

Autism

Understanding Treatment Options



Anna Freud
building the
mental wellbeing
of the next
generation

What is autism?

Autism is a type of neurodivergence, which means a difference in the way your brain develops before birth and during childhood. Autistic people are all individual, although many people's experiences of being autistic are shared and relatable. Most autistic people learn, live and work independently, while others may have learning differences or health conditions that need specialist support. There is no evidence that vaccines or poor parenting cause autism. We currently don't know why some people are autistic and others aren't.

Knowing whether someone is autistic can sometimes be difficult, for example if you also have other physical or mental health conditions, or use autistic masking (which can involve hiding your natural behaviours and experiences in order to show an 'acceptable' version of yourself to the outside world). Certain groups are also less likely to get a diagnosis of autism, such as people assigned female at birth, people from minoritised ethnic groups and people who don't show a 'typical' way of being autistic.

To be diagnosed as autistic, a professional would look at whether you have grown up with differences in communication, social interaction, behaviour and sensory processing:

Communication and social interaction

Social interaction is complicated. Communication can happen in a huge range of ways and you may struggle in social situations if you are expected to use specific types of communication or follow specific social rules and expectations. Autistic people can experience differences in speech, for example in the amount of speech that you might use. Autistic people sometimes also use less common spoken communication methods (such as echolalia, which involves repeating words, phrases or noises). Some autistic people may have very good speech and language skills but struggle to use their voice in social situations, which is often related to anxiety.

Behaviour

Autistic children and young people can sometimes behave in ways that non-autistic people think is unusual. For example, playing in a repetitive way or alongside (rather than directly with) someone else. Autistic people often have intense interests and can become very interested in a few specific things, finding it difficult to transition away from these things. The benefits of this strong focus can be in-depth knowledge about certain topics, attention to detail and dedication.

Different sensory experiences

Autistic people can show different from 'typical' responses to sensory information of all kinds, not just textures, sounds, smells or tastes. For example, some people hear or feel things that non-autistic people usually don't, such as noise from lights or electricity buzzing in the walls. This can cause differences in how autistic people behave and can sometimes lead others to think that they are 'behaving badly'. Some autistic people make repetitive flapping, finger-twirling or other body movements, known as 'stimming'. Stimming is something that everyone does, but it can be more obvious in autistic people. Stimming behaviour can be used for different reasons - some autistic people find stimming calming, while it can help others process information (for example during school lessons).

Autism and mental health

Autism is not a mental health condition. However, autistic people may struggle with their mental health and wellbeing due to stigma and the pressures of daily life when trying to fit in with non-autistic people.

Autistic children and young people have a higher chance of experiencing a mental health condition, including:

- oppositional defiant disorder (ODD)
- anxiety
- depression
- sleep problems
- feeding/eating issues

Getting support

Referral and assessment

If you feel that a diagnosis would be helpful, a first step is to get in touch with your GP.

Often your parents or carers, a GP or someone at your school could refer you to a specialist for an assessment. Assessments for autism are usually carried out by community child teams (also known as community paediatrics or child development centres) or by specialist teams at child and adolescent mental health services (CAMHS).

If you are diagnosed with autism then your professional should give you and your family information to help you understand how autism affects you. They should

also give you information about any local or national organisations that provide support or help you to meet other families and autistic people.

You may also wish to explore the online autistic community, which has a lot of knowledge and support for autistic people. For example:

- The Autistic Advocate
- Ann Memmott's blog

Local autism teams

Local autism teams are made up of professionals from health, mental health, learning disability, education and social care services. You should be given a case manager or keyworker who will:

- arrange any care you need
- help you and your family to access any communication or sensory support you might need
- help you and your family to manage any behaviours that challenge
- help you to manage any other mental or physical health problems
- support you to develop important skills (e.g., communication and daily living skills)
- help you with education, housing and employment services
- support you to take part in leisure and other activities
- help to support your family, including arranging short breaks and other respite care.

There will be times when you might need more support, for example when you have just been diagnosed with autism or if you are changing school. Your professional should make sure that you have any extra support you need at these times and support you to ask for any changes (e.g., at school) that would help in your daily life.

Your professional should also make sure that you receive any support you need if you also have a mental health condition (e.g., anxiety or depression), physical health problem (e.g., epilepsy), sleep problem or another type of neurodivergence (such as ADHD or Tourette's syndrome).

If it's not possible to provide your care locally, you could be referred to regional or national services. This might be because you need very specialist care or the care from your local team isn't working well for you.

