

Managing autism in children and young people

Information for the public

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About this information

NICE clinical guidelines advise the NHS on caring for people with specific conditions or diseases and the treatments they should receive. The information applies to people using the NHS in England and Wales.

This information explains the advice set out in NICE clinical guideline 170 about managing autism in children and young people. NICE has also produced information for the public on diagnosing autism in children and young people (see <http://publications.nice.org.uk/IFP128>).

All of the treatment and care that NICE recommends is in line with the NHS Constitution (<https://www.gov.uk/government/publications/the-nhs-constitution-for-england>).

Does this information apply to me?

Yes, if you are:

- a child or young person (up to age 18) with autism
- a parent, carer or family member of a child or young person with autism.

This information has been written mainly for older children and young people, but parents, carers and family members should read all the information to understand the care the child or young person should be offered. NICE has also made specific recommendations about [supporting parents and carers and pre\u2011school children](#).

Autism

People with autism have difficulties interacting and communicating with people in social situations and also have restricted interests and rigid and repetitive behaviours.

Autism affects children and young people in different ways, but the main signs include:

- problems communicating with other people, such as not saying much or sometimes not speaking at all, having an unusual way of talking, saying certain things over and over, or only talking about things they like
- problems showing how they feel or what they think, and problems understanding and responding to how other people show their thoughts and feelings
- not knowing how close they can get to other people
- finding it hard to make friends and play with them or preferring to be alone
- reacting strongly to certain smells, sounds, textures, or to any change in routine
- making unusual hand or body movements again and again.

A child or young person with autism may find it more difficult to settle to sleep or have problems with feeding or with what they eat.

Some people with autism may also have a [learning disability](#), a mental or physical health problem (to find out more, see the [Other medical and mental health problems](#) section) or sometimes they may become upset or aggressive (for more about this see the [Behaviour that challenges](#) section). Although there is no cure for autism, providing care and support can help with some aspects of autism and other problems that children and young people with autism may have.

Autism is used in this information to refer to autism spectrum disorder, autistic spectrum condition and Asperger's syndrome.

Your local autism team

The team will be made up of different professionals, which may include:

- paediatricians (doctors who are experts in children's health)
- speech and language therapists (professionals who help with speech, language and communication problems)
- psychologists (professionals who specialise in mental, emotional and behavioural problems)
- social workers
- psychiatrists (doctors who specialise in mental health problems)
- occupational therapists (professionals who help promote people's health and wellbeing through everyday activities).

The care and support you receive will usually be provided or organised by your autism team and will be coordinated by one person (your 'case manager' or 'key worker'). If your autism team is not able to provide the care you need, you may be offered an appointment with a national autism service.

Having a say in your care

A member of the team should discuss autism with you and whether you would like to be involved in making decisions about your care. Your wishes should be taken into account and you should have a chance to ask any questions – there are lists of questions at the end of each section you might like to ask to help you with this.

Using care services

Your autism team should give you details about other support available. This may include information about services and managing your autism and about organisations that

provide:

- a chance to meet other people with autism and their parents or carers
- details about courses about autism
- advice on benefits and your rights
- information about supporting you in school and at home
- information about leisure activities.

Having autism should not prevent you receiving health and social care services if you need them. You have the same right to be cared for and supported as any other child or young person.

The services you use should be suitable for your needs so that you feel comfortable. For example, if you don't like being close to other people or you react badly to bright lighting, too much noise or waiting around, the service should take account of this.

Providing care and managing autism

You may be offered a kind of programme called a 'social-communication intervention'. This aims to help you communicate and interact with people and make social situations easier for you. Depending on your age, it may take place at school with your classmates, or with a parent, carer or teacher. Your autism team should organise support to help you cope with everyday situations that you may find difficult. It can also help you to stay in school or college, or help if you move to a new school, and, if you are older, find or stay in a job. You may find that you need different kinds of support at certain times.

Special diets that do not contain certain foods (such as [gluten](#) or [casein](#)) and medication ([anticonvulsants](#), [antidepressants](#) and [antipsychotics](#)) should not be offered to treat the main signs of autism in children and young people. (However, you may be offered medication for other problems you may have – see [Behaviour that challenges](#) and [Other medical and mental health problems](#). You may also be offered a special diet to help with problems other than autism.)

Treatments called 'hyperbaric oxygen therapy', 'secretin' or 'chelation' should not be offered to treat autism or any other problem associated with autism.

Questions about care and managing autism

- Why have you offered me this type of care and management programme?
- What does this type of care involve and how long does it last?
- How will this type of care help me?
- What are my options other than the recommended programme for autism?
- What will happen if I choose not to have the recommended programme?
- Is there more information about the care and treatment that I can have?
- Why can I take medication to treat other problems but not autism?

