

## Understanding NICE guidance

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Information for people who use NHS services

# Diagnosing, supporting and caring for adults with autism

*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 diagnosis, support and care for adults with autism 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 adults with autism but it may also be useful for their families, partners or carers or for anyone with an interest in the condition. For adults with autism who have a learning disability, a family member, partner or carer may need to help explain the content of this booklet.

The booklet is to help you understand the care and support options that should be available in the NHS and services working with the NHS. It does not describe autism or the care and support options 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 15. Medical terms printed in **bold** type are explained on pages 14 to 15.

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### The advice in the NICE guideline covers:

- the care of people over the age of 18 with suspected or confirmed autism.

NICE has developed a separate guideline on diagnosing autism in children and young people, and is developing another guideline that explains how children and young people with autism should be supported and cared for in the NHS. Details are available at [www.nice.org.uk](http://www.nice.org.uk)

## Your care

In the NHS, patients and healthcare professionals have rights and responsibilities as set out in the NHS Constitution ([www.dh.gov.uk/en/DH\\_113613](http://www.dh.gov.uk/en/DH_113613)). All NICE guidance is written to reflect these. You have the right to be involved in discussions and make informed decisions about your care and support with your healthcare team. Your choices are important and healthcare professionals should support these wherever possible. You should be treated with dignity and respect.

To help you make decisions, healthcare professionals should explain autism and the possible care and support options for it. They should cover possible benefits and risks related to your personal circumstances. You should be given relevant information that is suitable for you and reflects any religious, ethnic, or cultural needs you have. It should also take into account whether you have any physical or learning difficulty or disability, sight or hearing problem or language difficulties, for example, it should be in an easy read format and available in different colours and fonts, or be communicated by video or sound. You should have access to communication aids, an independent interpreter (someone with whom you do not have a personal relationship) or advocate (someone who helps you put your views across) if needed.

You should be able to discuss or review your care and support at any time, including if your circumstances change. This may include changing your mind about the care and support you are receiving.

All care and support should be given with your informed consent. If, at any point, you are not able to make decisions about your care, your healthcare professionals have a duty to talk to your family, partner or carer unless you have specifically asked them not to. Healthcare professionals should follow the Department of Health's advice on consent ([www.dh.gov.uk/en/DH\\_103643](http://www.dh.gov.uk/en/DH_103643)) and the code of practice for the Mental Capacity Act. Information about the Act and consent issues is available from [www.nhs.uk/CarersDirect/moneyandlegal/legal](http://www.nhs.uk/CarersDirect/moneyandlegal/legal)  
In Wales healthcare professionals should follow advice on consent from the Welsh Assembly Government ([www.wales.nhs.uk/consent](http://www.wales.nhs.uk/consent)).

## Autism

Autism is a condition that affects brain development, which means that the brain develops in a different way from other people. There are different types of autism including atypical autism and **Asperger's syndrome**. This booklet covers all types of autism.

Although autism affects people in different ways, the main symptoms are:

- finding it hard to deal with social situations, such as understanding other people's emotions, expressing one's own feelings and thoughts, and maintaining eye contact; some people with autism may prefer to be on their own
- having difficulties with speech and communicating with other people, responding to their facial expressions or tone of voice, and understanding common sayings; some people with autism may have limited speech or prefer to communicate with sign language
- having narrow interests or obsessions, repeating routines or movements (such as rocking) or finding it hard to prepare for change or plan for the future
- being under- or over-sensitive to sound, light, colour, smell and taste (called **sensory sensitivity**).

Although autism is a lifelong condition, some adults with autism are able to live fairly independently. Others may also have a **learning disability** and need support and care throughout their lives. Some people with autism may also have other difficulties, such as a mental health problem (see page 11) or they may behave in a way that other people find challenging (see page 12).

This booklet uses the word 'autism', but there are other terms that different people prefer to use, for example autism spectrum disorder, autistic spectrum condition, autistic spectrum difference and neuro-diversity.

## How do I get help for autism?

You can get help for autism in a variety of ways, including seeing your GP or by contacting or visiting health or social care services yourself.

If you, or a healthcare professional, family member, partner or carer, think that you have autism, and you were not diagnosed as a child, you should be offered an **assessment**. If you were diagnosed with autism as a child, you may be offered an assessment in adulthood if you are being transferred from a service for children to an adult service.

