

What is Down's Syndrome?

Down's syndrome is a genetic condition that causes delays in a baby's development. Every year around 750 babies are born with Down's syndrome in the UK (*Source: Learning Disability Today*). The condition affects people of all ages, races, religions and economic situations and there are currently around 40,000 people living with Down's Syndrome in the UK (*Source: Learning Disability Today*).

When a foetus is developing, it has genes passed on from both parents, these genes are carried in chromosomes. Half of the chromosomes come from Mum and the other half from Dad. Down's syndrome occurs when there is a presence of an extra chromosome 21.

In babies with Down's syndrome, chromosome 21 doesn't separate properly and instead splits into three, rather than two. This extra chromosome is responsible for the cognitive and physical features of Down's syndrome.

It is important to note that Down's syndrome is not a disease or an illness, but a condition or syndrome, and many people with Down's syndrome go on to have jobs and live independently, living happy and fulfilled lives.

Where does the name Down's Syndrome come from?

Contrary to popular belief, Down's syndrome wasn't named after the doctor who first discovered it. Instead, it is named after English doctor, John Langdon Down, who was the first person to categorise the common features of people living with the condition.

What causes Down's Syndrome?

At this time, Scientists do not know what causes the presence of the extra chromosome and there is no way of predicting whether a person is more or less likely to produce it.

There is a known link with advanced maternal age and Down's syndrome, but the reasons for this are currently unknown. Interestingly, most babies with Down's Syndrome are born to women under the age of 35, due to higher fertility rates.

So, whilst the reason behind an extra chromosome remains somewhat of a mystery, there is one thing that doctors know for sure: nothing done before, during or after pregnancy can cause Down's syndrome. The condition happens by chance at the time of conception.

Is Down's Syndrome classed as a learning disability?

Down's Syndrome is a condition in its own right but can sometimes be the cause of some forms of learning disability. In fact, it is the most common genetic cause of learning disability affecting approximately 1 in every 1000 children globally (*Source: United Nations*).

Usually somebody living with Down's syndrome will have a mild to moderate intellectual impairment, which will be different for everyone. However, thinking and learning problems are rarely severe and many people go on to pursue higher education. In recent years there

have been a lot of headlines of people all over the world with Down's Syndrome breaking conventional barriers and gaining bachelor's degrees in everything from law to education.

Are there different types of Down's syndrome?

There are three different types of Down's syndrome. Trisomy 21 is the most common form, affecting 95% of those with Down's syndrome. With this form, every cell in the body has three copies of chromosome 21 instead of two.

Another form of Down's syndrome is called translocation Down's syndrome. In this type, each cell has part of an extra chromosome 21, or an entirely extra one. But it's attached to another chromosome instead of being on its own.

Mosaic Down's syndrome is the rarest type, where only some cells have an extra chromosome 21. Someone with this type of Down's syndrome may not have as many characteristics as those who have translocation or Trisomy 21, because fewer cells have the extra chromosome.

What are the characteristics of Down's syndrome?

People with Down's syndrome will often share similar physical features. They tend to have a small nose with a flat nasal bridge, a small mouth, eyes that slant upwards, a short neck, and restricted growth. People with Down's syndrome will also tend to have movement and speech delay due to anatomical and physiological differences, such as low muscle tone.

Down's syndrome is also very closely linked to Alzheimer's disease. One of the hallmarks of Alzheimer's disease is the presence of something called beta-amyloid plaques in the brain. These plaques are basically a build-up of protein clumps caused by too much amyloid precursor protein (APP). The protein (APP) is produced by a gene that is specific to chromosome 21, of which people living with Down's syndrome have an extra copy. By age 40, most people living with Down's syndrome will have these plaques along with other protein deposits, which may cause problems with how brain cells function and therefore increase the chances of developing Alzheimer's symptoms. Scientists estimate that around 50 percent of people living with Down's syndrome will develop dementia due to Alzheimer's disease as they age (*Source: National Institute on Aging*).

People living with Down's syndrome also have an increased risk of several different health problems, including heart and gastrointestinal problems. Not everybody living with Down's syndrome will have these issues, but it is important to be mindful of them in case you or somebody you know starts experiencing symptoms.

Because of early intervention, today the average life expectancy for a person living with Down's syndrome is 60 years old, with some living into their seventies (*Source: National Institute on Aging*).

What language should we use when talking about Down's syndrome?

It is crucial to use the right language when discussing Down's syndrome, as this helps frame perceptions. Simple changes in our language can make a real difference to how others view and treat people living with Down's syndrome.

For example: instead of saying '*a Down's syndrome baby*', swap it for '*a baby with Down's syndrome*'. This simple change reminds people that there is a person before there is a condition and that disabilities do not define an individual.

Also, try and avoid use of the word '*normal*', instead opt for the word '*typical*', even when referring to children's milestones. Referring to a person without Down's syndrome as '*normal*' can be very hurtful and upsetting for a person living with Down's syndrome.

Even medical professionals are starting to make changes, previously the phrase '*there is a high risk your baby has Down syndrome*'. The use of the word risk insinuates that the parents are likely to be exposed to danger, swapping the word '*risk*' for the word '*chance*' removes those negative connotations.

By using person-centred language it conveys respect and emphasises that people with disabilities are first and foremost, people. By using non-judgmental, accurate and balanced language we can break down stigmas and misconceptions that surround Down's syndrome.

Can people living with Down's syndrome lead a fulfilling life?

Of Course! People living in your local communities are living life to the full as you read. Due to the increased awareness of Down's syndrome, there are now more opportunities than ever for people living with the syndrome to take control of their own life and do what they love. And yes, some people need more support to do this than others, but that doesn't matter, there are support workers out there right now working in partnership, eager to help.

In fact, all over the world people living with Down's syndrome are making amazing things happen. Here are a few recent good news stories, to make you smile.

Éléonore Laloux of France recently became the country's first ever appointed official with Down's syndrome. As well as having a part-time job at a hospital, a very busy volunteer schedule and a board position with a charity, Éléonore acts as a municipal councillor under the mayor. She is leading from the front and bringing a new perspective on Down's syndrome to the people of Arras.

Sofía Jirau has hit headlines very recently as the first model for Victoria's Secret with Down's syndrome. Sofía, who is 24 and from Puerto Rico featured in the company's Valentines Day collection.

In 2021 the BBC announced that actor George Webster would be joining one of their most popular children's shows as a presenter. George worked with the BBC to create a short video dispelling the myths associated with Down's syndrome and has now been offered the opportunity to join the network on a regular basis. George started out as a dancer before pursuing his love for presenting, he also featured as an extra in Emmerdale.