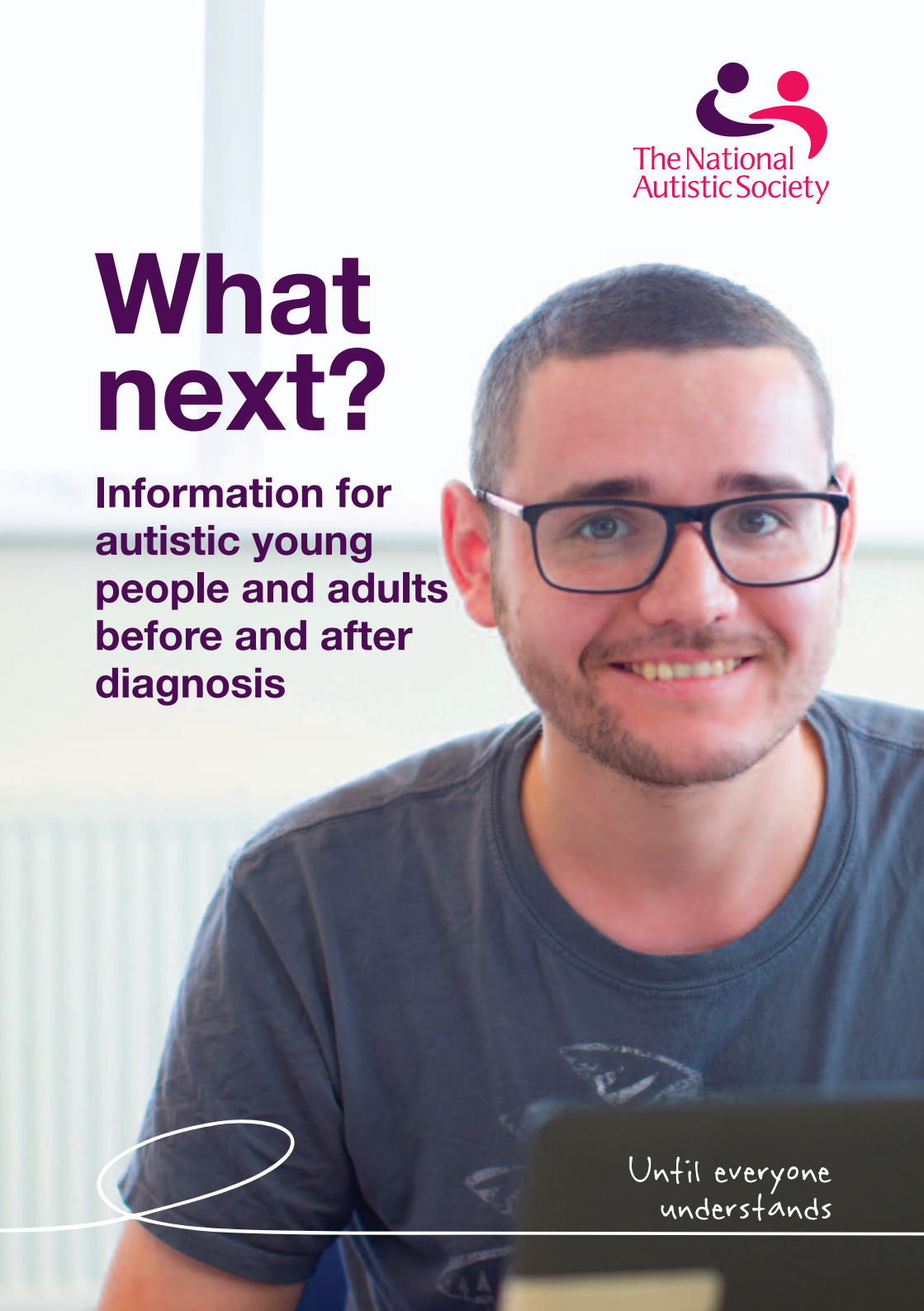


# What next?

Information for  
autistic young  
people and adults  
before and after  
diagnosis



Until everyone  
understands



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

**Our aim is that 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.

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



## Who is this booklet for?

- › Adults who think they may be on the autism spectrum and are considering getting a diagnosis.
- › Adults who have been diagnosed as autistic.

## 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 others.

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](http://www.autism.org.uk/diagnosisinfo).

