed and monitor your physical health.

If you wish to use treatments that have not been prescribed by your healthcare professional, including complementary therapies, you should discuss this with your healthcare professional. They should advise you whether such treatments are safe, helpful and whether they are likely to affect how well your prescribed medication and psychological treatments work.

Healthcare professionals should advise you that drinking alcohol, smoking or taking other drugs while taking medication for schizophrenia could stop the treatment working properly and make your symptoms worse.

Some treatments may not be suitable for you, depending on your exact circumstances. If you have questions about specific treatments and options covered in this booklet, please talk to a member of your healthcare team.

What should happen if my symptoms get worse?

If your symptoms get worse and are distressing (called an acute episode), your healthcare team should offer you a range of treatments, including medication and psychological treatment.

You may receive care at home from a crisis resolution and home treatment team, an early intervention service or an **assertive outreach team**. If these teams cannot provide all the treatment and support you need, you may also be asked to go to an acute day hospital. You will have treatment and help at the hospital during the day and go home at night.

If your symptoms are very severe, or you are being treated under the Mental Health Act, you may be asked to stay at an inpatient unit in hospital. Once you have left hospital, the crisis resolution and home treatment team may be able to help you adjust when you are back home.

Questions about what happens during an acute episode

- Do I have to have treatment in hospital during an acute episode?
- Can I choose to stay in hospital for treatment?
- What treatment should I be given during an acute episode?
- Can I write something about what treatment I would like during an acute episode?

Medication

You should be offered medication as described in the section 'What treatment should I be offered when I first become ill?' (see page 7).

If you are very unwell and it is thought that there is a risk to yourself or others, you may be given medication that will help to calm you down or 'sedate' you. This process is called rapid tranquillisation. You should only be sedated like this in hospital. Afterwards you should be closely monitored to check that you are OK, as recommended in the NICE guideline on violence (www.nice.org.uk/CG25).

As soon as possible after rapid tranquillisation, healthcare professionals should spend time talking to you about what has happened and explain why you were sedated. They will make detailed notes about what has happened. They should encourage you to write your own account of events and why you were distressed, to go in your notes.

If you have harmed yourself, you should receive treatment and support as recommended in the NICE guideline on **self-harm** (www.nice.org.uk/CG16).

Psychological treatment

As well as medication you should be offered a psychological treatment called **cognitive behavioural therapy (CBT)**. This will involve meeting with a therapist on a one-to-one basis for at least 16 sessions. If you live with your family or are in close contact with them, you and your family should also be offered a psychological treatment called **family intervention**. Treatment should last for between 3 months and a year and include at least 10 sessions.

You may also be offered one of the **arts therapies**, particularly if you have symptoms such as withdrawing from family and friends and losing interest in things that were once enjoyable. Therapy should usually take place in groups with people with similar problems.

Your therapist should make sure that you, and your family or carer if appropriate, are happy with how the psychological treatment is progressing.

If you start psychological treatment during a hospital visit for an acute episode, it should continue once you have left hospital until you have completed the course.

There are other types of psychological treatment, such as counselling, **supportive psychotherapy** and **social skills training**. These are not thought to be as effective as CBT, family intervention and arts therapies for people with schizophrenia. However, your personal choice should be taken into account, especially if the other treatments are not available in your area and you wish to talk about your feelings, thoughts and symptoms.

You should not be offered a treatment called **adherence therapy** because there is not enough good evidence that it can help people with schizophrenia.

You should be offered social, group and physical activities (such as exercise) as part of your treatment programme, especially as you begin to get better. The activities should be recorded in your care plan.

If you have talked to your healthcare team, and you think that a treatment is suitable for you but it is not available, you can contact your local patient advice and liaison services ('PALS').

