Information pack for parents with a child with hemiplegia
This pack has been put together to give you an introduction to HemiHelp and the information and support we can give you. In this pack you will find:

- **What is hemiplegia** – an information sheet that gives an overview of hemiplegia and the impacts it may have on your child.
- **HemiHelp Services** – an overview of the services you will get as a HemiHelp member.
- **A family membership form** - Join HemiHelp to make sure you can access all these support services when you need them
- **Information about the Hemiplegia Handbook** - Contains all you need to know about living with hemiplegia; including sections on causes, treatments, education and family life. HemiHelp members receive a discount on this publication.

If you have any further questions about any of the information in this pack, please don’t hesitate to get in touch with the HemiHelp office by phone 0845 1203713 or email support@hemihelp.org.uk

You can also find lots more information on the HemiHelp website www.hemihelp.org.uk
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 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 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. Childhood hemiplegia is a relatively common condition, affecting up to one child in 1,000. About 80% of cases are congenital, and 20% acquired.

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. An adult who has a stroke loses 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 treatment will probably be based on a multidisciplinary approach, involving physiotherapy, occupational therapy, and speech therapy where necessary.
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.

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.

Many children have less obvious additional challenges, such as perceptual problems, specific learning difficulties or emotional and behavioural problems.

As the child grows these difficulties 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.

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.

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. Some children may also benefit from other forms of treatment such as orthoses (splints), Botulinum Toxin injections or orthopaedic surgery.

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.
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.

“What 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.”

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. 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 the national organisation for children and young people with hemiplegia and their families, HemiHelp

What is HemiHelp?

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 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
- 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
Join HemiHelp and become part of the community of families affected by hemiplegia. Here you can read about the different services we offer.

**Find information**

**Magazine**

Our quarterly magazine is full of the latest information and news. It gives families and professionals the opportunity to learn more about treatments, activities and tips about everyday life. Have you ever thought about writing an article for our magazine? We need your letters and articles to ensure that our magazine continues to provide our members with information, support and encouragement, so please email info@hemihelp.org.uk NB to receive the Magazine you must be a member of HemiHelp.

**Website and Forum**

Visit www.hemihelp.org.uk and check out our website for all our latest news and events. The site includes all our information sheets and a forum where parents, professionals and people with hemiplegia share their experiences with others.

**The Hemiplegia Handbook**

A practical guide for parents and professionals that provides an overview of living with hemiplegia with straightforward explanations of what can go wrong and the different management options, with clear descriptions of approaches to therapy. You can order a copy from our online shop www.hemihelp.org.uk/support_us/shop or by contacting the office on 0845 120 3713 / support@hemihelp.org.uk NB HemiHelp members will get a discount.

**Primary Schools Pack**

This pack contains information and guidance for teachers on a range of issues to help them support children with hemiplegia throughout primary school. It can be adapted and added to for the child’s individual needs. Parents may also find this pack useful. You can order your pack from our online shop www.hemihelp.org.uk/support_us/shop or by contacting the office on 0845 120 3713 / support@hemihelp.org.uk

**Public Affairs Updates**

A quarterly e-mail summary of news and policy changes relating to health, education, welfare and disability to be up-to-date on important issues that may affect you and to know how to have your say in the making of policy.
Get support

Helpline
Fully trained volunteers with personal experience of hemiplegia staff our Helpline Monday – Friday, 10am -1pm, during term time. Whether you would like to talk through some of your concerns with someone or need some information on any aspect of hemiplegia you can call our Helpline on 0845 123 2372 or email at helpline@hemihelp.org.uk

Family Back Up
We visit families at their homes if they need extra one-to-one practical and emotional support. Our trained visitors, who have personal experience of hemiplegia, also offer training for schools to help educational staff better understand hemiplegia and how to support pupils with the condition. NB you must be a member of HemiHelp to use this service. This service is available throughout England, Wales and Scotland.

Transition Service (for young adults 16-25)
We have a transition support service for young adults moving from education to employment, higher education and/or independent living that provides one-to-one support with a transition adviser, work placements and employment workshops. If you need some extra help with any of these aspects our mentoring scheme will match you up with an adult with hemiplegia for one-to-one and face-to-face personalised support over a longer period of time. Contact our Transition Adviser Karen Mount at karen@hemihelp.org.uk or 07754 103340 for more information.

Make contact with others

Fun Days
We hold hugely popular regional “Try It” activity days, where children with hemiplegia and their siblings can try out activities in a comfortable environment with their families around them. It is a great opportunity for your child and you to meet other families in a similar situation. And most importantly it is a chance to have some fun!

Conferences for parents
We run a regional conference programme for parents that provides the latest information on medical, educational and social aspects of living with hemiplegia. Parents/carers have the opportunity to meet other families in their region and share their experiences.

