



The National
Autistic Society

What next?

Information for adults with autism
before and after diagnosis



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.**

We rely on your help to provide all the support we give to people living with autism, including leaflets like this one. Find out more about how you can support us: www.autism.org.uk/getinvolved

Who is this booklet for?

- › Adults who think they may be on the autism spectrum, and may be considering getting a diagnosis.
- › Adults who have a diagnosis on the autism spectrum.

How diagnosis helps

Getting a diagnosis of autism – or an autism spectrum disorder (ASD) – can be a really positive thing. A lot of people say their diagnosis has helped them to understand why they have difficulties with some things and why they are especially good at some things.

Having a diagnosis also means you can get easier access to support and benefits. This guide tells you more about the support you can get, the benefits you may be entitled to, and how The National Autistic Society (NAS) can help you. It also includes a section about support for parents and carers.

Find out more about how a diagnosis can benefit you at www.autism.org.uk/diagnosisinfo

Terminology

You may have received a diagnosis of autism, autism spectrum disorder (ASD), pervasive developmental disorder – not otherwise specified (PDD-NOS), atypical autism, Asperger syndrome or another related condition. These conditions are collectively called the autism spectrum. We use the term autism throughout this leaflet to cover all of these conditions.



About autism

Autism 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, while all people with autism share certain areas of difficulty, their condition affects them in different ways.

Asperger syndrome is a form of autism.

People with autism usually:

- > find it difficult to understand and use language to communicate, and may find it impossible not to take phrases literally
- > find it difficult to understand and use tone of voice, facial expressions, body language, and the unspoken rules of language, like the give-and-take nature of conversations
- > have difficulty recognising people's feelings or expressing their own
- > struggle to make and keep friends and maintain other social relationships
- > find it difficult to understand and predict people's behaviour
- > have a strong desire to stick to the familiar and find change and unexpected situations stressful
- > have sensory sensitivities, for example hyper-sensitivity to loud noises, certain lights and strong smells
- > have intense special interests.

The way these characteristics present themselves will

vary from person to person. People with autism may have related conditions such as dyslexia or epilepsy, and they may have learning disabilities. People with Asperger syndrome do not usually have learning disabilities but share the main areas of difficulty described on page 2.

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, their social circumstances and is not the fault of the person with the condition.

There is no known 'cure' for autism. This does not mean, however, that nothing can be done for a person with autism. There is a growing movement among activist adults with autism and Asperger syndrome who don't think in terms of 'curing' a disorder but instead of celebrating difference.

Strengths

- > People 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.
- > Most people with autism are good at learning visually. Using real objects, pictures, demonstrations and written material can all help.
- > Some people with autism have a good eye for detail and accuracy.



- › People with autism are likely to remember information, routine or processes once they've learned them.
- › Some people with autism can focus on their special interest for a long time and may choose to work in a related area.

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 educate people, including professionals, about your condition and need for support. Find out more at www.autism.org.uk/aboutasds

Getting support

Find services in your area

You can find out more about services near where you live at www.autism.org.uk/inyourarea

We also offer an online information service called Signpost. It asks you some questions about yourself, your diagnosis and where you live, and gives you personalised information about services in your area: www.autism.org.uk/signpost

Talk to us

Our **Autism Helpline** can give you impartial information and practical, confidential advice about living with autism.

Our trained advisers can:

- › talk in depth about the autism spectrum and related issues
- › give you details of support in your local area
- › send you information about subjects related to autism.

We offer a **telephone interpretation service**, allowing us to provide information through interpreters in 150 different languages. Callers need to speak in English at first to let staff know which language they prefer to use, and someone will then call you back.

Our Autism Helpline



We offer confidential information, advice and support:

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

Free from landlines and most mobiles

Email: autismhelpline@nas.org.uk

(We will reply within 14 working days or sooner)

Website: www.autism.org.uk/helpline



Social support

Social groups

Social groups are a way of meeting and socialising with other people with autism. They operate in different areas of the UK and can be run by local support groups, organisations like The National Autistic Society (NAS), or councils.

