

What Is Hemiplegia?

Information resources

What is hemiplegia?

This leaflet aims to provide an overview of hemiplegia, the impacts it may have on a child and the support available from HemiHelp.

Childhood hemiplegia (sometimes called hemiparesis) is a condition that affects one side of the body (Greek 'hemi' = half). We talk about a right or left hemiplegia, depending on the side affected. It is caused by injury to parts of the brain that control movements of the limbs, trunk, face, etc. This may happen before, during or soon after birth, when it is known as **congenital hemiplegia**, or later in childhood as a result of injury or illness, in which case it is called **acquired hemiplegia**. Generally, injury to the left side of the brain will cause a right hemiplegia and injury to the right side a left hemiplegia.

Hemiplegia is a relatively common condition, affecting up to one child in 1,000. About 80% of cases are congenital, and 20% acquired.

You may also be told that hemiplegia is a form of cerebral palsy, a descriptive name for a wider group of conditions in which movement and posture are affected owing to injury to the brain. These conditions are lifelong and non-progressive i.e. they do not get worse, but they may look different over time, partly because the child is growing and developing.

How does hemiplegia occur?

The causes of congenital hemiplegia are mostly unknown, and usually parents only become aware of their child's hemiplegia during infancy or early childhood as the child's difficulty with movement on one side gradually becomes obvious. There is a higher risk in very premature babies and with multiple pregnancies, and it is unclear whether a difficult birth may be an occasional factor. But in most cases, the injury occurs at some point during pregnancy, and researchers have as yet been unable to isolate any contributory factors. However, some studies suggest that there could be an increased risk in communities where marriage between close relatives is common. Parents often worry that they may be somehow to blame, but this is not the case as it would appear to be mostly a matter of chance.

Acquired hemiplegia results from damage to the brain during childhood. The most common cause is a stroke (when a bleed or blood clot damages part of the brain), but it can also result from a head injury or infection.



What are the effects of hemiplegia?

It is difficult to generalise: hemiplegia affects each child differently. The most obvious result is a varying degree of weakness, stiffness (spasticity) and lack of control in the affected side of the body, rather like the effects of a stroke. In one child this may be very obvious (he or she may have little use of one hand, may limp or have poor balance); in another child it will be so slight that it only shows when attempting specific physical activities.

What can be done to help?

Hemiplegia cannot be cured, but a lot can be done to minimise its effects and help children achieve their potential. Your child, once diagnosed, will probably be referred to a Child Development Centre (CDC) or the children's department of your local or regional hospital. A paediatrician and therapists, who work as part of a wider network of professionals including paediatric neurologists and orthopaedic and neurosurgeons, will work in partnership with you to develop his or her abilities.

“Understanding hemiplegia and knowing how you can help your child achieve his or her potential is vital.”

Parent of a child with hemiplegia

The immature brain is very flexible, and some of the functions of the damaged area can be taken over by undamaged parts of the brain in a process known as neuroplasticity. An adult, whose brain pathways are already organised, has much

less neuroplasticity and so after a stroke may lose very specific functions, depending on which part of the brain was affected. In contrast, which area of the brain was damaged and which side of the body is affected makes relatively little difference in children and young people with hemiplegia.

Your child's management will probably be based on a multidisciplinary approach, involving physiotherapy, occupational therapy, and possibly speech therapy where required. A physiotherapist and often an occupational therapist will work closely with each other and with parents or carers, to agree a programme of management with specific goals that are tailored to the child's development and needs. The aim will be to improve the child's participation in everyday activities e.g. play, feeding, dressing, school life. The therapists will work to develop the child's skills, assessing posture and providing muscle stretching, and possibly strengthening activities. This will help prevent possible secondary consequences of the condition such as pain or the development of contractures (abnormal shortening of the muscles).

Goals could include improving function so that the child can grasp an object with the affected hand, or walk better. They should take into account the child and parents/carers' views, the time and effort involved in carrying out therapy activities, the impact on the child and his/her family and how effective the activities might be.

A therapy programme will probably include training parents/carers, and later the child him/herself, to carry out exercises or techniques which they should continue to use at home, e.g. during dressing or

bathing, so that they become part of the child's everyday life. The child's progress should be reviewed regularly to assess how well the therapy programme is working and consider whether there is a need for other treatments as well. These might include orthoses (devices, such as splints, fitted to the body to improve posture and/or function); drugs such as baclofen; Botulinum Toxin injections or orthopaedic surgery (for more information read our information sheets on therapies).

