A GUIDE FOR PARENTS AND CARERS

Supporting Your Autistic Child

A Guide for Parents and Carers of Children Aged 5 to 11

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The latest version is always at umid.co.uk/resources

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Before you begin

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About this guide

This guide is for parents and carers of children aged 5 to 11 who have recently been told that their child is autistic. It is written for the primary school years. A separate UMID guide covers young people aged 12 to 17, because the questions families face in the teenage years are different.

The guide is the same for every family whose child receives this diagnosis at this age. It is not a summary of your child's assessment and it does not describe your child. Your child's report sets out what we found and what we recommend for them. This guide gives the wider background: what autism is, what tends to help at home and at school, what support you are entitled to ask for, and where to find more help.

You do not need to read it all at once. Part 2 gives the essentials for the first few weeks. The later parts can be read when a particular question comes up. Not every section will apply to your child, and it is fine to skip what does not.

KEEPING THIS GUIDE UP TO DATE

This guide is updated regularly. The most recent version is always available at umid.co.uk/resources. If you received this guide some time ago, please check there for the current edition.

If you need help urgently

WHERE TO GET URGENT HELP

UMID is not an emergency or crisis service and cannot respond to urgent situations. If you are worried about your child's safety, or your own, please use one of these services straight away.

- **Call 999 or go to A&E** if someone's life is at risk, for example after a serious injury or if someone has taken an overdose, or if you do not feel you can keep yourself or someone else safe.
- **Call NHS 111 and choose the mental health option**, or use 111 online, if you need urgent help with mental health that is not an emergency. You can also ask your GP surgery for an urgent appointment.
- **Samaritans**: call 116 123, free, at any time of day or night, to talk to a trained volunteer.
- **Shout**: text SHOUT to 85258 for free, confidential text support at any time.
- **Childline**: children and young people under 19 can call 0800 1111, free, at any time, or use the online chat at childline.org.uk. The number does not appear on the phone bill.
- **YoungMinds Parents Helpline**: call 0808 802 5544, Monday to Friday, for advice if you are worried about your child's mental health. This is not an emergency service.

A note about words

Throughout this guide we say “autistic child” rather than “child with autism”. Research with autistic people in the United Kingdom has found that many prefer this wording, because they see autism as part of who they are rather than something they carry. Some families and some autistic people prefer other terms, and that choice is theirs. You will find short explanations of the other terms we use in the glossary at the end of this guide.

PART 2

First steps after diagnosis

IN THIS PART

- The essentials, at a glance
- What to do in the first few weeks
- The feelings many parents have at this stage
- Support from UMID after the diagnosis

At a glance

If you read nothing else for now, these are the points we most want you to know.

- **Autism is a difference in how your child's brain develops.** It affects how your child communicates, relates to other people, experiences the senses and makes sense of the world. It is not an illness, and it is not caused by anything you did or did not do.
- **Your child is the same child they were before the diagnosis.** What has changed is that you now have a way of understanding them, and a basis for asking for the right support.
- **Good support starts with understanding your child and adjusting things around them, rather than trying to change who they are.** Predictable routines, clear communication and a comfortable sensory environment make a real difference to many autistic children.
- **Your child's school has legal duties to support them.** A diagnosis is not needed for school support, but it helps the school to understand your child's needs. Ask for a meeting with the school's special educational needs co-ordinator (SENCO).
- **You can get free, independent advice about school support** from your local SEND Information, Advice and Support Service (SENDIASS) and from the charity IPSEA.
- **Financial help may be available.** Disability Living Allowance for children does not depend on your income or savings.
- **Talking to your child about being autistic, in a positive way and at their level, tends to help.**
- **Looking after yourself is part of looking after your child.**
- **If you are unsure what support would help, you can book a free 30-minute appointment with UMID's Clinical Director** to talk it through, as described at the end of this part.

What to do in the first few weeks

There is no deadline for any of this, and many families take things one step at a time. The table sets out the steps most families find useful, roughly in the order they tend to happen.

Step	What it involves	Where to find help
Read the report	Take time to read your child's report. Note anything you want to ask about.	Support from UMID after the diagnosis, at the end of this part
Share the report	Give a copy to your child's school and to other professionals involved in their care, if you are	Part 7 of this guide

Step	What it involves	Where to find help
	happy to. You decide who else sees it.	
Meet the school	Ask for a meeting with the class teacher and the SENCO to plan support.	Part 7; SENDIASS; IPSEA
Find your local offer	Every local council in England publishes information about services for children with special educational needs and disabilities, called the local offer.	Your council's website, via www.gov.uk/find-local-council
Consider Disability Living Allowance	Check whether your child may qualify.	Part 10; Contact helpline
Ask for a carer's assessment	You have a right to ask your council to assess your own needs as a parent carer.	Part 10
Connect with others	Many parents find it helps to talk to other families.	Part 11
Look after yourself	Rest where you can and accept offers of help.	Part 6

The feelings many parents have

Parents react to an autism diagnosis in many different ways, and all of them are understandable. Some feel relief that there is finally an explanation for things they had noticed for a long time. Some feel sadness, worry about the future, or guilt about things they wish they had understood sooner. Some recognise themselves or another family member in what they have read. Many feel several of these things at once, and feelings often change over the following months.

It may help to know that nothing you did caused your child to be autistic, and that the early signs of autism are easy to miss or to explain in other ways. What matters now is what you do with the understanding you have.

Support from UMID after the diagnosis

At the feedback meeting we talked with you about the support options that may help your child. Some families find that the diagnosis and the information in this guide are what they need. Others want further help, either now or later on. Both are fine.

We offer a range of services after diagnosis: occupational therapy, psychological therapies and, where it suits your child's age and needs, psychiatric care, for example for ADHD from the age of 7 or for mental health needs that occur alongside autism as your child grows older. These are arranged separately from the assessment, and current fees are on our website at umid.co.uk/our-fees.

If you are unsure what would help, you can book a free 30-minute appointment with UMID's Clinical Director to talk through your child's support needs after the diagnosis and which options would best meet them. To arrange this, or with any question about the assessment, please email umid@umid.co.uk.

PART 3

Understanding autism

IN THIS PART

- What autism is, and what it is not
- How autism often shows itself in primary school children
- Strengths and differences
- Autistic girls and children who mask
- Communication as a two-way process

What autism is

The NHS describes autism as a difference in how the brain develops that affects how a person sees and experiences the world. It is lifelong and is present from birth, although it may not be recognised until later. Autism is often described as a form of neurodivergence, meaning that a person's brain works differently from what is considered typical.

Autism affects people in very different ways. Some autistic children need a great deal of support every day. Others need very little. Some have a learning disability, and many have average or above average intelligence. Two autistic children can look very different from each other, and the same child can look very different on a calm day and on a difficult one.

The medical term for the diagnosis is autism spectrum disorder. Clinicians in the United Kingdom diagnose it using internationally agreed criteria, which describe differences in two broad areas: social communication and interaction, and patterns of behaviour, interests and sensory experience.

