

Cerebral Palsy

A Guide for MPs & their Parliamentary Caseworkers

What is cerebral palsy?

Cerebral palsy is the name given to a group of lifelong conditions that affect movement and co-ordination caused by abnormal development or damage to the parts of the brain that control balance, movement and posture before, during or soon after birth. There is a large variance in the severity of the condition and, whilst there is currently no cure for cerebral palsy, treatments and interventions are available to assist those with it to have as independent a life as possible.

What are the signs that a child may have cerebral palsy?

Signs that a child may have cerebral palsy include:

- Unusual fidgety movements.
- Abnormalities of movement or tone, such as floppiness or stiffness or a combination of these.
- Feeding and swallowing difficulties.
- Abnormal motor development, including late crawling, head control and rolling.
- A range of other problems, such as communication, learning and vision difficulties.

Which 'milestones' can parents look out for?

Symptoms of cerebral palsy are not usually easily identifiable at birth, but become noticeable during the first three years of a child's life. Every child is different and develops at different rates, but medical professionals have identified some early indicators that a child may have cerebral palsy, including:

- 8 Months - Not sitting
- 1 Year - Not actively using both hands
- 18 months - Not walking

It should be noted that these are merely indicators, and there may be other reasons for delay in development.



How should I advise a constituent whose child has, or is suspected of having, cerebral palsy?

- A good place to start is always to signpost to the constituent details of the National Institute for Health & Care Excellence's guidelines which can be found here: www.nice.org.uk/guidance/ng62
- If your constituent is concerned that their child may have cerebral palsy, you should advise them to speak to their GP, and/or request an assessment for an Education, Health and Care Plan from their local authority as soon as possible, so as to ensure that all necessary care and intervention can be specified and entitlements quantified. This assessment can be done from birth and at any point in their child's development.
- Your constituent should be able to find their local authority's 'Local Offer' online, with details of local services, specialist providers and education establishments for children with cerebral palsy and/or other special education needs. These often also contain details of local support groups for parents.
- Local Children's Centres, Children with Disabilities Teams and Health Visitors should also be able to signpost and refer to other relevant support agencies.
- Your constituent may seek medical and therapeutic advice from: a paediatrician, paediatric occupational therapist, speech and language therapist or physiotherapist and tests can be undertaken on their child to assess whether they have the condition. Constituents should request that a General Movement Assessment (PrechtI) is carried out as soon as possible, as this assessment is a good indicator of potential developmental difficulties with movement.
- Treatments can include: occupational therapy, physiotherapy and speech and language therapy, medication and, in some cases, surgery.
- Centres offering Conductive Education programmes may also be able to provide input.
- If your constituent experiences delay or difficulties, they should consider contacting the Independent Parental Special Education Service on: **01799 582030**. This service provides free advice, information and support to parents of children and young people with special educational needs and disabilities.
- Under certain circumstances, parents may consider taking legal advice regarding entitlements if they feel their child's education and care needs are not adequately met.

What kind of a future do children with cerebral palsy have?

This is a question we are asked a lot. Cerebral palsy affects each person differently and it is very difficult to predict what the outlook will be for any child. Generally, most children with cerebral palsy live into adult life, and some can live for many decades. Whilst the condition can limit activities and independence, many go on to live full, independent lives.

It is worth noting that, whilst cerebral palsy can mean a lot of strain on the body, causing problems such as painful joints later in life, the initial brain damage is not thought to deteriorate over time. It is also advisable that those who do live independently may be prone to mental health issues, such as depression, due to the stress caused by strain on the body.

Many children with cerebral palsy attend mainstream schools with varying levels of support, but some may benefit from attending a special school, depending on the severity of their condition.

Who are Action Cerebral Palsy?

Action Cerebral Palsy is a UK charity which works with a range of stakeholders to improve outcomes for children and young people with cerebral palsies and their families.

Our vision is that every child and young person in the UK with cerebral palsies is able to access, from birth onwards, the best possible care, education and support which meets their complex and changing needs.

Our mission is to work towards improving political, professional and public awareness of the issues facing children and young people with cerebral palsies and we are committed to facilitating the development of models of best practice at international, national and local levels. If you would like to read more about our work, please visit our website at: www.actioncp.org

Who do I contact for more information?

We are always happy to meet with Members of Parliament to brief them on the work that Action Cerebral Palsy undertakes and to talk about how you can help to improve the lives of your constituents who have cerebral palsy.

If you would like to meet with our team, please contact Paul Church from The Whitehouse Consultancy at: actioncp@whitehouseconsulting.co.uk