## What can I expect during an assessment?

At the beginning of the assessment, the purpose of it should be explained to you and you should be asked how you would like the results explained to you. If you agree, a family member, partner, carer or advocate may be involved to support you and help explain the results. (See the box on page 7 on involving your family, partner, carer or an advocate.)

Staff should be aware of any communication needs or **sensory sensitivities** that you have, and make adjustments to the assessment where necessary, including how long it takes. You may be asked to fill in a questionnaire about your thoughts and behaviour, or the questionnaire may be read out to you if you have difficulties with reading.

During the assessment, professionals will want to get to know you and find out more about your problems so they can work out what kind of support would suit you best. They will ask about and assess your behaviour in social situations (including how you behave and communicate with other people), your early life, your life at home, college or work, and if you have any mental and physical health problems, learning disabilities, problems with speech and language, or sensory sensitivities.

If professionals suspect you may have additional problems, they may suggest that you have further medical tests, such as hearing or sight tests, **genetic tests** or a recording of brain activity (called an **electroencephalogram** or EEG) or other tests if there is a sudden change in your behaviour or weight or it is thought that you are in pain and not able to communicate this. However, for many people further tests are not needed.

Any particular risks should be assessed, such as the possibility of **self-harm**, your problems becoming worse very quickly, not being able to look after yourself, removal of support from family or other carers, and abuse or exploitation by others. A plan should be developed to manage any risks.

*If you, or a healthcare professional, family member, partner or carer, think that you have autism you should be offered an assessment.*

Some people with autism may occasionally behave in a way that other people find challenging (for example, they may become very distressed, agitated, disruptive or sometimes violent). Professionals will want to know about such challenging behaviour and if there is anything that might cause it or make it worse (such as communication problems, a physical or mental health problem, relationship difficulties, a sensory sensitivity or changes to daily activities). Professionals may want to see how you behave in certain situations so that they can offer you the right support if there is a specific behavioural problem.

If necessary, professionals may develop a plan of what should happen if you have a **crisis**. This should include situations that might lead to a crisis, any changes that need to be made to your surroundings so that you are able to manage the crisis, the role of any professionals involved in your care and how your family, partner or carer can support you.

If you, or your family, partner or carer, disagree with professionals about the results of the assessment and any diagnosis, or professionals think it might help with the diagnosis, you may be offered a second opinion from another professional.

#### **What can I expect from health and social care professionals?**

Health and social care professionals should work with you, and your family, partner or carer if they are involved, so that you can make decisions about your care. They should encourage you to manage your own condition, if possible. This may include helping you to recognise signs that you are finding it hard to cope. They should offer care and support respectfully, and they should be supportive, understanding and not critical of you or your lifestyle. Ideally once you and a professional have established a good working relationship this should continue throughout your care. However, if you do not feel supported by the professional responsible for your care, you should have the opportunity to transfer your care to another professional.

Health and social care professionals should be easy to identify (for example, they should wear a name badge), they should tell you what they do and they should be friendly and welcoming. They should address you using the name and title you prefer. Professionals should clearly explain any medical language and check that you fully understand what is being said about your care and support options.

### **Involving your family, partner, carer or an advocate**

Health and social care professionals should discuss with you whether you would like your family, partner or carer to be involved in your care. If you agree, professionals should talk to you and your family, partner or carer about what information about your care you would like shared with them, and when. They should also be given information to help them understand autism and the care and support options for it.

You should also be asked whether you would like a trained advocate, who can help you put your views across.

### **Questions you could ask your healthcare team**

- Who will do the assessment? Where will it be carried out?
- How long will the assessment take?
- How will I be told about the results and will I have a chance to discuss them?
- Will my diagnosis remain confidential?
- Are there any support organisations specifically for people with autism in my local area?
- Who can I contact in a crisis?

### **What happens after I have been assessed?**

If you have been diagnosed with autism, you should be offered another appointment to discuss the diagnosis, what it means for you, any concerns you have and care and support for the future. You should be offered this appointment even if you have decided not to have further care and support.

Professionals should put together a plan for your care that takes into account your needs (such as any communication needs you have, or other needs related to any sensory sensitivities) and those of your family, partner or carer.

