

Psychosis and schizophrenia in adults

Information for the public

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About this information

NICE guidelines provide advice on the care and support that should be offered to people who use health and care services.

This information explains the advice about psychosis and schizophrenia in adults that is set out in NICE clinical guideline 178.

This is an update of advice on schizophrenia that NICE produced in 2009.

Does this information apply to me?

Yes, if you are an adult at risk of or with a diagnosis of psychosis or schizophrenia.

For children and young people, see the NICE website for advice on [psychosis and schizophrenia in children and young people](#).

Psychosis and schizophrenia

Psychosis and schizophrenia are mental health problems that affect how a person thinks, feels and behaves. They can make it hard for the person to think clearly and tell the difference between what's real and what's not. The person may act differently or lose interest in things and other people.

The main symptoms are called 'psychotic' symptoms. These are:

- hearing voices and sometimes seeing things that are not really there (called a hallucination)
- believing that something is real or true when it is not (called a delusion); such as, believing they are being watched or having their thoughts monitored.

For most people the symptoms start when they are young adults, but they can happen at any age. The first time a person has these symptoms is called a 'first episode of psychosis'. Some people only ever have one episode of psychosis, but others may have more than one. There are different types of psychosis; schizophrenia is one type, but psychosis can also sometimes occur in people with bipolar disorder or depression. (See the [Other NICE guidance section](#) for details of our guidance on bipolar disorder and depression.)

Your care team

A range of care professionals who specialise in different areas of treatment and support may be involved in your care. These could include psychiatrists, psychologists, GPs and other primary care professionals, specialist nurses and social workers.

Working with you

Your care team should build a supportive relationship with you and your family or carers based on hope, optimism and trust. They should talk with you about psychosis and schizophrenia and explain any tests, treatments or support you should be offered so that you can decide together what is best for you. Your family or carer can be involved in helping to make decisions, but only if you agree. There is a [list of questions](#) you can use to help you talk with your care team.

You may like to read NICE's information for the public on [Service user experience in adult mental health](#). This sets out what adults should be able to expect when they use the NHS. We also have more information on the NICE website about [using health and social care services](#).

Some treatments or care described here may not be suitable for you. If you think that your treatment does not match this advice, talk to your care team.

Getting help early if you are at risk of or have a first episode of psychosis

You should be assessed by a psychiatrist or a specialist in psychosis and treated quickly if you are at risk of developing psychosis or have a first episode of psychosis.

If you are at risk of developing psychosis

You may be at risk of developing psychosis if you are distressed and finding life difficult and have:

- hallucinations or delusions that last for a short amount of time
- other experiences or behaviour that suggest you may have psychosis or
- a close relative with psychosis or schizophrenia.

If you are at risk, you should be offered:

- an assessment straightaway
- psychological therapy called cognitive behavioural therapy (or CBT for short) to help with the symptoms.

You and your family may also be offered psychological therapy called family intervention.

See [Psychological therapy](#) for more information.

If you have another mental health problem, or a problem with drugs or alcohol, you should be offered treatment for those as well.

You should not be offered medication to treat the symptoms of psychosis (called antipsychotic medication) at this point.

If, after psychological therapy, you are still having the same problems, but your healthcare professionals do not think you are experiencing psychosis, they should keep seeing you regularly for up to 3 years to make sure your symptoms are not getting worse.

If you don't want to see your health professional regularly, you should be given advice about contacting services if your symptoms get worse.

If you have a first episode of psychosis

The first time you have an episode of psychosis you should be assessed straightaway and offered help and treatment from an early intervention service, which provides support for people with symptoms of psychosis. If you are having a crisis and need urgent help you may be seen and given treatment at home by a crisis resolution and home treatment team.

Assessment

An assessment is a meeting with healthcare professionals to find out if you have a mental health problem and which treatments might be most suitable. These professionals should include a psychiatrist, psychologist or a professional who specialises in psychological therapy for people with psychosis or schizophrenia.

If you are at risk of developing psychosis, you should be assessed at a specialist mental health service or an early intervention service.

If you have a first episode of psychosis, you should be assessed at an early intervention service.

The healthcare professionals should ask you about your life, your thoughts, feelings and behaviour, your general health and wellbeing, and your mental health. They should carry out a physical examination and check for any health problems. In particular, they should check for mental health problems such as post-traumatic stress disorder, depression and anxiety, and problems with drugs or alcohol.