## Terminology

You may have received a diagnosis of autism, autism spectrum disorder (ASD), Asperger syndrome (AS), Pathological Demand Avoidance (PDA), pervasive developmental disorder – not otherwise specified (PDD-NOS), atypical autism or another term used by the professional making the diagnosis. 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 autistic people share certain areas of difficulty, their condition affects them in different ways. Some people are able to live relatively independent lives; others may require a lifetime of specialist support. Asperger syndrome and pathological demand avoidance (PDA) are forms of autism.

### Autistic people can:

- › find it difficult to understand and use language to communicate, and may interpret 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 need 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.** Autistic people may have other conditions such as epilepsy, and they may have learning disabilities. People with Asperger syndrome do not usually have learning disabilities, but they may have a learning difficulty such as dyslexia.

People with PDA seem to have a better social understanding than others on the spectrum and are able to use this to adapt avoidance strategies to the person making the demand. This is driven by an anxiety-based need to be in control.

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

There is no known 'cure' for autism. As our understanding of the condition improves, autistic people have more opportunity than ever of reaching their full potential.

There is also a growing movement among autistic people who think in terms of celebrating difference as opposed to 'curing' a disorder.

### Strengths

- > Autistic people have a unique and individual view of the world which lots of people who don't have autism can find interesting, refreshing and valuable.
- > Most autistic people are good at learning visually. Using real objects, pictures, demonstrations and written material can all help.
- > Some autistic people have distinctive vision and are able to notice detail that others would miss. They can also have a strong drive towards finding explanations. These skills can be useful in the workplace.
- > Autistic people are likely to better remember information, routine or processes that they have learned.
- > Some autistic adults have extraordinary focus on their special interest and choose to work in a related area.

You can't tell that someone has autism just by looking at them. Some autistic people 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/aboutautism](http://www.autism.org.uk/aboutautism).

## Getting support

### Find services in your area



You can find out more about services near where you live at [www.autism.org.uk/inyourarea](http://www.autism.org.uk/inyourarea) and find services and support groups across the country at [www.autism.org.uk/directory](http://www.autism.org.uk/directory).

Our Autism Helpline offers confidential information and advice on autism and related issues.

### Our Autism Helpline

We offer confidential information, advice and support.

Call: **0808 800 4104**

The Helpline is open Monday-Thursday 10am-4pm, Friday 9am-3pm. It is free to call from landlines and mobiles. The Helpline offers a telephone interpretation service for callers whose first language is not English. Find out more at [www.autism.org.uk/interpretation](http://www.autism.org.uk/interpretation).

Information is also available at [www.autism.org.uk/enquiry](http://www.autism.org.uk/enquiry). The Helpline experiences high demand and it will take at least 14 working days to reply to an enquiry.



## Social Support

### Social groups

Social groups are a way of meeting and socialising with other autistic people. You can find out if there are any social groups in your area by searching our Autism Services Directory at [www.autism.org.uk/directory](http://www.autism.org.uk/directory) or calling our Helpline (see above).



Find information about social groups run by the The National Autistic Society at [www.autism.org.uk/socialgroups](http://www.autism.org.uk/socialgroups).

### Social skills training

Some autistic people say they would like social skills training. This usually focuses on things that autistic people can find difficult, like having a conversation, identifying and expressing emotions, problem solving, or understanding body language and tone of voice.



Find out about social skills training where you live by calling our Autism Helpline (see page 7).

Our website has a guide to social skills for young people and adults at [www.autism.org.uk/socialskills](http://www.autism.org.uk/socialskills).

## Befriending services

Our befriending service offers the opportunity to socialise, learn new skills and participate in the community. We take care to find someone who shares your interests so that you can get together to do activities that you both enjoy. For example, going out to lunch, seeing a film or visiting the gym.

We also have an e-befriending scheme which matches you with someone whom you can talk to over email.



Read more about befriending and e-befriending at [www.autism.org.uk/befriending](http://www.autism.org.uk/befriending).

Find out if there are befriending opportunities in your area by calling our Autism Helpline (see page 7).

## Benefits

### Benefits for autistic adults

There is a range of different benefits available. Which ones you may be entitled to will depend on your circumstances. Some common benefits are:

- > Personal Independence Payment
- > Disability Living Allowance
- > Working Tax Credit
- > Housing Benefit
- > Jobseekers Allowance
- > Employment and Support Allowance.

In England, Wales and Scotland, Personal Independence Payment is replacing Disability Living Allowance. For more information go to [www.autism.org.uk/adultdla](http://www.autism.org.uk/adultdla).

In England, Wales and Scotland a new benefit called Universal Credit is being introduced to replace a range of existing means tested benefits. Find out more at [www.autism.org.uk/universalcredit](http://www.autism.org.uk/universalcredit).

