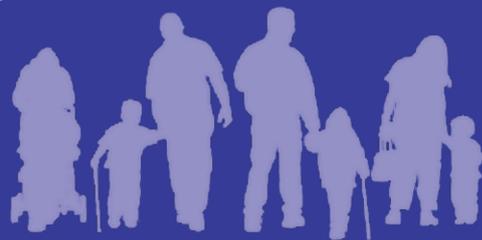


DOWN SYNDROME

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 have some level of learning disability, which may be mild, moderate or severe. As with any condition, this will be different for every person. 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** – this is the most common – about 94 per cent of people diagnosed with Down syndrome have this form.
- **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

Down syndrome is a lifelong condition. 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 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.





DOWN SYNDROME

Ask About

- **Chichester Down Syndrome Support Group** – support group for parents and families of children and adults with Down syndrome. Tel: **07500 775596**, email: **cdssgwelcome@gmail.com**. Go to: **<https://chichesterdownsyndrome.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/disability-living-allowance-children**.
- **Down Syndrome OK** – parent-led charity with information and support to families in Surrey, Sussex and South London. Visit: **<http://downsyndromeok.org.uk>**.
- **Facebook support groups** – T21 Brighton and Hove: An inclusive group for parents and carers of children & young people with Trisomy 21 (Down Syndrome); Worthing Down's Syndrome Group provides discussion and support for parents local to Worthing; Reaching Families.
- **Portage** – a home-based educational programme tailored to a child's individual needs. Available to very young children. Crawley and East Grinstead: **01293 572480**, Chichester and Horsham: **01243 536182**, Mid Sussex: **01444 243150**, Worthing: **01903 242558**.
- **Reaching Families** – provides training, information & other fact sheets related to this topic. We also offer benefits advice, peer support, a Facebook group & handbook (see below) for parent carers of children & young people with SEND in West Sussex: See: **www.reachingfamilies.org.uk**.
- **Sensory Toys** – sensory toys are available for loan through local family hubs and libraries. Go to: **www.westsussex.gov.uk/education-children-and-families/support-for-families/toy-libraries**.
- **West Sussex Children's Services** – support from health and social care. If your child is under 18, contact the Integrated Front Door (IFD) for West Sussex Children's Services. Tel: **01403 229900** or email: **WSChildrenservices@westsussex.gov.uk**. The IFD is also an entry point for the Children with Disabilities (social care) service for children & young people with severe and/or complex disabilities. Eligibility criteria apply – See: **<https://westsussex.local-offer.org/services/265>**. For over 18s call the Adults' CarePoint: **01243 642121**, or email: **socialcare@westsussex.gov.uk**.

Further reading and useful links

- ***Making Sense of it All: From Birth to Adulthood*** – Reaching Families' handbook for parent carers of children and young people with SEND in West Sussex. This provides essential information on money matters, including claiming DLA and PIP, as well as social care, health, leisure, travel, education and employment. Go to: **www.reachingfamilies.org.uk/guides.html**.
- **Down's Syndrome Association** - **www.downs-syndrome.org.uk**. Helpline: **0333 1212 300**.
- **National Deaf Children's Society (NDCS)** – has information about Down syndrome and hearing loss. Go to **www.ndcs.org.uk** or call their helpline: **0808 800 8880**.
- **NHS Health A-Z** has information on this condition at: **www.nhs.uk/conditions/downs-syndrome**.
- **West Sussex Libraries** – For books on this topic available to borrow for free, go to: **<https://arena.westsussex.gov.uk/welcome>** and search the library catalogue for 'Down syndrome'.
- **West Sussex Local Offer** – go to **<https://westsussex.local-offer.org>** for local services, support and details of Short Breaks providers for children & young people aged 0 - 25 years with SEND.

