



# Down's Syndrome

## **What is Down's Syndrome?**

A syndrome is a collection of signs or characteristics. The term Down's Syndrome came from the doctor who first described the condition in 1866, John Langdon Down.

Children and adults with Down's Syndrome will share many of their family's characteristics, and will resemble their parents, brothers and sisters. They will also have physical features shared with others with Down's Syndrome.

All individuals with Down's Syndrome have learning difficulties. This means they have greater difficulty learning than the majority of people their age.

It is important to remember that children with Down's Syndrome are all individuals with their own temperaments, likes and dislikes, strengths and weaknesses. The ability of children with Down's Syndrome to learn new skills and to take care of themselves varies widely, just as it does with all children. Some adults with Down's Syndrome are able to join the workforce and to live independently of their families in supported accommodation, while others need extensive support.

## **How common is Down's Syndrome?**

For every 1,000 babies born, one will have Down's Syndrome. About 600 babies are born with Down's Syndrome each year.

## **How does it occur?**

Down's Syndrome is a genetic condition caused by the presence of an extra chromosome. Chromosomes are tiny particles which carry the blueprint for all the characteristics we inherit. Normally there are 46 chromosomes in every cell; half come from the father and half from the mother. In a person with Down's Syndrome there is an extra chromosome, making 47 in all. This extra chromosome results in disruption to the growth of the developing baby. The extra chromosome can come from either the mother or the father, or can occur when the initial cell is dividing after conception.

There are three types of Down's Syndrome:

- Standard trisomy 21 accounts for 95% of cases of Down's Syndrome, is always an accident of nature and can happen to anyone:
- Approximately 1 in 100 people with Down's Syndrome have inherited the condition from their father or mother because of a genetic problem called translocation (this does not mean that either the father or mother themselves have Down's Syndrome):
- The third, rare type of Down's Syndrome is known as mosaic Down's Syndrome.

The risk of a mother having a baby with Down's Syndrome increases with age, particularly after 35 years. At 25 years the risk is 1 in 1,400, but by 45 years the risk is 1 in 30. The chance of parents with one child with Down's Syndrome having a second child with this condition can be greater than that of the general population, so parents of a child with Down's Syndrome are often advised to have genetic counselling before starting another pregnancy.

### Characteristics

Down's Syndrome is usually suspected soon after a baby is born because a doctor, nurse or parent recognises the characteristic features. Chromosome tests are then carried out to confirm the diagnosis.

The features which are often present are:

- Eyes that slant upwards and outwards, with a fold of skin between the lids at the inner corner:
- A head which is rather flat at the back and with a low hairline and often rather loose skin in that area:
- A rather flat face with a flattened bridge to the nose:
- A smaller than average mouth, coupled with a slightly larger tongue:
- Broad hands with short fingers, and a little finger that curves inwards. The palm may only have one crease across it:
- A deep cleft between the first and second toes:
- Reduced muscle tone causing floppiness (hypotonia):
- A below average weight and length at birth.

**But** any of these features can occur in people who **do not** have Down's Syndrome.

## Health

Many children with Down's Syndrome enjoy good health, and it is not unusual for people with Down's Syndrome to live to 40 or 60 years of age.

However, some medical conditions are common:

- 40% of babies have heart conditions at birth, half of which are serious and require surgery:
- More than 50% of children have hearing problems, and even more have problems with vision, and may need to use hearing aids and wear glasses:
- 30% of people with Down's Syndrome may develop thyroid disease:
- People with Down's Syndrome may be at greater risk of developing Alzheimer's disease:
- Minor complaints such as coughs, colds and dry skin are common.

But it is important to remember that many children with Down's Syndrome can be fit and healthy much of the time.

## Growth and development

Children with Down's Syndrome tend to be shorter than average. Many will gain weight easily (although, as with all children where this is a problem, weight can be controlled through diet and exercise). The bodies of children with Down's Syndrome mature in the same way as other children's, and they reach puberty in their early teens.

All children develop at their own rate, but the development of children with Down's Syndrome is likely to be slower than that of other children. A rough guide is that they will:

- Sit alone at 6 to 30 months:
- Walk at 1 to 4 years:
- Say their first word at 1 to 3 years:
- Be toilet trained at 2 to 7 years.

Programmes to help children develop are available for all children with disabilities, including those with Down's Syndrome. They may include:

- Physiotherapy to improve muscle tone and co-ordination:
- Occupational therapy to improve motor skills:
- Speech therapy:
- General development programmes such as Portage.

### **Support in the early days**

A paediatrician is usually responsible for telling parents that their child has Down's Syndrome. Many parents will feel shocked and distressed. Some may feel that they have 'lost' the child they were expecting, or may feel that they are unable to care for their child. They may be distressed by the way the child looks, and concerned about possible health problems. Some parents may want to discuss the possibility of fostering or adoption. A few parents may have been prepared for the fact that their child might have Down's Syndrome due to ante-natal testing.

The baby may have to spend time in a special care baby unit if there are health problems. This can also be very stressful for parents. Many babies will, however, be able to go home with their parents soon after the birth.

Once home, parents can expect support and information from the community midwife and health visitor.

### **Support as the child is growing up**

The health visitor will continue to visit and to keep an eye on the health of the child. The child may be seen by a paediatrician or at the Child Development Centre, where advice can be obtained from a range of professionals.

Children with Down's Syndrome can enjoy many of the same activities as other children, including attending toddler groups, playgroup and nursery. Some may attend ordinary groups, while some parents may choose to take their child to an Opportunity playgroup which includes children both with and without special needs, or a nursery attached to a special school.

Children with Down's Syndrome will usually receive a Statement of Special Educational Needs before or soon after they start school. This will help to make sure that their educational needs are assessed and understood and that the school they attend can

offer them the support they need. Many children with Down's Syndrome attend mainstream schools, while others are educated in special schools.

### National and local support groups

#### Down's Syndrome Association

This is a national organisation - membership is open to anyone with an interest in the condition, but full membership is restricted to parents of people with Down's Syndrome and adults with Down's Syndrome.

The Association offers help and support to families and carers of people with Down's Syndrome, and produces information on all aspects of the condition.

There is a network of parent-led support groups throughout England, Wales and Northern Ireland, and a 24-hour helpline so that parents can talk over any problems they have.

Each year the Association organises an annual Achievement Award to show the public just how much can be achieved by an individual with Down's Syndrome.

Contact: Down's Syndrome Association  
155 Mitcham Road  
London  
SW17 9PG  
020 8682 4001

Website: [www.dsa-uk.com](http://www.dsa-uk.com)

#### Shropshire Support Group

Contact: Sarah & Mike Sheppard  
01939 270477

Christine & William Dunne  
01694 771672

The Down Syndrome Educational Trust

Conducts original scientific research with practical outcomes, provides accurate information and advice, organises conferences and workshops, and offers advisory and consultancy services for families and professionals involved with people with Down's Syndrome.

Contact: The Down Syndrome Educational Trust  
The Sarah Duffen Centre  
Belmont Street  
Southsea  
Hampshire  
PO5 1NA  
023 9282 4261

Website: [www.downsed.org](http://www.downsed.org)