What autism is not

Autism is not an illness, and it is not something that needs to be cured. The NHS states clearly that autism is not caused by vaccines or medicines. The National Autistic Society is equally clear that it is not caused by the way a child is parented. In September 2026 the Society published a review of the research and concluded that autism is genetic: most autistic people are autistic because of genes passed on in the family, which is why autism often runs in families. Thousands of genes are involved, there is no single autism gene, and there is no genetic test that can diagnose autism. Genes are not anyone's fault, and knowing this is not a reason for any parent to feel blame.

BE CAUTIOUS OF ANYTHING THAT PROMISES A CURE

Some products and therapies sold online claim to cure or reverse autism. There is no good evidence that any of them work, and some are dangerous. For example, the Food Standards Agency warns that "Miracle Mineral Solution", which has been falsely promoted as a treatment for autism, contains a chemical used at high strength as a bleach, is not suitable for anyone to swallow, and can cause serious harm. If you are unsure about any treatment, please speak to your GP or a specialist before trying it. Part 9 explains what the evidence does and does not support.

How autism often shows itself in the primary years

Every autistic child is different, and your child will not show all of the things described here. You may recognise some of them.

Communication

Some autistic children talk a great deal, sometimes in detail about the things they love. Others speak a little, or not at all, and communicate in other ways, such as gestures, pictures, signs or devices. Many autistic children:

- take words literally, so that a phrase like “pull your socks up” may be puzzling;
- find it hard to follow long spoken instructions, especially in a noisy room;
- need a little more time to process what has been said before they answer;
- repeat words or phrases they have heard, which is called echolalia and is often a way of communicating, processing or self-soothing;
- find it tiring to make eye contact, and may listen better when they do not have to.

Relating to other people

Autistic children often want friends and company, but may approach friendships differently. They may prefer to play alongside another child, to play by clear rules, or to share an interest rather than chat. Unwritten social rules, such as when it is your turn to speak or how close to stand, may not come naturally. Many autistic children find groups more demanding than time with one familiar person.

Sensory experiences

Many autistic children experience sounds, lights, smells, tastes, textures, temperature or touch more intensely than other people. A hand dryer, a scratchy label or the smell of the school dining hall can be genuinely distressing. Some children are under-responsive instead, and may seem not to notice pain, cold or being called, or may seek out strong sensations such as spinning, climbing or deep pressure. Some find it hard to notice signals from inside their own body, such as hunger, thirst, tiredness or needing the toilet. Part 5 covers practical ways to help.

Routines, predictability and repetition

Many autistic children feel safest when they know what is going to happen. Sameness and routine can make the world feel manageable, and unexpected change can feel alarming. Repetitive movements such as hand flapping, rocking, jumping or spinning objects are often called stimming. For many autistic people stimming is calming, helps them concentrate or expresses strong feelings, including happiness. Autistic adults who took part in research described stimming as a useful way of coping, and asked that it be accepted rather than stopped. The NHS advises that a child’s behaviour should not be changed unless it is harmful to them or to others.

Interests

Many autistic children have deep, focused interests, sometimes called special interests. A child may know everything about a particular animal, a transport system, a game or a period of history. These interests are often a source of real joy and calm, and they can be a powerful way into learning and friendship.

Strengths and differences

Many autistic children show strengths such as a strong memory for facts, close attention to detail, honesty, a clear sense of fairness, deep knowledge of a subject they love, visual thinking or creativity. These strengths vary from child to child, and not every child will show them in the same way. We encourage you to notice what your child is good at and enjoys, and to make sure the people around them notice it too.

Autism also brings real difficulties for many children and families. Recognising strengths does not mean pretending those difficulties are not there. Both are part of understanding your child.

Autistic girls and children who mask

Autism is diagnosed more often in boys than in girls. Research suggests the true difference is smaller than diagnosis figures imply, and that girls who are autistic are more likely to be missed or diagnosed later. One reason is that some autistic children, girls and boys, learn to hide their differences in order to fit in. This is called masking. A child who masks may copy other children, rehearse conversations, or hold in their distress all day at school.

Masking can help a child to get through the day, but it takes a great deal of effort. The National Autistic Society notes that it can affect mental health and a person's sense of who they are. A child who masks at school may seem fine to teachers and then become very upset or exhausted at home. This is not a sign of poor parenting or of a child "playing up" for you. It often means that home is the place where they feel safe enough to let go.

Communication is a two-way process

Autism has often been described as a difficulty with social communication. Research over the last decade has added an important idea, sometimes called the double empathy problem. It suggests that misunderstandings between autistic and non-autistic people happen in both directions: non-autistic people also find it hard to read autistic people. In one study, autistic people passed information to each other as well as non-autistic people did, and the difficulty arose mainly when the two groups were mixed.

This matters because it shifts the goal. Rather than only teaching your child to behave in non-autistic ways, it is just as important for the adults and children around them to learn how your child communicates and to meet them part of the way.

PART 4

Talking with your child about autism

IN THIS PART

- Why telling your child tends to help
- When and how to talk about it
- Ideas for different ages and stages
- Talking to brothers, sisters, family and friends

Why telling your child tends to help

Many parents wonder whether to tell their child that they are autistic, and when. The research is limited, with small studies, but it points in the same direction. In a survey of autistic university students, those who had learned they were autistic at a younger age felt happier about their lives as adults. The students felt that children should not have to wait until adulthood to be told, and that parents should explain it in a way that helps children understand and feel good about who they are. In another small study, teenagers whose parents had chosen to talk with them about autism spoke about autism and about themselves more positively.

Children often notice that they are different from others well before anyone explains why. Without an explanation, some conclude that there is something wrong with them. A calm, honest explanation gives them a better story to tell themselves.

When and how to talk about it

There is no single right moment. Many families start with small conversations and build on them over time, rather than having one big talk. These ideas may help.

- **Start from your child's own experience.** Talk about things they already know about themselves, such as loving a particular topic, finding loud places hard, or noticing details other people miss.
- **Keep it simple and matter of fact.** For example, "Everyone's brain works in its own way. Your brain is an autistic brain. That is why some things feel easy for you and some things feel harder."
- **Balance strengths and difficulties honestly.** Children can tell when something is being made to sound better than it is.
- **Use their preferred way of learning.** Many children take in information better from pictures, books or short written explanations than from talk.
- **Let them ask questions over time,** and answer honestly. It is fine to say that you do not know and will find out.
- **Choose a calm time,** not straight after a difficult moment.
- **Expect a range of reactions.** Some children are relieved, some are curious, some seem uninterested, and some are upset at first. Reactions often change as they get older.

Ideas for different ages and stages

Younger children, around 5 to 7, usually need only a short, concrete explanation linked to things they notice, such as why they wear ear defenders or why they have a picture timetable at school. Picture books can help.

