

March 21st is World Down Syndrome Day, which has been officially recognised by the United Nations since 2012.

On this day, people all around the world celebrate the lives and achievements of people with Down syndrome. March 21st provides an opportunity to raise awareness about the rights and inclusion of people with Down syndrome around the world.



Dear Parents,

This is Issey. She is 6. Issey was born with Down syndrome. Issey is an only child, and we are her parents, Anne and Haydn.

Issey loves coming to school! Everyone has been so warm and welcoming, and we feel fortunate to join the Teesdale Primary School and have such supportive peers at school for Issey. She has made some beautiful friends already.

We are new to Teesdale and looking forward to joining the local community.

Issey enjoys many of the things most six-year-olds enjoy! Dancing, drawing, camping, playing outside, playing Barbies, and building cities with lego.

Or watching some of her favourite movies like 'Brave', 'Encanto' and 'the Croods', going to the beach to jump waves and taking her dog Bo (Bo Bo) for a walk.

Children are naturally curious and often have questions about things they observe as different to them. Your child might have questions about Issey, such as; "Why doesn't she talk much?", "Why is she hard to understand?", "Does she want to be my friend?".

The fact that Issey is different is not something to be ignored, sorry or embarrassed about. We want to take the opportunity to provide some information about Down syndrome so you might be better placed to answer any questions your child may have. Many people need to learn more, or have outdated information about Down syndrome, which is why we have written this letter.



What is Down syndrome?

Down syndrome is a naturally occurring chromosomal arrangement that has always existed throughout history. While art and historical pieces portraying people with Down syndrome have been found dating back to 500 AD, Down syndrome was first characterised in 1862 by John Langdon Down, which is where the name was derived from.

Down syndrome is a genetic condition, and it is not a disease or illness. It occurs when someone has an extra copy of chromosome 21 (also known as Trisomy 21). People with Down syndrome have 47 chromosomes in all of their cells instead of 46. This results in a range of physical characteristics, health and development indications and some level of intellectual disability. Down syndrome is usually recognisable at birth and confirmed by a blood test. One in every 700-900 babies born will have Down syndrome.

People with Down syndrome are more like their parents, siblings and family members than anyone else who shares the same condition. Whilst everyone is different, some common characteristics include speech difficulties and low muscle tone, which can impact gross motor and fine motor skills. The low muscle tone also means Issey has to work much harder to perform tasks, so she can become more physically tired from doing things than her peers.

People with Down syndrome all around the world live independently, study at university, choose careers, compete in sports, find love, pursue passions and live a lot longer due to improved human rights and access to health management.

Talking to your child about disability

We always make sure when we talk about Down syndrome or any disability with kids, and we are matter of fact about it. We answer questions in positive language; we encourage them to see the individual rather than the disability. A big message we focus on is how we're all different. We all have strengths and challenges and how this is a good thing. Everyone needs help sometimes. Children will mimic our attitudes, so if we accept and embrace differences without judgement, they will too.

All our bodies are made up of tiny balls called cells. Every cell in our body has a set of instructions called chromosomes that tell our body how to be us - they say what our hair colour is, what our eye colour is and if we like chocolate or not. Most people have 46 sets of instructions in every cell. People with Down syndrome, like Issey, have an extra one (47 altogether). These extra instructions can make people with Down syndrome extra good at doing some things (like being super flexible) but also make it harder for them to do other things (like learning to talk) because Issey's mouth works differently.

About Issey

For Issey, her extra chromosome means her body takes a little longer to grow and learn. Issey has to practice more and work harder to learn some things, like talking clearly, because the muscles in her mouth are soft and still growing and still gaining strength. Even though some things are harder for Issey to do, that's ok. She will eventually get there, and it's important that Issey learns to do things for herself.

The best way to be Issey's friend is to sometimes slow down and give her a chance to respond. Ask her to show you what she is talking about, or give her choices. She may want to watch a little longer before she tries something new. She can say lots of things, but sometimes she might feel shy, and sometimes she may be so excited that she mumbles her words and they are harder to understand.

She can use keyword sign language because her receptive language is higher than her spoken word. Signing gestures allow her to communicate while her speech development catches up. She loves playing games with other kids like hide and seek, tag, coffee shop, dancing, painting and or trying to play sports games like basketball. If she is by herself, you can ask her to join in. She might love that, or it's also ok if she just needs some quiet time. Sometimes some quiet time helps her regulate her emotions and also work through something new she might have just learnt.

She may also need a bit more time to do things. You can ask her if she needs help if you want to, but she loves doing things herself and it's important to always let her try. Instead of doing something for her, it would be great if you could show her how you did it, so she can have a go by herself.

Inclusive education

In the past children with disabilities were taught in segregated special schools. Research now shows that all children with disabilities and children who develop neurotypically, regardless of their IQ or 'function', do better socially and

academically if they are educated in inclusive mainstream schools. Studies have shown that special schools set children up for a 'special life' of segregated employment and low expectations.

Children without disabilities do better in inclusive schools where children are fully included.

Issey loves to learn and is always eager to learn new things and experience new challenges.

Like all parents, our aim for Issey is to live a life fully included in the community, to work in a mainstream job, to live independently with people of her choosing and to have close friends of all abilities.

Starting school is a really important step in this journey for her and your children are an essential part of her success. Issey may require additional support to meet her needs, but her needs are the same as everyone's needs, they aren't special needs. They are human needs.

If you're ever unsure, have a question or want to know more about her, or about Down syndrome then please ask. We won't be offended and in fact we love to know how we can support you more in understanding inclusion. As her advocates, our responsibility is to correct outdated stereotypes and open doors for Issey and others alike.

Here are a few short videos for WDS that you might like to watch. We look forward to getting to be a part of the TPS community and getting to know your kids. We already have felt so welcomed :)

<https://www.youtube.com/watch?v=kNMJaXuFuWQ>

<https://www.youtube.com/watch?v=SKku4RAWa4M>

Anne, Haydn and Issey
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