Find out if there are any social groups in your area by calling our Autism Helpline. Tel: 0808 800 4104 (Monday–Friday, 10am–4pm)

Email: autismhelpline@nas.org.uk

Find information about social groups run by the NAS at www.autism.org.uk/socialgroups



Social skills training

Lots of people with autism say they would like some form of social skills training. Social skills training usually focuses on things that people with autism can find difficult, like having a conversation, identifying and expressing emotions, problem solving, or understanding body language and tone of voice.

You may find that you can get social skills training as a result of a social care assessment by your local social services department (social work services in Scotland). They will consider what needs you have, and which services you might find useful.

Find out about social skills training where you live by calling our Autism Helpline.

Tel: 0808 800 4104

Email: autismhelpline@nas.org.uk

More help with social skills

Our website has this guide to social skills for young people and adults: www.autism.org.uk/socialskills

Simon Perks's book, *Body language and communication – a guide for people with autism spectrum disorders*, is available to order at: www.autism.org.uk/pubs

Socialeyes is a learning resource with a new and innovative approach to facilitating social skills and social understanding with people on the autism spectrum. It has been developed with people with autism and Asperger syndrome, alongside leading professionals in the field. You can order it at www.autism.org.uk/pubs

Befriending

Some people with autism find our befriending service helpful. It's a way for you to spend time with one of our volunteers who knows about autism, doing something that you enjoy. You might, for example, go for lunch or to see a film.

Find out if there are befriending opportunities in your area by calling our Autism Helpline.

Tel: 0808 800 4104

Email: autismhelpline@nas.org.uk

Website: www.autism.org.uk/befriending

We also have an e-befriending scheme.

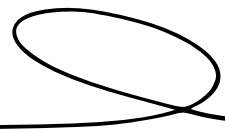
Housing

Residential services

We provide residential settings for adults with varying needs in different locations around the UK, offering specialised, person-centred support.

Supported living

Our supported living service is for people who need extra help to live in their own homes, as tenants or owner occupiers, living alone or with others. This can mean 24-hour support or just a couple of hours a week to help with shopping and budgeting. NAS supported living operates in a number of places around the UK.



Community support

Outreach services

We offer a flexible outreach service to help people access opportunities outside the home in their local community. NAS outreach services operate in a number of places around the UK.

Day services

In lots of areas we provide day services, where adults can come for support, social interaction and to develop new skills. We also provide several services for families and carers.

Housing and community support

Find out more about the NAS residential, supported living, outreach and day services.

Tel: 0117 974 8430

Website: www.autism.org.uk/communitysupport

Our Autism Helpline can advise you on the different kinds of support provided by the NAS as well as other organisations. Tel: 0808 800 4104

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 if you're not happy with their decisions or the services they offer.

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

Website: www.autism.org.uk/communitycare





Education

Colleges and universities have disability support departments where you should find a team of disability officers, learning support assistants/tutors, and mentors who can support students. All students with a disability should be able to get support. It's a good idea to contact colleges and universities that you are interested in to find out exactly what support they can offer.

Support for students with disabilities in higher education is funded through Disabled Students Allowance (DSA). You can claim DSA as well as other types of financial support for students, for example a student loan. DSA does not have to be repaid.

Support for students in further education is funded by colleges. You can still claim other benefits while you're in further education, for example Disability Living Allowance.

Find out more about further education and higher education for people with autism at: www.autism.org.uk/fe

Student support

We offer support to students with autism who are in further or higher education.

Our student support services

We offer support tailored to individual need, which may include:

- > time management
- > organisational skills
- > personal management
- > communication skills
- > social skills
- > dealing with the transition to university life.

www.autism.org.uk/studentssupportservices

Employment

There are careers services in England, Northern Ireland, Scotland and Wales that can give you information and advice on employment and career choice. Careers services generally provide information – they cannot find a job for you.

If you want to find a job, you can visit your local Jobcentre Plus. Jobcentre Plus has disability employment advisers (DEAs) who support people with a disability, including people with autism. Not all disability employment advisers will know a lot about autism, but they can try to help you find a suitable job.

The NAS works in partnership with Remploy, who provide employment services for people with disabilities. Remploy can offer support in areas such as writing CVs and job applications.



In London, Glasgow and South Wales, we have an employment service called Prospects.

