

Your child has been assessed and has been diagnosed with an Autism Spectrum Disorder (ASD).

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Alder Hey Autism Spectrum Pathway

Information for Parents & Carers

It's not your fault! Autism has nothing whatsoever to do with parenting style or the way you brought up your child. Parents of children with an ASD are just like everyone else.

You may have been told that your child was just being 'naughty'. A diagnosis should help you to explain to people why your child is behaving in a certain way. It will also help you to understand your child better.

Your feelings are normal! You may experience a range of feelings from relief to sadness and anger. This is normal; so don't feel too guilty about this. You have been given news which will affect you for the rest of your lives. You need time to come to terms with this and to think about the next steps. It may help you to speak to someone about how you are feeling.



What is Autism Spectrum Disorder?

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ASD is a lifelong neurodevelopmental condition that affects the way an individual communicates and relates to people around them. Children with ASD can find the world a very confusing place and may often have high levels of anxiety, whatever their level of intelligence. It may also impact upon other aspects of their behaviour, for example they may find it difficult to be flexible or to accept change.

ASD is not an illness. It is not a condition that children will 'grow out of'. They may always find certain things more difficult than other children. However, with the right help and support they will be able to flourish and build on their own strengths.

There are some important things to remember:

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- ✓ You may have been told that your child was just being 'naughty'. A diagnosis should help you to explain to people why your child is behaving in a certain way. It will also help you to understand your child better.
- ✓ Your feelings are normal! You may experience a range of feelings from relief to sadness and anger. This is normal; so don't feel too guilty about this. You have been given news which will affect you for the rest of your lives. You need time to come to terms with this and to think about the next steps. It may help you to speak to someone about how you are feeling.



- ✓ Diagnosis is the key to support. It should enable you to get the right help and support for your child. They may need extra support in school, or you may need help managing their behaviour at home.
- ✓ Try not to worry too much about what might happen in the future. Just like any other child, your child will change and develop. With the right help and support they will learn to manage some of their difficulties. Many adults with ASD lead happy and fulfilled lives.
- ✓ Be wary of searching for ASD information on the internet. There is a lot of misinformation on the internet. If you want to do some research start with a reputable website, such as the National Autistic Society and work from there.

What causes ASD?

After 50 years of research, there is still no agreed explanation for ASD. There does appear to be genetic involvement, but it is very unlikely that there is any one single cause for ASD.

ASD can affect anyone, no matter what their intellectual ability or background. More boys than girls are affected, with a ratio of 4:1.



The Autistic Spectrum and 'Triad of Impairments'

It is now recognised that Autism and Asperger Syndrome are both part of the Autism Spectrum. Wing and Gould recognised that individuals with ASD share three areas of difficulty:

- ✓ Social Interaction
- ✓ Flexibility of thought or impaired imagination
- ✓ Social Communication

These difficulties are named the 'Triad of Impairments'

It is important to realise that each child with ASD has their own distinct personality, strengths and needs, just like anyone else.

Social Interaction

Children may:

- Appear aloof or to be in a world of their own
- Not respond to physical affection
- Not show or recognise emotion
- Use an adults hand to get things
- Not respond to their own name
- Avoid eye contact or have impaired eye contact
- Not join in others' games
- Difficulty understanding what other people are thinking or feeling
- Have little or no sense of danger



Flexibility of Thought

Children with ASD may:

- Use toys in a repetitive and stereotypical way e.g. lining them up
- Show complex patterns of play copied from videos, which can be repeated over and over again
- Engage in repetitive activities such as watching the same TV clip over and over again
- Have difficulty playing imaginatively with parents or other children

Social Communication

Communication comes in many different forms and includes speech, sign and facial expressions, gestures, body movement and vision. We read all of these on a daily basis. A child with ASD can have great difficulty understanding these messages.

Some examples of other associated difficulties:

Sensory Perceptions

Individuals with Autism Spectrum Disorders may show unusual responses to sensory experiences, they may underreact or overreact to sensory stimuli.

