



**Down's Syndrome  
Association**

A Registered Charity No. 1061474



# People with Down's syndrome

*Your Questions Answered*

## What is Down's syndrome?

*"Being a person with Down's syndrome makes me proud. I am a person to make a difference to a lot of people. That's me. We may find things difficult, everybody does. We should tell people about Down's syndrome – the more people, the better. Being a person with Down's syndrome I can do anything in life. We may need help (to do the things we want to do in life) ... It is good to see people with Down's syndrome achieving their dreams. That's my dream."*

Kate Powell

Down's syndrome is caused by the presence of an extra chromosome in the body's cells. In the majority of cases, Down's syndrome is not an inherited condition. It usually occurs because of a chance happening at the time of conception.

About one baby in every thousand in the United Kingdom is born with Down's syndrome. There are approximately 40,000 people with Down's syndrome living in the United Kingdom.

Everyone with Down's syndrome will have some degree of learning disability. Certain physical characteristics are more common among people with Down's syndrome, and they can be more prone to certain medical conditions. However, the most important thing to remember is that everyone with Down's syndrome is an individual, with their own strengths and weaknesses and personality traits that make them who they are.



## What causes Down's syndrome?

The human body is made up of cells. Each cell is like a tiny factory, which makes the materials needed for growth and maintenance of the body. All cells contain a nucleus in which genes are stored. Genes are grouped along rod-like structures called chromosomes.

Usually, the nucleus of each cell contains 23 pairs of chromosomes – 23 we inherit from our mother and 23 we inherit from our father. In people with Down's syndrome the cells contain 47 chromosomes, with an extra copy of chromosome 21. This additional genetic material results in Down's syndrome.

As yet we do not know what causes the presence of an extra chromosome 21. There is a definite link with advanced maternal age for reasons yet unknown. However many babies with Down's syndrome are born to women under the age of 35.




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Nothing done before or during pregnancy can cause Down's syndrome. It occurs in all races, social classes and in all countries throughout the world. Anyone can have a baby with Down's syndrome.

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## When was Down's syndrome discovered?

It is believed that people with Down's syndrome have always existed. However, it was not until 1866 that the English doctor, John Langdon Down, published the first comprehensive description of the condition, which subsequently took his name.

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In 1959 Professor Jerome Lejeune proved that Down's syndrome is caused by the presence of an extra copy of chromosome 21.

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## Are there different types of Down's syndrome?

There are three types of Down's syndrome:

**Trisomy 21** – in which all the cells have an extra chromosome 21.

About 94% of people with Down's syndrome will have this type.

**Translocation** – in which extra chromosome 21 material is attached to another chromosome. Around 4% of people with Down's syndrome have this type.

**Mosaic** – in which only some of the cells have an extra chromosome 21. About 2% of people with Down's syndrome have this type.

*The type of genetic variation that a person has does not significantly alter the effects of Down's syndrome.*





## How is Down's syndrome diagnosed?

In some cases, babies with Down's syndrome are identified before birth as a result of the mother having a diagnostic test. In most cases, it is discovered that a baby has Down's syndrome soon after birth.

The initial diagnosis is usually made because a doctor notices certain physical characteristics that are more common in people with Down's syndrome. The diagnosis is confirmed by analysis of a blood sample from the baby.

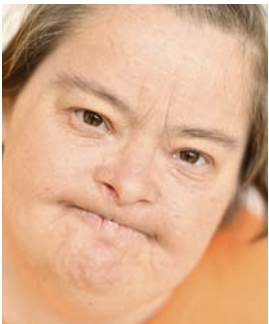
## What are people with Down's syndrome like?

People with Down's syndrome are all unique individuals with their own personalities, family backgrounds and preferences that make them who they are. Like most people, they learn at school, have interests, hobbies and talents, and have friends and relationships.

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There are certain physical characteristics that are more common in people with Down's syndrome. However, they will look more like members of their own family than other people with the condition.

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Everyone with Down's syndrome will have a learning disability. Having a learning disability means that it takes longer for a person to process information and to learn new skills and tasks. A learning disability will last throughout a person's life.

People with a learning disability may not learn things as quickly as other people and they may need more help and support to learn. This does not mean that people cannot learn new information and skills.

Sometimes people are told that people with Down's syndrome are always 'happy' or 'smiling'. This is not the case. People with Down's syndrome experience the same range of moods and emotions as anyone else.

## What should I do if I meet someone with Down's syndrome?

People sometimes feel nervous or unsure what to do when they first speak to someone with Down's syndrome. After they have met someone, people often wonder what they were so worried about!