Questions about treatment

- What are the advantages and disadvantages of having this treatment?
- Please tell me what the treatment will involve.
- How will the treatment help me? What effect will it have on my symptoms and everyday life? What sort of improvements might I expect?
- How long will it take to have an effect?
- Are there any risks associated with this treatment?
- What are my options for taking treatments other than the recommended treatment?
- What will happen if I choose not to have the recommended treatment?
- Are there any leaflets about the treatment that I can have?
- How long will I have to take the medication for?
- Might I have problems when I stop taking the medication?
- Are there any serious side effects associated with this medication that are likely to affect me, given my circumstances?
- What should I do if I get any side effects? (For example, should I call my GP, or go to the accident and emergency department at a hospital?)
- Are there any long-term effects of taking this medication?

What support should I be offered after an acute episode?

Your healthcare team should encourage and support you to write an account of what has happened to go in your notes. Many people with schizophrenia find this helps them to think about which treatments helped, how they can recognise the early signs of an acute episode and understand their illness.

You should be encouraged to take your medication for 1–2 years after an acute episode. There is a risk that if you stop taking it your symptoms may get worse. However if you get distressing side effects your medication should be changed. When you no longer need medication because your symptoms have improved, it should be stopped gradually and your healthcare professional should see you regularly during this time. They should continue to see you for at least 2 years after you have stopped taking medication.

If you think that your care does not match what is described in this booklet, please talk to a member of your healthcare team in the first instance.

How can I stay well?

The services and teams that can help you stay well include your GP, community mental health teams, assertive outreach teams, crisis resolution and home treatment teams and early intervention services.

Staying in touch with services is very important so that you can obtain treatment as soon as possible, and continue to have help and support. If you plan to move to a different area, a meeting should be arranged with you to talk about the transfer to a new healthcare team. Your care plan should be sent to the new team.

Many people with schizophrenia are at risk of developing physical health problems, such as significant weight gain and diabetes, from some of the medications used to treat the condition and for other reasons associated with having schizophrenia, such as changes in lifestyle. Your GP or another healthcare professional can help you stay well. They should check your physical health at least once a year, including your weight, blood pressure, blood sugar levels and cholesterol levels and you should be asked about any side effects of your medication. You should be offered treatment for any physical health problems. The person organising your care (called a 'care coordinator') and your psychiatrist should be kept informed about your physical health so you can have the best possible care.

Continuing psychological treatment and medication can also help you recover from schizophrenia (see pages 8 and 9). Your healthcare professional should help you find the most suitable way for you to take your medication long term. This could be by taking antipsychotics that have long-lasting effects. These are called 'depot antipsychotics' and are usually given every 2–4 weeks, depending on which type you take. Your healthcare professional should explain that depot antipsychotics are given by injection into the muscle and can be given in different settings (for example, your GP's surgery or a day hospital). You should be asked whether you want to receive your medication in this way, and which setting you would prefer. If you do decide to try a depot antipsychotic, your healthcare professional should give you a test dose to check that it suits you. Once you are taking a depot you should have your treatment reviewed regularly.

What if the treatments do not help me?

If medication does not help your symptoms, your healthcare professional should check that you have been taking it as prescribed. You should be assessed again to make sure there are no other reasons why you are not getting better. These could include physical illness, drinking too much alcohol or taking non-prescribed drugs, which can stop the medication working properly.

If you have tried at least two different antipsychotics (including an atypical one) and these have not helped, you should be offered an antipsychotic called clozapine. If this does not help, you may be offered a second antipsychotic to take at the same time as clozapine.

If psychological treatment has not helped you, your healthcare professional should check that your therapist has provided treatment as recommended in the NICE guideline. You may be offered a different type of therapy.

What happens if I become ill again?

If you see a healthcare professional because you have another acute episode, they should treat you according to your care plan. This should include referring you to the most appropriate service for your needs.

If you are being cared for by your GP and they think your treatment is not working or if you have unpleasant side effects from your medication, they should refer you to your local mental health service. If you need further treatment from mental health services they should take account of any specific requests you may have. This may include discussing any side effects and other treatments you wish to have, such as psychological therapies.

What other support is available?

If you have not been able to work because of your illness and wish to return to work or get a job, you should be offered a place on an employment scheme called a 'supported employment programme'. There may be other types of work schemes available in your local area.

What happens after my symptoms improve?

If treatment has helped you and your symptoms have improved, you should be given the option to continue care with your GP.