Children around 8 to 11 are often ready for more detail. They may want to know what autism means, whether other people are autistic, and what it will mean for them at secondary school. This is often a good age to help them learn how to explain their needs to others. Books written for this age, including some by autistic authors, are listed in Part 11.

Children with a learning disability or limited spoken language also benefit from understanding themselves, at a level that makes sense to them. The focus may be on what helps them feel calm and what they like, rather than on the word autism itself.

Talking to brothers, sisters, family and friends

Brothers and sisters often notice more than adults realise. A simple, honest explanation at their level can help them understand why some things are different for their sibling, and reassure them that it is nobody's fault. Books written for siblings are listed in Part 11, and Part 6 says more about sibling support.

It is your family's decision who else to tell and when. Some parents find it helps to share the diagnosis with grandparents, close friends and regular carers so that everyone can respond in the same way. Others prefer to wait. As your child gets older, it becomes important to involve them in decisions about who is told.

PART 5

Everyday life at home

IN THIS PART

- Communicating with your child
- Routines and predictability
- Sensory differences
- Distress, meltdowns, shutdowns and exhaustion
- Sleep
- Eating
- Play and interests
- Health appointments and everyday care

Communicating with your child

Small changes in how adults communicate often make a big difference. These suggestions are general practical advice and will suit some children more than others.

- **Say their name first,** then give the message, so they know you are talking to them.
- **Use clear, direct language.** Say what you want to happen ("Please put your shoes on") rather than what you do not want, and avoid hints and sarcasm.
- **Give one step at a time,** and allow processing time before repeating. Repeat using the same words rather than rephrasing.
- **Use visual supports.** Pictures, symbols, written lists or objects help many children to understand and remember. Visual supports are useful even for children who speak well.
- **Reduce background noise** when you need your child to listen.
- **Accept all forms of communication.** Pointing, pictures, signing and devices are all valid ways to communicate.

Some children who speak very little, or who lose words when stressed, use alternative and augmentative communication, known as AAC. This can mean picture exchange, signing, communication books or speech-generating devices. Parents sometimes worry that AAC will stop their child from learning to talk. Research reviews have found that it does not, and some children's speech increases a little when they use it. A speech and language therapist can advise on what might suit your child.

SOCIAL STORIES AND COMIC STRIP CONVERSATIONS

A social story is a short, simple description, often with pictures, of a situation your child finds confusing, explaining what usually happens and why. A comic strip conversation uses simple drawings and speech bubbles to talk through something that has happened, including what people may have been thinking. Both approaches are widely used in UK schools. Keep them positive and descriptive, and write them with your child where you can.

Routines and predictability

Predictability lowers stress for many autistic children. It helps to:

- keep daily routines, such as mornings and bedtime, as consistent as you reasonably can;
- use a visual timetable showing what is happening today, in order;

- give advance warning of changes, and explain what will happen instead;
- use a timer or countdown to show how long is left before a change of activity;
- prepare for new places with photos, videos or a short visit beforehand;
- build a little planned flexibility into routines, such as a “change” card on the timetable, so that small changes become more familiar.

Routines are not about rigid control. They give your child a secure base from which new things feel less threatening. Many children become more able to cope with change when they feel generally safe.

Sensory differences

Watching your child closely is the best way to learn which sensations they seek and which they avoid. Some families keep a simple diary for a few weeks.

Practical adjustments that many families find helpful include:

- ear defenders or headphones in noisy places;
- softer or dimmer lighting at home;
- removing clothing labels, choosing seamless socks or allowing the same comfortable clothes;
- a quiet, calm space at home where your child can retreat;
- opportunities for movement and deep pressure if your child seeks them, such as a trampoline, swing, heavy lifting jobs or a tight hug if they like it;
- sunglasses or a hat in bright places;
- avoiding strong smells, such as perfumes or air fresheners.

> **WHAT THE EVIDENCE SAYS ABOUT SENSORY PRODUCTS AND THERAPIES**
> Many families find comfort items such as weighted blankets, fidget toys and chewable jewellery helpful, and children often like them. They are best thought of as comfort and preference rather than treatment. For example, in a carefully conducted trial in autistic children with severe sleep problems, weighted blankets did not help children sleep longer, although children and parents preferred them. A UK trial of a specific therapy called sensory integration therapy, carried out with autistic children in mainstream primary schools, found no clear benefit on its main measure of behaviour, although carers and therapists reported improvements in daily functioning. An occupational therapist can assess your child’s sensory needs and suggest practical changes.

Distress, meltdowns, shutdowns and exhaustion

Understanding distress

Autistic children often behave in ways that help them manage or respond to the world around them. When the demands on a child build up, whether from noise, change, uncertainty, social effort, hunger, tiredness or pain, they can become overwhelmed. What looks like a small trigger is often the final straw after a long, hard day.

Meltdowns

A meltdown is an intense response to overwhelm in which the child temporarily loses control of their behaviour. It may involve crying, shouting, running, throwing things, or lashing out. A meltdown is not a tantrum. A tantrum is aimed at getting something and usually stops when the goal is reached or clearly not available. A meltdown is not chosen, and the child cannot simply stop it.

During a meltdown it usually helps to:

- keep your child and others safe, moving away objects or people if needed;
- say very little, calmly and simply, because words add to overload;

- reduce noise, light and audience where you can;
- give time and space, staying nearby if your child wants you;
- avoid punishment, arguments or demands until your child is calm.

Afterwards, many children are exhausted and may feel embarrassed. Once they have recovered, and sometimes much later, you can think together about what led up to it and what might help next time.

Shutdowns

A shutdown is a quieter response to overwhelm. The child may go silent, withdraw, seem not to hear, freeze or want to lie down. Shutdowns are easy to miss or to mistake for defiance. The response is similar: reduce demands, lower sensory input and allow time to recover.

After-school exhaustion and burnout

Many autistic children hold themselves together at school and then release their feelings at home, sometimes explosively. The NHS notes that autistic children may need time to settle when they return from school. A predictable, low-demand period after school, with a snack, quiet time or a favourite activity, often helps.

Some autistic children become very exhausted from trying to cope with daily life over a long period. The NHS calls this autistic fatigue or burnout. Families often notice that their child is much more tired than usual, loses skills they had, has more frequent meltdowns or shutdowns, or withdraws from activities they used to enjoy. If you notice this, talk to your child's school about reducing demands, make sure your child has time to rest, and speak to your GP if it continues.

Preventing distress

Over time, noticing patterns is one of the most useful things you can do. Keep in mind the common contributors: sensory overload, change and uncertainty, hunger, tiredness, pain or illness, difficulty communicating a need, and demands that feel too high. Many children also benefit from learning, at their level, to recognise their own early signs of stress and to use a calming strategy or a break card.

