

# Adults on the Autism Spectrum: What You Need to Know



**RESEARCH AUTISM**  
IMPROVING THE QUALITY OF LIFE  
IDENTIFICATION INTERVENTION INCLUSION

## Introduction

This leaflet is for adults on the autism spectrum living in the UK. It provides the key facts about autism, explains how autism affects different people, and describes some of the issues they may face. It also provides information about different forms of support, rights and services, along with a list of useful organisations.

## What is autism?

Autism is a lifelong condition that affects just over 1 in 100 people. Autism affects how individuals communicate with, and relate to, other people. It also affects how they make sense of the world around them.

Some people claim that autism is not a disorder but simply an expression of neurodiversity. In other words, they think that autism is a difference, not a disability.

## Types of autism

Autism or autism spectrum disorder or ASD are all terms used to describe a very wide range of similar conditions including Asperger syndrome, autistic disorder and atypical autism.

## Core features

Individuals on the autism spectrum vary enormously from each other but they all share the two 'core' features of autism:

- difficulties with social communication and social interaction. For example, they may not be able to talk, may find it hard to hold a conversation, may not understand social rules such as how far to stand from somebody else, or may find it difficult to make friends
- restricted, repetitive patterns of behaviour, interests, or activities. For example, they may develop an overwhelming interest in something, may follow inflexible routines or rituals, may make repetitive body movements, or may be hypersensitive to certain sounds or smells.

Many people on the autism spectrum will also experience high levels of anxiety thought to be made worse by the stress of living in a 'neurotypical' world.

Some individuals on the autism spectrum have significant strengths. These often include a good eye for detail, an excellent memory for facts and figures, and the ability to thrive in a structured, well-organised environment.

## Level of functioning

Some individuals on the autism spectrum are highly intelligent while others may have a significant learning disability. Some may also be non-verbal or have very limited speech. However the fact that someone doesn't speak does not necessarily mean that they have limited intelligence. Some people classified as having 'severe' autism can function very well with the right kind of support. Some individuals classified as having less severe autism, on the other hand, may face considerable difficulties which are overlooked because they appear to be coping.

## Uneven profile of abilities

Many individuals on the autism spectrum have an uneven profile of abilities. This means that they may be relatively good at certain things (for example, computer programming) but may not be so good at other things (for example, thinking flexibly). Or, even more confusingly, they may have different abilities in the same area (such as good long-term memory but poor short-term memory).

## Causes of autism

Autism has a variety of causes, which are likely to be a complex mix of genetic and environmental factors.

Other conditions which sometimes occur alongside autism include:

- genetic conditions — such as Fragile X syndrome, PKU or tuberous sclerosis
- medical conditions — such as epilepsy or gastro-intestinal problems
- developmental conditions — such as attention deficit hyperactivity disorder

## Diagnosis

If you think you are on the autism spectrum you should contact your GP. You may then be referred onto a specialist diagnostic service which will make a formal assessment. Alternatively you can contact an independent diagnostic service, although you will have to pay for this and the diagnosis may not be accepted by some local authorities. If you receive a formal diagnosis of autism, the diagnostic team should share information from the assessment with your GP. If you agree and it is appropriate, they will share this with other public services to help them offer you the support you need. If you receive a diagnosis of autism you may want to consider if any of your siblings or other close relatives could be on the autism spectrum.

## Issues

Adults on the autism spectrum face many issues on a day to day basis. However it is important to remember that each person is a unique individual, with unique needs and abilities. Because of this, they will experience those issues in a different way or may not experience them at all.

Common issues facing adults on the autism spectrum include:

- cognitive problems - such as difficulties understanding other people, thinking flexibly or planning ahead
- sensory processing differences — such as an aversion to bright lights, loud noises or strong smells
- mental health problems — such as anxiety, depression and compulsions
- physical difficulties — such as chronic fatigue — or motor problems like finding it hard to hold a pencil between fingers and thumb
- functional difficulties — such as problems with sleep or travelling independently

People on the autism spectrum are also more likely to be socially excluded, being denied access to employment or community facilities. They are also more likely to be mistreated by others, being bullied, being given inappropriate treatments or having their liberty restricted.

Some people on the autism spectrum have behaviours that other people may find challenging (such as anger, reluctance to follow instructions, self-injury etc.). Such behaviours may be caused by a range of factors including anxiety and stress, sensory processing differences, underlying medical conditions, and specific situations that the person finds distressing. For example a 'meltdown' may be caused by someone's inability to communicate their basic needs and/or by a sensory overload. Challenging behaviours can usually be prevented or reduced if the right kind of support is provided. All challenging behaviour happens for a reason and we should not rush to judge what that might be. It is very important to explore the possible causes with the individual and their family before providing any kind of intervention.

## Interventions

There are many interventions (treatments, services and other forms of support) used to help adults on the autism spectrum. Those interventions include health and social care services, employment support programmes, behavioural techniques, assistive and adaptive technology, augmentative and alternative communication systems, medication, diets etc. However there is no one-size fits all solution. Each person on the autism spectrum is unique, with unique needs and abilities. So what works for one person may not work for another. The most effective interventions are personalised to meet the unique characteristics of each individual.