Decisions about your care

The support options listed here include the types of support that your local autism team could help you to access. You should talk to your professional and parents or carers about any types of support you might find helpful. The options here are not intended to ‘treat’ autism and will not be helpful for everyone. Your support should be personalised to you and your specific needs.

You and your parents or carers should be involved in making decisions about the support you receive. Your professional should talk with you about your mental health experiences and how your home and school life affects you. They should also talk with you and your parents or carers about your support options, including support for any mental health conditions or sleep difficulties.

Your professional may also talk with you and your parents or carers about:

- preparing for the future (e.g., your transition to adult services)
- organisations that could provide you with more support (e.g., by helping you to meet others with experience of autism, giving you advice on benefits and rights or giving you information about social support and leisure activities).

Types of support

You will usually be offered support with:

- your intellectual and emotional development
- understanding yourself and managing everyday life
- adjustments at school or other activities that you take part in
- any other difficulties you might have (e.g., behaviours that challenge, anxiety or sleep problems).

Once this support is in place, you and your parents or carers may only need support through primary care (e.g., GPs, practice nurses) and your school. If you need support with other difficulties, you might be referred to specialist services such as CAMHS, a CAMHS-learning disability service or community child health.

Going to appointments

Your professional should help you to feel comfortable at your appointments. For example, it might help to adjust the lighting, have lower noise levels, have appointments at less busy times of day or use visual or written appointment plans. Your professional should talk with you about how you would like to arrange your appointments, for example if you would like longer appointments, shorter and more frequent appointments or if you would like written information before your appointments.

Your professional should support you to use whatever communication method suits you best during your appointments, which might include sign language, word or picture boards.

Primary care

If you are autistic, you might be regularly reviewed in primary care (e.g., through your GP or practice nurse) to check how you are and whether you're receiving the right level of support.

You and your parents or carers should also be given information about autism and the kinds of support available. This should include:

- how to contact your key worker (if you have one) for advice
- how to request a special educational needs assessment (if you have not had one already) and the support you could have at school (GOV.UK has more information on special educational needs and disabilities)
- any benefits you might be entitled to
- how to arrange a carer's assessment so that your parents or carers can also get support (the NHS website has more information on carer's assessments)
- how to find more information about autism
- how to manage sleep problems or challenging behaviour.

You should have another assessment with specialist services when you are around 14 years old, to plan the support you might need as you get older. If you are diagnosed with autism when you are older than 14, your professional should start thinking about any support you might need as an adult straight away.

Secondary care

If you need other types of support (e.g., for a mental or physical health condition), then you might be referred to specialist services such as community child health, CAMHS or CAMHS-learning disability services.

Your specialist care team might offer:

- support with your social and communication skills
- support with any other kind of neurodivergence you might have, such as attention deficit hyperactivity disorder (ADHD)
- support with any mental health conditions you might have, such as anxiety or oppositional defiant disorder (ODD)
- treatment for any physical health problems you might have (e.g., epilepsy)
- help with behaviour that challenges if you need more support than your primary care or school professionals can offer.

If you are in contact with secondary care services, you will usually have a key worker who will make sure that everyone is working together to get you the support you need.

Support at school

Your school should support you to learn in ways that are best for you. This could include making changes to communication (such as using alternative communication systems) and supporting social interactions. Autistic children and young people sometimes struggle to communicate in the classroom and it's important that your teacher makes sure that you have heard and understood any instructions and that you are listened to during lessons. Group work may be very challenging and your teachers may need to support other pupils to enable you to be part of the group and feel that you can safely be yourself.

You can find out more through the National Autistic Society's Education Rights Helpline.

Support for your family

Support for your family is important. They should be given information on how to access assessments of their own needs, services that could advise or support them and how to access training that helps them to support you with any specific things you need. This is especially important if your parents or carers need help with your personal, social or emotional care, or if they are helping to deliver your support with professionals.

Help for your family could include:

- personal, social and emotional support
- practical support with your care
- planning in case of emergencies
- short breaks and other respite care
- planning for the future (e.g., your transition to adult services).

Your professional should involve you and your parents or carers in decisions about your care. If you are able to make your own decisions about your care, then your professional should ask you how you would like your parents or carers to be involved.

Transitions between services

If you are supported by CAMHS or child health services, you should have another assessment when you are about 14 years old. This is to see if you will still need support when you are an adult. If you do need your support to continue, your keyworker or case manager should arrange for your support to be changed over from child to adult services. This should happen by the time you are 18 years old.