Prospects can help you with:

- > preparing for work
- > searching for a job
- > getting ready for an interview
- > managing in the workplace.

They can also give advice, support and training to employers.

Our Prospects employment service

Email: prospects@nas.org.uk
Website: www.autism.org.uk/prospects

Ask for more information:
www.autism.org.uk/contactprospects

Some of our adult services also offer support to people who are looking for work, and the chance to obtain certain qualifications.

Find out more by calling our Autism Helpline: 0808 800 4104.

Help from an advocate

An advocate helps people to say what they want, secure their rights, represent their interests and get services they need.

An advocate may be able to help you:

- > if you have been turned down for housing, asked to consider moving to a different place or if you are being threatened with eviction
- > if you want to find out whether you are on the autism spectrum and are having to wait a long time for a diagnostic assessment
- > if you have a diagnosis of autism and are not being offered services that you feel you need.

Advocates are independent of organisations such as your local council or the job centre. Not all advocates have experience of working with people with autism.

You can find out more about advocacy in our book *Advocacy for adults with autism spectrum disorders*, available from www.autism.org.uk/pubs

Find an advocacy organisation near you by contacting one of these organisations.

Action for Advocacy (England and Wales only)

Website: www.actionforadvocacy.org.uk

Advocacy Resource Exchange

Tel: 08451 22 86 33

Website: www.advocacyresource.org.uk



BILD (British Institute of Learning Disabilities)

Tel: 01562 723 027

Website: www.bild.org.uk/04advocacy.htm

Scottish Independent Advocacy Alliance (Scotland only)

Tel: 0131 260 5380

Website: www.siaa.org.uk

Benefits

These are some of the benefits you may be entitled to:

- > Disability Living Allowance
- > Working Tax Credit
- > Housing/Council Tax Benefit
- > Jobseekers Allowance
- > Employment and Support Allowance.

Employment and Support Allowance replaced Income Support and Incapacity Benefit in October 2008. However, people who already claim Income Support and/or Incapacity Benefit can continue to claim these benefits for now. If you are already claiming Income Support (on the basis of disability or sickness) or Incapacity Benefit, you will be reassessed by 2014 to see if you can be transferred onto Employment and Support Allowance.

Parents and carers of adults with autism may be entitled to:

- > Carer's Allowance
- > Income Support

- > Housing/Council Tax Benefit

- > Child Tax Credit.

Parents and carers can apply to be 'appointees' for an applicant's benefit claim, meaning they can complete claim forms, report changes in circumstances and receive money on their child's behalf.

Find out more about benefits at www.autism.org.uk/benefits

Benefit Enquiry Line

The Benefit Enquiry Line can give you basic advice about benefit entitlement and send you Disability Living Allowance claim forms.

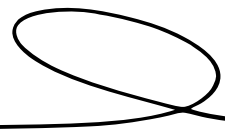
Tel: 0800 88 22 00 (England, Scotland or Wales)

Tel: 0800 22 06 74 (Northern Ireland)

Find out which of the benefits administered by the Department for Work and Pensions you can claim online at www.dwp.gov.uk/eservice

Find out more about filling in claim forms from:

- > our Welfare Rights Service. Telephone 0808 800 4104 to make an appointment to speak to our adviser
- > your local Citizens Advice Bureau
- > professionals who work with you, such as social workers, advocates and support workers, who may be able to give advice on filling in particular sections of claim forms.



Personal budgets and individual budgets

A personal budget is money for support that comes from social services.

An individual budget is money that comes from more than one place. For example, if you receive money from your social services department and also Access to Work, this is called an individual budget.

Personal budgets and individual budgets are available from many local authorities, and will be offered by all local authorities by April 2013. They are offered to adults over 16 and give people who need support more choice and control over their lives. You can spend your budget on services, equipment or people to support you, in agreement with your council's social services department.

Your council will need to assess your needs before you can discuss the option of a personal or individual budget.

If you have already had an assessment and are receiving services from your council, you may be offered the option of a personal or individual budget when you have your yearly review, or you can ask your social worker if this is an option.

Direct payments

You can get money from social services paid to you in different ways. A direct payment is just one way.