### Benefits for carers

Parents and carers of autistic adults may be entitled to a range of different benefits depending on their circumstances. Some common benefits are:

- > Carer's Allowance
- > Income Support
- > Housing Benefit
- > Working 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 manage benefit money on their adult son or daughter's behalf.



For further advice:

- > visit [www.autism.org.uk/benefits](http://www.autism.org.uk/benefits)
- > contact our Welfare Rights Service for advice on all aspects of social security benefit entitlement
- > contact your local Citizens Advice Bureau
- > contact your local advice centre. You can do this at [www.adviceuk.org.uk/find-a-member](http://www.adviceuk.org.uk/find-a-member).

## Our Welfare Rights Service

To get support from our Welfare Rights Service, email [welfarerights@nas.org.uk](mailto:welfarerights@nas.org.uk) and ask for advice or request a telephone appointment.

If you do not have internet or email access, call 0808 800 4104 to request information or to make an appointment to speak to our adviser

Find out more at [www.autism.org.uk/welfarerights](http://www.autism.org.uk/welfarerights).

If you are 40 or over and need advice about welfare benefits or housing, email our Autism and Ageing Service at [advice40plus@nas.org.uk](mailto:advice40plus@nas.org.uk).

## Housing and community support

### Housing options

#### Residential services

We provide residential settings for autistic adults with varying needs in both rural and urban settings around the UK. These offer specialised and 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 simply a few hours a week to help with everyday tasks. NAS supported living operates in a number of places around the UK.

### Community support options

#### Outreach services

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

#### Support centres

Our support centres provide a place for autistic people to come for support, social interaction and to develop new skills. We offer a wide range of groups, classes and activities outside the home that enable autistic adults to pursue their interests and develop their life skills.



To find out more about the NAS residential, living and outreach services:

- > call **0117 974 8430**
- > email **services@nas.org.uk**
- > visit **www.autism.org.uk/communitysupport**
- > call our Autism Helpline (see page 7) to find out about the different kinds of support provided by the NAS as well as other organisations.

### Brokerage services

In some areas, we can provide a broker to help an autistic adult plan the things they want and need to do in their lives. Brokerage is about giving people and their families' assistance to plan and make choices about their support.



Find out more at **www.autism.org.uk/brokerage**.

## Community Care Services

### Self-directed support and personal budgets

#### Self-directed support

Self-directed support is a system of social care that lets you take more control over how your support is arranged and delivered.

If you are assessed as being eligible for help, you will agree a support plan with your adult social care department. Your support may then be provided directly by social services or your social work department. Alternatively, you may use your funding to pay for services of your choice to meet your needs. Nation-specific terms may be used to describe this type of support. What's important is that this support is made available to you and that you are able to choose how you would like to receive it.

## Personal and individual budgets

A personal budget is the money for support that comes from social services. An individual budget is money that comes from more than one source. For example, you may receive money from social services and from the access to work scheme. This funding combined is your individual budget.

Personal and individual budgets should be offered to most adults, aged 16 or over, who are eligible for social care support. You can spend your budget flexibly on services, equipment or people to support you. The money must be spent to meet your needs.

## Direct payments

Direct payments are one way of receiving the money in your budget. Direct payments are made straight to your bank account so you can arrange and pay for services yourself.

You can arrange for someone else to manage the direct payments if you need to. You can also arrange for direct payments to pay for some services, while allowing social services to directly provide some of your support.

## Support for parents and carers

In England, the Care Act 2014 gave carers of adults the same rights as those they care for - the right to have an assessment. Those that are assessed as having eligible needs will then be entitled to a care and support plan and personal budget.



To get further advice:

- > visit [www.autism.org.uk/supportforcarers](http://www.autism.org.uk/supportforcarers) or [www.autism.org.uk/parents](http://www.autism.org.uk/parents) if you are a parent
- > contact our Community Care Service (see purple box)
- > contact our Parent to Parent Service on **0808 800 4106**, which allows you to talk to someone who really understands what being the parent of an autistic adult is like.

## Our Community Care Service

To get advice on community care, including how to get help from your local social services department and how to make a complaint if you're not happy with their decision or with the services they offer:

- > call our Autism Helpline (see page 7). An adviser will take details of your query and arrange a call-back telephone appointment for you at a specific time.
- > email [communitycare@nas.org.uk](mailto:communitycare@nas.org.uk) to book a telephone appointment, or to ask advice by email. Please include your age (or the age of the person in question), your query and your local authority name. We aim to respond to emails within 10 working days but this may take longer if one of our advisers is away.
- > complete our short online form at [www.autism.org.uk/community-care-service-form](http://www.autism.org.uk/community-care-service-form).

