

Childhood hemiplegia (sometimes called hemiparesis) is a condition affecting 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 damage to some part of the brain, which may happen before, during or soon after birth, when it is known as congenital hemiplegia, or later in childhood, 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. Childhood hemiplegia is a relatively common condition, affecting up to one child in 1,000.

How does hemiplegia occur?

The causes of congenital hemiplegia are mostly unknown, and usually parents become aware of their child's hemiplegia gradually during his or her infancy. There is a higher risk in premature babies, and it is unclear whether a difficult birth may be an occasional factor. In most cases, however, the damage occurs during pregnancy, and researchers have as yet been unable to isolate any contributory factors - in other words, it would appear to be mostly a matter of chance. Parents often worry that they may be somehow to blame, but this is not the case. 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 an accident 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 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. 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, where therapists will work 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.

The immature brain is very flexible, and many of the functions of the damaged area can be taken over by undamaged parts of the brain. So whilst an adult who has a stroke loses very specific functions, depending on which part of the brain was affected, in children and young people with hemiplegia it makes relatively little difference to their general development which area of the brain was damaged. Your child's treatment will probably be based on a multitherapy approach, involving physiotherapy, occupational therapy, and speech therapy where necessary. Therapists work closely with each other and with parents and carers, teaching them exercises and techniques which they can continue to use at home, so that they become part of the child's everyday life. In general the child with hemiplegia should be treated as normally as possible.

However, it is essential to include the weaker 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 better use of their weaker 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 damage to the brain, it is not just 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. In the last few years it has also become clear that many children have less obvious additional problems, such as perceptual problems, specific learning difficulties or emotional and behavioural problems.

As the child grows these problems may become more frustrating and disabling than the more obvious physical ones, but with specialist treatment their effects on the child's life can be minimised.

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 that teachers be given 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 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 children with disabilities and their families in your own area - your CDC, hospital or library should have information. There may also be other useful local services such as a toy library for children and young people with special needs. And you may want to join the national organisation for children with hemiplegia and their families, **HemiHelp**.

See also HemiHelp's Information sheet **If you have just been told your child has hemiplegia**

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.

How can HemiHelp help you ?

HemiHelp:

- has a Helpline staffed by trained volunteers who all have personal experience of hemiplegia (0845 123 2372)
- runs a UK-wide home visiting service
- has an extensive website with a members' message board
- 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 leaflets 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 and in the Republic of Ireland for parents and professionals
- organises sports and activity days for members in different regions
- 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

I phoned the helpline in tears, spoke to lovely woman. Made us realise we're not alone.

L met other children with hemiplegia, both at the music workshop and the fun day. This helped her to realise she was not the only one with a funny hand.

HemiHelp has a range of information sheets for both families where there is a child with hemiplegia and adults with the condition, as well as a Useful Names and Addresses List to help you contact other organisations.

Hemiplegia is a neurological condition that weakens one side of the body and affects one child in a thousand. It is sometimes described as a form of cerebral palsy and the effects are similar to those of a stroke. **HemiHelp** is a membership organisation offering information and support to children and adults affected by hemiplegia and their families.

HemiHelp is happy for you to make photocopies of any part of this document.

Helpline: 0845 123 2372 (Mon-Fri 10am-1pm)

Admin: 0845 120 3713 • Fax: 0845 120 3723

Email: support@hemihelp.org.uk • Web: www.hemihelp.org.uk

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