> **WHEN TO SEEK MORE HELP**
>
> Please speak to your GP, your child's school or a specialist if your child is hurting themselves, if distress is frequent or severe, if there has been a sudden change in behaviour, or if you are worried that pain or illness may be involved. NICE guidance says that when an autistic child's behaviour is distressing or harmful, professionals should first look for and address possible causes, including physical health problems such as pain or digestive problems, difficulties with communication, mental health difficulties and problems in the environment, before other treatment is considered.

Sleep

Sleep difficulties are common in autistic children. Some find it hard to settle, some wake often in the night, and some wake very early. Poor sleep affects the whole family, and it is right to ask for help.

NICE guidance recommends that sleep problems are first assessed, and that a personalised sleep plan is developed with the family. Things that often help include:

- a consistent, calm bedtime routine, with the same steps in the same order, shown in pictures if helpful;
- regular times for going to bed and getting up, including at weekends where possible;
- a bedroom that suits your child's senses, for example dark, quiet and at a comfortable temperature, with bedding they find comfortable;
- a wind-down period without screens before bed;
- daytime physical activity and daylight;

- checking for things that disturb sleep, such as pain, reflux, constipation, hunger, anxiety or needing the toilet.

> **SNORING OR PAUSES IN BREATHING**
> If your child snores loudly, chokes or seems to stop breathing while asleep, please ask your GP about a referral to check for obstructive sleep apnoea, as NICE recommends.

If a sleep plan has been followed and problems continue, and they are having a negative effect on your child and family, NICE suggests that melatonin may be considered. Melatonin is a hormone the body makes to regulate sleep. In the UK it is a prescription medicine. One form of melatonin is licensed for sleep problems in autistic children aged 2 to 18 when sleep routines alone have not helped enough. NICE advises that it should only be used after consultation with a specialist paediatrician or psychiatrist with expertise in autism or children's sleep, used alongside the sleep plan, and reviewed regularly. Please do not give melatonin bought online or abroad, as the strength and content of such products cannot be relied on.

The children's charity Cerebra offers free sleep guides and, for families who meet its criteria, one-to-one sleep support. The Sleep Charity also provides information for parents.

Eating

Many autistic children are selective about food. They may eat a small range of foods, prefer particular brands, textures or colours, or dislike foods touching on the plate. This is often linked to sensory differences, a need for predictability or anxiety about new foods. For many children, eating gradually broadens with time and without pressure.

Things that often help include:

- offering familiar, accepted foods at every meal alongside small amounts of something new, without pressure to eat it;
- letting your child explore new foods by looking, touching and smelling first;
- keeping mealtimes calm and predictable;
- allowing a quiet place to eat if the dining room or table is overwhelming;
- involving your child in shopping or preparing food if they enjoy it.

> **WHEN EATING NEEDS MEDICAL ADVICE**
> NICE advises that restricted eating can lead to nutritional deficiencies with serious consequences, and that feeding, growth and nutrition should be assessed and monitored where needed. Please speak to your GP if your child's range of foods is very small or getting smaller, if they are losing weight or not growing as expected, if they are often constipated, or if eating is causing great distress. Some children have avoidant restrictive food intake disorder, known as ARFID, in which avoidance of food is severe enough to affect health or daily life. ARFID is different from anorexia nervosa and is not about body weight or shape. A dietitian, speech and language therapist or eating disorders service may be involved.

NICE advises against exclusion diets, such as gluten-free or casein-free diets, as a way of treating autism itself. A diet should only be changed for a clear medical reason, such as a diagnosed allergy or coeliac disease, and with professional advice.

Play and interests

Play is how children learn, relax and connect with others. Autistic children may play in their own ways, for example by lining up, sorting or taking things apart, replaying scenes from films, or exploring how things work. This is real play and it has value. You can join in on your child's terms, following their lead, commenting on what they are doing and gradually adding small new ideas.

Your child's interests are a strength. Many parents use them to:

- build connection, by learning about the interest and sharing it;
- support learning, for example practising counting or reading through a favourite topic;
- help with difficult tasks, by linking them to the interest;
- find friends, through clubs or groups built around shared interests.

Interests may sometimes need gentle limits, for example if they crowd out sleep or meals, but they are best treated as a source of comfort and joy rather than something to be reduced.

SCREENS AND DIGITAL GAMES

Many autistic children enjoy screens, and for some they offer calm, predictability and a way to connect with others through shared games. As general advice, it is usually more useful to think about what your child is doing on screens, whether it affects sleep and other activities, and whether they are safe online, than to focus only on the number of hours.

Health appointments and everyday care

Visits to the doctor, dentist, optician or hairdresser can be very hard for autistic children because of unfamiliar places, noise, waiting and touch. It often helps to:

- ask for the first or last appointment of the day, when it may be quieter;
- tell the service in advance that your child is autistic and what helps;
- prepare your child with photos, a social story or a practice visit;
- bring comfort items and something to do while waiting.

Your GP practice can add a note to your child's record about reasonable adjustments. Personal care such as washing, tooth brushing, hair cutting and toileting may take longer to learn and may be affected by sensory differences. Breaking tasks into small steps with pictures, and building them into routines, helps many children. If toileting is a particular concern, speak to your GP or school nurse, because constipation is common and treatable.

PART 6

Family life

IN THIS PART

- Brothers and sisters
- Grandparents, family and friends
- Going out and about
- Looking after yourself

Brothers and sisters

Having an autistic brother or sister can bring closeness and understanding, and it can also bring challenges. Siblings may feel protective, proud, embarrassed, left out or worried, sometimes all at once. They may take on extra responsibility or feel that their own needs come second.

It often helps to:

- explain autism simply and honestly, and answer questions as they come up;
- make regular time for each sibling on their own, even if it is short;
- let siblings say how they feel, including negative feelings, without being told off for them;
- give siblings a private space for their belongings;
- avoid making siblings responsible for their autistic brother or sister.

The charity Sibs supports brothers and sisters of disabled children and adults, and their parents. Some areas also run young carers' groups. Books for siblings are listed in Part 11.

Grandparents, family and friends

Wider family can be a great source of support, but they may need help to understand. You might share parts of this guide, suggest a book or explain two or three things that help your child most. It is fine to set boundaries if advice or comments from others are not helpful.

Going out and about

Days out, shopping and holidays can be enjoyable with some planning. Many families find it helps to look at photos or videos of a place before visiting, to go at quieter times, to plan breaks and a quiet spot, and to bring ear defenders and comfort items. Many attractions, cinemas and supermarkets now offer quieter sessions, and some offer free carers' tickets or queue assistance on proof of disability. The Hidden Disabilities Sunflower lanyard is a widely recognised, voluntary way of letting staff know that someone may need extra help or time.

Looking after yourself

Caring for an autistic child can be deeply rewarding and also tiring, isolating and at times overwhelming. Looking after your own health is not selfish. It is part of being able to care for your child over the long term.

- **Talk to other parents.** Many parents say that speaking to others who understand is one of the most helpful things they did. The National Autistic Society's Parent to Parent service offers emotional support from trained volunteers who are themselves parents of autistic children. Local parent groups, National Autistic Society branches and online communities are other options.