Conferences for professionals
Our regional conference programme for professionals aims to increase awareness about hemiplegia and share knowledge and best practice about the condition and associated therapies. A great opportunity to hear the latest developments in the management of hemiplegia and network with other professionals.
Creative workshops

We hold Creative Workshops across the country, where children and their families can get together in an informal, friendly atmosphere. Workshops may incorporate music and include trying out a range of different instruments. Drama and creative movement workshops are fun and engaging sessions for children of all ages.

Regional Reach Groups

Would you like to be able to meet and share your experiences with other families in your area? We have a number of groups getting together on a regular basis across the U.K. It is a great opportunity for you and your child(ren) to meet others and share experiences. NB to become part of your Regional Reach Group you must be a member of HemiHelp.

Pen Pals (for children 5+ yrs)

Would your child like a pen pal to share their experiences with another child or young person? Our pen pal scheme can put your child in touch with others of a similar age so they can share experiences and hopefully form lasting friendships. NB to take advantage of the Pen Pal Scheme you must be a member of HemiHelp.

Online social media

Follow us on Twitter @HemiHelp for daily updates about events, new opportunities and all the latest information relevant to you.

Join the HemiHelp Facebook Group to share tips, info and experiences with other parents or young adults with hemiplegia (type ‘HemiHelp’ into the search box and be part of a community of over 1,700 people!).

We also have a charity page you can “like” to get lots of useful information and links to stay up-to-date: www.facebook.com/pages/HemiHelp/320187584740175

Subscribe to the HemiHelp YouTube channel to see videos featuring children with hemiplegia and their parents www.youtube.com/hemihelp

Loan schemes

One-handed recorders

We have a stock of one-handed recorders that our members can borrow for a small fee. Find out more information here www.hemihelp.org.uk/about_us/what_we_do/hemihelp_loan_schemes

Support us

Volunteering and fundraising

Do you have any time to spare? Would you like to help improve the information and support provided to families affected by hemiplegia? Why not request a volunteer form or a fundraising pack? Please contact the HemiHelp office for further information on how you can help us: 0845 120 3713 or email the office at fundraising@hemihelp.org.uk
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. [www.hemihelp.org.uk/hemiplegia/publications](http://www.hemihelp.org.uk/hemiplegia/publications)

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

Please complete your membership form and return to

HemiHelp
6 Market Road
London
N7 9PW

Office Tel: 0845 120 3713
Helpline Tel: 0845 123 2372

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Please tick this box if you do not wish us to send you HemiHelp updates and event news by email (3 or 4 emails a year) □
## Child & Parent Details

- **Child’s First Name:**
- **Child’s Last Name:**
- **Date of Birth:** *(dd/mm/yyyy)*
- **Male or Female:** [M] [F]
- **Main Language:**
- **Ethnic Origin:**
- **Mother’s Name:**
- **Mother’s Occupation:**
- **Father’s Name:**
- **Father’s Occupation:**

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## Additional Information

### Which side is affected by hemiplegia?
- [ ] Left
- [x] Right

### Do you consider your child's hemiplegia to be:
- [ ] Mild
- [ ] Moderate
- [x] Severe

### Do you think your child has always had hemiplegia?
- [x] Yes
- [ ] No

*If no, how did your child acquire hemiplegia?*

### Age your child was diagnosed: ........ Years ........Months

### Does your child have any of the following associated difficulties?
- [ ] Speech
- [ ] Behavioural
- [ ] Visual
- [ ] Epilepsy
- [ ] Autistic Spectrum Disorder
- [ ] Other *(please give details)*

### Learning difficulties: Yes [ ] No [ ] Unknown [ ]

*(please indicate what level would best describe them)*
- [ ] Mild
- [ ] Moderate
- [ ] Severe

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We have included detailed questions on this form in order to understand how we can best help our members and to use anonymously in the form of funding application statistics. However, you are under no obligation to answer any questions which you feel uncomfortable giving answers.

If you need more room to answer any question, please continue on an additional sheet.
**Additional Information (continued)**

**Does your child attend a Hospital or Child Development Unit?**
- Yes ☐  No ☐  
  If yes, which one do they attend? …………………………………………………………………………………………………………………………………………………………………………………

**Do you think this Hospital/CDU is aware of HemiHelp?**
- Yes ☐  No ☐  
  If no, can we send you an information pack to pass on to them?  
- Yes ☐  No ☐  

**How did you hear about HemiHelp?**
- Physiotherapist ☐  Paediatrician ☐  GP ☐  
- Occupational Therapist ☐  Internet Search ☐  Another parent ☐  
- Another website ☐  ……………………………………………………………
- Another charity ☐  ……………………………………………………………
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