If you are 40 or over and need advice about community care or housing, email our Autism and Ageing Service at [advice40plus@nas.org.uk](mailto:advice40plus@nas.org.uk).



## 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). In Scotland you can also access DSA in further education – you need to study higher national certificate or above. 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.

In England, support for students in further education is funded by colleges. You can still claim other benefits while you're in further education.



Find out more about further education and higher education for autistic people at [www.autism.org.uk/fe](http://www.autism.org.uk/fe).

### Student support services

We offer two types of support for autistic students in further or higher education: mentoring support and education outreach. Mentoring covers things like:

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

Outreach is more intensive support across the timetable for those students who need support with things like orientation, accessing lectures, note taking, support during break times.



Find out more at [www.autism.org.uk/studentsupportservices](http://www.autism.org.uk/studentsupportservices).

## Employment

### Finding work

A visit to your local Jobcentre Plus may help you to find suitable employment.

A Disability Employment Adviser (DEA) can help you find a job or gain new skills and tell you about disability-friendly employers in your area. They can carry out an 'employment assessment' to find out what skills and experience you have and what type of work you are interested in. Not all disability employment advisers will know a lot about autism, but they can try to help you find a suitable job.

If accessing support through your local Jobcentre Plus, you may be referred to an organisation that can provide direct support to help you find a job.

You can also search careers on:

- > the National Careers Service website at <http://nationalcareersservice.direct.gov.uk> (England only)
- > Skills Development Scotland at [www.myworldofwork.co.uk](http://www.myworldofwork.co.uk) (Scotland only)
- > Careers Wales at [www.careerswales.com](http://www.careerswales.com) (Wales only)
- > Careers Service Northern Ireland at [www.nidirect.gov.uk/careers](http://www.nidirect.gov.uk/careers) (Northern Ireland only).

Some of our local services offer support to people who are looking for work, including the chance to obtain certain qualifications. Find out more by calling our Autism Helpline (see page 7).

We work in partnership with various organisations who provide employment services for people with disabilities. Details of these organisations can be found at [www.autism.org.uk/trainingpartners](http://www.autism.org.uk/trainingpartners).


### Prospects employment service

In Glasgow, we have an employment service called Prospects for autistic people aged 16-25 years.

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.

 To find out more about how Prospects can help you, email [prospects.glasgow@nas.org.uk](mailto:prospects.glasgow@nas.org.uk) or call **0141 248 1725**.

### Training for autistic people in employment and their colleagues

In England and Wales, our Employment Training Team offers support with:

- > training for autistic people in employment
- > training for managers and colleagues to help them make reasonable adjustments.



To find out more about how our Employment Training Team can help you, visit [www.autism.org.uk/lookingforwork](http://www.autism.org.uk/lookingforwork), email [employmenttrainingteam@nas.org.uk](mailto:employmenttrainingteam@nas.org.uk) or call **020 7704 7450**.

To help with the costs associated with these services you can contact Access to Work which is a government scheme. For more details, go to [www.gov.uk/access-to-work](http://www.gov.uk/access-to-work).

## 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 autistic 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 autistic adults.



Find out more about autism and advocacy at [www.autism.org.uk/advocacyandautism](http://www.autism.org.uk/advocacyandautism).

Search for advocacy services with experience of working with autistic people at [www.autism.org.uk/directory](http://www.autism.org.uk/directory).



Get information from BILD (British Institute of Learning Disabilities) on **0121 415 6960** or at **[www.bild.org.uk/advocacy](http://www.bild.org.uk/advocacy)**, or from the Scottish Independent Advocacy Alliance (Scotland only) on **0131 556 6443** or at **[www.siaa.org.uk](http://www.siaa.org.uk)**.

## Self-advocacy

Self-advocacy means speaking up for yourself and stating your own needs. The National Autistic Society has a self-advocacy booklet that was developed by a group of autistic adults and is designed to help you communicate your wishes and needs to the people you meet.



Find out more and download the booklet at **[www.autism.org.uk/selfadvocacy](http://www.autism.org.uk/selfadvocacy)**.

## Therapies and interventions

There is no 'cure' and no specific treatment for autism. Some autistic people prefer to celebrate their difference, as opposed to looking for a cure. 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](http://www.autism.org.uk/approaches)**.