*If you have children or you care for other people, you should be offered support.*

The decision about what kind of care and support options to have will depend on your preference and a number of other factors, including:

- whether you have had any support for autism or other problems in the past and how helpful it was
- how severe your autism is and how it affects your daily life
- whether you have a learning disability or physical or mental health problem, how severe it is and how long you have had it
- whether any sensory sensitivities could affect any support you are offered
- any problems that could lead to a crisis.

Professionals should be sensitive and supportive if you feel anxious about making decisions about your care. They should also be aware that if they are providing care and support they need to be clear and consistent.

You should be given information about the care and support options available, including what they involve and how long they will last, whether they are suitable for most people with autism, and whether they will affect any other treatment you are having.

You should also be given a 'health passport', which is a card that lists the care and support you are having and other details in your care plan. You should be advised to carry the card with you.

Professionals should give you details about recognised national or local organisations and websites that provide information for people with autism, and about self-help groups, support groups and one-to-one support. They should tell you how to find and participate in them, and support you if you use them.

### **Help for people with autism who care for other people**

If you have children or you care for other people, you should be offered support, such as childcare, so that you can attend appointments and support groups and also continue with or start college or a job. If you are a parent, professionals should offer you support and advice in your parenting role, which may include a parent training course (to help parents understand their own and their child's feelings and behaviour).

### **Help for your physical health**

Professionals should offer advice about the benefits of a healthy diet and exercise, taking account of any sensory sensitivities you may have. If you need extra help you may get more support from your GP or a dietician.



## What care and support should I be offered for autism?

A number of supportive programmes can help with specific problems you might be having because of your autism. Once you have started the programme professionals should check regularly that it is of benefit.

You may be offered a 'social learning' programme to help you to cope in social situations. It is usually provided in a group, but can be one-to-one with a therapist if you find group activities difficult.

You may be offered a 'leisure activity' programme, which is usually provided in a group of other people who meet regularly but can be done on an individual basis. The programme involves taking part in leisure activities (such as games, crafts, exercise, and going to the cinema or theatre) that ideally should reflect your interests and abilities. There should be support from a therapist.

If you have problems carrying out daily activities, such as eating and washing, you may be offered a 'skills for daily living' programme, which can help and support you to carry out these activities.

If you are having problems getting a job or staying in a job, you may be offered a 'supported employment' programme. The programme can help you to write your CV and job applications, and prepare for interviews. It can also help you to choose which job would suit you and provide training for that role. The programme providers can advise employers about any changes that need to be made to the workplace to suit people with autism, and support you and the employer before and after you have started work.

If you are at risk of being bullied, badly treated or taken advantage of because of your autism, you may be offered a programme to help you cope with such risks (called an 'anti-victimisation' programme). The programme can help to identify and positively change situations in which you are at risk of victimisation, help you to make decisions in such situations and teach you personal safety skills.

You should be offered an 'anger management' programme if you have problems with controlling feelings of anger. The programme can help to identify situations that can make you angry, teach you skills to cope with such situations and teach you relaxation and problem-solving skills.

Skills for daily living programmes are suitable for all people with autism regardless of whether they have a learning disability.

Social learning, leisure activity, anger management, anti-victimisation and supported employment programmes are suitable for people with autism who do not have a learning disability and for those who have a mild to moderate learning disability.

*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.*

## Who can provide care and support?

You can have supportive programmes for autism in the care of a **specialist autism team** or a mental health or learning disability service. You may also have some support from **primary care**.

Wherever you have care and support, professionals and other staff should make adjustments to the physical surroundings of the service if possible. This may include making sure that there is enough personal space and natural light (or blackout curtains or dark glasses if you are sensitive to light), rooms have adequate signs, the colour of walls and furnishings is neutral, and fluorescent lighting and noise are kept to a minimum. If staff are not able to change the surroundings, they may offer shorter meetings or regular breaks.

Some people with autism are cared for in a special unit in their local community (called 'residential care'). These should be small units for not usually more than six people and there should also be supported accommodation for people on their own. In residential care, there should be a range of activities both in the unit and in the local community, and the building and surroundings should be adapted to suit people with autism, including space to be alone. Your family, partner or carer should be encouraged to be involved in your residential care, if you agree.

