

After diagnosis

Information for parents
and carers of children with autism



Accept difference.
Not indifference.

We want a world where all people living with autism get to lead the life they choose.

Everyone living with autism will:

- 1. Get the support, education and training they need**
- 2. Live with dignity and as independently as possible**
- 3. Be a part of their community and wider society**
- 4. Be understood by all professionals who support them**
- 5. Be respected for who they are by a knowledgeable public.**

Your help makes our work possible

We are a charity and we rely on your help to provide all of the support that we give to people living with autism. Find out how you can help: www.autism.org.uk/getinvolved



We're here to help

When your child is diagnosed with autism (including Asperger syndrome) it can be a very uncertain time. A lot of parents are given a diagnosis without any guidance on what to do next, and knowing little or nothing about autism. You might be feeling confused, frightened or overwhelmed.

You're not alone. Thousands of parents contact us after diagnosis to ask, 'What next?' and we're here to help.

Talk to us

Our Autism Helpline



We offer confidential information, advice and support.

Tel: 0808 800 4104 (Monday-Friday, 10am-4pm).

Free from landlines and most mobiles.

Email: autismhelpline@nas.org.uk

Online: www.autism.org.uk/helpline

(and follow the link to the online form)



Our **Autism Helpline's** trained and experienced advisors can talk through your questions and concerns, suggest some next steps, and point you towards the support that's available.

Before you call our helpline, you may like to look at the information on our website at www.autism.org.uk If you prefer, you can email us at autismhelpline@nas.org.uk or use our online contact form at www.autism.org.uk/helpline

You've probably got a lot of questions, and it can be helpful to write them down before you call, as a reminder of what you want to cover.

Once we know about your situation, we can:

- › explain more about autism
- › help you explore strategies that could help you or your family
- › give you more information and contacts, if that's useful.


You can call us back whenever you like.

If English is not your first language, you can use Language Line (a telephone interpretation service) to provide information in your chosen language through an interpreter. Someone who speaks English needs to call us first to let us know which language you speak, and we will call you back.

Terminology

Autism is a spectrum condition, so we've kept description of autism as broad as possible. It probably won't fit your child exactly, because there are as many different ways of describing autism as there are people on the autism spectrum – everybody's different.

Your child may have received a diagnosis of autism spectrum disorder, childhood autism, atypical autism, Asperger syndrome or another related condition. We use the term **autism** throughout this leaflet to cover all of those conditions



(including Asperger syndrome). There's even more information about diagnostic labels at www.autism.org.uk/labels

Dealing with all the new terms and phrases that come with autism can be overwhelming to begin with. If you're feeling daunted, we're here to help. You can call our Autism Helpline with any questions and we can help make things clearer.

Dealing with diagnosis

Feelings and reactions

The emotional effect of a diagnosis can be really overwhelming, and even heartbreaking, at first. It can feel like a lot to deal with and a lot to take in, even if it's something you were expecting. It can be even more difficult when you're dealing with other family members' feelings as well as your own, which is why it's really important to get all the support you can.

Feelings and reactions vary from person to person.

It's completely natural to feel worry, sadness, grief, guilt or anger – or a combination. It's also natural to be unsure of how you feel, to go through some shock, or to want to get to work on finding solutions straight away.

Lots of parents find that diagnosis turns out to be a very positive thing, and can lead to practical support, from help at school to extra funding. Accepting support is not always easy at first, especially if you're used to coping on your own, but it can make a big difference.

A diagnosis can come as a relief. It can be a weight off your shoulders for someone to give a name to what you're dealing with. It's important to know that, just because you've been struggling, it doesn't mean you've done anything wrong or been a bad parent. Thousands of parents have found themselves in this situation and have got through it, with support.

Expectations and beliefs

You might find that you've got preconceptions of autism from films you've seen or articles you've read. You may even find that you've got prejudices that are challenged when you start to find out more about autism and the impact it can have on your child. For example, not everyone with autism has an outstanding talent, although every child can develop – some in very startling ways with the right support – and some go on to do great things in the world.

Accepting your child's diagnosis can be a really difficult process. Understanding autism, and getting the right help and support in place, takes time and effort. Early support, and well-targeted help at any time, can be really helpful in helping your child to achieve their potential. It's important to remember that there are other parents out there going through the same thing. One of the many ways we can help is by putting you in touch with other families who know what you're going through.



Coping with others

Dealing with people, including professionals, who don't yet know your child or your family can be a challenge. We know that it can be difficult to stay calm and to be assertive. Other parents have said that they find it really useful to keep leaflets or websites close by, and to record their progress by writing notes about phone calls or discussions.