You and your parents or carers should be involved in planning your transition to adult services. Your professional should give you and your family information about what to expect from adult services and the support they could offer you. Your professional should also talk to you about having a social care assessment when you are 18 years old, to see whether they could offer you any extra support.

Your professionals in child and adult services should work together while you transition to adult services. They should tell you who is in charge of your care and make sure you continue to get the support you need.

You may also transition to another CAMHS service (e.g., if you move house). If this happens, your professional should work with you to make sure that your care can continue smoothly and that your new service has all the information they need.

Psychosocial support



Strong evidence

If you feel that you would like support with communication and social situations, then your professional should be able to help you access psychosocial support. The type of support you receive will depend on the difficulties you have and what would be most helpful for you. For example, this type of support could include play-based approaches with your parents, carers and teachers to help them engage and communicate with you.

These approaches should:

- be based on your individual needs
- respect your focused interests and how you would like to communicate
- help your parents, carers, teachers and friends to understand your way of communicating and interacting
- include techniques to improve your communication, interactive play or social routines, depending on what you would find helpful
- include sessions with a therapist so that they can show you certain things captured by video recordings.

Some people find psychosocial support unhelpful and find that it encourages social masking. You could talk to your professional about this, and they should take care to provide psychosocial support in ways that avoid promoting masking.

Life skills support



Strong evidence

You should be offered support to develop daily living skills and coping strategies that will help you to live independently, with or without support. You should also be offered support with employment and support to use public transport and age-appropriate leisure facilities. Life skills support is often offered by special schools as part of their curriculum. If you go to a mainstream school, you might be offered life skills support by an occupational therapist.

Support for sleep problems



Strong evidence

What are sleep problems?

Sleep problems are common for autistic children and young people, which means that you could experience:

- difficulty settling, winding down and going to sleep
- waking up a lot during the night, or finding it hard to go back to sleep after waking up
- more anxiety, which will make it harder to sleep
- problems making the connection between others in the house going to bed and your own need to sleep
- neurological conditions such as epilepsy (which could affect your sleep)
- increased sensitivity to blue light from smart phones, laptops and other screens
- sensitivity to certain sounds or white noise, which may be upsetting or distracting
- problems with food intolerances, which could lead to stomach trouble and make it harder to sleep
- sleeping too much because you might be too tired.

What kind of support is available?

If you are having sleep problems, you or your parents or carers should ask for help from your GP or another professional involved in your care. They should put you in touch with a specialist who will ask about:

- the specific difficulties you are experiencing (e.g., difficulty falling or staying asleep)
- whether you have a regular bedtime
- anything in your room (e.g., noise or light) that could make it harder to fall asleep
- whether you have mental or physical health conditions which could make it harder to sleep
- the amount of exercise you usually do each day
- whether you have any physical pain or discomfort that makes it hard to sleep
- any medication that could be affecting your sleep
- whether you might be anxious about something (e.g., school), which is keeping you awake
- whether you snore or have any breathing problems when you sleep
- how the sleep problems are affecting your family.

If your sleep problems could be a symptom of medication or a physical or mental health condition, your professional should offer you help with this. You could also be referred to another specialist if you might have sleep apnoea (where your breathing briefly stops when you sleep and re-starts when you become short of breath), sleep-walking problems or seizure-like symptoms.

If there is no obvious reason for your sleep problem, your professional should help you and your parents or carers to improve your sleep routine, including regular bedtimes, thinking about your room set-up and a regular evening routine.

Your professional might suggest trying a sleep plan (which is also called a behavioural sleep intervention). This involves recording your sleep pattern in detail over a couple of weeks and reviewing it with your professional. They can then suggest a plan to help you improve your sleep.

If you have tried interventions to help you sleep but things haven't improved, you might be offered melatonin medication. Your family could also be offered respite care or short breaks. These usually involve you spending a night away or sometimes paid carers staying in your family home so that your family can catch up on their sleep. This is something that is usually arranged by your professional and organised by social care, although your parents or carers can request a short break.

Prevention and initial support for behaviours that challenge



Strong evidence

What are behaviours that challenge?

Behaviours that challenge include hurting others or yourself, damaging things and doing things that make everyday life difficult for yourself or others. Sometimes autistic people and their families prefer to use the term ‘distressed behaviours’. Not everyone who is autistic will have behaviours that challenge, but they are fairly common for autistic people who also have a learning disability.

