

## Patient information from BMJ

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# Autism spectrum disorder: information for parents - What is autism spectrum disorder?

Autism affects how a person understands and interacts with the world. The medical name for autism is autism spectrum disorder. Understanding autism and recognising your child's support needs early can make a big difference for both them and your family.

This information helps explain what autism is and how to recognise if your child may be autistic.

#### What is autism?

**Autism** affects how a person's brain develops and works. This can affect how they communicate, interact with others, and understand the world around them.

Autistic people are often described as **neurodivergent**, meaning their brains work in ways that are different to how most people's brains work. This term is also used to describe people with ADHD or dyslexia, for example. **Neurotypical** refers to people whose brains are considered to develop and work in a 'typical' or 'standard' way.

Autism is a **spectrum**, which means it affects people in very different ways. For example, some people need very little support with their everyday lives and live independently. Other people might need daily help from a parent or carer. Some autistic people have a learning disability and need support with communication and learning. Others may not need this support and instead may have particular strengths and skills in learning.

Doctors aren't sure what causes autism, but it seems to run in families. It may be down to a combination of genes. If your child is autistic, you might worry that something you did caused it. There's no evidence to suggest that any specific parenting action or behaviour causes autism. There's also no evidence that vaccinations, including the measles, mumps and rubella (MMR) vaccine, can cause autism.

#### Autism, autistic spectrum disorder, and Asperger's syndrome

Doctors used to use different names for different 'types' of autism, often depending on how much support a person needed. For example, you may have heard of Asperger's syndrome, which was often thought of as a 'form' of autism linked to above-average intelligence.

Nowadays, doctors use the medical name autism spectrum disorder (ASD for short) for all autistic people.

## How can I tell if my child is autistic?

Some countries screen for autism at regular well-child visits. You might be asked to fill in a questionnaire about how your child usually behaves, or a healthcare professional might ask you some questions. If they think your child may be autistic, they will refer your child to a specialist doctor.

If your country doesn't screen for autism and you think your child is autistic, you should talk to your doctor.

Some signs of autism can start before the age of 2. You may notice that your child:

- Doesn't look when you call them, even if they seem to hear other sounds
- May not look you in the eye or smile at you
- Might be quiet and placid, or very irritable and difficult to put down
- Often seems to be in their own world.

As your child grows they may show other signs of autism. Doctors look at several main areas of development to find out if your child is autistic.

## Language

- Some autistic children start to talk later than other children. You may notice that your child hardly makes any sounds and doesn't 'babble'. Children who don't say any words by the age of 2 years old are said to have delayed language skills. But not all children who have delayed language skills are autistic.
- Some autistic children learn some language skills but then lose them, and stop talking completely.
- Your child may often repeat or 'echo' words and phrases they hear. In young children,
  this is part of learning to talk, where they copy sounds and words. It typically ends by
  the age of 3, when children can create sentences on their own. In autistic children, it can
  last longer and may include longer phrases, sometimes used out of context as a way to
  communicate.
- Some autistic children develop advanced language skills at a very young age. They
  might use complex words or have 'adult-like' speech.

#### General communication

- From the age of about 9 months, most children point to things they are interested in, or that they want. This often happens at the same time as looking at their parents. It's an early form of communication. Autistic children may not do this much, or at all.
- Your child may not use facial expressions and gestures in the way that other children do, so it can be hard to know what they're thinking and feeling. Their mood may therefore seem to change quickly. They may also find it hard to read your facial expressions.
- Your child might become frustrated in making their feelings, thoughts and needs known to others.

## Socialising and playing

- Young autistic children might not want to have physical contact and cuddle their parents as much as other children do. Or they may not want to cuddle until they are a little older. This can be upsetting for parents and carers.
- Your child may not interact with you through play in the way that other children do. For example, they may not want to play 'peek-a-boo' or similar games. They might not initiate play or bring you books or toys.
- Your child may prefer to play alone rather than with other children. Or they may want
  to play with others, but they may approach and interact with other children in ways that
  seem intense or inappropriate. For example, they might become distressed if other
  children don't join their games in the way they expect.
- Some autistic children might misunderstand social cues, which can lead to friendship difficulties.

## Repetitive and rigid behaviours

- Autistic children may show repetitive behaviours like spinning around, bouncing, flapping their hands or objects, or flicking their fingers. This is sometimes called **stimming**.
   Stimming can happen for different reasons: for fun, to get sensory feedback, to block out an overstimulating environment, or to manage anxiety.
- Autistic children tend to like routines and may become anxious or upset when their routines are changed, or when they are not told in advance about changes to routines. They might want to do things the same way every time.
- Your child may feel upset about changes in the home, for example if furniture or other household items are moved.
- Your child might become fascinated by one mechanical part of a toy, rather than with the whole toy. Or they might play with a toy in an unusual way, then get distressed if you try to change the game.
- When old enough to talk, your child may become fascinated by one subject and want to talk about it all the time.
- Older autistic children might have intense interests that they focus on so much that they ignore other things. These interests can make them happy and relaxed, give structure,

and help them start conversations and feel more confident. But if the interest becomes too strong, it could turn into an obsession that impacts their daily life.

#### Meltdowns and shutdowns

- A **meltdown** is an intense reaction to feeling overwhelmed. Your child may temporarily lose control of their behaviour, which might include crying, shouting, hitting or kicking. Unlike a tantrum, meltdowns aren't 'bad' behaviour but happen when an autistic person can't handle or express their feelings.
- A shutdown is another response to feeling overwhelmed, but instead of reacting outwardly, your child might withdraw or become very quiet. They might be unable to talk or interact.

Other signs of autism may include difficulties with learning, being sensitive to loud noises or bright lights, and finding writing or other tasks that require a lot of physical coordination more challenging.

Signs of autism can vary greatly from one person to another. Having some of these behaviours doesn't always mean that your child is autistic.

Autism can often be harder to notice in girls. Girls may seem to handle social situations better, but this might be because they are **masking** (hiding) their signs by copying others or withdrawing from difficult situations. They might be part of a strong friendship group or learning well in school, which can make their differences less noticeable.

## What will happen to my child?

If your child has autism you may worry about what will happen in the future. In particular, you may worry about what will happen when your child is grown up, and whether they will be able to look after themselves.

Research shows that out of every 100 autistic children:[1]

- About 20 grow up to be mostly independent
- About 30 grow up to be quite independent, but they'll need some support
- About 50 will not be able to live alone, and will need a lot of support or full-time care.

It's hard to say what will happen, as every autistic child is different and has different support needs.

Recognising that your child is autistic, understanding their needs, and starting support strategies as early as possible can make a big difference to your child and your family. Support strategies focus on helping your child with their communication, learning, and emotional needs. These skills are important for becoming more independent as adults. For more information about different **support strategies for autistic children**, see our information titled: *Autism spectrum disorder: Information for parents - Support strategies*.

## Where to get more help

There are many charities and support groups for autistic people and their families. Your doctor may be able to help you find one in your area, or you could search online. These groups often have useful resources and services and can connect you with others who care for an autistic child or relative.

#### References

1. Steinhausen HC, Mohr Jensen C, Lauritsen MB. A systematic review and meta-analysis of the long-term overall outcome of autism spectrum disorders in adolescence and adulthood. Acta Psychiatr Scand. 2016 Jun;133(6):445-52.

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