Other medical and mental health problems

If you also have a medical or mental health problem as well as autism, you should be offered treatment as recommended by NICE (for more information see the [Other NICE guidance](#) section).

Anxiety

If you get very anxious (you can't stop worrying and feel scared), you may be offered a [psychological therapy](#) called cognitive behavioural therapy (or CBT for short). You may have CBT either as part of a group of children or young people with autism, or on your own. Your parents or carer may be involved in the treatment too.

Speech, language and communication problems

If you have problems talking to, communicating with or understanding other people, a member of the autism team can help you or will find someone who can help. You should not be offered procedures called [neurofeedback](#) or [auditory integration training](#) to help you with speech, language and communication problems.

Sleeping problems

If you have problems getting to sleep at night, staying asleep or you feel sleepy during the day, you should be offered an [assessment](#) to look at what might be causing the problem. The assessment may include looking at where you sleep, any medication you are taking or other problems you may have. Your parents or carers will work with the autism team to make a plan to help you to sleep better at night. You should not be offered medication unless the sleeping problem continues or is affecting your life. If you take medication for a sleeping problem it should only be started after you have seen a paediatrician or psychiatrist who is an expert in autism or in sleep medication, and you should continue to follow the sleep plan. The team should check regularly to see whether the medication is still helping you. If you still have problems sleeping, or you snore loudly, choke or seem to stop breathing while asleep, you should be offered an appointment with a specialist.

You should not be offered a substance called an [omega\u20113 fatty acid](#) for a sleeping problem.

Questions about treatment for other problems

- Can I have treatment for other problems as well as for autism?

If you are taking medication for another problem you might like to ask:

- How long will I have to take the medication?
- What are the possible side effects of this medication?
- Might I have problems when I stop taking the medication?

Behaviour that challenges

Some people with autism may behave in a way that other people find challenging or difficult (for example, they may become very upset or aggressive). You should be assessed by a member of your autism team to see if this is a problem for you or other people.

A member of the autism team should develop a care plan that sets out the steps that

should be taken to prevent behaviour that challenges. This might include treatment for physical or mental health problems, or agreeing with your family, teachers or carers about changes that might be needed at home or at school.

Psychological therapy

If your behaviour continues to cause problems for you and other people, and there is no obvious cause for it, you should be offered a psychological therapy to help to change the behaviour. You and your parents or carers should have a say in the choice of treatment you are offered. It should be clear how long the therapy will last and how it will be judged to have worked.

Medication

If psychological therapy does not help, or the behaviour is severe, you may be offered medication called 'antipsychotic medication'. This should only be offered by a paediatrician or psychiatrist who should talk to you about which medication suits you best and whether you have taken similar medication before. You should have a check-up after 3–4 weeks and the medication should be stopped after 6 weeks if it is not helping

Some care and management may not be suitable for you, depending on your exact circumstances. If you think that your care or management does not match this advice, talk to your autism team.

Questions about behaviour that challenges

- What is causing me to behave like his? What could help me to behave in a different way?
- What does this type of therapy involve and how long does it last?
- How will this type of therapy help me?

If you are offered medication:

- How long will I have to take the medication?

- What are the possible side effects of taking this medication?
- Might I have problems when I stop taking the medication?

Moving to adult services

When you are about 14 years old, you should be assessed to see whether you might need support from adult services after you turn 18. You should be given information about the kind of support that you might need, and you and your parents or carers should be involved in planning the move if you wish. You should usually have moved in to the care of adult services by the time you are 18. If necessary you may be given information about having a [social care assessment](#) when you are 18.

NICE has produced information for the public on the care and support adults with autism should expect (see 'Diagnosing, supporting and caring for adults with autism' at <http://publications.nice.org.uk/IFP142>)

Information for parents and carers

Supporting you

Families and carers of children and young people with autism should be offered information about autism and about local and national organisations for families and carers. You should also be offered information about your right to a [carer's assessment](#) and about other support available to you (such as short breaks and other [respite care](#)). You may be offered breaks or respite care for a night or more if your child has sleeping problems that continue after the treatment described in [sleeping problems](#). The autism team should discuss with you how regular the breaks should be.

The autism team should ask you about the personal, emotional, social and practical support you need to care for your child. The team should organise the support you need, including during periods of change, such as when your child starts a new school, or if you go on to have another child. The support you need may change as your circumstances change.