It's important to remember that you're learning, and there are organisations that provide free courses to help you in these areas, and even attend meetings with you. You don't have to do it all on your own. You can get as much support as you need, for as long as you want.

You're not alone.

About autism

Autism (including Asperger syndrome) is a lifelong developmental disability that affects the way a person communicates with other people and relates to the world around them.


It's a spectrum condition, which means that it affects people in different ways. **Everyone with autism is different.** Some children with autism may have an accompanying learning disability, or related conditions such as dyslexia or epilepsy. Children with Asperger syndrome do not usually have learning disabilities.

After diagnosis

The exact cause of autism is still being investigated. Research suggests that a combination of factors – genetic and environmental – may account for changes in brain development. Autism is not caused by a person's upbringing or social circumstances, and it's not anyone's fault.

All children with autism find it harder to manage in the world the way it is. They approach the world differently from other people and have difficulty with communication, social interaction and social imagination. You may hear these referred to as the 'triad of impairments'. This means that children with autism usually:

- find it hard to understand non-verbal communication, like facial expressions and tone of voice
- take language very literally and find metaphors and idioms confusing and sometimes frightening
- have difficulty recognising people's feelings or expressing their own, so they find it hard to understand social conventions like the give-and-take nature of conversations
- struggle to understand and predict people's behaviour, and find change and unexpected situations stressful
- have a strong preference for routines and can develop intense, sometimes 'obsessive', special interests
- don't engage in imaginary play, preferring to act out something they've seen and repeating the same scene over and over again.



Lots of children with autism are over- or under-sensitive to certain sounds, light, touch, smells and tastes, and they may avoid or seek out sensory stimuli.

Strengths

- Children with autism have a **unique and individual view of the world**, which lots of people who don't have autism find interesting, refreshing and valuable.
- Some children with autism have a good eye for detail and accuracy.
- Children with autism are likely to remember information, routine or processes once they've learned them.
- Most children with autism are good at learning visually. Using real objects, pictures, demonstrations and written material can all help.
- Some children with autism can focus on their special interest for a long time and may choose to work in a related area.

These are just some of the main characteristics of autism. You can find out more at www.autism.org.uk/aboutautism

Some people ask if there is a 'cure' for autism. There is currently no known cure for autism – children with autism grow up to become adults with autism. But there are plenty of ways that we can help children with autism. Early diagnosis and the right education and support can all help people with autism to fulfil their potential.

Contact with professionals

You can't tell that someone has autism just by looking at them. Some people with autism can appear to be very able, so you may need to tell social, education and healthcare professionals about your child's condition and their need for support. Professionals can find out more at www.autism.org.uk/professionals





Support for your child

One of the biggest challenges parents face is understanding and coping with their child's behaviour. There are plenty of ways that you can get support with this.

- Our **Autism Helpline** can offer you useful guidance and information about different kinds of behaviour in children with autism. Tel: 0808 800 4104 (Monday-Friday, 10am-4pm) Email: autismhelpline@nas.org.uk
- There's lots of useful information on **our website** to help you understand and manage your child's behaviour: www.autism.org.uk/behaviour
- We also offer an online service called **Signpost** which asks you to enter some basic information about your child and their diagnosis, then provides personalised information relevant to your child's age, diagnosis and local area. www.autism.org.uk/signpost
- Your child might benefit from speech and language therapy, occupational therapy or help from a psychiatrist or psychologist. These are available through the NHS with a referral from your GP, or privately. They may sometimes be provided by your child's school.
- There are other approaches, therapies and interventions that can improve the quality of life for a child with autism, including communication-based interventions, behavioural therapy and dietary changes. You can find out more at www.autism.org.uk/approaches

Social services

Another good starting point is to contact your local **social services** department (or social work services in Scotland) if your child needs extra support at home; your child's **school** or local authority, or Education Library Board in Northern Ireland, if they need extra support in school.


Social services work to improve people's quality of life and help them to live more independently. Children with autism are entitled to an assessment of their needs by a social worker who will visit your home.

As a result of an assessment of your child's needs, you may be entitled to a number of services, including:

- home help or respite care
- aids, equipment or grants for housing adaptations.

Social services can arrange for services to be put in place for your child. If they can't provide the services your child needs, they should talk to other agencies and ask if they can. Alternatively, you can be given a Direct Payment – a cash payment to buy these services yourself.