Behaviours that challenge can happen when:

- people around you do not understand what you need and how you feel
- you have not been offered enough information about what is happening now and what is happening next
- you feel like you have no control
- you find it hard to cope with unstructured time or unplanned changes
- you are unhappy or upset about something
- you are ill or in pain
- your routine or surroundings have changed
- you experience things like loud noises or particular smells (if you have sensory sensitivities).

Autistic people and their carers often use the term ‘meltdowns’ to describe situations when an autistic person becomes completely overwhelmed by their current situation and temporarily loses control of their behaviour.

What kind of support is available?

As part of your initial autism assessment, the team should ask about any behaviours that challenge. They should also look at any situations that might make these behaviours more likely.

Your professional should give you, your parents or carers and (where appropriate) your teachers information about anything that creates emotional, sensory or communication stress so that together you can find ways of managing these. They should support your parents, carers and other people in your life to be proactive and use approaches that aim to reduce stress and prevent crisis situations, as well as making adjustments at home and school.

If behaviours that challenge start to become a problem, you and your parents or carers should seek advice from one of the professionals involved in your care.

Your professional should look at:

- what happens, where and when any behaviours that challenge happen, and whether there are there any triggers or patterns
- how severe the behaviours are and the effect they have on you, your family and other people you come into contact with
- any recent changes to your routine or environment which might have triggered the behaviours
- any evidence of a physical health problem or change in your physical health
- whether you might be experiencing bullying or maltreatment
- whether you might be experiencing a mental health difficulty

The aim of managing behaviour that challenges is to reduce the risk of harm to you and others, as well as to find and support you with any difficulties that could be triggering these behaviours. If this process isn't helping you, you could be offered psychosocial support for behaviour that challenges.

Psychosocial support for behaviours that challenge



Strong evidence

If your professional doesn't think that something to do with your mental health, physical health or environment is triggering your behaviour that challenges, then you and your parents or carers should be offered a psychosocial intervention. If your behaviour that challenges happens at school, then your teachers might also be involved.

A functional assessment of behaviour (also called a functional analysis) involves looking in detail at your behaviour that challenges. This often involves asking the people supporting you (your parents, carers or teachers) to record what they think happened, what was happening before the behaviour and what happened afterwards. Although people who show behaviour that challenges often find it difficult to communicate, the professional carrying out the functional assessment should try to find out from you how you were feeling, whether you were upset by something, and if there was something you wanted other people to know. Your professional might also spend time observing what is happening.

A functional assessment will try to figure out:

- if there is anything that triggers your behaviours that challenge
- if there are any patterns to your behaviours that challenge
- whether you are trying to get something you need through your behaviours that challenge

- whether there are things that happen during or after the behaviours that challenge which mean that the behaviours are likely to keep happening.

You may want to work with a professional to create a plan with strategies to help reduce distress and reduce any behaviours that may be unsafe for you and others. Everyone in your life will need to work together to put this plan into action. This means the plan and strategies will need to be agreed with you, your parents or carers, your teachers and anyone else involved in your care.

The plan should:

- be targeted at specific behaviours
- aim to improve your quality of life (the strategies used to help you or others manage your behaviour should not feel like a punishment)
- make changes to anything in your environment which could be contributing to the behaviours that challenge
- include strategies that you or the people around you can use in situations likely to trigger behaviour that challenges
- include strategies that you or the people around you can use when behaviour that challenges happens
- include goals (such as being able to do things that you currently can't do because of the behaviour that challenges) and a timescale for achieving these goals
- measure how often the behaviours that challenge occur and how severe they are before and after the support, so you know whether it is working
- make sure the approach to supporting you is consistent, so that your family and school respond to the behaviour that challenges in the same way.

This approach is often used as part of a positive behaviour support approach. You can find more information about behaviour that challenges from the National Autistic Society and the Challenging Behaviour Foundation (this information is specifically focused on people who have a severe learning disability).

While this type of support is recommended by NICE guidelines, some people do not find functional analysis useful. Some people feel that it over-simplifies their experiences rather than trying to understand the full picture of the support they need. Functional analysis can focus on a few 'problem behaviours' rather than recognising the more complicated challenges of the wider situation and how other people are behaving. Some people feel that this can lead professionals to ignore bigger and more important issues that matter to them.

Medication for behaviours that challenge

✓ Some evidence

If psychosocial interventions for behaviour that challenges are not helping enough or you haven't been able to try one, then your professional might offer you antipsychotic medication. If your professional suggests that you take medication, this should be one part of the support you're offered rather than the only type of support you are offered.