Helping you support your child

Your child may be offered a programme to help with specific problems that they may have in social situations and communicating with other people. If they are of pre-school age, you or a pre-school teacher may be asked to be involved to help provide direct support. If they are of school age, this may take place in their school classroom with their classmates and you may also be involved to support them during the programme. If you are involved, you should be offered information, training and support in how to engage your child's attention and improve their communication with you and other people. If you and your child are not offered this programme, speak to a member of your autism team.

Your autism team can also help so that your child is able to stay in pre-school.

If your child also has anxiety (see [Anxiety](#)), they may be offered a psychological therapy called [cognitive behavioural therapy](#) (CBT) – you may be asked if you would like to be involved in the treatment sessions.

Questions for family members and carers to ask

- Can you give me some information about autism, and the care and management options for it?
- Is there anything in particular that I can do to support my child?
- Can you give me any information about specialist support for parents and carers, such as helplines?
- Who can I contact for help during a crisis?
- Can I have a carer's assessment?

Terms explained

Anticonvulsant

Medication used to treat seizures and convulsions (for example in epilepsy).

Antidepressant

Medication used to treat depression.

Antipsychotic

Medication used to treat serious changes in mental state (such as hearing voices and seeing things that are not real). At the time of publication antipsychotic medication did not have a licence in the UK for treating behaviour that challenges in children with autism. Medicines need to have a licence before they can be marketed. To get a licence, the manufacturer of the medicine has to provide evidence that shows that the medicine works well enough and is safe enough to be used for a particular condition and for a particular group of patients. A medicine can be prescribed 'off-label'. This means the prescriber wants to use it in a different way than is set out in its licence. This could mean using the medicine for a different condition or a different group of patients, or it could mean a change in the dose or that the medicine is taken in a different way. There is more information about licensing medicines at <http://www.nhs.uk/chq/Pages/1004.aspx?CategoryID=73&SubCategoryID=101>

Assessment

A meeting or meetings with a health or social care professional in which they ask questions about a person's mental and physical health, their family background and everyday life, to establish what the condition or problem is, how severe it is and what care would suit them best. Professionals might want to assess children and young people in different situations, such as at home or at school.

Auditory integration training

A procedure that involves listening to music that varies in tone, pitch and volume.

Carer's assessment

An assessment by social services of a carer's physical and mental health, and their needs in their role as a carer. 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 plan, which is given to the carer.

Casein

A substance found in milk and cheese.

Cognitive behaviour therapy

A psychological therapy that is based on the idea that the way we feel is affected by our thoughts and beliefs and by how we behave.

Communication

Expressing or sharing ideas and feelings through speech and other means such as facial expression, body language (for example, shrugging or nodding), tone of voice, signs, gestures and pictures or writing.

Gluten

A substance found in cereals such as wheat, barley and rye.

Learning disability

A condition that affects intellectual ability and leads to problems in learning, developing new skills, communication and carrying out daily activities. Learning disabilities are different from 'learning difficulties', like dyslexia, which do not affect intellect.

Omega-3 fatty acids

A type of fat found in fish and plant oils.

Neurofeedback

Monitors brain activity usually with electrodes placed on the head. The person being treated can see their brain activity on a screen and is taught how to change it (such as

making it more regular).

Psychological therapy

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

Psychologist

Someone who can assess children's psychological functioning, emotional wellbeing and development, and provide help with behavioural, emotional and mental health problems.

Respite care

Support for parents and carers so that they can take a break from caring for a short while. This may involve the child or young person being looked after by someone else in residential or nursing care, or in the family home.

Social care assessment

An assessment carried out by social care services to find out what help and support people need, such as help at home.

Sources of advice and support

- Ambitious about Autism, 020 8815 5444
www.ambitiousaboutautism.org.uk/support and www.talkaboutautism.org.uk
- Autism Education Trust, 0207 903 3650
www.autismeducationtrust.org.uk
- National Autistic Society
www.autism.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

- [Autism in adults](#) (NICE clinical guideline 142).
- [Autism in children and young people](#) (NICE clinical guideline 128).
- [Attention deficit hyperactivity disorder \(ADHD\)](#) (NICE clinical guideline 72).
- [Conduct disorders in children and young people](#) (NICE clinical guideline 158).
- [Constipation in children and young people](#) (NICE clinical guideline 99).
- [Depression in children and young people](#) (NICE clinical guideline 28).
- [Epilepsy](#) (NICE clinical guideline 137).
- [Obsessive-compulsive disorder \(OCD\) and body dysmorphic disorder \(BDD\)](#) (NICE clinical guideline 31).
- [Post-traumatic stress disorder \(PTSD\)](#) (NICE clinical guideline 26).

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Accreditation

