Reaching Families FACT SHEET Updated October 2023

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 lifelong conditions affecting a person's movement, posture and co-ordination. It is caused by damage to the brain 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.
- **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).



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Ask About

- Chailey Heritage Clinical Services a range of services and therapies available to children with complex physical or neurological physical disabilities. Email: sc-tr.chaileyenquiries@nhs.net, Tel: 01825 722112.
- **Dame Vera Lynn Children's Charity** early intervention and support to under fives with cerebral palsy and other motor learning impairments. Tel: **01444 473274** or email: **info@dvlcc.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**.
- **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**.
- Cerebral Palsy information website go to: www.cerebralpalsy.org.uk.
- NHS Health A-Z has a section devoted to cerebral palsy. Go to: www.nhs.uk/conditions/cerebral-palsy.
- Scope The disability equality charity, www.scope.org.uk or call the helpline: 0808 800 3333.
- **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 'cerebral palsy'.
- 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.



