

Down Syndrome



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0845 300 1818

What is Down Syndrome?

Down Syndrome was first identified in 1860 by Dr Landon Down, who noticed a number of people in institutions had similar physical characteristics.

Down syndrome is *not* a disease. People do *not* suffer from it, nor are they victims. Down Syndrome is a genetic condition. As the word syndrome implies, it is a collection of common characteristics that is evident not only physically, but also by a degree of learning disability. Down Syndrome is caused by the presence of an extra chromosome 21, hence the classification Trisomy 21. Chromosomes are in simple terms the 'building blocks' that give us our individual characteristics, for example, blue eyes, blonde hair etc. Similarly, people with Down Syndrome, who share this extra chromosome, also share common physical features.

It is important to remember that, however similar young people may look at first glance, they carry family likenesses that become obvious very quickly. It is vitally important to remember that the shared traits are *no* indication of future ability, or capability to learn.

Living with Down Syndrome

- Hearing - Many young people are prone to colds and infection. They have reduced nasal cavities, which contribute to this because of the increase in catarrh. This in turn can affect hearing that if left untreated can lead to problems with learning. It is therefore vital to ensure instructions are given clearly, simply and face to face.
- Communication – Young people with Down Syndrome generally have a small frame, the nasal

passages and the sinuses are smaller and the roof of the mouth is small and high. The tongue is often thicker which can result in difficulties in keeping it inside the mouth. This can affect breathing and articulation, which can lead to speech difficulties.

Expressive language is of vital importance to any young person and no less to one with Down Syndrome.

Great patience is required to ensure that there is no discouragement from attempting to speak. Always listen carefully and ensure that opportunities are given for attempting to answer the questions.

- Eyesight - Visual aids are of great assistance. Because of the small or absent bridge of the nose the young person may find it difficult to keep their glasses on.
- Mobility - Mobility is not generally a problem with young people with Down Syndrome unless they have multiple disabilities.

However, the muscle tone is often looser and this can lead to difficulties with co-ordination and gait. Jumping, hopping, skipping and running may be difficult, but they should not be discouraged from joining in games and activities.

- Diet - Most people with Down Syndrome have excellent appetites but obesity could cause serious problems, therefore a good diet should be encouraged. Some individuals have difficulty in chewing food and may need extra time to finish meals.
- Heart Problems - some young people with Down Syndrome have heart problems of varying

The Scout Information Centre

Gilwell Park Chingford London E4 7QW Tel + 44 (0)20 8433 7100 Fax + 44 (0)20 8433 7103 email info.centre@scout.org.uk www.scoutbase.org.uk

severity. Liaison with the parents or carers who will know that to do is essential.

- General - One of the most difficult misconceptions to live down for anyone with Down Syndrome is that they are always loveable and affectionate. Some are, some are not. Leaders must be aware of physical contact i.e. cuddles and take every precaution to avoid misinterpretation by others, sensitive discouragement is required.

All young people, on occasion, have annoying irritating habits, behave badly and are disobedient or easily distracted. Those with Down Syndrome are *no* different,

It must be explained that although the list of physical needs may seem daunting, not all young people with Down Syndrome have all the problems at once, if at all. Many will have learnt to deal with the problems in their own way. Learn from the individual by being with them and together you will be able to bring out the best. Obvious benefits will accrue from keeping in close contact with the family and keeping them informed of the young person's progress.

Support Organisations

Down's Syndrome Association

Langdon Down Centre
2a Langdon Park
Teddington
TW11 9PS
Telephone: 0845 230 0372
Fax: 0845 230 0373
Email: info@downs-syndrome.org.uk
Web site: <http://www.downs-syndrome.org.uk>

Northern Ireland office:

Graham House
Knockbracken Healthcare Park
Saintfield Road
Belfast
BT8 8BH
Telephone: 028 9070 4606
Fax: 028 9070 4075
Email: downs-syndrome@cinni.org

Wales office:

Suite 1
206 Whitechurch Road
Heath
Cardiff
South Glamorgan
CF4 3NB
Telephone: 029 2052 2511
Fax: 029 2052 2511
Email: dsa.wales@lineone.net

Down's Syndrome Scotland

158/160 Balgreen Road
Edinburgh
EH11 3AU
Telephone: 0131 313 4225
Fax: 0131 313 4285
Email: info@dsscotland.org.uk
Web site: <http://www.dsscotland.org.uk>

Down Syndrome Educational Trust

Sarah Duffen Centre
Belmont Street
Southsea
PO5 1NA
Telephone: 023 92 855330
Fax: 023 92 855320
Advice Line: 023 92 855 337 (Fridays 2pm – 3.30pm)
Email: enquiries@downsed.org
Web site: <http://www.downsed.org>
Web site: <http://www.down-syndrome.info>