### Questions about care and support

- Why have you offered me this type of programme?
- What will the programme involve?
- How will the programme help me? What sort of improvements might I expect?
- How long will it take to have an effect?
- What are my options other than the recommended programmes for autism?
- What will happen if I choose not to have the recommended programmes?
- Is there a leaflet about the programme that I can have?

## Is there anything I should not be offered for autism?

There are a number of medical and drug treatments that you should not be offered specifically to treat the main symptoms of autism (see page 4). These include:

- a treatment called chelation (sometimes called detoxification) that involves taking one substance to remove other metallic substances from the body
- diets that limit the amounts or do not contain some types of food (such as **gluten-free**, **casein-free** or **ketogenic diets**)
- drugs usually given for problems with memory and thinking, such as cholinesterase inhibitors
- hormones (such as oxytocin and secretin) and a procedure (called testosterone regulation) that involves using a drug to reduce the amount of the hormone testosterone (or oestrogen) in the body
- treatment with oxygen in a pressurised chamber (called hyperbaric oxygen therapy)
- vitamins, minerals and supplements (such as vitamin B6 or iron supplements)
- medication usually given for seizures (called **anticonvulsants**), depression (called **antidepressants**) or serious changes in mental state (**antipsychotics**).

However, you may be offered antipsychotic or antidepressant medication for a mental health problem or challenging behaviour (see page 12), or anticonvulsant medication if you also have epilepsy.

In addition, you should not be offered a programme called 'facilitated communication' where a therapist or other person supports and guides a person's hand or arm while using a device such as a computer keyboard or mouse. There is no evidence that it helps people with autism, and in some cases it has caused harm.

## What treatments should I be offered if I also have a mental health problem?

If you have autism and a mental health problem, you should be offered **psychological treatments** as recommended by NICE. However, professionals should be aware of any changes that need to be made to the treatment because of your autism. This might include more written or visual information (for example, worksheets and images), and using plain English. Professionals should offer you regular breaks during the treatment and include things you are interested in where possible. A family member, partner or carer may be involved in the treatment if you agree.

*There are a number of treatments that you should not be offered for the main symptoms of autism.*

You may also be offered medication for a mental health problem, but professionals should be aware of your autism when prescribing medication, and they may make adjustments to the dose.

## What support should I be offered for challenging behaviour?

Sometimes certain situations or problems (such as a physical or mental health problem, relationship or communication problems, **sensory sensitivities**, or changes to your routine) may lead to challenging behaviour (for example, being very distressed, agitated, disruptive or sometimes violent). Before treatment is offered for challenging behaviour, professionals should offer you treatment for any physical or mental health problems and make sure changes are made to your surroundings if that is causing a problem, for example, using earplugs or dark glasses if you find loud noises or bright lights distressing.

If the challenging behaviour does not improve, you should be offered a **psychological treatment** that can help to address and change the behaviour. The choice of treatment should be based on your physical needs, your everyday surroundings, how helpful any previous treatment has been, and your own preference.

If the psychological treatment does not help, you may be offered **antipsychotic** medication in addition to the psychological treatment. You may be offered antipsychotic medication on its own by a specialist if the challenging behaviour is very severe. Professionals should check whether the medication is working after 3 to 4 weeks; it should be stopped after 6 weeks if there is no improvement.

You should not be offered **anticonvulsants** for challenging behaviour.

### Taking medication

When discussing medication for a mental health problem or for challenging behaviour, professionals should take into account the possible side effects of medication and explain clearly how much of the drug should be taken and how often. You may be given a low dose of the drug to start with.

Once you have started taking medication, professionals should check regularly that it is working, ask about any side effects and check that you are continuing to take it. They should also check your physical health.

## Information for families, partners and carers

If you are caring for a family member, partner or friend with autism, they should be asked by a professional whether they would like you to be involved in their care. However, professionals should respect your family member, partner or friend's privacy if they would prefer to cope on their own.

If your family member, partner or friend agrees to you being involved, you may be asked to attend **assessment** meetings with them and help explain the results of the meeting to them. If your family member, partner or friend has a mental health problem, you may also be asked to be involved with any **psychological treatment** they are having. You should be offered training and support to do this.

If they do not agree to your involvement, you should be given details of who to contact if you are concerned about the person's care.

