

# DOWN SYNDROME

This fact sheet has been written by parent carers for parent carers.  
Clinical information has been approved by West Sussex practitioners.



## What is Down syndrome?

Down syndrome is a lifelong genetic condition. It is caused when a person inherits an extra chromosome (chromosome 21). People with Down syndrome tend to have some characteristic physical features, as well as having a level of learning disability, which may be mild, moderate or severe. But as with any condition, each person will be affected in differing ways. In the UK it is estimated that around 750 babies are born with Down syndrome every year.

## Characteristics of Down syndrome

When a baby is found to have certain physical characteristics associated with the condition, it may lead to further tests and a diagnosis of Down syndrome. In most cases, this tends to happen shortly after birth. There are many services that offer support to parents whose child has recently been diagnosed with Down syndrome – some contact details are listed overleaf.

There are some other health issues associated with Down syndrome and you will want to talk to your community paediatrician about this. However, it is important to remember that although there is an increased likelihood of your child having related health conditions, he or she may not be affected by them and most are routinely treatable. With the right support, the long-term prospect for the majority of children with Down syndrome is positive in terms of participation in school, work and community life.

## Types of Down syndrome

- **Full trisomy 21 Down syndrome** – the most common form of the condition accounting for almost 94 per cent of all cases.
- **Translocation Down syndrome** – a rarer form of the condition that affects about 4 per cent of people who are diagnosed with Down syndrome, where an extra piece of chromosome 21 attaches itself to other chromosomes.
- **Mosaic Down syndrome** – the least common form of the condition accounting for just 2 per cent of cases, where only some cells have an extra copy of chromosome 21.

## Types of treatment

There is no 'cure' for Down syndrome, but there are a number of therapies and interventions that can help people with the condition to lead a full life:

- **Audiology and Ophthalmology** – regular assessments with an Audiologist (hearing) and an Ophthalmologist (sight) are important as people with Down syndrome are more at risk of hearing loss and sight problems.
- **Cardiology** – regular check ups with a cardiologist may be advised as a precautionary measure, as people with Down syndrome have a slightly higher risk of heart problems.
- **Diet** – children and adults with Down syndrome can be more susceptible to weight gain. A dietician can advise on any adjustments that may need to be made.
- **Early Intervention** – early intervention programmes have shown to be effective in helping all children with learning difficulties. A home-based package of support in education, speech therapy and physiotherapy will help maximise your child's development.
- **Occupational Therapy (OT)** – can help your child develop their hand skills and can identify solutions



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to help your child develop their independence with every day tasks such as dressing and eating and drinking.

- **Physiotherapy** – important intervention to help a child develop and maximise their range of movement and posture.
- **Speech and Language Therapy (SALT)** – specialist support provided by a therapist to help build language and communications skills.

### Ask about

- **Chichester Down Syndrome Support Group** – support group for parents and families of children and adults with Down syndrome. Also holds monthly coffee mornings. Tel: **Jessica Craft** on: **07500 775596**, email: **sussexrose@hotmail.co.uk**, or contact **Kath Lake** on **07795 595675**. Go to: **www.chichesterdownsyndrome.org.uk**.
- **Child Disability Service** – a social work service for children and young people with severe and/or complex disabilities, it works with families and other agencies to ensure they get the right support. Call: **01403 229888** or email: **cdt@westsussex.gcsx.gov.uk**. Please note that some children may be referred on to the MASH (see contact details below).
- **Compass Card West Sussex** – a free leisure discount card for 0 to 25 year olds with SEND, which is run by Amaze. Find out more at: **www.amazebrighton.org.uk** or by calling: **0300 123 9186**.
- **Down Syndrome OK** – parent-led charity with information and support to families in Surrey, Sussex and South London. Visit: **www.downsyndromeok.org.uk**.
- **Independent Support** – Amaze's Independent Supporters provide advice and support to parent carers and young people applying for or transferring to an EHC Plan in Sussex. For Sussex Independent Support, call: **0300 123 7782**.
- **MASH** – support from health and social care. If your child is under 18, call the MASH, tel: **01403 229888**, email: **MASH@westsussex.gcsx.gov.uk**. For over 18s call the Adult Social CarePoint: **01243 642121**, or email: **socialcare@westsussex.gov.uk**.
- **Portage** – a home-based educational programme tailored to a child's individual needs. Available to very young children. **Chichester: 01243 536182, Crawley: 01293 572480, Horsham and Mid-Sussex: 01444 243150, Worthing: 01903 242558**.
- **Worthing Kids & Dapper Snapper** – Worthing-based charity who have strong connections with families of children with Down syndrome. They run a number of projects and services including drop-ins for parents and children, a youth club and swim school. Visit: **www.wkds.org**, call: **07570 768893** or email: **info@wkds.org** for more information.
- **Other resources** – the **Ashdown Club**, Worthing: **01903 528607**; **Kangaroos**, Haywards Heath: **01444 459108**; **PACSO**, Chichester: **01243 533353**; **Springboard Project**, Crawley: **01293 531963**, **Horsham: 01403 218888**.

### Further reading and useful links

- **Making Sense of it All** – our handy parent/carer guide contains information and advice on benefits, support for your child at school, getting help from social services and accessing social & leisure activities – **www.reachingfamilies.org.uk**.
- **Disability Living Allowance (DLA)** – your child may qualify for DLA, a state benefit that will help with their care. For further information visit: **www.gov.uk/dla-disability-living-allowance-benefit/overview**.
- **Down's Syndrome Association: www.downs-syndrome.org.uk**.
- **National Deaf Children's Society (NDCS)** – has information about Down syndrome and hearing loss. Go to: **http://www.ndcs.org.uk** and click on 'Family Support' or call their helpline: **0808 800 8880**.
- **West Sussex Local Offer** – go to **https://westsussex.local-offer.org** and search for 'Down Syndrome'.

