




What can you say to someone living with autism



Your guide to
understanding
autism





“ I just feel so helpless because I don't know what to say... ”

When you hear that a child you know or love has, or may have, autism it can be devastating. You want to say the right thing and show support, but if like most people you don't know much about autism, you will probably feel totally lost for words.

We've written this guide to help you understand autism, how it affects people with it and what impact it has on carers and families. With this understanding you can then help your friends or family get the support they so badly need.

FACT:
1 in 110 people have autism and 2 million are affected by it

What is autism

Autism (including Asperger syndrome) is a lifelong developmental disability that affects the way a person communicates, relates to others and makes sense of the world. It's a spectrum condition, which means it affects people in many different ways. 'Classic' autism is often accompanied by learning difficulties, whereas Asperger syndrome describes those with average or above-average IQ. At its worst it can leave the person feeling totally alienated from everything and everyone around them, including their parents. Here's how one mother imagines what life must be like for her little boy with autism:

“*Jamie, a human, was born into a Martian family, in a Martian town, on the planet Mars. His human brain is programmed to understand the world in a different way to the Martian brain – and he struggles to survive. He wants to join in with the Martian children, but he cannot cope with the strange movement of their tentacles and the way they use sounds – the rules of the games are impossible for him to work out and so he plays by himself... ”*

Imagine how frustrating and even frightening it must be to live in a constant state of total confusion. You shouldn't be surprised if the person with autism you know becomes frequently anxious, agitated, or even angry. A simple trip to the shops for you may be a terrifying journey into the unknown for someone with autism.

What are the causes of autism?

The exact cause or causes of autism are still not known. However, research shows genetic factors are important and that it may be associated with a variety of conditions affecting the brain's development, which occur around the time of birth.

The importance of diagnosis

The earlier a child is diagnosed with autism, the better. With early intervention and the right education, a child with autism can learn to communicate and engage with the world around them.

However, many families wait years for an exact diagnosis – in fact, 40% of all children with autism wait more than 3 years. Why must they wait? Often GPs don't recognise the symptoms and therefore don't refer families to specialists.

This wait takes its toll on families. They're left worried and confused, not knowing exactly what the problem is. If your friends or family still don't have a diagnosis, encourage them to be persistent and assertive with their GP. It's also worth suggesting they prepare notes before they see their GP, keep a diary of their child's behaviour, suggest their doctor contact the National Autistic Society for more information or ask to see another doctor.

What is Asperger syndrome



Asperger syndrome is difficult to diagnose. People with this condition have better language skills than those with 'classic' autism and don't usually have the accompanying learning disabilities. In fact, they're often of average or above average intelligence. However, they still have many of the same characteristics as those with autism, including difficulty with communication and relationships.

Facts and figures While people with Asperger syndrome often excel at learning facts and figures, don't fall into the trap of believing they're a 'savant' or a genius. This is a common misconception. It's more likely due to the fact that they've developed an almost obsessive fascination with a certain topic, such as train timetables. In fact, only 1% of all people with autism are 'savants'.

Please remember that because their disability is usually less obvious than that of someone with 'classic' autism, a person with Asperger syndrome is, in a sense, more vulnerable.



“At times we have felt so hurt and angry – a whole lot of confused emotions – at not being able to know what to do or say to help our son understand his condition, let alone explain to him why he’s not asked to join in games or is not invited to parties, or why he gets kicked, punched, sworn at and generally turned into an outcast by his peers at school.”

Mrs S, mother of a little boy with Asperger syndrome

Diagnosis may take much longer and they may just be seen as 'odd'. This is why they often become an easy target for teasing or bullying at school.

It's worth remembering that as people with Asperger syndrome are extremely aware of their social isolation, they often become depressed.

FACT:
42% of children with autism say they have no friends

“It’s so sad! Why does anyone slightly ‘different’ always seem to get bullied?”

What are the characteristics of autism

As autism (or autistic spectrum disorder) is so wide ranging it shows itself in a number of different ways. But generally people with autism, including Asperger syndrome, experience these main areas of difficulty:

Communication Some people with autism can't speak at all, and because of the added difficulty understanding or demonstrating body language, they may find it difficult to communicate without being taught to sign or to use visual aids.

Even if your friend or relative with autism can talk, they may still find it hard to have a conversation. They may repeat themselves, focus only on their special area of interest and talk at you, rather than to you. They won't understand any metaphors you use and will take your words very literally. *For example, say to a child with autism; 'If you eat much more you will burst', they may actually believe you and become very upset.*

Relating to others People with autism may want to form relationships, but find it difficult as they can't relate to others. They can't always read facial expressions or body language. Your sad or happy face will look the same to them. Hug them and it may actually confuse or even terrify them.

