

Psychosis and schizophrenia in children and young people

Information for the public

Published: 1 January 2013

nice.org.uk

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 children and young people that is set out in NICE guideline CG155.

Information about newer (second generation) antipsychotic medications was added in 2016. This information is in the taking antipsychotic medication section.

Does this information apply to me?

Yes, if you are younger than 18 and:

- have psychosis but do not have a diagnosis of schizophrenia, or
- have schizophrenia (including types called schizoaffective disorder and delusional disorder), or
- are thought to be at risk of psychosis.

This information is also for parents and carers (see the information for parents and carers section).

Psychosis and schizophrenia

Psychosis and schizophrenia are mental health problems that affect a person's thoughts, mood and behaviour. The main symptoms are called 'psychotic' symptoms. These are:

- hearing voices and sometimes seeing things that are not really there (called a hallucination)
- believing strongly that something is real or true when it is not (called a delusion); for example, some people with delusions may be sure they are being watched or having their thoughts monitored.

Because of these symptoms the person may not be able to think clearly or concentrate. There may be changes in the way they behave. They may lose interest in things and other people.

There are different types of psychosis, and the healthcare team will try to work out which one the person has. Schizophrenia is one type, which is covered by this information. People with [bipolar disorder](#) and [depression](#) can also have psychosis. See the [other NICE guidance](#) section for details of our guidance on these conditions. Some people only ever have one experience of psychosis, whereas others have more than one. Some people go on to have a [diagnosis](#) of schizophrenia, bipolar disorder or depression. It is also possible to have psychosis without one of these diagnoses.

Your care team

A range of professionals who specialise in different areas of treatment or support may be involved in your care. These could include psychologists, psychiatrists, GPs, nurses and social workers. All these professionals should be trained and experienced in working with children and young people with mental health problems and their parents and carers. Your healthcare team will work in either:

- a service that specialises in mental health problems in children and young people aged 17 and under (called [child and adolescent mental health services](#) or 'CAMHS'), or
- a service that specialises in early treatment for psychosis for people aged 14 to 35 (called an [early intervention in psychosis service](#) or 'EIP' for short).

If you receive treatment and care from an early intervention in psychosis service, you should stay with that service for up to 3 years or until your 18th birthday, whichever is longer.

Care should be provided by one team throughout your illness.

Considering your needs

Health and social care professionals should take into account your religious, cultural and ethnic background when assessing your condition and planning treatments. They should also consider learning ability, maturity and developmental stage. They should offer [assessment](#) and treatment suited to your culture, gender, age and communication needs. They should also offer you access to an interpreter and a list of local education providers who can teach English if needed. The team should ask whether you would prefer to be contacted by letter, phone, email or text message.

A member of your healthcare team should discuss psychosis or schizophrenia with you and give you information about the condition and its treatments in a language or format you can understand. They should also give you details of organisations providing support and information, support groups and useful websites. You should be given the chance to ask questions – there are lists of questions you might like to ask in the [questions to ask about psychosis and schizophrenia in children and young people](#) section.

The health and social care team should know that you may feel nervous about attending mental health services and they should make you feel comfortable and put you at your ease. They should work with you to build trusting relationships, support you to feel optimistic and encourage you to manage your condition and meet people of your own age with similar problems, if possible. Children and young people should be treated with respect and dignity, and discussions with healthcare professionals should take place in private.

Professionals should explain that they may need to discuss your treatment and care with other professionals, or write to them. You should be sent a copy of the letter, if you would like this.

Your healthcare team should support you to continue your education while you are unwell. If agreed, they can contact your school or college to ask the teachers to give you extra support if needed. If you are too ill to go to school or college, you may be offered other help with your education (which may be at home or at a special school) until you get better.

Involving your parents or carers

If you are a young person and you are able to make decisions about your care, your healthcare team should discuss with you how you would like your parents or carers to be involved. They should talk to you about this again from time to time in case you change your mind. If you would like your parents or carers involved, professionals should talk to you about what they can tell your parents or carers about your condition and when.

You should be asked whether you would like a trained advocate (someone who can help you put your views across).

