

# NCMH

National Centre for Mental Health

## Autism Spectrum Disorder in Young People

Information for parents, carers and children



Ymchwil Iechyd  
a Gofal Cymru  
Health and Care  
Research Wales



Ariennir gan  
Lywodraeth Cymru  
Funded by  
Welsh Government

# What is Autism Spectrum Disorder (ASD)?

Autism Spectrum Disorder (ASD) is a term for a condition that affects specific aspects of a person's development.

Under some classification systems ASD is split into autism, Asperger's syndrome and pervasive developmental disorder not otherwise specified (PDD-NOS), but more people are now using the broader term 'ASD' instead.



ASD usually becomes apparent in early childhood, but people with less obvious problems may not have them identified until their teenage years or later. Around 1% of the population has an ASD. Boys are much more often affected than girls.

Scientists are yet to find a single cause for the development of ASD, but research has shown that genetics play a strong role, and environmental factors may also be involved.

Broadly, research suggests that the early development of brain systems seems to be affected, but exactly how this occurs is unclear. Despite media reports in the past, there is no reliable evidence linking childhood vaccinations to ASD, and the research which first triggered these concerns has now been discredited and retracted.

People with ASD can experience a range of difficulties - you may have heard the phrase 'autistic spectrum'. This is another way of saying that people with ASD can be affected in a wide variety of different ways, and that no two individuals will have identical difficulties and needs.

They often feel more comfortable with routines and have repetitive behaviours, and can find it difficult to cope when these

are disrupted. Sometimes people with an ASD may also have physical and mental health problems, and/or learning problems.

However, there are some types of problems which all people with an ASD will experience. For example, people who have an ASD have trouble with social communication.

## Getting help

If you think your child may have an ASD, the first step is to speak to your GP, or in the case of a very young child, your health visitor. If they agree that your child shows signs of having an ASD, they will then refer them for a formal assessment. This can sometimes take time.

Because ASD can affect people in such a wide variety of ways, a child may be assessed by several different specialists before a formal diagnosis is made – this is known as a “multi-disciplinary” assessment. Similarly, once they have a diagnosis they may receive support from a multi-disciplinary team.

These specialists might include a doctor or nurse in paediatrics or in child & adolescent mental health services (CAMHS), a clinical psychologist, a speech and language therapist or an occupational therapist. Again, this can vary between individuals. Information from a young person’s school will also be required as part of the process.

There are no specific treatments for the main symptoms of ASD, although there are strategies to help reduce the difficulties linked with symptoms. These aim to improve quality of life for individuals with ASD and their families. Helpful strategies vary greatly between individuals, so it is important that a care plan is tailored to a person’s specific needs.

Medication is not routinely prescribed for ASD, but there are circumstances in which it may be appropriate to do so.

## ASD at school

A young person with an ASD might also need help at school or college to get the most out of their learning.

Some people with ASD stay in mainstream schools though they may need extra help, and some people may have their needs better met in a special school.



Also, in some situations, a 'statement of special educational needs' may be put in place.

Within a school setting, a young person may need to see an educational psychologist, or have help from learning support assistants or a special educational needs co-ordinator.

## ASD in adults

As young people with an ASD reach adulthood, how their condition affects them may change as their circumstances change – for example when they leave full time education or if they move on from their family home.

Some people with an ASD are able to live independently as adults, however, some may need significant ongoing support due to their condition.

People with an ASD are also more likely to experience mental health problems (e.g. depression and anxiety) than people without an ASD, and they may need help with these difficulties.

## Tips for young people with ASD and families

Whether an individual or a family member has been expecting it or not, receiving a diagnosis of an ASD may come with all sorts of different emotions which may change over time.

The assessment process may have been lengthy and young people and their families are likely to have been living with the difficulties for a long time.

It is important to ask for help when a young person is diagnosed with an ASD, both for the person themselves but also for other family members.

As well as the services mentioned in the sections above, there are a range of local and national agencies in Wales, including social care and voluntary organisations, which are available to help people with ASD and their families. Some of these are listed in this leaflet.

These agencies can provide education and emotional and practical support to individuals with ASD and their families. They can put people in contact with other young people and families in similar situations. They can also direct people to other agencies which may be helpful.



## Useful websites

### **National Autistic Society**

This charity offers information, support and services for people with an ASD and their families. It has many local branches throughout Wales.

[autism.org.uk](http://autism.org.uk)

### **Royal College of Psychiatrists**

This site provides a patient information leaflet about autism and Asperger's syndrome, as well as other mental health information. Search 'autism' from the homepage.

[rcpsych.ac.uk](http://rcpsych.ac.uk)

### **Autism Cymru, All Wales Autism Resources (AWARES)**

AWARES signposts autism resources and information within Wales and online resources outside of Wales.

[awares.org](http://awares.org)

### **NICE (National Institute for Health and Care) Guidance**

Autism diagnosis in children and young people: Recognition, referral and diagnosis of children and young people on the autism spectrum

[nice.org.uk/guidance/CG128](http://nice.org.uk/guidance/CG128)

Autism: The management and support of children and young people on the autism spectrum

[nice.org.uk/guidance/CG170](http://nice.org.uk/guidance/CG170)

Autism: recognition, referral, diagnosis and management of adults on the autism spectrum

[nice.org.uk/guidance/CG142](http://nice.org.uk/guidance/CG142)

## **Wales Autism Research Centre**

WARC is a collaboration between Cardiff University, charities and the Welsh Government. It carries out research into ASDs.  
[sites.cardiff.ac.uk/warc](https://sites.cardiff.ac.uk/warc)

## **MindEd**

MindEd contains information for anybody working with children and young people's mental health issues.

[minded.org.uk](https://minded.org.uk)

## **Young Minds**

YoungMinds is a charity committed to improving the emotional wellbeing and mental health of children and young people.

[youngminds.org.uk](https://youngminds.org.uk)

## **NHS Choices: Living with Autism**

Information on autism, including a guide for parents, key facts and real people's experiences.

[nhs.uk/livewell/autism](https://nhs.uk/livewell/autism)

## **Autistica**

This charity raises funds for medical research into autism.

[autistica.org.uk](https://autistica.org.uk)

# Help with our ASD research

The National Centre for Mental Health (NCMH) is working to better understand autism spectrum disorder. The aim of our research is to improve diagnosis, treatment and support for the future.

But to do this we need **your** help.

Helping with our research is quick and painless, and all information we collect is stored confidentially. Taking part involves:

- an informal interview with one of our trained researchers, either at your home or in a local clinic
- providing a small blood or saliva sample
- completing and returning some questionnaires

For more information about our research and how you can help, visit our website ([www.ncmh.info](http://www.ncmh.info)) or contact us:



**info@ncmh.info**



**/walesmentalhealth**



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Produced by the National Centre for Mental Health.  
The information in this leaflet is correct at the time of printing.  
Printed June 2016.

NCMH is funded by Welsh Government through Health and Care Research Wales.

Mae'r wybodaeth hon hefyd ar gael drwy gyfrwng y Gymraeg. I ofyn am gopi, cysylltwch â ni: [info@ncmh.info](mailto:info@ncmh.info)



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