

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.





DOWN SYNDROME

- **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 and monthly coffee mornings for parents and families of children and adults with Down syndrome. Tel: Jessica Archer on: **07500 775596**, email: sussexrose@hotmail.co.uk. Go to: <https://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. Information can be found via the local offer website: <https://westsussex.local-offer.org/services/265-child-disability-teams-lifelong-services-social-care> or families should call the Integrated Front Door (IFD) for West Sussex Children Services on **01403 229900** or complete the online referral: www.westsussex.gov.uk/Raiseaconcernaboutachild.
- **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.compasscard.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: <http://downsyndromeok.org.uk>.
- **Home start** – support for parents with at least one child under five. For more information see: www.home-start.org.uk.
- **Portage** – a home-based educational programme tailored to a child's individual needs. Available to very young children. Chichester: **01243 536182**; Crawley and East Grinstead: **01293 572480**; Horsham: **01243 536182**; Mid-Sussex: **01444 243150**; Worthing: **01903 242558**.
- **Sensory toys** – available for parents and carers to borrow from a number of children and family centres and some libraries. See: www.westsussex.gov.uk/education-children-and-families/support-for-families/toy-libraries
- **Short Breaks for Disabled Children** – commissions holiday clubs, after school clubs, buddy schemes and short breaks at home or in the community. Tel: **0330 222 2562** or email: SENDCommissioningTeam@westsussex.gov.uk.
- **T21 Brighton and Hove** (can be found on Facebook) - T21 Brighton & Hove A friendly and inclusive group for parents and carers of children AND young people with Trisomy 21 (Down Syndrome).
- **West Sussex Children Services** – support from health and social care. If your child is under 18, call the Integrated Front Door (IFD) for West Sussex Children Services, tel: **01403 229888** or email: WSChildrenservices@westsussex.gov.uk. For over 18s call the **Adults' CarePoint**: **01243 642121**, or email: socialcare@westsussex.gov.uk.
- **Worthing Down's Syndrome Group** (can be found on Facebook) - A discussion and support group for parents and carers of children or young people with Down's Syndrome local to Worthing.
- **Other resources** – the Ashdown club, Worthing: **01903 528607**; Kangaroos, Haywards Heath: **01444 459108**; PACSO, Chichester: **01243 533353**; Springboard Project, 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/disability-living-allowance-children.
- **Down's Syndrome Association**: www.downs-syndrome.org.uk or call their 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**.
- **West Sussex Local Offer** – go to westsussex.local-offer.org and search for 'Down Syndrome'.