If you are a child, your parents or carers will usually be involved. There is a section for them called [information for parents and carers](#).

Getting help early

If a GP or another professional thinks that you may have psychosis, they should offer you an appointment without delay for an [assessment](#) in CAMHS or an [early intervention in psychosis service](#).

If you have had hallucinations or delusions for 4 weeks or more, you should be offered an urgent appointment with a consultant psychiatrist either in CAMHS or an early intervention in psychosis service. The psychiatrist should have training in child and adolescent mental health.

Assessment

An [assessment](#) is a meeting with a healthcare professional to talk about symptoms, physical health, medical and family background and everyday life at home, school, college or work. The assessment helps the healthcare professional to find out if you have a mental health problem and which treatments might be most suitable.

There should be enough time to talk about your problems and ask questions. If you are given a [diagnosis](#), this should be clearly explained and you should be given a booklet or leaflet about it. The healthcare professional should also give you information about different treatments and discuss these with you.

More than one assessment may be needed if healthcare professionals are not sure what the problem is, but these should be kept to a minimum. If you're not given a diagnosis, healthcare professionals in specialist services will ask to see you regularly for up to 3 years after the assessment to make sure your symptoms are improving and not getting worse. You or your parents or carers can decline this. If you do, you'll be offered another appointment and advised to contact services yourself if your symptoms get worse. There should be time to talk after the assessment, especially if you found any of it upsetting.

Developing care and crisis plans

If the healthcare professional thinks you may have psychosis, they should develop a [care plan](#) with you and your parent or carer. The care plan should give details of treatment and how you can manage your symptoms. The plan should also include:

- ideas about how you can keep in contact with other young people through education, work, volunteering or leisure activities
- what you can do to keep well, including eating healthily, exercising and stopping smoking
- how you can cope with and reduce any risks to yourself or others.

Health and social care professionals should support you to follow the plan, and arrange to look at it again to make sure it is still suitable.

If there is a risk you may be unable to cope (have a crisis), there should also be a crisis plan, which should include:

- how to recognise warning signs that might suggest a setback or a crisis
- the support available to help you to carry on treatment without staying in hospital
- whether your parents or carers are involved in your care
- the names of professionals involved in your care
- where you would prefer to go if you need to stay in hospital.

If you are unhappy about the assessment and diagnosis, you should be given time to discuss this and offered a second opinion.

Treating possible psychosis or schizophrenia

If you find your symptoms very upsetting but professionals are not certain whether you have psychosis or schizophrenia, they may offer you [cognitive behavioural therapy](#) (or CBT for short). This is a type of [psychological therapy](#) (therapy for short). They may also offer a type of therapy involving your family called [family intervention](#). If you also have [anxiety](#), [depression](#), [personality disorder](#) or a problem with drugs or alcohol, you may be offered treatment for that as well. Medication called [antipsychotic medication](#) should not be offered at this stage.

Healthcare professionals in specialist services will ask to see you regularly for up to 3 years after an [assessment](#) to make sure your symptoms are improving and not getting worse. If you, or your parents or carers, don't want this you will be offered another appointment and healthcare professionals should advise the family to contact services if your symptoms get worse.

Treating a first episode of psychosis

If professionals think that you have psychosis, they should offer you therapy and [antipsychotic medication](#). Therapy works better with antipsychotic medication. However, if you (or your parents or carers) decide that you would rather not take this, professionals should see you regularly and arrange a time (usually within a month) to discuss again whether you would like to start medication.

You should be offered [CBT](#) with a type of therapy involving your family called [family intervention](#). Family intervention should last between 3 months and a year and include at least 10 meetings. CBT involves at least 16 meetings with a healthcare professional without your family or carers. The healthcare professional should make sure that everyone is happy with how the therapy is going.

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

If you wish to try treatments not usually prescribed by healthcare professionals (called 'complementary therapies'), you should discuss these with your healthcare team. The team should advise you whether these are safe, helpful and whether they are likely to affect your prescribed medication and therapy.

Taking antipsychotic medication

Your healthcare professional should give you all the details of the possible different medications, how they can help and their benefits and [side effects](#). They should involve you and your parents or carers in deciding which medication to take. They should ask which side effects you would most like to avoid.