Direct payments are made straight into your bank account, so you can arrange and pay for services yourself, rather than getting the services provided by your council.

Adults and young people with autism can apply for direct payments. First, you need to ask your council to assess your needs. Your council may then offer you direct payments.

If you get direct payments, you must use them to pay for the services that your council has assessed you as needing.

If you have already had an assessment and are receiving services from your council, you can discuss the option of direct payments with your social worker.

Our Welfare Rights Service



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

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

Website: www.autism.org.uk/welfarerights





Therapies and interventions

There is no 'cure' and no specific treatment for autism.

Lots of people do not look for a cure and prefer to celebrate their difference. However, there is a wide range of therapies and interventions that can improve a person's quality of life. Find out more at www.autism.org.uk/approaches

Counselling

Counselling is one form of therapy that you might find helpful. Some people with autism find counselling helps them to cope with everyday life.

Counselling usually involves going to talk with someone at an agreed time and place once a week. The sessions can last up to an hour but can be for a shorter period. A counsellor will not tell anyone else what you say to them.

Find out more about counselling at www.autism.org.uk/counselling

You may also like to contact the British Association for Counselling (BACP), which can give you a list of accredited counsellors who work in your area.

British Association for Counselling (BACP)

Tel: 01455 883316

Website: www.bacp.co.uk

Information and publications

We publish and sell a wide range of tried, tested and trusted **books and resources** for adults with autism, families and professionals. Website: www.autism.org.uk/shop

Our website has information about autism; details of our nationwide services for people with autism, parents and professionals; ideas for getting involved with our work; and our latest news and events: www.autism.org.uk It also contains information in other languages: www.autism.org.uk/languages

Our **Information Centre** is a specialist information service for professionals, students and researchers working with people with autism and their families.

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

Website: www.autism.org.uk/infocentre

Our **Autism Services Directory** allows you to search for autism services, support groups and training courses across the UK: www.autism.org.uk/directory

Autism Data is a searchable database providing information on published research, articles, books and multimedia on autism: www.autism.org.uk/autismdata

Asperger United is a quarterly magazine for people with autism age 16+ (some parents subscribe on behalf of under-16s). It is written and edited by people with autism, or by professionals with this group specifically in mind. Subscription

is free, so we ask overseas subscribers and professionals in the autism field to make a donation to help cover costs:
www.autism.org.uk/aspergerunited

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: www.autism.org.uk/community

Support for parents and carers

People providing care for someone on a regular and substantial basis are entitled to a carer's assessment. This assessment is done by a social worker at home and will find out whether the council should be providing any services to help. Contact our Community Care Service for more information about carer's assessments. Tel: 0808 800 4104.

There is more information on our website for parents and carers of people with autism: www.autism.org.uk/parents

From here you can find out about services, benefits, short breaks, parent groups, our Parent to Parent telephone support service, and much more. You can also search for services in your area at www.autism.org.uk/signpost

Finally, you may like to join our online community - find out more at www.autism.org.uk/community

Get involved

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. We'll send you a pack of helpful information, opportunities and useful contacts.

✂

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"/>	Mobile	<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

Please return this form to:
Supporter Care team
The National Autistic Society
393 City Road
London EC1V 1NG

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

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

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

The National Autistic Society is the leading UK charity for people with autism (including Asperger syndrome) and their families. We provide information, support and pioneering services, and campaign for a better world for people with autism.

Over 500,000 people in the UK have autism. Together with their families they make up over two million people whose lives are touched by autism every single day.

From good times to challenging times, we're there at every stage to help transform the lives of everyone living with autism.

We're proud of the difference we make.

The National Autistic Society

393 City Road

London EC1V 1NG

Switchboard: 020 7833 2299

Autism Helpline: 0808 800 4104

Minicom: 0845 070 4003

Fax: 020 7833 9666

Email: nas@nas.org.uk

Website: www.autism.org.uk

NAS Cymru

Tel: 02920 629 312

Email: cymru@nas.org.uk

NAS Scotland

Tel: 0141 221 8090

Email: scotland@nas.org.uk

NAS Northern Ireland

Tel: 02890 687066

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 people with autism.

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