In general the child with hemiplegia should be treated as normally as possible. It is essential to involve the affected side in play and everyday activities, to make your child as "two-sided" as he or she can be. As they get older, many children and young people with hemiplegia can be encouraged to develop more use of their affected side through involvement in their chosen sports and hobbies.

Are there other problems associated with hemiplegia?

Yes, there may be. Because hemiplegia is caused by injury to the brain, it is not just motor pathways and motor development that may be affected. And despite the developing brain's effort to relocate functions to undamaged areas, approximately half the children do have additional diagnoses. Some of these are medical in nature, such as epilepsy, visual impairment or speech difficulties. Many children have less obvious additional challenges, such as perceptual problems, specific learning difficulties or emotional and behavioural problems (for more information read our information sheets

on the associated problems of hemiplegia). Each child should be fully assessed and regularly monitored to identify if any of these associated problems are present.

As the child grows these difficulties may become more frustrating and disabling than the more obvious physical ones, but with multidisciplinary management their effects on the child's life can be reduced.

What does the future hold?

In merely defining hemiplegia with its causes and effects we leave out perhaps the most important issue – the shock of diagnosis and the fear of the unknown. When a child is first diagnosed, it is often difficult for a doctor to predict whether problems will be mild or severe later in life. He or she will often adopt a 'wait and see' approach, which parents may find difficult to accept, since they may feel they are not being given all the facts. Understanding hemiplegia and knowing how you can help your child achieve his or her potential is vital. Make good use of the specialists dealing with your child's hemiplegia. Do ask them questions and make sure you understand their replies, if necessary asking them to repeat them using non- specialist terms.



Education

Most children and young people with hemiplegia attend mainstream schools, with or without some extra support. It is essential to give teachers as much information as possible about your child and how best to help him or her. HemiHelp has information materials for teachers in pre-school, primary and secondary education. These are of use not only to your child's teachers, but also to you as parents/carers, to help you support your child through his or her school years.

Support

Life can be difficult for children and young people with hemiplegia who want to do the same things as other children. They tire more easily and the effort involved in simple tasks can be considerable. They need all the help and encouragement you can give them. And you need support in your turn – ideally from other parents and carers who understand how you feel and with whom you can also share ideas and information.

You may find general support groups for disabled children and their families in your own area - your CDC, hospital or library should have information. Your local Sure Start children's centre may also have useful services for you and your child, such as Portage or a toy library. And you may want to join us - we are the national organisation for children and young people with hemiplegia and their families.

For more information about hemiplegia you can read *The Hemiplegia Handbook* - available at www.hemihelp.org.uk

What is HemiHelp?

HemiHelp was set up in 1990 by a small group of parents, and now has a thriving membership of families and professionals all over Britain. We provide information, support and events for children and adults with hemiplegia, their families and the professionals who support them.

"HemiHelp has made me into a fighter for my child, being able now to go anywhere and fight anyone for what I believe are his rights."

Parent of a child with hemiplegia



How can HemiHelp help you?

HemiHelp:

- has a Helpline staffed by trained volunteers who all have personal experience of hemiplegia
(0845 123 2372) - helpline@hemihelp.org.uk
- runs a UK-wide home visiting service
- has an extensive website with news and free information downloads
- has a Facebook group and Twitter feed
(@hemihelp)
- puts members in touch with others who have faced similar problems (available upon written request) and is developing a network of local groups
- has over 30 information sheets on various aspects of living with hemiplegia
- provides a resource booklet of useful names and addresses for members
- produces a quarterly magazine where members can share information and experience
- runs regular conferences and workshops around the UK for parents and professionals
- organises sports and activity days for children in different regions
- has a transition support service for young adults including employment workshops, 1:1 support, and work placements
- membership is from £10 a year and benefits include HemiHelp's quarterly magazine, access to our services and schemes and priority booking at HemiHelp events

We can provide references on the source material we used to write this information product. Please contact us at info@hemihelp.org.uk

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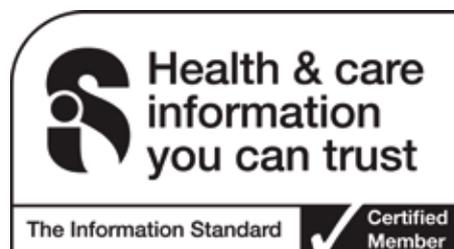
Website: www.hemihelp.org.uk

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