Your professional should talk to you and (if appropriate) your parents or carers about the side effects of the medication, whether you have taken antipsychotic medication before, and your preferences. You and your parents or carers should be involved in any decisions about medication, and you or your parents or carers will need to give informed consent before you start taking any medication.

Side effects of antipsychotic medications can include weight gain, increases in certain hormones and an unusually fast heart rate, so it's important to talk to your professional about whether the possible benefits of taking a medication would outweigh the risks.

How does taking medication work?

If you are prescribed medication to help with challenging behaviour, then your professional should talk with you (and your parents or carers, if appropriate) about exactly which behaviours they hope the medication will help with. Your professional should also talk with you and your parents or carers about how to measure whether the medication is working (e.g., whether your challenging behaviour happens less often and whether your challenging behaviour becomes less serious).

You should start taking medication at the lowest dose that could be helpful, and you should have regular reviews of the benefits and side effects. Ideally, you should be prescribed medication at the same time as having a psychosocial intervention.

Your professional should see you three to four weeks after starting the medication to talk with you and your parents or carers (if appropriate) about how well the medication is working and whether you are experiencing any side effects. If you have been taking the medication for six weeks and it has not been helpful, your professional should help you to stop taking it.

The professional who first prescribes your medication should make sure that other professionals prescribing your medication have all the information they need. This includes clear information about the behaviours you hope the medication will help with, how they should monitor the benefits and side effects, the dose you should be taking, how long you should be taking the medication and plans for stopping the medication.

When antipsychotic medications are prescribed for a long time (more than a few weeks), it's important to monitor physical effects. Monitoring can involve blood tests, an electrocardiogram (ECG) and a physical health check-up. Your doctor should talk to you and your parents or carers about what monitoring is needed and what could help with your physical health monitoring.

Prescribing should follow the principles set out in the stop over medicating people with learning disabilities (STOMP) and supporting treatment and appropriate medication in paediatrics (STAMP) leaflet.

Melatonin for sleep problems

Some evidence

If after trying other interventions you are still having sleep problems, your professional might suggest taking melatonin. Melatonin is a hormone that triggers sleep and is naturally produced by our bodies.

Melatonin can be prescribed by a paediatrician or child and adolescent psychiatrist and you would normally take a tablet about 30-90 minutes before bedtime. You should take the melatonin at the same time every day to help build up a regular sleep routine. You would usually start with a low dose, which might be increased until your sleep problems improve. Melatonin should be offered to you alongside other interventions, such as working with a professional on a sleep plan.

Cognitive behavioural therapy (CBT) for autism and anxiety

Some evidence

Anxiety is a common feeling among autistic people. About 50% of autistic people will experience anxiety that has a significant impact on their everyday lives.

Cognitive behavioural therapy (CBT) can be useful to treat anxiety among children and young people who are not autistic, and this will probably be the first type of support your professional suggests. CBT is a talking therapy which aims to help you see how your thoughts, beliefs and attitudes affect your feelings and behaviour. CBT aims to help you develop skills to cope with difficulties by changing the way you think about them. Your CBT professional will also support you to practice doing things that make you anxious so that you become more confident.

Traditional CBT might be more difficult for autistic people because it relies on being able to identify and talk about feelings and being able to think in an abstract

way. If you are offered CBT, this should be adapted to your needs as an autistic person.

You could be offered group CBT with other autistic young people who are also experiencing anxiety, or you could be offered individual CBT if you would find group therapy difficult (or if it isn't available).

Adapted CBT could include:

- extra support to help you recognise emotions
- written information and worksheets
- extra help with certain activities
- involving your parents or carers to support you
- regular breaks to help you pay attention
- involving your interests in the therapy.

Interventions which you should not be offered



Evidence of ineffectiveness of harm

There are some interventions that you might have heard of, but should not be offered to you because they don't have enough evidence or in some cases, they might be harmful.

These interventions would not be offered on the NHS:

- neurofeedback for speech and language problems
- auditory integration training for speech and language problems
- secretin (a hormone treatment)
- chelation (a treatment to remove heavy metal toxins from the blood)
- hyperbaric oxygen therapy (a high-pressure oxygen chamber)
- omega-3 fatty acids to manage sleep problems (although omega -3-fatty acids may be taken as a supplement to improve general health)
- a casein or gluten free diet, unless there is evidence of stomach problems (for example, if you have coeliac disease) or unless the diet is supervised by a paediatrician or dietician.

Feeding and eating problems are common among autistic children and young people, so it's important to monitor your growth and whether you're getting enough nutrients. If you have problems with eating, you or your parents or carers should get advice from your professional or GP.