If you choose a [newer \(second generation\) antipsychotic medication](#) and are considering olanzapine, your healthcare professional should tell you that you are likely to gain more weight with olanzapine than with other medications of this type, and that gaining weight is likely to happen soon after you start treatment.

You should not be prescribed antipsychotic medication by your GP unless they have had advice from a consultant psychiatrist with training in child and adolescent mental health.

Before starting medication, your healthcare professional should measure your weight, height, waist and hips, pulse and blood pressure, and give you blood tests to check your general health. They should make sure that you know it's especially important to keep healthy by eating well and taking regular exercise. They may check your heart (using an [electrocardiogram](#)).

Your healthcare professional should see you regularly while you are taking antipsychotic medication, especially at first. They should check whether the medication is helping and whether there are side effects. They should also check your general health and if there are problems taking the medication.

The medication may take some time to work (up to about 6 weeks), but if after a time it is not helping or you have distressing side effects, your healthcare team may offer a different antipsychotic medication. It may take a while to find the right medication, but your healthcare team should guide you through this. They should not offer you more than one antipsychotic at the same time, except for short periods if the medication is changed.

Your healthcare professional should review your medication each year to see if it is still helping. They should advise you that drinking alcohol, smoking or taking other drugs could stop the antipsychotic medication working and make your symptoms worse.

Treating another episode of psychosis or schizophrenia

If you have another episode of psychosis or schizophrenia, your healthcare team should offer you [antipsychotic medication](#) and therapy (CBT with [family intervention](#)) as described in the [treating a first episode of psychosis](#) section.

They may also offer [arts therapies](#) (dance, drama, music or art), particularly if you are withdrawn and have lost interest in things you used to enjoy. Arts therapy should usually take place with other children and young people who have psychosis or schizophrenia.

Other types of therapy, such as counselling and [supportive psychotherapy](#), are not thought to be as helpful as CBT, family intervention and arts therapies for children and young people with psychosis or schizophrenia. However, if you would like one of these treatments, your personal choice should be taken into account, especially if CBT, family intervention and arts therapies are not available in your area.

You should be encouraged to take medication for 1–2 years after an episode of psychosis because there is a high risk that if you stop taking it your symptoms will get worse. When you no longer need medication, it should be stopped gradually. Your healthcare professional should see you regularly during this time and for at least 2 years after you have stopped medication.

Treatment and care in a crisis

If you have a crisis, you should be seen by a professional in a specialist service (either [child and adolescent mental health services](#) or an [early intervention in psychosis service](#)) within 4 hours. They should support you to stay at home rather than going into hospital if possible. The team may offer you treatment at home and should help you continue your daily activities, including education, work, volunteering and leisure activities.

If you [self-harm](#), you should receive the treatment and support recommended by NICE. See the [Other NICE guidance](#) section for more details of NICE's advice on self-harm.

Treatment in hospital

If you go into hospital, the hospital should be suitable for someone of your age. You should be given information about the hospital, the treatments, activities and services available, the rules of the ward, your rights, meal times and when people can visit. You should also be told how often you can expect to meet health and social care professionals. There should be enough time for you to ask questions about the information you are given.

You should be able to continue your education while in hospital and you should be offered creative and social activities as part of your treatment. The hospital team should support you to eat healthily, exercise and stop smoking.

If therapy is started in hospital, it should continue once you have left hospital until you have completed the course.

Health and social care professionals who cared for you before you went into hospital should visit you while you are there.

If you are very unwell and it is thought that there is a risk to yourself or others, you may be given medication to help calm you down (this process is called 'rapid tranquillisation'). Afterwards healthcare professionals should talk to you about what happened and explain why the medication

was needed. They should encourage you to talk about your experiences. This will go in the notes about your care.

Further help if you are not getting better

If medication has not helped, your healthcare professional should check that you have been taking it as prescribed. They should also look for other reasons why you might not be 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 (for 6 to 8 weeks each) 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. Your healthcare professional should discuss the choice of antipsychotic with you and with other members of your healthcare team.