If you're asking your local social services department for an assessment of needs for your child, you can also ask for a carer's assessment. As a result, you may be entitled to things like travel assistance, training and counselling. You may also be eligible for Carer's Allowance. Find out more at www.autism.org.uk/benefitsforparents



Find out more about getting help from social services in:

- › England and Wales: www.autism.org.uk/17378
- › Scotland: www.autism.org.uk/17740
- › Northern Ireland: www.dhsspsni.gov.uk

Because community care law is constantly changing, it's worth checking our website for the latest developments affecting children with autism at www.autism.org.uk/benefitsforparents

Our Community Care Service



We offer confidential advice and information, including:

- › what help you can get from your local social services department
- › how to access that help
- › how to make a complaint to your social services department if you're not happy with their decisions or the services they offer.

Email us or call our Autism Helpline to make an appointment to speak to our community care specialist.

Tel: **0808 800 4104** (Monday-Friday, 10am-4pm) - telephone interpretation service available.

Email: **communitycare@nas.org.uk**

Online: **www.autism.org.uk/communitycare** (and follow the link to the online form)

Education



The right support in education can make a really positive difference to a child or young person with autism.

If your child has **special educational needs (SEN)**, or **additional support needs (ASN)** in Scotland, they are entitled to get extra help in school. This extra help is usually provided by the school, but they may bring in other professionals like educational psychologists, or speech and language therapists.

If your child's needs are very complex, you or the school can ask for a formal assessment – a detailed investigation to find out what your child's SEN/ASN are, and what provision is necessary to meet those needs. This may include the type of school your child should go to.

- In England, Wales and Northern Ireland, your local authority may issue a **statement of special educational needs**. (Next year, statements will be replaced with Education, Health and Care Plans in England.)
- In Scotland, if your child also has support needs in at least one area as well as education, such as health or social care, local authorities may prepare a **co-ordinated support plan** for your child.

Because the education system is constantly changing, it's worth checking our website for the latest developments affecting children with autism: www.autism.org.uk/education

Our Education Rights Service

We offer an Education Advice Line that can advise you on:

- › education rights and entitlements for children and young people with autism in school
- › what you can do if you are having difficulty getting your child the support they need.

We also offer a Tribunal Support Scheme in England, Wales and Northern Ireland and an Appeals and Tribunals Service in Scotland.

Tel: 0808 800 4102 - telephone interpretation service available. Free from landlines and most mobiles.



Email: educationrights@nas.org.uk;
educationrightsscotland@nas.org.uk;
educationrightsnl@nas.org.uk;
educationrightswales@nas.org.uk

Online: www.autism.org.uk/educationrights
(and follow the link to the online form)

"The help I received was outstanding and helped me to soldier on with renewed strength through a very long and stressful case. My advisor kept in touch with me and was my sounding board over and over. With bags of patience and kindness you helped me through the process. I will be forever grateful."

Parent

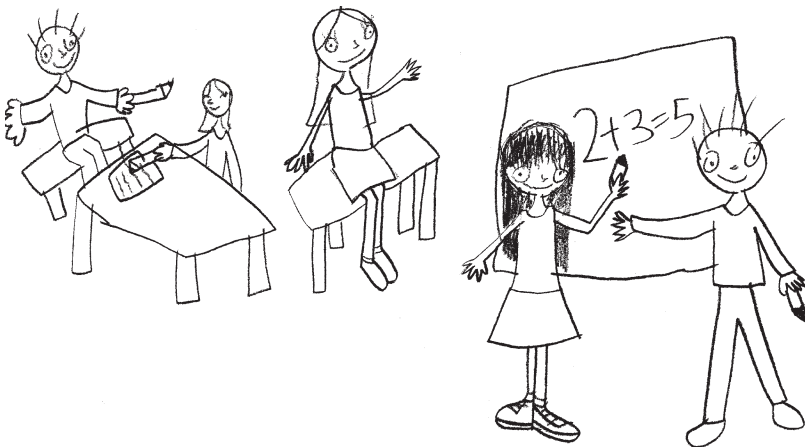
Our schools

We run specialist schools across the UK supporting hundreds of children and young people between the ages of four and 25. All of them provide a truly child-centred experience, working closely with each student to help them achieve their full potential and prepare for adulthood: www.autism.org.uk/schools

As well as our schools, we offer:

- an education support service for schools:
www.autism.org.uk/educationsupport
- short breaks services for families:
www.autism.org.uk/shortbreaks
- after-school and youth clubs for children and young people with autism: www.autism.org.uk/outofschoolsclubs
- Support and activities for parents and siblings:
www.autism.org.uk/supportcentres

To speak to us about schools and services near you, call 0117 974 8430





Benefits

Here are some of the benefits that you or your child may be entitled to claim. Some of these are available regardless of your income or employment status.