This can include one or more of the senses:

- ✓ **Vision** –children may find bright lights, sunlight, bright colours painful to look at. They may also seek these for stimulation.
- ✓ **Smell** – children may find certain smells overpowering (perfume, fabric conditioner, deodorant, cooking smells). They may also seek these for stimulation.
- ✓ **Touch** –children may experience sensitivity to touch. This may affect hair brushing or the type of clothes they wear. They may also seek these for stimulation.



- ✓ **Taste** – this includes the flavour and texture of food. The child may need to smell or touch food before they eat. They may not like their foods to touch each other on the plate
- ✓ **Hearing** – sounds can be perceived as intense or sudden unexpected noises (dog barking, hair dryer) or confusing complex multiple sounds (crowded places)
- ✓ **Pain** – children may not show distress in response to levels of pain that other people would find unbearable. At other times they may be more sensitive to pain than others

Obsessions and Routines

Repetitive behaviour patterns and resistance to change are notable features in ASD. Such behaviours can be a comfort and a way to relieve stress, which for a person with ASD could be essential. Sometimes the routines are inappropriate or prevent the person from doing other things. These behaviours may appear when the child is bored or frustrated.

These behaviours may include:

- Hand flapping, body spinning, finger tapping
- ‘Sighting’ – twisting or turning objects close to the eyes and looking at it from different angles
- Need for repetitive routines in everyday life e.g. following the same route to the shops
- Obsessional interests in certain activities/videos e.g. Thomas the Tank engine
- Special interests, collecting facts and information and may talk obsessively about them. May ask the same questions of everyone they meet.



There are various Psychological theories that have been proposed to aid our understanding of ASD.

Theory of Mind

Along with social communication, interaction and imagination difficulties, individuals with a diagnosis of ASD may also have difficulties understanding that other people have different thoughts and feelings to themselves. This has been termed 'mind blindness' or difficulties with 'theory of mind'. They may also have difficulty understanding their own feelings and emotions.

This can result in children having difficulty with:

- Predicting others' behaviour
- Reading the intentions of others
- Understanding the rules of conversation
- Negotiating friendships
- Understanding deception
- Understanding pretence sorting fact from fiction.

Common Terms

Asperger Syndrome is the term used for children at the more able end of the spectrum. They tend to have average or above average intelligence and have fewer difficulties with language. They often speak fluently, but their language can sound formal or stilted. They often wish to appear sociable but find it difficult. They may fail to adjust their language to different situations or the need of their listeners. They may be clumsy. It must be remembered that although individuals with a diagnosis of Asperger's Syndrome may appear quite able, they may have difficulties underpinned by the triad of impairments (see above).

It is worth noting that Asperger's is no longer used as a separate diagnosis according to the NICE guidelines, but may still be used as a descriptive term.



Autistic savant is the term used for someone with ASD who has a special talent, for example, drawing, memory, maths or playing an instrument. One possible reason could be the single minded concentration a child with ASD can give to one subject. The most well-known example is the character played by Dustin Hoffman in the film 'Rainman'. Only about 4 – 9% of individuals with ASD will have this special ability.

Receptive Language - this is the information we hear that leads to us developing understanding. Children with ASD may have difficulty understanding what is being said to them, especially if the language used is too difficult or hard to follow.

Expressive Language - this is the language we use to communicate information to others. This is not always just the use of speech but will also include other communication skills, such as body language and gestures.

Echolalia – some children may directly echo or copy another person's words or phrases (including from TV, videos and other sources). This may lead adults to have a false impression of a child's language ability. Echolalia often masks comprehension problems.

Literal Interpretation – Children with ASD may take what is said to them literally. For example, some children with ASD may look at their fingers in surprise if they enjoy gardening and are called 'green fingered'.

Hyperlexia – Hyperlexia is the skill for recognising written words without having the equal ability to understand what the words mean. This skill is not only held by children who can speak – sometimes the child may appear to read some words before acquiring speech.

