



Autism

An information booklet for parents/carers of children and young people with Autism Spectrum Condition in Newcastle

What is Autism?

Autism is a lifelong developmental condition that affects how a person communicates with, and relates to, other people.

It also affects how they make sense of the world around them. It is a spectrum condition, which means that, while all people with autism share certain difficulties, their condition will affect them in very different ways. People with autism may also experience over or under sensitivity to sounds, touch, tastes, smells, light or colours.



If you think your child/young person may have autism then visit your GP who can refer them for further assessment. Autism is a lifelong condition and support is often available to manage some of the difficulties that young people and their families might face.

The cause of autism is still unknown but research suggests that a combination of factors, both genetic and environmental, may account for changes in brain development.

Main Aspects of the Condition

There are three main areas of difficulty which all people with autism share. They are:

- Difficulty with social communication
- Difficulty with social interaction
- Difficulty with social imagination

Autism is often referred to as Autism Spectrum Condition (ASC), but the term Autism Spectrum Disorder (ASD) is also used. Asperger syndrome and Pathological Demand Avoidance (PDA) are part of the autism spectrum.

Asperger Syndrome

Asperger syndrome is a form of autism. People with Asperger Syndrome are less likely to have a learning disability and are likely to have fewer problems with speech, but will still have difficulties with understanding and processing language.

Asperger syndrome can often be associated with mental health difficulties such as anxiety, obsessive compulsive disorder and depression. It is important for these not to be overlooked.

For information visit the National Autistic Society web: www.autism.org.uk

Pathological Demand Avoidance (PDA)

Pathological Demand Avoidance is part of the autism spectrum. Individuals with PDA share difficulties with others on the autism spectrum, but the central difficulty is that everyday demands and expectations cause increased anxiety, leading to avoidance.

People with PDA seem to have a better social understanding and communication skills than others on the spectrum and are able to use this to attempt to control a situation in order to alleviate anxiety.

For information visit the PDA Society web: www.pdasociety.org.uk

Related conditions

Individuals on the Autistic Spectrum can often have an additional diagnosis of a related condition, for example ADHD or Dyspraxia. This is referred to as a dual diagnosis. For more information on these related conditions see our other information booklets on [ADHD](#) and [Dyspraxia](#).

Facts and Figures

- Severe autism occurs in around 4 per 1000 of the population
- Overall about 1 in every 100 children has an Autism Spectrum Condition (ASC)
- At least half of children with ASC are in mainstream school and many are able to become independent adults
- ASC will last throughout your child's life. The pattern of needs will change but it is a lifelong condition.
- Around 700,000 people in the UK are on the autism spectrum.

Useful tips

- Be consistent in your approach to inappropriate behaviour.
- Routines are important to reduce anxiety.
- Use simple language, speak clearly and precisely.
- Use visual prompts to accompany speech e.g. pictures or signs.
- Be aware of external stimuli as many children are hypersensitive to sound, smells and touch.
- Be specific - don't say "It's raining cats and dogs" when it isn't!
- Be positive not negative. Tell your child exactly what you want them to do, not what you don't want them to do.

Education

Additional help may be available for your child. Ask to speak to the Special Educational Needs Co-ordinator (SENCO) at your child's school. If the school thinks they need additional support this will be met through SEND support. They must tell you if they are making special educational provision for your child.



A small number of children or young people will need an Education, Health and Care Plan (EHCP) if they need more support than is normally available in mainstream education.

More information on education can be found in our Education Information booklet.

Early Bird/Early Bird Plus programmes

These are training programmes for parents/carers run by a multi-disciplinary team. They help parents to understand their child's autism, find ways to help develop communication and interaction and understand their child's behaviours and are by invitation only.

Autism Specific Education in Newcastle

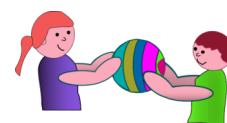
Busy Bees is a playgroup for pre-nursery aged children and their parents. It is run by a multi agency team and is by invitation only by the Early Educational Additional Support Team.
Tel: 0191 277 4621

Thomas Bewick School is a specialist provision for children with ASC and they also run two satellite nurseries in the east and west of the city.

Additionally Resourced Centres/Provision (ARC/ARP) are attached to the following schools across the city: Atkinson Road Primary, Kenton Bar Primary, Tyneview Primary, Kenton School, Walbottle Campus and Benfield School.

Siblings

Being a sibling of a person with autism can be a positive experience. Many siblings have a good relationship with their autistic brother or sister, and lots of siblings say that learning to see the world through the eyes of their sibling has taught them to appreciate difference.