Whether or not you are involved in your family member, partner or friend's care, you should be offered information about autism and how you can support them.

You may also need help and support yourself. You should be offered support in your role as a carer, including respite care and a plan of what should happen if there is an emergency. Professionals should also help you to plan the care of your family member, partner or friend in the future. Professionals should offer you information, including contact details, about local family and carer support groups and other voluntary organisations, and help you to make contact with them. You should be told about your right to a formal **carer's assessment** of your own physical and mental health needs, and how to access this.

*If you are caring for a family member, partner or friend with autism, they should be asked whether they would like you to be involved in their care.*

### Questions about care and support

- Can you give me some information about autism, and the care and support options for it?
- Am I entitled to be told about the care my family member, partner or friend is having?
- Is there anything in particular that I can do to support my family member, partner or friend?
- 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?
- Can I have a carer's assessment?

## Glossary

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

**Antidepressant** Medication used to treat depression. Antidepressants work by increasing the activity and levels of certain chemicals in the brain that help to lift a person's mood.

**Antipsychotic** Medication that is sometimes used to treat serious changes in mental state (such as hearing voices and seeing things that are not real).

**Asperger's syndrome** A type of autism. People with Asperger's syndrome usually have fewer problems with speaking and do not usually have a learning disability.

**Assessment** A meeting or meetings with a healthcare 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.

**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-free diet** A diet that does not contain casein, which is a substance found in milk and cheese.

**Crisis** A level of emotional distress that may make a person feel that they are unable to cope, and which sometimes requires an emergency response.

**Electroencephalogram** (or 'EEG' for short) A recording of brain activity using small metal discs (called electrodes) which are placed on the head.

**Genetic tests** A test to see whether any conditions or disorders have been passed down through a person's family. It involves looking at a chemical in the body called 'DNA'.

**Gluten-free diet** A diet that does not contain gluten, which is a substance found in cereals such as wheat, barley and rye.

**Ketogenic diet** A diet that has high amounts of fat, low amounts of carbohydrate and adequate amounts of protein.

**Learning disability** A condition that affects intellectual ability and leads to problems in learning, developing new skills, communication and carrying out daily activities. A person with a mild to moderate learning disability may only need support in certain areas. However, a person with a moderate to severe learning disability may have no speech or limited communication, a significantly reduced ability to learn new skills and require support with daily activities such as dressing and eating. Learning disabilities are different from 'learning difficulties', like dyslexia, which do not affect intellect.

**Primary care** A part of the healthcare service that provides care in the local community, including GPs, nurses, psychological therapists such as primary care mental health workers, or counsellors.

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

**Self-harm** An expression of personal distress by an act of self-injury (such as cutting oneself) or self-poisoning (such as overdosing with drugs or swallowing a poisonous substance).

**Sensory sensitivity** Being under- or over-sensitive to sound, light, colour, smell and taste.

**Specialist autism team** A team of health and social care professionals providing expert care and support for people with autism, including psychologists, nurses, occupational therapists, psychiatrists, social workers and speech and language therapists and support workers.

## More information

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

- Mencap, 0808 808 1111  
[www.mencap.org.uk](http://www.mencap.org.uk)
- National Autistic Society, 0808 800 4104  
[www.autism.org.uk](http://www.autism.org.uk)
- Research Autism, 020 3490 3091  
[www.researchautism.net](http://www.researchautism.net)

NHS Choices ([www.nhs.uk](http://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. If you live in Wales you should speak to NHS Direct Wales for information on who to contact.

## About NICE

NICE produces guidance (advice) for the NHS about preventing, diagnosing and treating medical conditions. The guidance is written by independent experts including healthcare professionals and people representing patients and carers. They consider the evidence on the condition and treatments, the views of patients 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](http://www.nice.org.uk/AboutGuidance)*

*This booklet and other versions of the guideline aimed at healthcare professionals are available at [www.nice.org.uk/guidance/CG142](http://www.nice.org.uk/guidance/CG142)*

*You can order printed copies of this booklet from NICE publications (phone 0845 003 7783 or email [publications@nice.org.uk](mailto:publications@nice.org.uk) and quote reference N2747). The NICE website has a screen reader service called Browsealoud, which allows you to listen to our guidance. Click on the Browsealoud logo on the NICE website to use this service.*

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