Imagination People with autism also have problems using their imagination. This makes it hard for them to play and empathise with others. They just can't see things from another's point of view. It also makes it hard for them to see the 'bigger picture'. They may walk into a room and instead of taking everything in they'll focus on one tiny object, such as a paperclip on the floor. They may find it hard to think in more creative ways. So avoid using metaphors or similes when you speak to them – they just won't understand them.

Repetitive behaviour A person with autism may continually repeat one body movement, such as constantly flicking their fingers or rocking to and fro. They may also show an all-consuming fascination with just one topic.

Fear of change People with autism and Asperger syndrome become very anxious about change and can be extremely rigid about their routines. It can cause them real distress if these are disrupted in any way. One way of dealing with this is for the family to arrange a timetable, so the person with autism knows when they'll have dinner, what they'll eat and drink and when they can play etc. Then, if things have to change, it can be

shown on the timetable. The person with autism will then know in advance what those changes will be and can prepare for them.

“Martin was a strange boy who found it impossible to integrate socially with other children. He was odd, obsessed with statistics on the Second World War. He talked at you, rather than to you; he had strange verbal and visual tics. He reacted in weird ways to normal things”


Marina Baker, who has a brother with autism

Once you become aware of these characteristics you can begin to understand them and start to make some connection. Try engaging with the person with autism on their special area of interest, avoid using abstract language and try not to upset their routine by being late or making sudden changes to plans. Show affection, but don't be surprised or offended if your smiles are not reciprocated or understood.

You can also begin to understand the effect this behaviour must have on the families and appreciate the endless patience it requires.

**FACT:
Boys are four
times more likely
to develop
autism than
girls**

**“It seems
so hard to
get through
to her”**



“ I just thought
he was a naughty
little boy ”

Autism is a condition that is generally present from birth, but can be diagnosed at any age. Therefore, there will be different issues for families to deal with depending on the age of the person diagnosed.

FACT:
National Autistic
Society volunteer
befrienders have
helped more than
2,000 families

The impact autism can have

On parents

To the outside world a child with autism looks like any other child. When they become anxious or distressed their behaviour may be seen as naughty and it may appear that the parents have simply lost control. Strangers often comment on this ‘failing’, which of course only adds to the parents’ stress.

Because of this lack of understanding in the general public, and for many other reasons, parents of children with autism are at greater risk from depression, anxiety, social isolation, fatigue and frustration.

However, they must be reassured that it’s not their fault! Autism has nothing whatsoever to do with parenting skills. They should also know that they’re not alone. In Britain there are over 535,000 people who have an autistic spectrum disorder. Each one’s behaviour will be unique, but nevertheless there are common problems which bond the whole group together.

On brothers and sisters

Children will pick up from an early age that their brother or sister is different, but may be afraid of asking questions for fear of upsetting their parents. So if you’re close to them, let them know that they can always

talk to you. And even if you don’t have the answers immediately, together you can find them out.