If therapy has not helped, your healthcare professional should check that it has been provided as recommended (see the section called [treating a first episode of psychosis](#)). They may suggest trying a different therapy.

Helping you to stay well in the future

When you start to feel better, your healthcare team should discuss with you and your parents or carers how you can stay well in the future. Continuing therapy and medication can help (see the section called [treating a first episode of psychosis](#)).

If you are of working age, you have not been able to work because of your condition and you wish to return to work or get a job, you should be offered a place on a 'supported employment programme'. This is a type of work scheme. There may also be other types of work schemes available in your local area.

Your physical health

Many children and young people with psychosis or schizophrenia are at risk of physical health problems, such as gaining weight and [diabetes](#), from some [antipsychotic medication](#) and because of changes in lifestyle due to their condition. Your GP can help you stay well by checking your physical health at least once a year, including your weight and blood pressure, and giving you blood tests. You should be offered treatment for any physical health problems.

Supporting you if you become ill again

If you become ill again, or your GP thinks that your treatment is not working or you have unpleasant [side effects](#), you should be offered an appointment at a specialist service and treated according to your [care plan](#). If you need further treatment from specialist 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 therapy.

When your treatment and care comes to an end

Before treatment ends or care is transferred to another service (such as a mental health service for adults or a GP), this should be discussed and planned with you, and your parents or carers (if you agree), and should not happen without warning. You should agree with health and social care professionals steps to help you cope with any crises. Advice should be offered about how to contact professionals if needed. If your care is being transferred to another service, you should be offered support during the transfer.

Information for parents and carers

For most children, parents and carers will be involved in the child's care, and you can help them to understand the information above. When young people are mature enough to make their own decisions, healthcare professionals should ask them how they would like you to be involved in treatment and care and what information can be shared.

As parents or carers of children with psychosis or schizophrenia you will usually be involved in the [assessment](#) (see the [assessment](#) section), developing the [care plan](#), crisis planning (see the [developing care and crisis plans](#) section) and treatment decisions. If the child or young person has a crisis, the healthcare team will try and support them at home if possible. If they need treatment in hospital, you should be supported, especially if the unit is a long way from where you live. You should be given information about the hospital, the treatments, activities and services available, the rules of the ward and when you can visit.

The recommended treatment for children and young people with psychosis or schizophrenia is [antipsychotic medication](#) together with [psychological therapy](#) (CBT with [family intervention](#)). Family intervention involves all the family (see the [treating a first episode of psychosis](#) section). Research shows that psychological therapy works better if the child or young person is also taking antipsychotic medication, and you can help the child or young person decide which medication to

try. The healthcare team will explain the pros and cons of different medications, and the possible side effects, and support you to make a decision.

You may need help and support yourself. Healthcare professionals should give you information about local family and carer support groups and other voluntary organisations, and help you to contact them. Anyone with a caring role has the right to a carer's assessment.

The healthcare team will work with schools and colleges to ensure that the child or young person can continue their education. If they think that they have special educational needs, they can advise you how to apply for an assessment and support you throughout the process.

Questions to ask about psychosis and schizophrenia in children and young people

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

Questions about psychosis, schizophrenia and assessment

- Can you tell me more about psychosis or schizophrenia?
- Can you tell me more about what happens during an assessment?
- Are there any support organisations in my local area?
- Is there any support to help me to continue my education or find a job?
- Do you have any information for my parents/carers?

Questions about treatments

- Why have you decided to offer this treatment?
- What are the pros and cons of this treatment?
- What will it involve and how long will it last?
- How will it help? What effect will it have on my symptoms and everyday life? What sort of improvements can I expect?
- How long will it take to work?

- Are there any risks with this treatment?
- Where is this treatment given?
- What other treatments are available?
- What will happen without this treatment?
- Do you have any more information about the treatment?

Questions about antipsychotic medication

- How long will I have to take the medication?
- Are there likely to be problems when I stop the medication?
- Are there any serious side effects with this medication?
- What should I do if there are side effects? Should I call the GP, or go to the emergency department at a hospital?
- Are there any long-term effects of taking antipsychotic medication?

