

Patient information from BMJ

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

People with autism are affected by it in some way throughout their lives. But this information mainly deals with recognising and treating autism in children.

Finding out that your child has autism can be very upsetting. But understanding autism and getting help early on can make a difference to your child's life and to yours.

What is autism?

If your child has autism, it means that his or her brain works in a different way from most children's brains. This affects how your child develops.

From the outside, children with autism usually grow like, and look like, other children. But children with autism don't develop the skills they need to get along well with others or to keep up in school in the same way as other children.

For example, you may have noticed that your child was different, even as a small baby. Most children with autism show clear signs of their condition by the time they're 3 years old.

The condition affects different children in different ways. Some children need help all their lives, and will not be able to take care of themselves as adults. Other children can learn the skills they need to live independently.

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 has autism, you may worry that something you have done has caused it. But there's no evidence to show this could be true. And there's 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, partly depending on how severe someone's symptoms were. For example, you may have heard of Asperger's syndrome, which was often thought of as a 'mild' form of autism.

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But doctors rarely make those distinctions any more. And you're more likely to hear the condition called autism spectrum disorder (ASD for short), and all people with autism described as being on the 'autism spectrum'.

What this means is that, while everyone on the autism spectrum has the same issues, these features can show up differently in different people with autism or be more severe in some people than in others.

What are the symptoms?

If your child has autism, you might begin to notice the signs between the ages of 18 months and 2 years, or even earlier.

You may notice that your baby:

- Doesn't look when you call them, even if they seem to hear other sounds
- May not look you in the eye, smile at you, or notice when you enter or leave a room
- Often seems to be in his or her own world.

As your child grows they may show other signs of having autism. Doctors consider several main areas before diagnosing autism in children.

Language

Language issues in children with autism range from children who don't talk at all to children who talk earlier than usual and use language that is complex and advanced far beyond their age.

- Some children with autism start to talk later than other children. 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 on the autism spectrum.
- Some children with autism learn some language skills but then lose them, and stop talking completely.
- Your child may often repeat or 'echo' words and phrases he or she hears.
- Some children with autism develop advanced language skills at a very young age, with complex vocabularies and 'adult' patterns of 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 complex communication. But children with autism may not do this much, or at all.
- 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.
- 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. They may also find it hard to read your facial expressions.

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Problems socialising

- Young children with autism 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 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 may get angry when other children don't fit into their games in exactly the way they want them to.
- Your child may form friendships that don't last because of misunderstandings.

These issues usually continue into adulthood to some degree. For example, some adults with autism become socially isolated (and are often happy this way) while others manage to have relationships, families, and jobs.

Repetitive and rigid behaviours

- Children with autism tend to like routines and may become anxious or upset when their routines are changed, or when they are not warned in advance about changes to routines.
- Your child may get upset about changes in the home. He or she might want to do things the same way every time.
- When old enough to talk, your child may become fascinated by one subject and want to talk about it all the time. These 'discussions' will probably be very one sided.
- Your child might become fascinated by one mechanical part of a toy, rather than with the whole toy. Or he or she might play with a toy in an unusual way, then get upset if you try to change the game.

Other signs of autism include having problems with learning, getting very upset by loud noises or bright light, and having problems with writing and other tasks that require a lot of physical coordination.

Only a specialist doctor can diagnose autism. If you think your child may have problems, talk to your doctor first. They should be able to refer your child to a specialist.

Some countries recommend screening for autism at regular intervals, starting in infancy. When screening for autism your doctor might ask you about how well your child is speaking, and whether they point, gesture, and interact with you.

What will happen to my child?

Many parents of children with autism worry about what will happen to their child 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.

It's hard to say what will happen, as autism affects each child differently. Some people with autism can live on their own. Others will always need a lot of help. The right support, education, and training as early as possible may help your child have fewer problems later on.

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Studies of people with autism suggest that:

- About 15 in 100 children with autism grow up to live on their own
- Between 15 in 100 and 20 in 100 people with autism can live alone but with some help
- Many adults with autism need full-time care for the rest of their life.

How well your child copes on their own is linked to how well they can speak and learn. Some children have a good chance of living alone and holding down a job later on. But many adults with autism need to live in homes that provide long-term care.

Where to get more help

There are many charities and support groups for autistic people. Your doctor may be able to help you find one in your area. For example, in the UK, the National Autistic Society (www.autism.org.uk) offers help and support to people with autism and their families.

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