What are my rights regarding my treatment and care?

Your healthcare team should build a supportive relationship with you and your family or carers based on hope, optimism and trust.

Healthcare professionals should ask you whether you wish your family or carers to be involved in your care and whether you would like information about your treatment and care shared with them.

If you are being treated under the Mental Health Act, you may not understand why, or you may disagree with the decision. You have a right to appeal to a committee called a 'first-tier tribunal (mental health)', and your healthcare professional should support you if you decide to appeal.

If you are concerned about not being able to make important decisions at any time (for instance during an acute episode) you can write some instructions (called advance statements and advance decisions). The instructions can say what treatments and other help you want and do not want to be given. For example, you may not want to be given a particular drug again because of its side effects. Your healthcare team should discuss your instructions with you and they can help you to write them. You should be given a copy of the instructions and your GP and psychiatrist should also have a copy. If you agree, your healthcare team can also give a copy to your family or carer. Your instructions may be overridden if you are being treated under the Mental Health Act, although healthcare professionals should only do this in special circumstances and when they believe it is in your best interests. You should be provided with an explanation about why it was necessary to override your instructions, should this occur.

If you need support and treatment from another mental health or social care service, this should be discussed with you first and, if you agree, with your family or carer. While your care is being transferred to the other service, your healthcare team should make sure you still receive the support you need, especially during a crisis.

Questions about being treated under the Mental Health Act

- Why have I been detained under the Mental Health Act?
- Do I have the right to refuse treatment?
- Do I have to go to hospital?
- How long will I have to stay in hospital?
- Can I leave the ward if I want to?
- How can I appeal against being treated under the Mental Health Act?
- How can I find a solicitor who can help me in my appeal?
- How long will it take before my appeal is heard?

Information for families and carers

Families and carers can play an important part in supporting someone with schizophrenia. Healthcare professionals should ask people with schizophrenia whether they would like their family or carers to be involved in their care and whether they would like information about their treatment and care shared with them.

If you are involved in the care of a family member or friend with schizophrenia and they agree, healthcare professionals should give you information on schizophrenia and its treatments, including how you can support your family member or friend throughout treatment. If you live with the person with schizophrenia or are in close contact with them, you and your family member or friend should be offered a psychological treatment for all the family, called family intervention.

Families and carers may need help and support themselves. Healthcare professionals should give you information about local family and carer support groups and other voluntary organisations, and help you to make contact with them. Anyone with a caring role has the right to a **carer's assessment**. The needs of any children in the family should also be assessed, including those of young carers.

Questions for families and carers

- Can we have some information about schizophrenia and its treatments?
- Are we entitled to be told about the treatment our family member or friend is having?
- What can we do to help and support our family member or friend with schizophrenia?
- Can you give us any information about how to get help and support if our family member or friend has a crisis?
- Is there any additional support that we might benefit from or are entitled to?

Explanation of medical words and terms

Acute episode An increase in distressing symptoms, often leading to a crisis.

Adherence therapy A type of psychological treatment that aims to help people take their medication as prescribed or to negotiate a change in prescription. This involves discussing their attitudes about the benefits and problems with taking medication.

Antipsychotic A type of medication that is sometimes used to treat serious changes in mental state (such as hallucinations and delusions). There are two types of antipsychotic medication, usually called 'typical' (conventional antipsychotics) or 'atypical' (newer antipsychotics).

Arts therapies Psychological treatments that help people with mental health problems to express themselves and work through their problems using art, music, dance or drama.

Assertive outreach team A service that delivers intensive, and often comprehensive, treatment and care in the community for people with serious mental health problems, especially people who have been ill before, have been in hospital, do not have a permanent home, or have drug or alcohol problems.

Assessment A meeting with a healthcare professional in which they ask questions about your physical and mental health, to establish what the illness is, how severe it is and what treatments would suit you best.

Carers All people who have regular close contact with a person with schizophrenia, including family members, friends and guardians.

Carer's assessment An assessment of a carer's caring, physical and mental health needs provided by social services. Every person aged 16 years and older who cares for someone on a regular basis has the right to request such an assessment. There should be a written carer's care plan, which is given to the carer.

