

CEREBRAL PALSY

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



What is cerebral palsy?

Cerebral palsy is a general term used to describe a group of conditions affecting a person's movement, posture and co-ordination. It is caused by damage to the brain, mostly before, during or shortly after birth. Around 1 in 400 children in the UK have cerebral palsy.

Characteristics of cerebral palsy

Cerebral palsy can affect people in a wide range of ways. Some people have very mild forms, whereas others have more severe forms of the condition. No two people are affected in exactly the same way. Cerebral palsy can cause problems with sitting, standing and walking, with controlling or relaxing muscles, and with fine motor skills.

Some people who have cerebral palsy may have other conditions such as epilepsy, scoliosis (curvature of the spine), hearing or visual impairments or learning difficulties. Cerebral palsy is not a progressive condition, which means it does not get worse as your child gets older. But over time the physical challenges of the condition can cause wear and tear on the body.

Types of cerebral palsy

- **Spastic cerebral palsy** – the most common form. This is characterised by stiff muscles, which might be affected in different parts of the body. Hemiplegia affects one side; diplegia mainly affects the legs and quadriplegia affects the upper and lower body.
- **Athetoid or Dyskinetic cerebral palsy** – a less common form of the condition characterised by random and uncontrolled body movements or sudden involuntary spasms.
- **Ataxic cerebral palsy** – another rare form of the condition characterised by problems with balance, depth perception and fine motor skills
- **Mixed cerebral palsy** – type of the condition characterised by a mixture of the above types, most commonly stiff muscles and involuntary movements.

Types of treatment

There is no 'cure' for cerebral palsy but there are a number of therapies available that can improve movement, co-ordination and independence, including:

- **Bobath therapy** – intense form of physiotherapy which seeks to maximise a child's ability to move, sit and function as normally as possible.
- **Conductive education** – a method of teaching children with motor difficulties like cerebral palsy how to maximise mobility and independence.
- **Medication** – a number of medicines can help children who are in pain or discomfort.
- **Occupational Therapy (OT)** – can help your child gain independence and master everyday tasks such as eating and going to the toilet.
- **Orthopaedic surgery** – sometimes used to correct bones and joints. May involve lengthening muscles that are too short.
- **Physiotherapy** – a vital component of any therapy for cerebral palsy, it prevents muscles from contracting or weakening and promotes independence.



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- **Selective Dorzal Rhizotomy (SDR)** – specialist surgery not suitable in all cases. Some nerve endings in the lower spinal column are cut to reduce muscle stiffness and aid mobility.
- **Speech and Language Therapy (SALT)** – can be useful in helping children speak or develop alternative means of communicating (for example, sign language).

Ask about

- **Chailey Heritage Clinical Services** – a range of services and therapies available to children with complex physical or neurological physical disabilities. Tel: **01825 722112**.
- **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**.
- **Dame Vera Lynn Children's Charity** – regional centre of excellence in the delivery of conductive education to parents and children with cerebral palsy. Tel: **01403 782294** or email: info@dvlcc.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**.
- **Sensory Toys** – available for parents and carers to borrow from a number of children and family centres. See: <https://www.westsussex.gov.uk/education-children-and-families/childcare-and-early-education/toy-libraries>.
- **Worthing Scope** – runs Super Scopers, a group for families of children with additional physical needs, as well as a grants scheme for children and adults with cerebral palsy. Visit www.worthingscope.org.uk. For information contact their community liaison worker, Jo McCaffrey, tel: **01903 821437** or email: joanna@worthingscope.org.uk.
- Other resources – the Ashdown Club, Worthing: **01903 528607**; Kangaroos, Haywards Heath: **01444 459108**; PACSO, Chichester: **01243 533353**; Scope Inclusion South East: **01273 695675**; 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.
- **Cerebral Palsy information website** – go to: www.cerebralpalsy.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 and search for 'DLA'.
- **Scope** – www.scope.org.uk or call the helpline: **0808 800 3333**.
- **West Sussex Local Offer** – go to <https://westsussex.local-offer.org>.