They should develop a care plan with you (with details of your treatment and support) as soon as possible after the assessment, and give you a copy.

Treatment options

Treatment for a first episode

If you have a first episode of psychosis, you should be offered both:

- antipsychotic medication and
- psychological therapies called cognitive behavioural therapy (or CBT for short) and family intervention (for you and your family).

See [Antipsychotic medication](#) and [Psychological therapy](#) for more information.

Treatment for another episode

If you have another episode, you should be offered the same treatment (antipsychotic medication, CBT and family intervention) as for a first episode, or a review of your current treatment.

You may continue to receive treatment and care from the early intervention service, but you may also be offered treatment by a crisis resolution and home treatment team if you need more urgent care. The team will try to treat you at home or in a crisis house (an alternative to hospital that helps people keep their independence during a crisis) or day hospital, but some people with psychosis and schizophrenia may need to be admitted to hospital (see [If you need to stay in hospital](#) below).

In addition to antipsychotic medication, CBT and family intervention you may also be offered an arts therapy, particularly if you are withdrawn and have lost interest in things that you used to enjoy.

See [Antipsychotic medication](#) and [Psychological therapy](#) for more information.

You should continue therapy after you have left hospital or another service until you have completed the course.

Treatments that have not been prescribed

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 your prescribed medication and psychological therapy.

If you need to stay in hospital

If you need to stay in hospital for treatment, the hospital should be suitable for someone of your age and gender, and your family or carer should be supported, especially if the unit is a long way from where they live. The crisis resolution and home treatment team can help you go home earlier.

For more information on [what should happen if you need to stay in hospital](#) and [what should happen if you are treated under the Mental Health Act](#) see our guidance on [Service user experience in adult mental health](#).

If there is a risk to yourself or others

If you are very unwell and could be a risk to yourself or others you may be given medication to help calm or 'sedate' you.

- You should only be sedated like this in hospital.

- You should be closely monitored afterwards.

As soon as possible afterwards, healthcare professionals should talk to you about what has happened and explain why you were sedated. They should make detailed notes and encourage you to write your own account to go in your medical notes.

If you have harmed yourself or your behaviour is threatening or violent, you should receive treatment and support. (See the [Other NICE guidance section](#) for details of our guidance on self-harm and managing disturbed or violent behaviour.)

Antipsychotic medication

Antipsychotic medications (also called antipsychotics) are used to treat symptoms of psychosis such as hearing voices and seeing things that are not real.

Before you start

Before starting medication, your healthcare professional will do a health check and discuss possible medications with you.

Your healthcare professional should check your:

- weight and waist measurements
- pulse and blood pressure
- general health (including some blood tests and asking whether you eat healthily and take regular exercise).

They may also check your heart using a test called an electrocardiogram (sometimes called an ECG).

Antipsychotic medication can often have side effects. Your healthcare professional should:

- give you the details of different antipsychotic medications, how they can help, and their benefits and side effects
- ask which side effects you are most willing to accept
- involve you (and your family or carer if appropriate) in deciding which medication to take.

You should not usually be prescribed antipsychotic medication by a GP (unless they have had advice from a psychiatrist).

Starting antipsychotic medication

When you first take antipsychotic medication, your healthcare professional should:

- give you a low dose, which can be increased if needed
- see you regularly while you are taking it, especially at first
- ask if it is helping, if you are having any side effects and if you are having problems taking the medication
- monitor your general health (including weekly weight checks for the first 6 weeks and weight, pulse, blood pressure and blood tests at 3 months).

See also [Looking after your general health](#).

The medication may take some time to work, but if you have distressing side effects or it is not helping after 4 to 6 weeks, your healthcare team may offer you a different antipsychotic medication.

You should not be offered more than one antipsychotic at the same time, except temporarily if your medication is changed.

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

Psychological therapy

Psychological therapy involves meeting with a therapist (a healthcare professional competent in giving psychological therapy to people with psychosis or schizophrenia) to talk about your feelings and thoughts and how these affect your behaviour and wellbeing.

Cognitive behavioural therapy

Cognitive behavioural therapy (CBT) involves at least 16 meetings on your own with a healthcare professional.

It can be used to help encourage you to find different ways of coping with your symptoms by helping you understand how your thoughts, feelings and behaviour are linked to your symptoms of psychosis or schizophrenia.

Family intervention

Family intervention should last between 3 months and a year and include at least 10 meetings; these meetings can take place with or without other families depending on your and your family's preference.