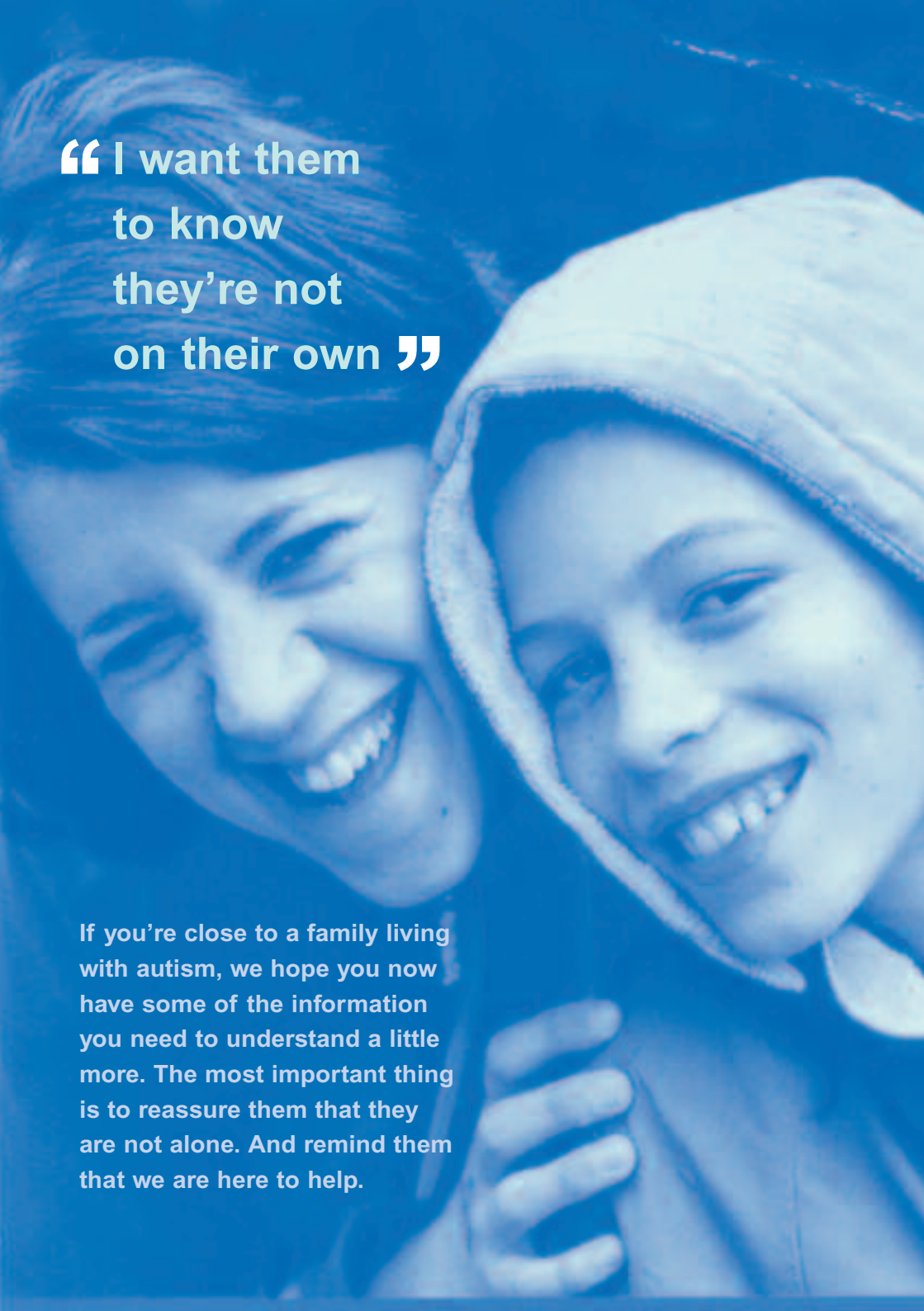
They may also be resentful at the amount of time their parents are spending with their brother or sister. They may even feel angry, embarrassed or guilty, as well as very protective of their sibling. All of which means they require even more love and attention from friends and family.

“At holiday play scheme I’d stick to Alexis like glue, helping to play and entertaining him and feeding him his lunch. I didn’t want anyone else to look after him, and one day when a member of staff took me away from him and told me to go and play, I felt lost. I was very protective, even as a small child.”

Celeste, who has a brother with autism

Family days out

Being able to go out and about and enjoy the activities that all families enjoy is important for children with autism, as well as their brothers and sisters. The key is to plan ahead and find places with all the right facilities for those with special needs. Perhaps you could help out with the organisation of the trip and investigate some of the best places to visit.



“ I want them
to know
they’re not
on their own ”

If you’re close to a family living with autism, we hope you now have some of the information you need to understand a little more. The most important thing is to reassure them that they are not alone. And remind them that we are here to help.

How the NAS can help

We are the UK’s leading charity for people with an autistic spectrum disorder (ASD) and their families. We champion the rights and interests of all people with autism and their families and carers. We have more than 12,000 members and over 60 NAS branches throughout the country.

We offer a wide range of services.

- We run helplines for parents, carers, people with an autistic spectrum disorder, researchers and professionals
- We offer specialist diagnosis and assessment services and training
- We offer post-diagnostic support and information
- We run specialist schools
- We offer advice and advocacy on special educational needs
- We run adult centres and social groups for adults
- We run a supported employment service
- We publish a range of books and leaflets
- We organise conferences and training programmes
- We support local groups and families around the UK
- We encourage research into the causes of autism and into interventions
- We organise volunteering schemes
- We campaign to improve autism services

If you’re affected by autism in any way, please contact the Autism Helpline which provides impartial and confidential information, advice and support.

NAS Autism Helpline 0845 070 4004

(Mon – Fri 10am to 4pm)

Email: autismhelpline@nas.org.uk

Websites: www.autism.org.uk

www.info.autism.org.uk



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