- **Ask for a parent carer's needs assessment.** In England, your local council must assess your needs for support as a parent carer if it appears you may have such needs or if you ask. This can lead to support such as short breaks. Part 10 explains more.
- **Get practical help.** Accept offers of help from people you trust, and explore short breaks through your local offer.
- **Look after your own mental health.** If you are feeling persistently low, anxious or unable to cope, please see your GP. In England, you can refer yourself to NHS Talking Therapies for common problems such as anxiety and depression. The Carers UK helpline and Contact's Listening Ear service offer support for parents and carers.
- **Share the load.** Where there are two parents or carers, it can help to share responsibilities and plan time for each other.

Some parents find, as they learn more about autism, that they recognise autistic traits in themselves or another adult in the family. If this applies to you, it may be worth reading about adult autism, and you can speak to your GP if you would like an assessment for yourself.

PART 7

School

IN THIS PART

- How support at school works in England
- Special educational needs support and the SENCO
- Reasonable adjustments
- Education, health and care needs assessments and plans
- If you disagree with a decision
- Difficulty attending school
- Moving to secondary school
- Changes being planned to the system

WHICH COUNTRY THIS COVERS

This part describes the system in England. Scotland, Wales and Northern Ireland have their own systems and laws. If you live outside England, your local council, your child's school or the organisations in Part 11 can tell you what applies.

How support at school works

Many autistic children attend mainstream schools with the right support. Some need a specialist setting, and a small number are educated in other ways. The right choice depends on your child's needs, what they find manageable and what is available locally.

The law on special educational needs and disabilities in England is set out in the Children and Families Act 2014, and statutory guidance is in the SEND Code of Practice. A child has special educational needs if they have a learning difficulty or disability that calls for special educational provision, meaning help that is additional to or different from what is normally available to children of the same age. A diagnosis is not required for a child to receive support; support should be based on need.

Special educational needs support and the SENCO

Every mainstream state-funded school, including academies and free schools, must have a special educational needs co-ordinator, known as the SENCO, and must publish information about its support for pupils with special educational needs. Support given within the school's own resources is called SEN support. It should follow a cycle of assessing your child's needs, planning support, putting it in place and reviewing how well it has worked, with you and your child involved throughout.

When you meet the school, it may help to:

- share the report and highlight the recommendations that relate to school;
- describe what you see at home, including after-school distress, since this may not be visible in class;
- agree what support will be put in place, who will provide it and when it will be reviewed;
- ask how your child's views will be gathered;
- ask for a named person your child can go to when they need help;
- follow up in writing with a short summary of what was agreed.

Examples of support that often help autistic children in primary school include a visual timetable, advance warning of changes, a quiet place to go and a way to ask for a break, adjustments to noisy or

crowded times such as assemblies and lunch, support at unstructured times like break, clear written or pictorial instructions, permission to use ear defenders or movement breaks, and help with friendships.

Reasonable adjustments

Autism often meets the definition of disability under the Equality Act 2010, because it has a substantial and long-term effect on day-to-day activities. Schools have a legal duty to make reasonable adjustments so that disabled pupils are not put at a substantial disadvantage, and this includes providing auxiliary aids and services. The duty also applies to school policies such as behaviour rules and uniform. For example, a school might allow a child to wear softer clothing, to leave class a few minutes early to avoid crowded corridors, or to stim without being told off. Reasonable adjustments do not need an education, health and care plan.

Education, health and care needs assessments and plans

Some children need more support than a school can provide through SEN support. An education, health and care plan, or EHC plan, is a legal document from the local council that sets out a child's needs and the support they must receive. It can cover education, health and social care.

Asking for an assessment

You can ask your local council for an education, health and care needs assessment yourself. The school can also ask, and so can others such as doctors. You do not need the school's agreement, and you do not need to wait for the school to have tried a particular amount of support.

The law says that the council must carry out an assessment if your child has or may have special educational needs, and may need special educational provision to be made through an EHC plan. This is a relatively low threshold. The charity IPSEA provides free template letters for making the request.

Timescales

The law sets out time limits:

- the council must tell you within 6 weeks of your request whether it will carry out an assessment;
- it must tell you within 16 weeks whether it will issue a plan;
- the final plan must be issued within 20 weeks of the request.

You will have at least 15 days to comment on a draft plan, including to name the school you would like your child to attend.

If you disagree with a decision

You can challenge the council's decision if it refuses to assess, refuses to issue a plan, or if you disagree with the support or school named in the plan. You can appeal to the First-tier Tribunal (Special Educational Needs and Disability). Before most appeals you will need to consider mediation. There are strict time limits, so it is important to get advice early. SENDIASS and IPSEA can explain your options, free of charge.

Difficulty attending school

Some autistic children find school so stressful that they become very distressed before school, refuse to go, or are able to attend for only part of the day. This is sometimes called emotionally based school avoidance. It is not the same as truancy and it is not a sign that you are not trying hard enough.

Government guidance on school attendance expects schools to work with families to understand the barriers to attendance and to support the child. If your child is struggling to attend, speak to the school early, ask what adjustments can be made, and ask whether additional support or an EHC needs assessment might be needed. SENDIASS and IPSEA can advise you. If your child's mental health is affected, speak to your GP.

Moving to secondary school

The move from primary to secondary school at the end of Year 6 is a big change for any child and often more so for autistic children. If your child has an EHC plan, the council must review it and, where needed, amend it to name the secondary school before 15 February in the year your child moves up, so it is wise to start thinking about schools during Year 5. For all children, it helps to visit the new school several times, to have photos of key places and people, to get a copy of the timetable and a map in advance, to meet a named member of staff, and to make sure information about your child's needs is passed on.

Changes being planned to the system

> **SEND REFORM IN ENGLAND**
>
> In February 2026 the government published proposals to reform the special educational needs system in England, including new individual support plans for every child with special educational needs. These changes need new laws and, according to the House of Commons Library, are not expected to take effect until September 2029 at the earliest, with no changes to support provided through existing EHC plans before September 2030. Until then, the current law described in this guide continues to apply. IPSEA and SENDIASS publish up-to-date information, and this guide will be updated as the position becomes clear.

PART 8

Friendships, wellbeing and other conditions

IN THIS PART

- Friendships and social life
- Bullying
- Emotional wellbeing and anxiety
- Other conditions that are more common in autistic children

Friendships and social life

Many autistic children want friends, but find making and keeping friendships harder. Some are content with one close friend or with time alone, and that can be a healthy choice. Quality usually matters more than quantity.

It can help to:

- look for activities built around your child's interests, where conversation has a natural focus;
- keep social time short, structured and predictable at first, such as a single friend for a set time with a planned activity;
- talk through social situations afterwards, without criticism, and explore what others might have been thinking or feeling;
- ask school about support at break and lunchtime, such as a structured club or a quiet space;
- look for groups where your child can meet other autistic children, for example through National Autistic Society branches or local groups, since many autistic children find it easier to relate to one another.