- › Disability Living Allowance
- › Carer's Allowance
- › Extra Child Tax Credit
- › Income Support
- › Housing Benefit or Council Tax reductions
- › Universal Credit.

Lots of parents of children with autism claim Disability Living Allowance (DLA) for their child. DLA can act as a gateway to other benefits and sources of help. Find out more at www.autism.org.uk/benefits

How to claim DLA

To request a claim form for DLA, call the Department for Work and Pensions.

Tel: 0845 123456 (England, Scotland and Wales)

Tel: 0800 220674 (Northern Ireland).

After diagnosis

Get help with filling in claim forms from:

- your local advice centre (eg Citizens Advice Bureau)
- professionals involved with your child who may give advice on filling in particular sections.

Because the benefits system is constantly changing, it is worth checking our website for the latest developments:
www.autism.org.uk/benefits

Our Welfare Rights Service



We offer confidential advice and information on all aspects of social security benefit entitlement.

Email or call our Autism Helpline to make an appointment to speak to our welfare rights specialist.

Tel: 0808 800 4104 (Monday-Friday, 10am-4pm)
- telephone interpretation service available.

Email: welfarerights@nas.org.uk

"It was such a relief for someone to actually listen to me, let alone offer help and support." Parent



Support for you and your family

When your child is diagnosed with autism, you're likely to be dealing with your family's reactions and feelings as well as your own. Getting support for yourself is really important and it can be really helpful to talk to other parents of children with autism in a similar situation to you. Here are just some of the kinds of support you can get.

Helplines

Our Autism Helpline can give you practical advice and information about living with autism. Tel: 0808 800 4104 (Monday-Friday, 10am-4pm) Email: autismhelpline@nas.org.uk

Our Parent to Parent Service

We offer confidential telephone support for parents and carers of children or adults with autism. One of our trained volunteer parents can:

- > listen from the perspective of someone who knows what life can be like for families living with autism
- > talk through problems, feelings and experiences.

Please leave a message and they will call you back at a time that suits you, including evenings and weekends.

Tel: **0808 800 4106.** Free from landlines and most mobiles.

Online: www.autism.org.uk/p2p (and follow the link to the online form)



After diagnosis

"It's been a whole year now since my son's diagnosis and life has changed immeasurably - and for the better. Although life is hard sometimes. My son is now six, he has proper focused support in his mainstream school, I have the support from the LEA to deal with a difficult school, I no longer feel the need to ring the Carers Centre, NAS, Parent Partnership, etc for support, the initial feeling of being overburdened by this brave new world has diminished and now I dip into courses, literature and campaigns when I feel the need or when something's available." Parent

Local support

Find and contact your nearest branch of the NAS for more local information and support: www.autism.org.uk/branches

Browse for **support groups** near you: www.autism.org.uk/directory. Contact parents of children with disabilities through

Contact a Family: www.cafamily.org.uk

Online community

Our Community is a safe, welcoming place to share your questions, thoughts and advice about autism. It's for people on the spectrum, parents, carers, professionals and other people interested in autism.

Visit today at www.autism.org.uk/community



Family support and courses

EarlyBird

This is a three-month training programme for parents and carers of pre-school children, involving group training sessions, individual home visits and ongoing work with the child at home. There is also an EarlyBird Plus programme for parents and carers of children who receive a later diagnosis (4-8 years). Find out more at www.autism.org.uk/earlybird

Autism Seminars for Families

Autism Seminars for Families are a series of one-day courses for parents and carers of children and young people with autism. The courses cover subjects including understanding autism, managing anger, and sensory needs. Find out more: www.autism.org.uk/familyseminars

Befriending

In some areas, we have befriending schemes, where a trained befriender spends a few hours each week with a child or young person with autism, or their family. Some spend time in the family home; others go out and about. Find out if there is a befriending scheme near you at www.autism.org.uk/befriending

Find out about other support for you and your family by:

