

What siblings need to know



What is a sibling?

In this fact sheet we use the term sibling to describe the brother or sister of an autistic child, young person or adult. A sibling can be any age, older or younger than their autistic brother or sister. What they have in common is they have at least one person in their family who has an autism diagnosis. If you have an autistic brother or sister this leaflet is for you.

What is autism?

Autism is lifelong and affects the social and communication centre of the brain. Autism affects the way your sibling relates to people, situations and the immediate environment. Many autistic people have difficulty processing everyday sensory information like sight, smells, touch, tastes and sounds.

The areas of difference which all autistic people share are:

Social communication and reciprocal social interactions: Differences can vary widely depending on the person. Although each autistic brother or sister is unique, some of the common communication and interaction difficulties include:

- Starting and maintaining social communication (for example small talk).
- Understanding nonverbal cues (for example, body language, tone of voice or facial expressions).
- Understanding the social context of a situation.
- Social skills (for example, personal space and eye contact).
- Understanding other people's thoughts and reactions.

Restricted, repetitive and inflexible patterns of behaviour (including sensory processing differences): Many autistic people will have inflexible patterns of behaviour, interests or activities, this means that they may prefer routines, plans and knowing what to expect. Changes within a day can be highly stressful for your brother or sister. Some of the common restricted, repetitive and inflexible patterns of behaviour include:

- High anxiety because of unexpected changes.
- The need to follow particular routines or rules.
- Repetitive behaviour (for example, hand flapping) or interests (for example, highly focused on particular topics or activities).
- Hypersensitivity (over sensitive) or hyposensitivity (under sensitive) to sensory information including noise, lights, smell, taste, touch and body awareness.

Many of these differences are due to how your brother or sister's brain is processing information about the world around them. There are lots of adaptations that can be beneficial to your brother or sister, including adapting the sensory environment and giving relevant information in a clear way. Everyone is different and can be affected in different ways.

What is the spectrum?

The term autism spectrum is used because autism varies from person to person. If you are confused it is a good idea to find a quiet time to ask your parent/carers about your brother or sister. If your brother or sister is younger than you, they may not have been told yet by your parent/carers that they are autistic.

It is important to understand how your brother or sister is impacted in these areas, to enable you to support them in a way that works best for them. This factsheet has been designed to give you as much information as possible but by talking with your parent/carers you may be able to work out how autism specifically affects your brother or sister.

Other supports your sibling might need

Some autistic people find it difficult to look into other people's eyes, this is called eye contact. It can be hard to know if your brother or sister is listening to you or hearing you if they frequently look away from you when you are talking. Some autistic people can only look at other people for any length of time from the side of their eyes. Older autistic people describe looking into other people's eyes as painful, or they feel distracted and can't concentrate on what is being said.

Some autistic brothers or sisters will also have difficulties with language. This isn't just about what people say but it is also about how they say it, the tone of their voice and the expression on their face. They may not fully understand the not so obvious meaning in social interaction.

Some autistic brothers or sisters will also find it hard to understand what other people are thinking or feeling. It can appear that they are selfish and rude and they may find it difficult to understand these things that you pick up without even realising it. For example, if your teacher has a cross look on their face you might know that they are unhappy. Your brother or sister will struggle to understand this type of communication. You might see this in your brother or sister's behaviour when they find it difficult to meet someone new, when they don't understand taking turns in a game, or when other people find it difficult to understand them.

Some brothers or sisters may find it difficult to understand what you are saying to them. You may need to speak in a clear way and that isn't saying too much at once. You may need to give them time to answer.

Sometimes your brother or sister may have a dual or multiple diagnosis that can occur alongside autism. If your parent/carers talk about other diagnoses such as ADHD, ADD, Dyspraxia etc. it might be useful to ask them to explain a bit more about that.

Sensory issues

Your brother or sister might also have sensory issues. This means they may respond to smells, sounds, things they see, things they taste or touch in a different way to other people. Sometimes a light touch can feel painful. or sometimes they look at certain colours and their eyes hurt. Everyone is different and can be affected in different ways.

Think about things you dislike, things you don't like the taste of, or the smell of, or the sound of. Some people don't like the smell of flowers, it makes them feel ill. Some people don't like to have dirt on their hands because it feels uncomfortable. Remember how you feel when you experience something you don't like. Multiply that feeling and you may understand what it's like for your brother or sister coping with their sensory difficulties.

Ask your parent/carers to explain if your brother or sister has sensory issues and this can help you understand why they react or behave in certain ways. You can help by avoiding doing something that seems innocent to you but can have a negative effect on your brother or sister.