Cognitive behavioural therapy (CBT) A psychological treatment that aims to reduce feelings of distress, to help people cope with symptoms and to support people in carrying out everyday tasks. It helps people by making links between their thoughts, feelings and behaviour and their current or past symptoms and can help people to re-evaluate their beliefs, feelings or behaviour in relation to their illness.

Community mental health services/team A group of professionals (including nurses, psychiatrists, psychologists, occupational therapists, social workers and support workers) who see people in the community (for example, in their community mental health centre, their GP's surgery, and sometimes in their own home).

Crisis A situation unique to the person, requiring an emergency response. This will usually mean that mental health services will assess what further action is needed as soon as possible. Sometimes emergency services will be involved.

Crisis resolution and home treatment team Services that provide intensive home-based, crisis-orientated treatment of an acute episode. They can also provide care after a person has left hospital.

Early intervention service A service that provides early identification and treatment to people who have symptoms of psychosis (hallucinations and delusions). The service should be able to provide a full range of psychological treatments, drug treatments and other support.

Electrocardiogram A test to record the rhythm and activity of the heart.

Family intervention A psychological treatment that helps families work together to improve outcomes for people with schizophrenia and to reduce stress in family members. It aims to help family members develop communication, problem solving, information sharing and coping skills as well as increasing family members' knowledge and understanding.

Mental Health Act A law that allows a person with a mental disorder to be treated against their will, or without their agreement, if they are judged to be at serious risk to themselves or others. This is sometimes called 'being sectioned'. A person treated under the Mental Health Act will receive care in hospital where they can expect as much care and support as anyone else. People treated under the Mental Health Act have a legal right to appeal to a first-tier tribunal (mental health).

Personality disorder A condition that leads to a person having unstable moods, thoughts, behaviour and self-image.

Post-traumatic stress disorder Psychological and physical problems that can sometimes follow threatening or distressing events.

Psychological treatment A general term used to describe meeting with a therapist to talk about feelings and thoughts and how this affects a person's life and wellbeing.

Self-harm An expression of personal distress by a person who hurts themselves. Common methods of self-harm include cutting oneself or taking too many tablets or recreational drugs.

Social skills training A type of psychological treatment designed to help people with schizophrenia rebuild their social skills and confidence, including how to cope in social situations.

Supportive psychotherapy A type of psychological treatment similar to counselling. The content of the sessions is largely determined by the person having therapy rather than the therapist. The therapist will listen and offer support.

More information

The organisations below can provide more information and support for people with schizophrenia. NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

- Afiya Trust
www.afiyatrust.org.uk
- Mental Health Foundation, 020 7803 1100
www.mentalhealth.org.uk
- Mind, 0845 766 0163
www.mind.org.uk
- Rethink, 0845 456 0455
www.rethink.org
- SANE, 0845 767 8000
www.sane.org.uk

NHS Choices (www.nhs.uk) may be a good place to find out more.

Your local patient advice and liaison service (usually known as 'PALS') may be able to give you more information and support. You should also contact PALS if you are unhappy with the treatment you are offered, but you should talk about your care with a member of your healthcare team first. If your local PALS is not able to help you, they should refer you to your local independent complaints advocacy service.

About NICE

NICE produces guidance (advice) for the NHS about preventing, diagnosing and treating different medical conditions. The guidance is written by independent experts including healthcare professionals and people representing service users and carers. They consider the evidence on the condition and treatments, the views of service users and carers and the experiences of doctors, nurses and other healthcare professionals. Staff working in the NHS are expected to follow this guidance.

To find out more about NICE, its work and how it reaches decisions, see www.nice.org.uk/aboutguidance

This booklet and other versions of the guideline aimed at healthcare professionals are available at www.nice.org.uk/CG82

You can order printed copies of this booklet from NICE publications (phone 0845 003 7783 or email publications@nice.org.uk and quote reference N1824).

We encourage NHS and voluntary organisations to use text from this booklet in their own information about schizophrenia.