Remember that social contact uses a lot of energy. Your child may need recovery time afterwards, and that is not a sign that the friendship went badly.

Bullying

Autistic children are more likely than other children to be bullied, and some may not recognise that what is happening is bullying or may find it hard to tell anyone. Signs can include not wanting to go to school, changes in mood or sleep, missing belongings or unexplained injuries. Every school must have a behaviour policy that includes measures to prevent bullying. If you are worried, raise it with the class teacher or headteacher, keep a record, and follow up in writing. The National Autistic Society and Ambitious about Autism have guidance for families.

Emotional wellbeing and anxiety

Autistic children are more likely than other children to experience anxiety, and some later experience low mood or depression. Possible contributors include constant sensory demands, uncertainty, the effort of masking, and experiences of being misunderstood or excluded. Anxiety in autistic children may not look like worry. It may show itself as more meltdowns, a stronger need for sameness, more repetitive behaviour, difficulty sleeping, stomach aches, or avoiding places or activities.

Many of the approaches in this guide, such as predictability, sensory comfort, clear communication and understanding, also reduce anxiety. When anxiety is affecting your child's daily life, NICE recommends that, for autistic children who are able to take part, professionals consider cognitive behavioural therapy,

a talking therapy that looks at the links between thoughts, feelings and actions, adapted for autistic children. Adaptations include more visual and written material, a more structured approach and involving parents.

> **WHEN TO SEEK HELP FOR YOUR CHILDS MENTAL HEALTH**
> Please speak to your GP if your child seems persistently anxious, sad or withdrawn, loses interest in things they used to love, talks about wanting to die or hurting themselves, or if their sleep, eating or behaviour change noticeably. Your GP can refer to child and adolescent mental health services (CAMHS) or other local services. If you are worried about immediate safety, use the urgent help routes in Part 1.

Other conditions that are more common in autistic children

Autistic children are more likely than other children to have some other conditions. Knowing this can help you and your child's professionals notice them early. Having one of these does not change the autism diagnosis, and a clinician can assess for them if there are concerns.

- **Attention deficit hyperactivity disorder (ADHD).** A large review of research found that more than one in four autistic people, around 28 in every 100, also have ADHD. Signs include marked difficulty with attention, restlessness or impulsivity beyond what is explained by autism.
- **Anxiety and other mental health conditions,** as described above.
- **Sleep problems,** described in Part 5.
- **Learning disability.** Some autistic children have a learning disability, which affects understanding and everyday skills across many areas.
- **Specific learning differences and coordination difficulties,** such as dyslexia or developmental coordination disorder, sometimes called dyspraxia.
- **Epilepsy.** Epilepsy is more common in autistic people. Please see a doctor if you notice episodes of staring or unresponsiveness, unusual jerking movements, or unexplained loss of skills.
- **Digestive problems and constipation,** which can cause pain and affect sleep and behaviour.
- **Eating differences and ARFID,** described in Part 5.

Some families come across the term pathological demand avoidance, or PDA, which is used to describe a profile in which a child strongly avoids everyday demands, often because of high anxiety and a strong need for control. PDA is not a separate diagnosis in the international classification systems used in the United Kingdom, research is limited, and professionals hold differing views about it. The National Autistic Society has information about demand avoidance and approaches that some families find helpful.

PART 9

Support, therapies and what the evidence says

IN THIS PART

- What NICE recommends
- What NICE says should not be used
- Applied behaviour analysis and the debate about it
- Medication
- Questions to ask about any therapy or service

A starting point

There is no treatment that removes autism, and the aim of support is not to make a child less autistic. Good support aims to improve your child's wellbeing, communication, independence and participation, and to reduce distress, in ways that respect who they are. Research on autism interventions is growing, but much of it is of limited quality, many studies are small or short, and much of the research has been carried out with pre-school children, so less is known about what helps in the primary years. We have tried to describe the evidence honestly.

What NICE recommends

The National Institute for Health and Care Excellence (NICE) publishes guidance for the NHS in England on supporting autistic children and young people. In summary, NICE recommends or suggests considering:

- **Adjusting the environment and how care is provided,** for example by reducing sensory overload and providing clear, predictable information.
- **A social communication intervention** delivered by a trained professional, using play-based strategies with parents, carers and teachers to increase shared attention, engagement and two-way communication. For school-aged children, NICE suggests this may be delivered through peers.
- **Help with life skills,** such as coping strategies and learning to use community facilities.
- **Adapted cognitive behavioural therapy for anxiety,** as described in Part 8.
- **A sleep plan,** and in some cases melatonin, as described in Part 5.
- **Assessment of possible causes** when behaviour is distressing or harmful, followed by an individual plan to reduce distress, as described in Part 5.
- **A named key worker or case manager** to coordinate care.

In practice, NHS services vary a great deal from area to area, and many families find that some of these are not readily available. Your local offer and your GP can tell you what is available locally. Occupational therapists, speech and language therapists and clinical psychologists are the professionals most likely to be involved.

One of the best-studied UK approaches for young autistic children is a parent-led social communication programme known as PACT, in which parents are coached to notice and respond to their child's communication. When the children in the original trial were followed up at around 10 years of age, some benefits appeared to have lasted over the whole study period, particularly in how often children started

communication with their parents, although there was no lasting difference in language. The trial involved pre-school children, so it tells us more about early support than about the primary years.

The National Autistic Society runs a parent programme called EarlyBird Plus for families of autistic children aged about 5 to 10. It is delivered locally by licensed professionals, covers understanding autism, communication, sensory experiences, daily living and wellbeing, and is available in some areas. Ask your local autism team or search the National Autistic Society website.

What NICE says should not be used

NICE is clear that some interventions should not be used for autistic children and young people.

NICE says do not use	For what purpose
Secretin, chelation and hyperbaric oxygen therapy	To manage autism, in any circumstances
Antipsychotic, antidepressant and anticonvulsant medicines	To treat the core features of autism
Exclusion diets, such as gluten-free or casein-free diets	To treat the core features of autism
Neurofeedback and auditory integration training	To manage speech and language difficulties
Omega-3 fatty acids	To manage sleep problems

This does not mean these medicines or diets are never appropriate. For example, a child with epilepsy may need an anticonvulsant, and a child with coeliac disease needs a gluten-free diet. It means they should not be used to treat autism itself.

Applied behaviour analysis and the debate about it

You may come across applied behaviour analysis, or ABA, particularly in materials from other countries. ABA is a broad term for approaches based on observing behaviour and changing what happens before and after it. Some programmes are intensive, involving many hours a week.

ABA is the subject of strong disagreement. Some families and professionals report that it has helped their child to learn skills. Some autistic adults who received ABA as children describe it as distressing and harmful, and many autistic people object to any aim of making children behave less autistically. The National Autistic Society describes views as strongly polarised, notes that there are significant limitations and gaps in the research, particularly about long-term effects, and says that some ABA interventions used today are not sufficiently person-centred and are too intensive. NICE does not recommend ABA by name.