However, having a person with autism in your family has an impact on everyone. Younger people who have a sibling with autism might experience a lack of privacy, disruption of their home life and even a feeling of resentment that the whole focus of the family is always on the person with autism. Some young people might face negative attitudes from their peers.

Older siblings may worry about whether they are going to have to look after their brother or sister when their parents are no longer able to do so, and what support they might receive.

Supporting siblings

When possible:

- make time for siblings
- do some activities separately
- allow siblings to have time to themselves, eg a sleepover at a friend's home
- allow siblings to bring their own friends home sometimes and enjoy themselves without interruption
- listen to their worries and concerns and the things that are important to them
- listen to their ideas - older children may have good ideas about how best to manage certain situations. They may be able to ask their sibling to do things that you can't.

National Autistic Society (NAS)

This is a charity for people with autism and their families. They provide information, support and pioneering services, and campaign for a better world for people with autism.



Helpline: 0808 800 4104
Web: www.autism.org.uk

Newcastle Autism Resource Centre

Their aim is to provide information, advice and support to people whose lives are affected by autism. They have a lending library, parent and carer support group, training and workshops. For more information contact Deborah Garland.
Tel: 07884 117741
Email: Deborah.garland@nas.org.uk

NAS Tyne & Wear Branch

The local branch offers support to families who have a child or family member with autism or Asperger syndrome. They organise regular parent carer support meetings, social activities including a gym club and holiday activities.
Tel: 07920 086299
Email: NASTyne&WearBranch@nas.org.uk
Facebook: NAS Tyne and Wear

New Prospects - Social Groups

They run two projects for children/young people on the autistic spectrum:

The Social Project is for children aged 8-12 and is held on Tuesday evenings at Thomas Bewick School - fun sessions to increase skills and confidence.

The Inclusion Project is for children aged 13-18 and is held on Thursday evenings at Thomas Bewick School- learn new skills and have fun

For more information and an application form about either project please contact charlotte.emmerson@new-prospects.org or Tel: 07917 315339

Community Dental Service

Provides treatment for people with learning difficulties/dental phobic. Please contact the service in your area for an appointment:



Arthur's Hill Clinic - 0191 282 3209
Kenton Centre - 0191 282 3800
Walker Centre - 0191 213 8997
Molineux Street NHS Centre - 0191 213 8550

Useful Contacts

Children and Young People's Service (CYPS)

This team is based at Benton House and offer a specialised service for young people up to the age of 18 on emotional and behavioural problems. Your child will need to be referred to this service by a health professional, Social Care or your child's school.

Newcastle Carers

Provides support for carers of someone who lives in Newcastle. Offers free and confidential information and advice.

Tel: 0191 275 5060
Email: info@newcastlecarers.org.uk
Web: www.newcastlecarers.org.uk



Parent Carer Participation & Families United

Families United is a support network for parents, carers and families of children with disabilities in Newcastle.

Web: www.newcastlefamiliesunited.com
Tel: 0191 277 4700
Email: Sharon.Hand@newcastle.gov.uk



Newcastle Special Educational Needs and Disabilities Information, Advice and Support Service

This service provides information specialising in education matters and includes information and signposting on social care and health issues.

Contact: Judith Lane
Tel: 0191 284 0480



Local Offer

The Local Offer describes the services available for children/young people with special educational needs or disabilities (SEND) aged 0 - 25 and their families.

Email: localoffer@newcastle.gov.uk
Web: www.newcastlesupportdirectory.org.uk
Select SEND Local Offer



Contact

(New name for Contact a Family)
Helping families in the North East who care for disabled children.

Tel: 0191 213 6300
Email: northeast.office@contact.org.uk
Web: www.contact.org.uk

Look for advice in your area - select North East



Skills for People

This booklet is produced by the Skills for People, a charity run by disabled people. We are based in Newcastle upon Tyne and for over 25 years we have been helping disabled people to speak up for themselves and make their own choices about their lives. Our work is led by disabled people and their experiences are at the heart of all we do.

Our Family Advice Workers support families with disabled children/young people up to the age of 25. They help families by giving practical advice, appropriate to their needs and working across all agencies such as education, social care, health, benefits, leisure and voluntary services. Their services are free to parents/carers.

We produce a range of information booklets, factsheets and "How To" guides. Visit our website to see the full range: www.nsn.org.uk/resources

How to get in touch

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Facebook: facebook.com/skillsforpeople

Twitter: [@skillsforpeople](https://twitter.com/skillsforpeople)



Facebook: on.fb.me/1istYKg



Newcastle parents of children with disabilities
and special needs working together

Facebook: Pass it on Parents Newcastle

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