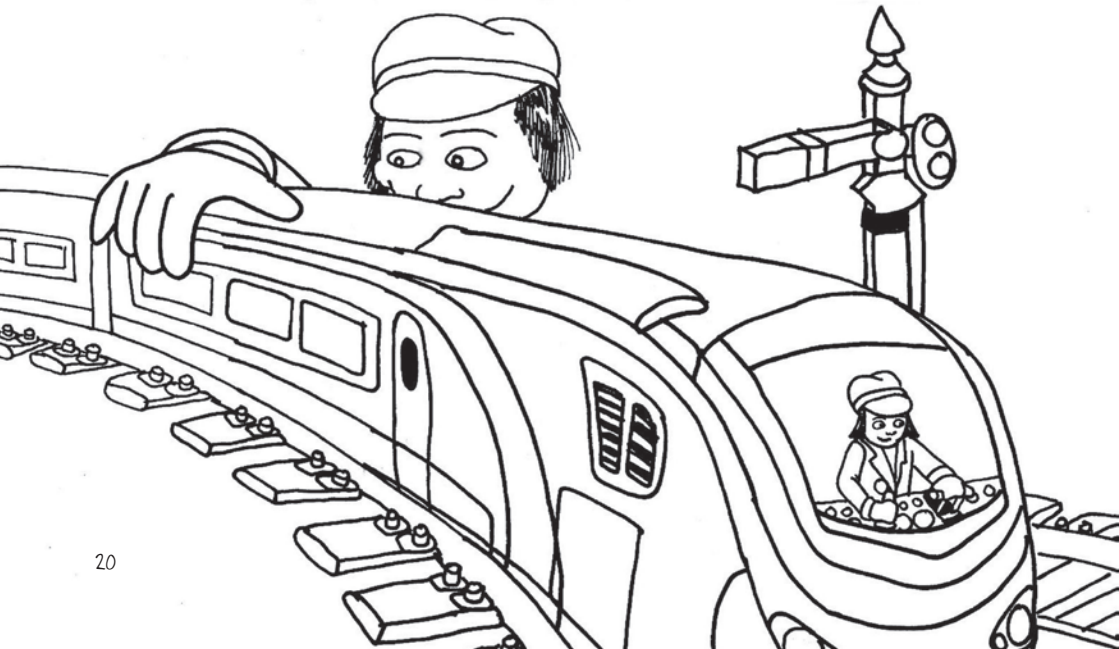
- using **Signpost**: www.autism.org.uk/signpost
- using our **Autism Services Directory**:
www.autism.org.uk/directory
- calling our **Autism Helpline** on 0808 800 4104

Information and publications

Our **website** gives you information about autism; details of our UK-wide services for people with autism, parents and professionals; ideas for getting involved with our work; and plenty of news and events: www.autism.org.uk

Our online **shop** sells a wide range of tried, tested and trusted books and resources for children with autism, their families and professionals working with them: www.autism.org.uk/shop

Illustration by Darshan Raja Rayan





Keep in touch

Find out more about how we can help you and your family, and how you can get involved with our groundbreaking work. Just fill in this form and post it back to us.



Title	<input type="text"/>
First name	<input type="text"/>
Last name	<input type="text"/>
Address (line 1)	<input type="text"/>
Address (line 2)	<input type="text"/>
Town/city	<input type="text"/>
Postcode	<input type="text"/>
Telephone	<input type="text"/>
Email	<input type="text"/>

By providing your email address you are giving us consent to contact you via email.

The National Autistic Society would like to keep you informed about our services, upcoming news, events and fundraising activities. We will look after your data as set out in our privacy and data protection policy: www.autism.org.uk/privacypolicy

If you prefer not to receive information by post please tick this box

If you prefer not to receive information by telephone please tick this box

Please return this form to:

Publications team
The National Autistic Society
393 City Road
London EC1V 1NG

Give us your feedback
We'd love to hear your feedback on the information in this leaflet. Please email your comments and suggestions to publications@nas.org.uk

We are the leading UK charity for people with autism (including Asperger syndrome) and their families. With the help of our members, supporters and volunteers we provide information, support and pioneering services, and campaign for a better world for people with autism.

Around 700,000 people in the UK have autism. Together with their families they make up over 2.7 million people whose lives are touched by autism every single day. From good times to challenging times, The National Autistic Society is there at every stage, to help transform the lives of everyone living with autism.

We are proud of the difference we make.

The National Autistic Society (NAS)

393 City Road
London EC1V 1NG
Switchboard: +44 (0)20 7833 2299
Autism Helpline: 0808 800 4104
Minicom: 0845 070 4003
Email: nas@nas.org.uk
Website: www.autism.org.uk

NAS Cymru

Tel: 029 2062 9312
Email: cymru@nas.org.uk

NAS Scotland

Tel: 0141 221 8090
Email: scotland@nas.org.uk

NAS Northern Ireland

Tel: 028 9068 7066
Email: northern.ireland@nas.org.uk

The National Autistic Society is a charity and relies on voluntary income to support its work – including the development of resources, like this one, for parents and carers.

The National Autistic Society is a charity registered in England (269425) and in Scotland (SC039427) and a company limited by guarantee registered in England (No.1205298), registered office: 393 City Road, London EC1V 1NG

© The National Autistic Society 2013

1253 011013

