



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 a child, young person or adult with an Autism Spectrum Disorder (ASD). A Sibling can be any age, older or younger than their brother or sister with ASD. But what they have in common is they have at least one person in their family who has a diagnosis of an ASD. If you have a brother or sister who has an Autism Spectrum Disorder this leaflet is for you.

What is ASD?

Autism Spectrum Disorders are a lot of different types of conditions that are described under the same label. You might hear the terms Autism, ASD, Asperger's Syndrome, AS, High Functioning Autism, Kanner's Autism, Classic Autism or Autistic Traits used to describe your brother or sister's condition. Whatever the label that is used, it means that your brother or sister has been diagnosed with a condition that have similarities to other conditions on the Autism Spectrum.

Sometimes the term Autism is used as a general term to describe in a simple way the difficulties that your brother or sister have. ASD is a very complex disorder that can affect your brother or sister in many different ways. This fact sheet is designed to give you as much information as possible to this range of disorders but by talking to your parents you may be able to work out how ASD specifically affects your brother or sister.

Triad of Impairments (3 areas of difficulty)

Anyone who has ASD has three main areas where they experience difficulties. Firstly, there is a social difficulty called social interaction. You might see this in your brother or sister's behaviour when they find it difficult to meet someone new, or they don't understand about taking turns in a game, or don't understand instructions, or other people find it difficult to understand them.

Some people with ASD 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 people with ASD can only look at other people for any length of time from the side of their eyes. Older people with ASD describe looking into other people's eyes as painful, or they feel distracted and can't concentrate on what is being said.

Someone with ASD 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.

Your brother or sister may also find it hard to understand what other people are thinking or feeling. It can appear that they are selfish and rude. They will find it difficult to understand these things that you pick up without even realising it. If your teacher has a cross look on their face when they are looking at you chances are you will know that you have done something that has made them unhappy. Your brother or sister will struggle to understand this type of communication.

Some brothers or sisters may find it difficult to understand what you are saying to them. You may need to speak in a simple and clear way and in a way 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 diagnosis of several disorders. There are a number of disorders that can occur alongside Autism. If your parents talk about other disorders such as ADHD, ADD, Dyspraxia or other labels it might be useful to ask your parents to explain a bit more about that.


What is the Spectrum?

A Spectrum is wide ranging and is used to describe conditions that are similar, although may have some significant differences. If you are confused it is a good idea to find a quiet time to ask your mother or father what your brother or sister has been diagnosed with. If your brother or sister is younger than you they may not have been told yet by your parents that they have this diagnosis. So if your parents ask you not to say to your brother or sister it means they are waiting until they are ready to be told and for the condition to be explained. If you tell your brother or sister before they are ready it might scare or worry them. This is something that it is important for your parents to do. Even if you are angry with your brother or sister remember that you wouldn't like to be told something that will affect the rest of your life in an angry way.

What other difficulties might my brother/sister have?

Sensory Issues

Many people with ASD will 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. 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 by 100 and you may understand what it's like for your brother or sister coping with their sensory difficulties.

Ask your parents to explain if your brother or sister has sensory issues. 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 can I explain about ASD to other people?

ASD is a very complicated and unique disability. It is invisible to see and isn't easily explained. Think about your brother or sister's behaviours. This behaviour 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. Help them understand by asking them to remember when they felt very scared, very confused, or very worried. Get them to multiply that feeling by 100 and explain that this is what your brother or sister feels every day.

Explain that your brother or sister cannot control those feelings and that's why they sometimes behave differently from other people. Use information in this leaflet to help you work out what to say. Talk to your parents about how they explain Autism to other people. Remember Autism is a disability and although your brother or sister is not in a wheelchair or blind that doesn't mean they are less affected. If friends are true friends they will accept your brother or sister and their unusual behaviours. Help them by explaining why your brother or sister does these things and that it's something they cannot control without help from other people.

Other questions I might have?

Will my brother or sister die from ASD?

ASD is a condition affecting the brain. While there is no cure for ASD your brother or sister cannot die from it. It is a condition

that will remain with your brother or sister throughout their life but with special help they may be able to live with some independence.

Can I catch ASD?

ASD is something you are born with. It is not like the cold, you cannot catch ASD from another person. ASD is what is called a 'hidden disability' and can be hard to understand how it affects someone who has it. If someone needed to wear glasses you wouldn't worry about catching poor eyesight from them. In a similar way you cannot catch ASD because it is not a disease.

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 how much your brother or sister will be affected in the future. Many people with ASD growing up, can have a job, can make friends, or meet a special friend. If your brother or sister gets help when they are young they can have a slightly easier time as a grownup. Some people with ASD can develop a good knowledge about the things in everyday life that confuse or worry them. They may be able to develop ways of coping or managing those things. But some people with ASD have many complex problems that mean they will still need a lot of help as a grownup. When you are grownup you will be able to understand how much help your brother or sister needs and be able to make a choice about how much help you can provide. 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?

ASD 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 help with certain things, they may develop and mature to be more independent but they are likely to need some additional help 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 to make noises, try to break it, or start running around, then 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. Do you have a lock on your bedroom door to keep your brother or sister out? Could you use a STOP sign to prevent your brother or sister entering?

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Can you keep a supply of toys your brother or sister likes nearby to give them if they start behaving aggressively?

What are my needs?

Brothers and sisters of someone with Autism have many different needs. Sometimes it can feel as though every activity you do as a family revolves around your brother or sister who has ASD. 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 parents are so busy helping your brother or sister and dealing with their behaviours that they are too tired to allow you to have sleepovers.

You may feel embarrassed by your brother or sister with ASD when you are out and about with them. Sometimes their behaviour can seem bizarre, scary or rude. You may feel confused about why they behave like this and why they don't do as your mum or dad tells them. 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, e.g. when your parents ask you to keep an eye on them or to keep them occupied while they do housework, do the shopping, etc. 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 parents or a family member you trust. Sharing

your feelings is important. Your parents care about you just as much as your brother or sister who has Autism. 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 parents your worries and concerns. Sometimes siblings feel they don't want to add to their parent's worries. However if your parents know something is bothering you they will try to make it better. Try to work out solutions together.

Resources

There are some really good books to read that help explain Autism more. Perhaps you could save up and buy them or perhaps ask your parents if they can help you get a book because you want to learn more.

Able Autistic Children: Children With Asperger Syndrome: Julie Davies

Amazingly...Alphie - Understanding and Accepting Different Ways of Being: Roz Espin

Andy and His Yellow Frisbee: Mary Thompson

Autistic Planet: Jennifer Elder

Brotherly Feelings: S Frender and R Schiffmiller

Can I Tell You About Asperger Syndrome: Julie Welton

Children with Autism: A Booklet for Brothers and Sisters: Julie Davies

Do You Know Someone With Autism: Janet Smith

Everybody Is Different: Fiona Bleach

My Brother is Different: Louise Gorrod

Little Rainman: Karla Simmons

My Brother Matthew: Mary Thompson

Special People Special Ways: Arlene Maguire

Toibin Learns To Make Friends: Diane Murrell

Views From Our Shoes: Donald J Meyer