

## Down's Syndrome

A baby will have Down's Syndrome if it is born with an extra whole or part of chromosome 21, giving her 47 chromosomes instead of the usual 46. It is a genetic condition, and for the majority of people with Down's Syndrome there is no specific reason why the mutation has occurred: it is not the result of anything the parents did or did not do. The syndrome is named after Dr John Langdon Down who first described it in 1866. At present there is no treatment or cure for the condition, but advances in genetic manipulation may eventually provide answers.

Down's Syndrome occurs in around 1 out of every 1,000 births, in both girls and boys. It can affect anyone, regardless of race or background. It is said to be the most common cause of learning difficulties.

The extra chromosome can come from either the father's sperm or the mother's egg cells, or can occur just after conception. Women who conceive after they are 35 appear to be particularly susceptible to having a child with Down's, but the age of the father does not appear to have a similar effect. If a couple has one child with the syndrome, then their chances of having another are increased. Genetic counselling is advised. There are pre-natal tests which will be offered to prospective parents by their GP or health centre if there is any reason for concern. The most common test (at present) is the amniocentesis test, when a sample of the amniotic fluid, which surrounds the foetus in the woman's uterus, is assessed.

### Physical and mental characteristics

A child who has Down's Syndrome will be affected in both growth and development, but each child is an individual and will be different. Not all children with Down's will display all of the symptoms, and some children who appear to have the physical characteristics will not have Down's Syndrome. Although the child with Down's Syndrome will share some physical features with others who have the disorder, like any child she may also look like her mother, her father and her brothers and sisters. The child with Down's Syndrome will have some moderate learning difficulties.

### Some of the physical features of Down's Syndrome include:

- Low birth weight and length
- Slanting eyes
- Flat bridge to the nose giving the face a rather flat appearance
- Rather flat back to the head
- Low, somewhat uneven hairline at the neck
- Small mouth, but large tongue, causing it to protrude a little - training can minimise this
- Reduced muscle tone - improves with age
- Smaller than average height

### Other conditions which someone with Down's Syndrome may also have:

- Heart problems
- Hearing problems
- Thyroid disease later in life
- Weight problems
- Dry skin
- Coughs and colds

Developmental milestones will be reached on average some months or years later than is considered the norm. The children are generally very happy, fit and healthy. Some years ago people with Down's Syndrome often did not survive much past young adulthood, but many now live well into their 50's and beyond, and early thought and planning will ensure their adult lives are as satisfying as possible.

### Management Hints

- Do not be afraid to ask your GP, midwife, health visitor, social services, and independent voluntary organisations for whatever advice and practical help they can offer you
- A multi-disciplinary approach is advised and should include advice and intervention from, for example, physio-, occupational and speech and language therapists
- Provide a controlled diet and exercise plan. Children with Down's Syndrome do not grow as tall as other children, and they can easily put on weight. Your doctor and health visitor will be able to supply you with diet sheets, growth charts, etc
- Children with Down's Syndrome are quite capable of going to school and learning. Most will need a Statement of Special Educational Needs so that any extra resources they require can be provided
- In their teen years, an independent living skills programme should be an important component of their formal education to let them move on, when they are ready, to some form of sheltered living.

Teachers should be aware that, because of low muscle tone and developmental delays, children with Down's Syndrome will take longer than others to learn ordinary childhood skills such as:

- running, jumping, skipping, throw-and-catch
- doing up buttons, laces and buckles
- handwriting

They will also need regular hearing and sight tests. Always check that the child has understood what is expected of her by asking her to repeat what she has to do. Make sure she can see and hear you clearly. Inform your classroom teaching assistant of her difficulties; check regularly with the parents - they are your experts, and will know if their child is enjoying - or dreading - coming to school.

Both parents and teachers should encourage, praise, build confidence and self-esteem at all times: an ultimate goal of everyone should be a child who is as happy, independent, self-reliant and self-motivated as possible. She will probably know that she is different. Our concerns should be to reduce the negative impact of this for her, while acknowledging that we are all different, and to make sure that she can enjoy the same rights and privileges as everybody else.

## Other Useful Contacts:

**Down's Syndrome Association** Langdon Down Centre, 2a Langdon Park, Teddington TW11 9PS. They provide support and information for people with Downs Syndrome, families, carers and professionals. Their website has excellent information for teachers, as well as downloadable booklets for parents, grandparents and others.

**Web:** [www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk)

**Helpline:** 0845 230 0372

**Email:** [info@downs-syndrome.org.uk](mailto:info@downs-syndrome.org.uk)

**Down's Syndrome Scotland** 158/160 Balgreen Road, Edinburgh EH11 3AU They offer support and information, produce leaflets and have local branches.

**Info Line:** 0131 313 4225

**Web:** [www.dsscotland.org.uk](http://www.dsscotland.org.uk)

**Email:** [info@dsscotland.org.uk](mailto:info@dsscotland.org.uk)

**Down's Heart Group** Helpline: 0845 166 8061 PO Box 4260, Dunstable, Beds, LU6 2ZT. The above organisation offers one-to-one support and information relating to heart conditions associated with Down's.

**Web:** [www.dhg.org.uk](http://www.dhg.org.uk)

**Email:** [info@dhg.org.uk](mailto:info@dhg.org.uk)

## Reading

See also OAASIS information sheet '**Books – where to find them**'

Contact the above for their publication lists.

New books on childhood disorders are coming out faster than ever before, contact:

**Routledge Education** (member of the Taylor Francis Group)

**Tel:** 020 7017 6563 (Marketing)

**Web:** [www.routledgeeducation.com](http://www.routledgeeducation.com) (academic and research based) or [www.routledgegeteachers.com](http://www.routledgegeteachers.com) for teachers.

**Jessica Kingsley Publishers**

**Website:** [www.jkp.com](http://www.jkp.com)

**Tel:** 020 7833 2307

**Email:** [post@jkp.com](mailto:post@jkp.com)

**Sage Publications**

For all professionals working in schools and educational settings (includes Paul Chapman Publishing and Lucky Duck books).

**Web:** [www.sagepub.co.uk](http://www.sagepub.co.uk)

**Email:** [market@sagepub.co.uk](mailto:market@sagepub.co.uk)

The internet book shop [www.amazon.co.uk](http://www.amazon.co.uk)

## Internet Sites

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

The Contact a Family website has information and articles and can put you in touch with other parents.

[http://www.zen123082.zen.co.uk/uk\\_downs\\_syndrome/index.html](http://www.zen123082.zen.co.uk/uk_downs_syndrome/index.html)

- useful list of UK resources for parents with a child with Down's Syndrome, including both local and national groups.

Note: The OAASIS Information Sheets use 'he'/'his'/'him' rather than the cumbersome 'he / she'/'his / her'/'him / her'. No sexism is intended. The sheets are checked annually; please ensure you have the current version.



Cambian is the largest provider of specialist residential education and care for young people with Autism, Asperger Syndrome and other associated complex needs in the United Kingdom. Cambian is trusted by hundreds of parents and over 70 Local Education Authorities

[www.cambianeducation.com](http://www.cambianeducation.com)

## OAASIS publications

- SEN Information Sheets
- First Guide to ...
- Cards explaining 9 learning disabilities
- Legal advice Information Sheets
- SEN 'How to' guides

All OAASIS publications can be downloaded from [www.oaasis.co.uk](http://www.oaasis.co.uk)