### Counselling

Some autistic people find counselling helps them to cope with everyday life. Counselling usually involves talking with someone at an agreed time and place once a week. The sessions can last up to an hour and can be done face-to-face, on the phone or using Skype. A counsellor will not tell anyone else what you say to them.



Find out more about counselling at **[www.autism.org.uk/counselling](http://www.autism.org.uk/counselling)**.

The British Association for Counselling (BACP) can give you a list of accredited counsellors who work in your area.

British Association for Counselling (BACP)

Call: **01455 883300**

Website: **[www.bacp.co.uk](http://www.bacp.co.uk)**

## Information and publications

### Our website

Go to **[www.autism.org.uk](http://www.autism.org.uk)** to find:

- > information about autism
- > details of our services for autistic people, their families and professionals
- > ways you can get involved with our work
- > latest news and events.

Our Autism Services Directory allows you to search for autism services, support groups, counsellors and events across the UK:

**[www.autism.org.uk/directory](http://www.autism.org.uk/directory)**.

The NAS library catalogue provides information on published research, articles, books and multimedia on autism: **[www.autism.org.uk/library](http://www.autism.org.uk/library)**.

## What next?

*Asperger United* is a quarterly magazine for autistic adults aged 16+ (some parents subscribe on behalf of under-16s). It is written and edited by autistic people. Subscription is free, although we ask overseas subscribers and professionals in the autism field to make a donation to help cover costs: [www.autism.org.uk/aspergerunited](http://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 autistic people, their parents, carers, professionals and others interested in autism. Visit today: [www.autism.org.uk/community](http://www.autism.org.uk/community).

## Membership

You might like to think about becoming a member of The National Autistic Society. Membership is the best tool for staying up to date on important news and information about autism. The more members we have, the more influential we are when campaigning for the rights of people affected by autism. As a member, you'll be joining more than 20,000 people who understand the impact that autism has on people's lives, and can help us to shape the work that we do.

As a member, you get:

- > the award-winning *Your Autism Magazine* delivered quarterly, plus access to *Your Autism Extra* online
- > a 10% discount on all orders from our publications catalogue
- > up to £75 discount on NAS conferences and events
- > access to low cost Personal Liability and travel insurance products
- > the chance to influence the direction of our charity at our annual general meeting.

To find out more about membership, visit [www.autism.org.uk/membership](http://www.autism.org.uk/membership), call **0808 800 1050** or email [supportercare@nas.org.uk](mailto:supportercare@nas.org.uk).

## Get involved

To find out more about how we can help you and your family, simply fill in this form and post it back to us. We will then send you some useful information and contacts.

Title	<input type="text"/>	First name	<input type="text"/>
Surname	<input type="text"/>		
Address (line 1)	<input type="text"/>		
Address (line 2)	<input type="text"/>		
Address (line 3)	<input type="text"/>	Postcode	<input type="text"/>
Town/city	<input type="text"/>		
Mobile phone number	<input type="text"/>		
Telephone number	<input type="text"/>		
Email address	<input type="text"/>		

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. To view please go to [www.autism.org.uk/privacypolicy](http://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.

We'd like to keep in touch by SMS on your mobile. If you are happy with this, please tick this box.

We'd like to keep in touch by email. If you are happy with this, please tick this box.

What is your date of birth?

We would like to tailor our communications with you to ensure they are relevant to your interests.

What is your connection with autism? (Please tick all that apply.)

- I am autistic
- I am a parent/carers of someone on the autism spectrum
- Someone in my family is diagnosed with autism
- I know someone who's autistic
- I am a professional working in the field of autism
- I have another connection with autism
- I have no connection with autism

Please return this form to:

Print and Publications officer, The National Autistic Society, 393 City Road, London EC1V 1NG

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

Around 700,000 people in the UK are autistic. Together with their families they make up around 2.8 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.

And with more than 50 years of learning from real experience, no one has more practical knowledge of autism.

We want everyone to understand autism, and to accept and appreciate autistic people for who they are.

### **Until everyone understands.**

#### **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](mailto:nas@nas.org.uk)  
Website: [www.autism.org.uk](http://www.autism.org.uk)

#### **NAS Cymru**

Tel: **02920 629 312**  
Email: [wales@nas.org.uk](mailto:wales@nas.org.uk)

#### **NAS Scotland**

Tel: **0141 221 8090**  
Email: [scotland@nas.org.uk](mailto:scotland@nas.org.uk)

#### **NAS Northern Ireland**

Tel: **02890 687066**  
Email: [northern.ireland@nas.org.uk](mailto: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 autistic people.

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.