Family intervention can help support your family to work together to help you cope and to reduce stress for your family members.

The healthcare professional should make sure that everyone involved is happy with how the therapy is going.

Arts therapies

Arts therapies can help you to express yourself and work through your problems using art, music, dance or drama.

They usually take place in groups of people with similar mental health problems.

Other psychological therapies

You should not usually be offered other types of therapy (such as counselling and therapies called supportive psychotherapy and social skills training) because they have not been found to be as helpful for people with psychosis or schizophrenia. However, your personal choice should be taken into account, especially if CBT, family intervention and arts therapies are not available.

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

Support after an episode

After an episode of psychosis or schizophrenia, you should take your medication for 1–2 years to help prevent your symptoms returning.

When you no longer need medication:

- you should stop taking it gradually with help from your healthcare professional
- you should see your healthcare professional regularly while stopping medication and for at least 2 years after you have stopped taking it.

Your healthcare team should encourage you to write about each episode for your medical notes. Many people find this helps them spot the early signs of an episode and understand their illness and treatment.

Looking after your general health

You should be offered help to prevent weight gain, diabetes and other health problems that can happen because of your medication and changes in your lifestyle.

Healthy eating and physical activity

You should be offered:

- advice on healthy eating
- help to increase your physical activity.

If you start to gain weight and are concerned about it, or you are at risk of diabetes, you should be offered further help. (See the [Other NICE guidance section](#) for details of our guidance on obesity and diabetes.)

Smoking

If you smoke, you should be offered help to stop smoking. You may be offered one of the following:

- nicotine patches and an inhalator, gum, lozenges or spray, or
- medication called bupropion, but only if you have a diagnosis of schizophrenia, or
- medication called varenicline.

Possible side effects of bupropion and varenicline

If you are offered bupropion or varenicline your healthcare professional should discuss with you that there may be an increased risk of anxiety, depression or thoughts of suicide.

If you take either of these drugs you should be monitored regularly, particularly during the first 2-3 weeks.

There is more information about medicines on [NHS Choices](#).

If you are in hospital and don't want to stop smoking you should be offered help (such as nicotine patches and an inhalator, gum, lozenges or spray) to reduce the amount you smoke or stop temporarily.

General health checks

You should have a health check with your GP at least once a year.

Your GP should:

- check for weight gain, diabetes, and heart, lung and breathing problems (this should include measuring your weight and waist, taking your pulse and blood pressure, and giving you blood tests)
- ask if you are eating well and taking regular exercise
- keep your care coordinator and psychiatrist informed about the results.

If you have a heart problem or diabetes, or there is a risk you could develop them, your GP should offer you further help and treatment. (See the [Other NICE guidance section](#) for details of our guidance on heart problems and diabetes.)

Peer support and self-management

You may be offered 'peer support' which is support from someone who has recovered from psychosis or schizophrenia and has trained to be a peer support worker.

You may also be offered support from a health or social care professional to help you manage your condition and other parts of your life yourself (called a self-management programme).

Both types of support should include:

- information and advice about psychosis and schizophrenia
- how to take medication
- how to recognise and cope with symptoms
- how to get help from mental health and other support services
- what to do in a crisis
- meeting other people who can support you
- help to recover and stay well.

Helping you to stay well in the future

Professionals and services that can help you stay well

Once you have recovered from an episode of psychosis or schizophrenia, you can continue to receive care and treatment from the early intervention service or from another local team of professionals called a 'community-based team'. This team should offer you treatment, and support you to stay well in the future. If you need help and support from more than one service, a 'care coordinator' should organise all the care you receive.

You should have an annual appointment to check that your medication is still working and any side effects are manageable.

If you feel well enough, your care can be transferred to your GP, if you prefer. When this happens your GP should do a health check, which should include your mental and physical health (see [Looking after your general health](#)).

If you are moving and need support and treatment from another mental health or social care service, this should be discussed with you first (and with your family or carer if you agree). 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.

Support with work and education

If possible you should be supported by mental health services to stay in work or education, or find new work or education opportunities. You may also be offered a place on an employment scheme or other training or activities, including help to continue with your education at home or at a special college until you get better.

Treatments to help you stay well

Taking medication and continuing psychological therapy can help you to recover and stay well in the future.

Your healthcare professional should help you decide on the best medication for you and the best way for you to take it in the long term.