There is still a lack of high quality research evidence to support most interventions, although that does not necessarily mean they are not helpful. With support and understanding it is possible for all adults to develop new skills and better achieve their potential . However some interventions are scientifically unfeasible, potentially harmful or both. For these reasons we recommend that you only use reliable sources of information when considering interventions. Reliable sources include:

- National Institute for Health and Care Excellence (NICE) at [www.nice.org.uk](http://www.nice.org.uk) UK agency which provides national guidance and advice to improve health and social care
- Research Autism at [www.researchautism.net](http://www.researchautism.net) UK charity which is dedicated to the promotion of high-quality research into autism treatments, therapies and other approaches.

## Rights

As a person on the autism spectrum you have some legal rights, especially if you have a formal diagnosis of autism. This is because the government considers autism to be a disability. So, for example, if you live anywhere in the UK you have rights under the Equality Act (2010) or the Disability Discrimination Act (1995). These Acts require employers and service providers to make 'reasonable adjustments' in order to ensure they do not discriminate against you. If you live in England, you also have rights under the Autism Act (2009), and the autism strategy which followed it. The autism strategy tells local authorities and NHS agencies what actions should be taken to meet the needs of autistic adults living in their area. The other countries in the UK have similar legislation and strategies.

## Services

NICE has made recommendations about the delivery of care to adults on the autism spectrum. This includes a recommendation that all staff should work in partnership with adults on the autism spectrum and, where appropriate, with their families, partners and carers. It also recommended that local services should be coordinated by a local autism multi-agency strategy group. For details of your local strategy group please contact your local council. In addition

- your primary health care trust may provide a range of health and therapeutic services — such as occupational therapy— and your local authority may offer a range of home-based social services — such as access to leisure facilities
- central government may provide financial benefits - such as universal tax credit
- some commercial and not for profit organisations may provide specialist employment services — such as supported employment schemes
- Other organisations may provide a range of other services and forms of support - such as advocacy, befriending, legal advice, mentoring, online support, residential care etc.

For more information about organisations which provide such services (some of which may also be able to advise you on your rights) please see the next page of this leaflet).

## Forums/Support Groups

- Aspie Village at <http://aspievillage.org.uk> UK-based social group for adults with Asperger syndrome and similar conditions
- Autistic Rights Group Highlands at [www.arghighland.co.uk](http://www.arghighland.co.uk) Group run by and for autistic adults
- Autistic UK at [www.autisticrightsmovementuk.org](http://www.autisticrightsmovementuk.org) Group which campaigns to advance the interests of autistic people and those with 'related conditions'
- Autscope at [www.autscope.org](http://www.autscope.org) Online conference specifically by and for autistic people
- Wrong Planet Web at [www.wrongplanet.net](http://www.wrongplanet.net) Community designed for individuals with autism, Asperger's syndrome, ADHD, PDDs, and other neurological differences.

## Organisations/Service Providers

- ASD Info Wales at [www.asdinfowales.co.uk](http://www.asdinfowales.co.uk) Describes itself as the national site for autism in Wales, providing information on autism and implementation of Welsh autism policies
- Autism Alliance at [www.autism-alliance.org.uk](http://www.autism-alliance.org.uk) The major UK network of specialist autism charities, providing a range of services and expertise
- Autism NI at [www.autismni.org](http://www.autismni.org) Parent led organisation which promotes collaboration between parents, professionals and individuals on the autism spectrum in Northern Ireland
- Irish Society for Autism at <http://autism.ie> National charity for people on the autism spectrum, parents and carers in the Republic of Ireland
- National Autistic Society at [www.autism.org.uk](http://www.autism.org.uk) National UK charity for people on the autism spectrum and their families, providing a range of services and expertise
- Scottish Autism at [www.scottishautism.org](http://www.scottishautism.org) Scottish charity that exists to help those diagnosed with autism to lead full and enriched lives.

## Portals/Directories

- Autism and Asperger support at <http://tinyurl.com/j853r52> NHS directory which provides details about services, schools, support groups, training courses, residential and day services
- Autism Connect Service Providers at <http://autism-connect.org.uk/index.php/users/providers> Autism Alliance directory of autism-friendly service providers within the UK
- Autism Services Directory at [www.autism.org.uk/directory.aspx](http://www.autism.org.uk/directory.aspx) National Autistic Society directory which lists thousands of organisations and other resources in the UK

## Further information

Additional information on adults on the autism spectrum, including links to more organisations and resources, at [www.researchautism.net/adults-on-the-autism-spectrum](http://www.researchautism.net/adults-on-the-autism-spectrum)

Research Autism, National Autistic Society,  
393 City Road, London EC1V 1NG.

Tel: 020 7923 5731

Email: [info@researchautism.net](mailto:info@researchautism.net)

Website: [www.researchautism.net](http://www.researchautism.net)

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