UMID does not recommend any programme whose aim is to make a child or young person appear less autistic, to stop harmless behaviours such as stimming, or to achieve compliance for its own sake. If you are offered any behavioural programme, we suggest you ask the questions below, and in particular whether it aims to reduce your child's distress and increase their wellbeing and communication, rather than to stop harmless autistic behaviours such as stimming.

Medication

There is no medicine for autism itself. Medication may help with some co-occurring conditions, such as ADHD, epilepsy or sleep problems, and very occasionally, when behaviour is causing serious harm and other approaches have not worked or could not be used, a specialist may consider a medicine, with close monitoring and regular review, as NICE describes. Any medicine should be prescribed and reviewed by a specialist or GP who knows your child.

Questions to ask about any therapy or service

Whether a therapy is offered by the NHS, a charity or a private provider, these questions can help you decide.

- What is it for, and what will be different for my child if it works?
- What is the evidence that it helps children like mine, and is it recommended by NICE?
- Does it respect my child's autistic identity, or does it aim to make them appear less autistic?
- Will my child's own views and comfort be taken into account, and can they say no?
- Who delivers it, what are their qualifications, and are they registered with a professional body such as the Health and Care Professions Council?
- How much time does it involve, and what will it cost?
- How will progress be measured, and when will we review whether to continue?
- Are there any risks or side effects?

> **ABOUT UMIDS OWN FEES**
> Current fees for UMID services are on the UMID website at umid.co.uk/our-fees.

PART 10

Practical and financial help

IN THIS PART

- Disability Living Allowance for children
- Carer's Allowance
- Your right to a parent carer's needs assessment
- The local offer and short breaks
- Blue Badge
- Grants and other help

Benefit rules and amounts change, so please check the official GOV.UK pages or ask an adviser before you apply. The charity Contact has a free helpline with advisers who specialise in benefits for families with disabled children.

Disability Living Allowance for children

Disability Living Allowance (DLA) for children is a benefit to help with the extra costs of looking after a disabled child under 16 in England or Wales. In Scotland, the equivalent is Child Disability Payment, and Northern Ireland has its own DLA scheme.

- Your child does not need a particular diagnosis. What matters is their needs.
- DLA is not means-tested, so your income and savings do not affect it, and you can claim whether or not you work.
- Your child must need much more looking after than a child of the same age without a disability, or have difficulty getting about. These difficulties must have lasted at least 3 months and be expected to last at least 6 months.
- DLA has a care component and a mobility component, each paid at different rates depending on your child's needs.
- Receiving DLA can also open the door to other help, including Carer's Allowance and extra amounts in some other benefits.

Many autistic children qualify, particularly when they need a great deal of supervision, help at night, or help with communication and personal care. The claim form asks detailed questions, and it helps to describe a typical day and a difficult day, and what would happen without your help. Contact publishes a detailed guide to completing the form. Your child's report may be useful supporting evidence.

When your child reaches 16, DLA is replaced by Personal Independence Payment, and you will be contacted about this.

Carer's Allowance

Carer's Allowance is a benefit for people aged 16 or over who spend at least 35 hours a week caring for someone who receives certain disability benefits, including the middle or highest rate of the DLA care component. There are rules about earnings and study. Carer's Allowance can affect other benefits, so it is worth getting advice before claiming.

Your right to a parent carer's needs assessment

In England, if you care for a disabled child, your local council must assess your needs for support as a parent carer if it appears that you may have such needs, or if you ask. The assessment should consider your wellbeing and whether you are able and willing to continue caring. It can lead to support for you and your family. Ask your council's children's services or disabled children's team, or look on your local offer.

The local offer and short breaks

Every local council in England must publish a local offer, which sets out the services available for children and young people with special educational needs and disabilities and their families. This includes education, health and social care services, leisure activities and support groups. Search for "local offer" on your council's website.

Councils must also provide a range of short breaks for families of disabled children. These give children enjoyable experiences and give parents and carers time to rest. They may include after-school or holiday clubs, activity schemes or overnight breaks. How to access them varies, so check your local offer.

Blue Badge

A Blue Badge allows parking closer to where you need to go. In England, children with non-visible conditions may be eligible, for example if they regularly have intense and overwhelming responses to situations causing temporary loss of behavioural control, are a significant risk to themselves or others near traffic, or struggle severely with journeys. Your local council decides, and you can apply at www.gov.uk/apply-blue-badge.

Grants and other help

- **Family Fund** gives grants to families on a low income raising a disabled or seriously ill child, for things such as household items, sensory equipment or family breaks. Eligibility depends on your child's support needs and your household income, and application rules change from time to time, so please check the Family Fund website.
- **Contact** can advise on other grants, benefits and help with costs.
- Some areas have schemes for free or reduced-price leisure activities, and many attractions offer free entry for a carer. Your local offer is a good place to start.

PART 11

Where to find more help

IN THIS PART

- Organisations for autism and for families
- Help with school and the law
- Support for parents, carers and siblings
- Books for parents
- Books for children
- Books for brothers and sisters

We have checked that every organisation listed here was operating, and every web address was working, in September 2026. We list them because they are widely used and respected, not because UMID has a formal relationship with them.

Autism organisations

- **National Autistic Society**. The UK's leading autism charity, with advice and guidance for families, the online Ask ASH tool to find relevant information, local branches, an online community, the Parent to Parent emotional support service, and the EarlyBird Plus parent programme for children aged about 5 to 10. www.autism.org.uk
- **Ambitious about Autism**. A national charity for autistic children and young people, with practical information for parents on behaviour, meltdowns, school and support, and an online community for parents and carers. www.ambitiousaboutautism.org.uk
- **Autistica**. A UK autism research charity with information about research findings and priorities set with autistic people. www.autistica.org.uk
- **NHS website: Autism**. Clear, reliable information about autism, supporting an autistic child and where to get help. www.nhs.uk/conditions/autism/

Help with school and the law

- **Your local SENDIASS**. Every local area has a free, impartial and confidential Special Educational Needs and Disability Information, Advice and Support Service for parents and children. You do not need a diagnosis to use it. Search your council's local offer, or use the directory on the Council for Disabled Children website. councilfordisabledchildren.org.uk
- **IPSEA (Independent Provider of Special Education Advice)**. Free, independent legal information and advice on special educational needs and disability law in England, with template letters and guides to EHC needs assessments, plans and appeals. www.ipsea.org.uk
- **GOV.UK: Children with special educational needs and disabilities**. The official guide to SEN support, EHC plans and appeals in England. www.gov.uk/children-with-special-educational-needs
- **Special Needs Jungle**. A parent-led website with news, resources and informed opinion on special educational needs and disability. www.specialneedsjungle.com