When you meet someone for the first time, talk to him or her and get to know the person as you would with anyone else. You may need to check if the person understands what you are saying and explain it again in a different way if she or he doesn't seem to understand. Take the lead from the person and don't worry about 'getting it wrong'.

## Health and development

### What are the more common health conditions in people with Down's syndrome?

Certain health conditions are more common in people with Down's syndrome although not every person with Down's syndrome will experience these. All of the health conditions more common in people with Down's syndrome are seen in the general population and many people will lead a healthy lifestyle with the right support and health checks.



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Around half of babies with Down's syndrome are born with heart problems.

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Where children have a heart problem, it may be a relatively minor condition that needs monitoring, or it may be a more serious complication that means the child will need surgery. Screening from an early stage and timely interventions now ensure that for most people the outlook is good.

A significant number of people with Down's syndrome will have a hearing impairment. This can be temporary or permanent, and some people may wear a hearing aid. Everyone with Down's syndrome will have poor visual acuity. This means they will see the world differently, with less fine details, even when wearing glasses. It is therefore important that people receive regular hearing and eye checks.



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Some other common health conditions include thyroid function, immune system development, picking up coughs and colds more frequently and gastrointestinal conditions. For more information, please visit the DSA website.

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The Down's Syndrome Association together with the Down Syndrome Medical Interest Group have produced health care guidelines to assist families and health professionals to set up screening programmes so that health problems can be picked up early on and treated before they become more serious.

All new parents will be given an insert for their Personal Child Health Record (PCHR) which contains information about the basic minimum health checks that babies and children with Down's syndrome should receive.

It is important to bear in mind that advances and increased access to medical care mean that people with Down's syndrome are now living much longer than in the past, with some people living into their 60s and beyond.

*The DSA has a range of information and resources about health and wellbeing available on our website.*



## How does Down's syndrome affect development?

Children with Down's syndrome generally take longer to reach developmental milestones and they will need some additional support to learn new skills, as well as extra help when they go to school.

Just as with all children there is a great deal of individual variation in the age at which different skills develop, and the way the syndrome affects a person's development, learning and health varies widely.

You may have heard or read about 'Early Intervention' for children with Down's syndrome. Early intervention is an umbrella term for a collection of services that can help babies and toddlers by giving early support for them and their families, with a focus on enhancing development. Practitioners from different professions may engage with families to provide the support they need, for example, to promote play and learning and to support communication, speech and language.

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Children and adults with Down's syndrome can and do continue to learn throughout their lives just like the rest of the population. The level of support that a person with Down's syndrome needs as they grow older will be different from person to person.

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## Life today

### What is life like for people with Down's syndrome?

The quality of life, life expectancy and role in the community for people with Down's syndrome have gradually been transformed as education and support have improved. There are now more opportunities for people with Down's syndrome to lead the lives they want to.



If you want to read about the lives of people with Down's syndrome today, take a look at the Down2Earth magazine and our publication 'Celebrating our Lives'.

The Down2Earth magazine is written by and for people with Down's syndrome. You can download past copies from the 'For People with Down's syndrome' section of our website. You can also find other stories and videos on our website about people's lives.

#### Find out more

If you have a question about Down's syndrome, or would like more information, please take a look at the Down's Syndrome Association website.

### What is the correct terminology regarding people with Down's syndrome?

Down's syndrome is not a disease and therefore people with Down's syndrome do not "suffer", nor are they "victims" of their condition. Down's syndrome is only a part of the person; they should not be referred to as "a Down's" or "a Down's person". People with Down's syndrome are all unique individuals and should be acknowledged as a person first and foremost. It is important to think of the person first, e.g. John is 29 and has Down's syndrome.

You can also contact our Information Team on 0333 1212 300 or email [info@downs-syndrome.org.uk](mailto:info@downs-syndrome.org.uk).

#### Don't Say

suffers from OR is a victim of Down's syndrome

a Down's baby/person/child

retarded/mentally handicapped/backward/mental disability

disease/illness/handicap

the risk of a baby having Down's syndrome (in relation to pre-natal screening and probability assessments)

#### Do Say

has Down's syndrome

a person/baby/child with Down's syndrome or who has Down's syndrome

learning disability

condition OR genetic condition

the chance of a baby having Down's syndrome

The Down's Syndrome Association provides information and support on all aspects of living with Down's syndrome.

We also work to champion the rights of people with Down's syndrome, by campaigning for change and challenging discrimination.

A wide range of Down's Syndrome Association publications can be downloaded free of charge from our website.

## Contact us

## Down's Syndrome Association

### National Office

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[www.dsworkfit.org.uk](http://www.dsworkfit.org.uk)



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