



Jo's Story

These notes are to accompany the Sibs Talk Lite Primary School worksheets

My name is Jo. I like playing with my friends at school. We have fun. My favourite game is playing football. Sometimes my friends invite me to their houses to play with them after school. That makes me happy. My home is different. My brother is called Ash. He has epilepsy and is autistic. He can't walk or speak very well. This means that my house is very busy after school. We have lots of people coming into my house to help my mum look after my brother. He has lots of stuff like wheelchairs, special chairs and medicine. There isn't much space for me to play as I share a bedroom with him. This means that I can't have friends over as there is nowhere for us to play. This makes me feel sad. I hope my friends know that I still like them.

Questions

1. What do you know about Jo?
2. What do you know about Ash?
3. What does Jo like doing?
4. What is making Jo feel sad?
5. Why does Jo worry about not being able to invite their friend's over?
6. What could you do to help Jo?

7. How could you help Jo to feel happier?

What is Epilepsy? (pre-reading)

Some people are born with epilepsy. Some people get epilepsy when their brain has been injured. This may have been because of a serious illness or a bad accident. For more than half the people who have epilepsy the doctors do not know what caused it. It can start at any age. Epilepsy can't be caught from someone else, like a cold can.

What does it mean?

There are lots of different types of seizures. The one people recognize most is called a tonic-clonic seizure. Some people call them grand mal. This is where the person falls to the floor and has jerking movements. There are many other types where the person doesn't fall to the floor. One of these is called an absence. The person having an absence will look as if they are staring into space, or daydreaming.

Most seizures start without warning, but some people have a funny feeling, feel sick or have butterflies in their tummy. Or they may have a weird smell or taste just before their seizure starts.

Some people find that certain things may bring on a seizure, like not getting enough sleep or not taking their epilepsy medicine. A few people find that playing video games or looking at flashing lights can bring on their seizures. After the seizure they may be tired and they may not remember anything about it. When someone has a tonic-clonic seizure they should be rolled onto their side, after the seizure has ended, have a cushion put under their head and have someone stay with them until they are better. Sometimes they may need an ambulance if the seizure lasts for longer than five minutes.

What treatment is there?

Most people who have epilepsy have to take medicine every day. This helps to stop them having seizures. Sometimes it can stop the seizures altogether. Some people will get better as they get older and can stop taking the medicine but they must never do this without talking to their doctor.

In a few people, when the epilepsy medicines don't work, they may need to have an operation.

Autism (ASC)

Nobody knows why people have ASC. People are born with it, though it may not be noticed while they are very young. You cannot catch it like a cold or flu.

What does it mean?

If someone has ASC, their brain works differently. They may not understand what is happening, or why. They sometimes find it hard to be around other people or they may react differently to what is going on around them.

People with ASC may be affected in five main ways.

They may find talking and listening much more difficult. They may find it hard to link words with their meanings and because of this they may find it difficult to understand what other people say. They may not be able to speak, or when they do speak, they find it hard to say what they mean. They may copy what people say, or only talk about their favourite subject and they may ask the same question lots of times.

They may find it difficult to use their imagination. This may mean they can't join in 'make-believe' games. They may like doing the same things at the same times every day and get very upset when these routines are broken. They may like to have things always in the same place. Your brother or sister may also have lots of things they are good at. They might be good at concentrating on one activity at a time or have interesting hobbies or topics they know lots about.

Autistic children may struggle to learn social skills. They may find making friends and getting on with people more difficult. They may find it difficult to join in with groups and to make new friends or find it hard to understand what other people are thinking or feeling. They often do not understand body language. They may not always realise that a smile means you are pleased, or a hug means you like them!

They may not understand how to behave, when to be quiet, when to wear clothes, what things are private. They find it very hard when there are lots of people around or lots of things happening at the same time.

Some people with autism are also affected through their senses. Their hearing may be very sensitive and they may not like loud noises. They may have a very strong sense of taste and be a bit limited in the food choices which they make. They may also dislike being touched or hugged. Some people with autism may also have epilepsy. Some people with autism may also have difficult behaviour.

What help is there?

There is no cure for autism but people who have it can have happy and enjoyable lives even if they need some extra help.

About Sibs

Sibs is the only UK charity representing the needs of siblings of disabled people. There are over half a million young siblings and at least 1.7 million adult siblings in the UK, who have grown up with a disabled brother or sister. Sibs aims to enhance the lives of siblings by providing them with information and support, and by influencing service provision throughout the UK.

Thank you for supporting siblings in your school.

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