This could be by taking an antipsychotic medication that has long-lasting effects (called 'depot antipsychotics'). These are usually given every 2–4 weeks (depending on the type) by injection into muscle. You should be asked whether you want to receive your medication in this way and where (for example, at your GP's surgery, a day hospital or at home).

If you 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 it you should have your treatment reviewed regularly.

It is usually better to take medication regularly. But if you would prefer not to take medication all the time or you have had unpleasant side effects, you may be given the option of taking medication only when you start to feel ill again.

If you start to feel ill again

Your GP should check your care plan and may refer you to your care coordinator or psychiatrist if:

- you start to have symptoms again
- your treatment is not working
- you have unpleasant side effects from your medication
- you are using alcohol or drugs

- there is a risk to yourself or others.

If you need further treatment the healthcare professionals should take account of your wishes and discuss side effects and other treatments you would like to try.

If treatment doesn't help

If treatment does not help, your healthcare professional should try and find out why and may offer you alternative treatments.

Your healthcare professional should check:

- that you have been taking your medication as discussed
- for other reasons why you are not getting better (such as illness, drinking too much alcohol or taking other prescribed or non-prescribed drugs).

Your healthcare professional should also check how your psychological therapy is going.

If you have tried at least two different antipsychotics 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 you are receiving care from an early intervention service and your symptoms have not improved, you may continue to attend this service beyond the usual 3 years.

Families and carers

Involving your family or carer

It can be helpful for a family member or carer to know about what you are going through and any risks that you may face, and to understand things from your point of view. They can also be involved in helping to make decisions about your care, if you agree.

The health and social care team should discuss regularly with you and your family member or carer, if they are involved in your care, how your personal information will be shared.

Information and support for families and carers

The health and social care team should:

- give your family or carer information (both written and spoken) about psychosis or schizophrenia, including diagnosis, treatment, the services and teams involved, and recovery, and offer them support if they have any questions
- tell them about the types of support available for carers and how to get help in a crisis
- offer them an assessment of their own needs and develop a care plan with them if needed, which is reviewed every year
- discuss with them their role in your care
- tell them about their right to a carer's assessment by social care services, and explain how to arrange this
- offer them education and support (which may be part of a family intervention).

Questions to ask about psychosis and schizophrenia

These questions may help you discuss your condition or the treatments you have been offered with your healthcare team.

Finding out what's wrong

- 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?

First episode of psychosis

- Where can I have treatment?
- Can I choose to stay in hospital for treatment?

- What happens if I decide not to have antipsychotic medication?
- Can I write down something about what treatment I would like?

Treatments

- 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 treatments other than the recommended treatment?
- Are there any leaflets about the treatment(s) that I can have?
- How long will psychological treatments last?
- How long will I have to take medication?
- 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?
- 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?

Questions for family members and carers to ask

- Can you give me some information about psychosis or schizophrenia, and the treatments for it?
- Is there anything in particular that I can do to support my family member?
- Can you give me any information about specialist support for families and carers, such as helplines?
- Who can I contact for help during a crisis?
- What help and support is available to me?
- Can I have a carer's assessment? What does it involve?

Sources of advice and support

- Mental Health Foundation
www.mentalhealth.org.uk
- Mind, 0300 123 3393
www.mind.org.uk
- Rethink Mental Illness, 0300 5000 927
www.rethink.org
- SANE, 0845 767 8000 (SANEline)
www.sane.org.uk

You can also go to [NHS Choices](#) for more information.

NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

Other NICE guidance

- [Smoking cessation in secondary care](#). NICE public health guidance 48 (2013).
- [Service user experience in adult mental health](#). NICE clinical guidance 136 (2011).
- [Psychosis with coexisting substance misuse](#). NICE clinical guideline 120 (2011).
- [Alcohol-use disorders](#). NICE clinical guideline 115 (2011).
- [Generalised anxiety disorder and panic disorder \(with or without agoraphobia\) in adults](#). NICE clinical guideline 113 (2011)
- [Depression in adults](#). NICE clinical guideline 90 (2009).
- [Type 2 diabetes](#). NICE clinical guideline 87 (2009).
- [Lipid modification](#). NICE clinical guideline 67 (2008).
- [Obesity](#). NICE clinical guideline 43 (2006).
- [Bipolar disorder](#). NICE clinical guideline 38 (2006).
- [Post-traumatic stress disorder](#). NICE clinical guideline 26 (2005).

- Violence. NICE clinical guideline 25 (2005).
- Self-harm. NICE clinical guideline 16 (2004).

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Accreditation