How to explain autism to other people

Autism is both complex and unique, it is invisible to see and isn't easily explained. Think about your brother or sister's behaviours, this is how autism becomes visible. It doesn't explain what is happening in your brother or sister's brain, but it helps us understand what they find difficult. Sometimes explaining what your brother or sister can't cope with helps other people to understand. Many more people have heard about autism and understand it a little, but your friends may not. There are many ways you can help them understand including:

- Ask them to remember when they felt very scared, very confused, or very worried and get them to multiply that feeling and explain that this is some of what your brother or sister might feel every day.

- Explain that your brother or sister cannot control their feelings and that's why they sometimes behave differently from other people.
- Teach your friends about the differences and that it is okay to be different, and it's alright to ask questions.
- Explain that it's not okay to ignore, look away or act like your brother or sister is not there.

Use the information in this leaflet to help you work out what to say, and talk to your parents about how to explain autism to others. If friends are true friends, they will support your brother or sister.

Other questions you may have

Can I catch autism?

Autism is something you are born with. It is not like the cold, you cannot catch autism from another person. Autism is what is called an 'invisible disability' and can be difficult to understand. If someone needed to wear glasses, you wouldn't worry about catching poor eyesight from them. In a similar way you cannot catch autism as it is a different way of thinking.

What will happen in the future when we grow up? Will I have to look after my brother or sister?

No one can be definite about the future. Autistic people with autism grow up, can have a job, can make friends and have relationships. If your brother or sister is supported as they grow up this will help them as adults. They may be able to develop ways of celebrating their differences, difficulties and achievements. Some will still need support in the future. When you are older you will be able to fully understand your brother or sister's needs and make a choice about how you can assist with these. You will not be forced to look after your brother or sister if you aren't able to.

Will my brother or sister get better?

Autism is a condition that your brother or sister was born with. It is not a condition that has a cure. As your brother or sister grows older, they may need less support with certain things, they may develop and mature to be more independent, but they are likely to need some additional support throughout their lives.

Difficult times – tips and hints

You may find that frequently you are frustrated, angry or hurt by your brother or sister's behaviour. If you know the things that trigger this behaviour it is important to try to avoid them. If the sound of your mobile phone triggers your brother or sister, try to find alternatives, it might be easier to keep your phone switched to silent/vibrate when your brother or sister is nearby.

If your brother or sister sometimes hurts you with their reactions it's important to work out if there is anything you could do to stop that happening.

What are my needs?

Brothers or sisters of an autistic person will have many different needs. Sometimes it can feel as though every activity you do as a family revolves around your autistic brother or sister. This can sometimes mean that you feel forgotten about, or frustrated and angry that what you had hoped to do has had to be cancelled or cut short because of your brother or sister's intolerance to that activity.

It can also be frustrating to invite friends round and see their reactions to your brother or sister's behaviour. You may not be able to have friends to visit or stay over because your parent/carers are so busy helping your brother or sister and dealing with their behaviours.

If you feel embarrassed or confused by your sibling's behaviour when you are out and about with them it is important to talk to your parent/carers, sometimes their behaviour can seem bizarre, scary or rude. You may not understand why they don't do as your parent/carers tell them and you may resent that they seem to get away with things that you are not allowed to do.

At times you might feel that you have to be responsible for your brother or sister, for example, when your parent/carers ask you to keep an eye on them or to keep them occupied while they do housework or do the shopping. It might feel at times that you are 'invisible' as your parents are frequently going to appointments with your brother or sister and attending meetings in school.

Sometimes siblings can feel left out and resentful and feel their family is different from their friend's family. It is normal to feel like this at times, but remember to talk to your parent/carers or a family member you trust. Sharing your feelings is important, your parent/carers care about you just as much as your autistic brother or sister. They may find it hard to get the time to tell you that. Think about the things they provide for you, think about how hard they are working to make things better. Tell your parent/carers your worries and concerns. Sometimes siblings feel they don't want to add to their parent/carers worries, however, if your parent/carers know something is bothering you they will try to make it better. Try to work out solutions together.

Resources that help start conversations

There are some really good resources to read that help explain autism more. Perhaps you could try online; Amazing things happen – autism.

Or you could borrow a book from your local library, save up and buy one or ask your parent/carers if they can help you get a book because you want to learn more.

- Boy Alone: by Karl Taro Greenfield
- Everybody is Different: by Fiona Bleach
- Autism through a Sister's Eyes: by Eve B. Band & Emily Hecht
- Autism the Invisible Cord: by Barnara Cain
- Siblings: by Jane Johnston and Anne Van Rensselaer



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To make a donation, please visit www.autismni.org or call us on **028 9040 1729**.

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