Support for families, parents and carers

- **Contact**. The charity for families with disabled children. Its free helpline, 0808 808 3555, gives advice on benefits, education and other matters, Monday to Friday. Contact also offers the Listening Ear emotional support service and workshops for parents. contact.org.uk

- **National Autistic Society Parent to Parent**. Emotional support from trained volunteers who are parents of autistic children. You request a call online and a volunteer calls you back, usually within about 12 working days. It offers emotional support rather than advice. www.autism.org.uk/advice-and-guidance/help-and-support/parent-to-parent-helpline
- **Carers UK**. Information and advice for unpaid carers, including on benefits and your rights, with a helpline on 0808 808 7777, Monday to Friday. www.carersuk.org
- **YoungMinds**. Advice for parents worried about a child's mental health, including the Parents Helpline on 0808 802 5544, Monday to Friday. www.youngminds.org.uk/parent/
- **Cerebra**. A charity for children with brain conditions and their families, offering free parent guides on topics including sleep, anxiety, sensory processing and autism assessment, a sleep advice service and a legal rights service. cerebra.org.uk
- **The Sleep Charity**. Information and support on children's sleep. thesleepcharity.org.uk
- **Family Fund**. Grants for families on a low income raising a disabled or seriously ill child. www.familyfund.org.uk
- **Sibs**. Support for brothers and sisters of disabled children and adults, and information for parents. www.sibs.org.uk
- **National Network of Parent Carer Forums**. Parent carer forums work with local services to improve support for children with special educational needs and disabilities. The national network can help you find your local forum. nnpcf.org.uk
- **PDA Society**. Information about the demand avoidant profile described in Part 8. www.pdasociety.org.uk
- **BookTrust**. A children's reading charity with a booklist of children's books featuring autistic characters; search its website for "autism". www.booktrust.org.uk

Books for parents

- **Autism: How to Raise a Happy Autistic Child** by Jessie Hewitson (2018). A practical, warm book by a journalist and parent, drawing on autistic adults, other parents and professionals; a good first book after diagnosis.
- **Uniquely Human: A Different Way of Seeing Autism**, revised and expanded edition, by Barry M. Prizant with Tom Fields-Meyer (2022). For parents who want to understand the reasons behind their child's behaviour and respond with respect.
- **Ten Things Every Child with Autism Wishes You Knew** by Ellen Notbohm (third edition, 2019). A short, readable book written from a child's point of view, useful to share with family members and teachers.
- **Talking Together About an Autism Diagnosis** by Rachel Pike (National Autistic Society, 2008). A short guide for parents of younger children on explaining the diagnosis to their child.
- **Autism: A New Introduction to Psychological Theory and Current Debate** by Sue Fletcher-Watson and Francesca Happé (2019). For parents who want an accessible, research-based account of current thinking about autism.

Books for children

- **All Cats Are on the Autism Spectrum** by Kathy Hoopmann (2020). A gentle, funny photographic book that introduces autistic traits through cats; suits children of all ages and their families.
- **Can I Tell You About Autism?** by Jude Welton (2014). An illustrated book in which a boy called Tom explains his autism; suits children aged about 7 and over, and classmates.
- **When My Worries Get Too Big** by Kari Dunn Buron (second edition, 2013). A picture book that uses a simple five-point scale to help young children recognise and manage worry.

- **The Awesome Autistic Go-To Guide** by Yenn Purkis and Tanya Masterman (2020). A positive, practical handbook by autistic authors for children towards the end of primary school and into the early teens.

Books for brothers and sisters

- **Me and My Sister** by Rose Robbins (2019). A picture book about life with an autistic sister, told with warmth by a brother; suits younger children.
- **My Family is Different** by Carolyn Brock (National Autistic Society, 2007). An activity workbook for children aged about 4 to 9 with an autistic brother or sister, to help them explore their feelings. It uses some older terms and may be easier to find through a library or second-hand.

Words used in this guide

Word	What it means
AAC (alternative and augmentative communication)	Ways of communicating other than speech, such as pictures, signs, communication books or devices that speak.
ADHD	Attention deficit hyperactivity disorder, a condition affecting attention, activity levels and impulsivity.
ARFID	Avoidant restrictive food intake disorder, in which avoidance or restriction of food is severe enough to affect health or daily life.
Autistic burnout or fatigue	Deep exhaustion that can follow a long period of coping with demands, sometimes with loss of skills.
CAMHS	Child and adolescent mental health services, the NHS services for children's mental health.
Co-occurring condition	A condition that a person has alongside autism, such as ADHD or anxiety.
Double empathy problem	The idea that misunderstanding between autistic and non-autistic people happens in both directions.
Echolalia	Repeating words or phrases heard before, often as a way of communicating or processing.
EHC needs assessment	An assessment by the local council to decide whether a child needs an education, health and care plan.
EHC plan	An education, health and care plan, a legal document setting out a child's needs and the support they must receive.
Interoception	The sense that tells us what is happening inside the body, such as hunger, thirst, pain or needing the toilet.
Local offer	Information every council in England must publish about services for children with special educational needs and disabilities.
Masking	Hiding autistic traits, consciously or not, in order to fit in.
Meltdown	An intense, involuntary response to overwhelm, in which a child temporarily loses control of their behaviour.
Neurodivergent	Having a brain that works differently from what is considered typical, for example because of autism or ADHD.

Word	What it means
Neurotypical	Having a brain that works in the way that is considered typical; not neurodivergent.
NICE	The National Institute for Health and Care Excellence, which publishes guidance for the NHS in England.
Occupational therapist	A professional who helps with everyday activities, including sensory needs, self-care and motor skills.
PDA	Pathological demand avoidance, a term some people use for a profile of strong avoidance of everyday demands. It is not a separate diagnosis in the systems used in the UK.
Reasonable adjustments	Changes that organisations such as schools must make so that disabled people are not put at a substantial disadvantage.
SENCO	Special educational needs co-ordinator, the teacher responsible for special educational needs in a school.
SEN support	Support for special educational needs provided from a school's own resources.
SENDIASS	Special Educational Needs and Disability Information, Advice and Support Service, a free local advice service.
Sensory processing	How the brain takes in and responds to information from the senses.
Shutdown	A quiet response to overwhelm, in which a child withdraws, goes silent or seems unable to respond.
Social story	A short description, often with pictures, explaining a situation and what usually happens.
Special interest	A deep, focused interest in a particular subject, common in autistic people.
Speech and language therapist	A professional who supports communication, including understanding, speech, AAC and eating and swallowing.
Stimming	Repetitive movements or sounds, such as flapping or rocking, which often help a person to calm, focus or express feelings.

Where this information comes from

This guide draws mainly on UK guidance from NICE, the NHS and the Department for Education, and on UK law. Where we refer to research, we have used published reviews and trials where possible, and we have said where the evidence is limited. Practical suggestions that are not based on formal research are offered as general advice drawn from clinical experience and from what autistic people and families tell us. All web addresses were checked in September 2026.

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