

DOWN SYNDROME

This fact sheet has been written by parent carers for parent carers



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 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 cautionary 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 skills and identify solutions to help your child develop their independence with daily tasks such as dressing, eating and drinking.



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- **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

- **Amaze SENDIASS** – the **Special Educational Needs and Disability Information, Advice and Support Service (SENDIASS)** offers impartial, confidential advice on anything to do with special educational needs and disabilities for 0 to 25 year olds, including education, health, and social care. Parents, carers, children and young people under 25 with SEND living in Brighton & Hove or East Sussex can use the service. Email sendiass@amazesussex.org.uk or call **01273 772289**. To find out more visit our website at amazesussex.org.uk
- **Compass Card** – a free leisure discount card administered by Amaze for 0 to 25 year olds with SEND who are registered on the compass. Go to: www.compasscard.org.uk, email Amaze at: compass@amazesussex.co.uk or call: **01273 772289** (Brighton & Hove) or **0300 123 9186** (West Sussex).
- **Disability Living Allowance (DLA)** – if your child's care or mobility needs are significantly greater than the needs of their peers you may be able to claim DLA for them. Visit www.gov.uk and search for DLA. Amaze can also give you advice and support with making a claim. Call our helpline: **01273 772289** or visit our website: amazesussex.org.uk
- **Parent support groups** – there are many parent-led groups for children with disabilities in Brighton & Hove. Some are for all children with SEND and some for children with specific disabilities. See a full list of local groups at: amazesussex.org.uk/parent-carers/info-advice-parent-carers/survival-strategies/parent-support-groups
- **Seaside View Child Development Centre** – this is where many children are diagnosed and where health professionals such as paediatricians and occupational therapists work together to support and treat your child. Assessments will usually be via a health or education professional but you can contact Seaside View directly on: **01273 265780**.
- **T21 Brighton & Hove** – a support group for children and young people with Down syndrome and their families. For more information, contact Pippa on **07930 418298**, email pippahodge@icloud.com or go to Facebook and search for 'T21 Brighton & Hove'.

Further reading and useful links

- **Down's Syndrome Association** – go to their website, www.downs-syndrome.org.uk or call their helpline: **0333 1212 300**.
- **Down Syndrome Education International** – www.dseinternational.org.
- **Local Offer** – the local authority's online listing of all the services and support that are available to families with children with SEND in the area. Visit new.brighton-hove.gov.uk/special-educational-needs-and-disabilities
- **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**.