Questions if you are not getting better

- When should I start to feel better and what should I do if I don't start to feel better by then?
- Are there different treatments to try?
- Does the dose of my medication need to be changed?
- Would more therapy or a different type of therapy help me?

Questions for parents and carers

- Can I/we have some information about psychosis/schizophrenia and its treatments?
- What can I/we do to help and support the child/young person with psychosis/schizophrenia?
- Can you give me/us any information about how to get help and support if the child/young person has a crisis?
- Is there any additional support that I/we as carer(s) might benefit from or be entitled to?

Terms explained

Antipsychotic medication

A type of medication that is sometimes used to treat serious changes in mental state (such as hallucinations and delusions).

Anxiety

Feelings of worry or fear that can be difficult to control.

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.

Assessment

Meeting with a health or social care professional to discuss your mental and physical health, family background and everyday life, to find out what the illness is, how severe it is and the most suitable treatments.

Bipolar disorder

A mental health problem in which a person has periods of mania (extreme happiness or feeling 'high' and over-confident) and periods of [depression](#).

Care plan

A plan of your treatment and care, which also includes what you can do to keep well and how to manage your symptoms.

Carer's assessment

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

Child and adolescent mental health service (or CAMHS for short, pronounced 'cams')

A service that provides treatment for and supports children and young people with mental health problems and their parents and carers.

Cognitive behavioural therapy (CBT)

A psychological therapy 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.

Depression

A common mental health problem, the main symptoms of which are losing pleasure in things that were once enjoyable and losing interest in everyday activities and other people.

Diabetes

An illness caused by having too much sugar in the blood. The main symptoms are feeling tired, thirsty and needing to go to the toilet more than usual, and having blurred vision.

Diagnosis

Identifying an illness or problem after having considered the person's symptoms.

Early intervention in psychosis service

A service that provides early identification and treatment to people aged 14 to 35 who have symptoms of psychosis. The service should be able to provide a full range of psychological therapy, antipsychotic medication and other support.

Electrocardiogram

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

Family intervention

A psychological therapy that supports families to work together to help people with psychosis or 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.

Newer (second generation) antipsychotic medications

A type of antipsychotic medication first developed during the 1990s, sometimes called 'atypical' antipsychotic medications. Examples are aripiprazole, olanzapine, risperidone and quetiapine. Older (first generation) antipsychotic medications were developed in the 1950s.

Personality disorder

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

Psychological therapy

A treatment that involves meeting with a healthcare professional to talk about feelings and thoughts and how these affect behaviour 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.

Side effect

An unwanted symptom caused by a medicine or other treatment.

Supportive psychotherapy

A type of psychological therapy similar to counselling. The content of the sessions is largely determined by the person having treatment rather than the healthcare professional, who will listen and offer support.

Sources of advice and support

- HeadMeds
www.headmeds.org.uk
- Mind, 0300 123 3393 (telephone number for people who are nearly 18, or are 18 and over)
www.mind.org.uk
- Rethink Mental Illness, 0300 5000 927
www.rethink.org
- YoungMinds, Parent Helpline 0808 802 5544
www.youngminds.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

- [Diabetes \(type 1 and type 2\) in children and young people](#) (2015) NICE guideline NG18
- [Bipolar disorder](#) (2014) NICE guideline CG185
- [Psychosis and substance misuse in over 14s](#) (2011) NICE guideline CG120
- [Alcohol-use disorders](#) (2011) NICE guideline CG115
- [Generalised anxiety disorder and panic disorder in adults](#) (2011) NICE guideline CG113
- [Aripiprazole for the treatment of schizophrenia in people aged 15 to 17 years](#) (2011) NICE technology appraisal guidance 213
- [Borderline personality disorder](#) (2009) NICE guideline CG78
- [Drug misuse in over 16s](#) (2007) NICE guideline CG51
- [Depression in children and young people](#) (2005) NICE guideline CG28
- [Post-traumatic stress disorder](#) (2005) NICE guideline CG26
- [Self-harm in over 8s](#) (2004) NICE guideline CG16 (2004)

ISBN: 978-1-4731-1870-6

Accreditation

