

# If you have just been told your child has hemiplegia

This leaflet has been put together to help you as you begin the long relationships you as a family will develop with the professionals who will play such an important role in your child's life.

You are reading this leaflet because you have been told your child has hemiplegia. You, your health visitor, your doctor or a nurse at the baby clinic may have first noticed that your child was only using one hand to explore their world. Or maybe your baby was late in sitting up or achieving some other developmental milestone and you were referred to hospital for further investigations.

When you heard the news that your child had hemiplegia, you were probably in a state of shock and confusion. You may feel okay one day but distraught the next. You might be feeling isolated from your family and friends, who may appear to be denying that there is any problem — after all, your child probably looks just like any other child of the same age. Even talking to your partner may not be easy, since you will each have different ways of dealing with your feelings about the situation.

Many parents have said that the process of coming to terms with the diagnosis is rather like bereavement, when parents mourn the child they might have had whilst adjusting to this 'different' child and an unknown future.

Everyone is entitled to grieve over their child's diagnosis but the best gift you can give yourselves and your child is to come to accept the disability and love your child for who they are

At first you don't know what to do, and it's devastating. You are waiting to feel normal again, actually what will happen is that you will develop a 'new normal'.

Telling parents that their child has a developmental problem is not easy for the professionals either. You may feel that you would like to know more, or on the other hand you may feel that you have been told more than you can take in all at once.

Don't panic. Help is there. Ask as many questions as you can from professionals and take in as much information as you can from them and from HemiHelp

Ask and ask again if you don't understand anything. Read the leaflets and don't think your child will be affected by everything. Everyone is different. Join a group so you have some support.

# What are the effects of hemiplegia?

#### The most common questions we are asked are:

#### Will my child walk and talk?

Nearly all children with hemiplegia will eventually walk and talk, although they may be a little later than their peers. Some children have other problems in addition to their hemiplegia which may have an impact on walking and speech.

#### Will the hemiplegia get worse?

No, although as your child grows you may find that it affects more aspects of their development than are immediately obvious. Nor will it get better. However, its effects can be minimised with appropriate therapy.

#### Will my child go to a mainstream nursery and school?

Most children with hemiplegia attend mainstream schools, with or without some extra support

# What next?

After diagnosis you will probably be referred to your local Child Development Centre (CDC) or Child Development Unit (CDU). For the early years of your child's life this will be your most important link to information and support. It is the place where your child will be offered appropriate therapy and all aspects of their development will be assessed and monitored.

Your GP will of course continue to deal with your child's normal, everyday ailments but more specialised care will be provided by paediatricians at the CDC/CDU.

Some CDCs/CDUs run parents' groups where you can meet and share experiences with other parents. They are also good sources of information about services and benefits.

Make sure you ask all the questions you want to; there is no need to feel awed by professionals - it is your child and you are the only one with an emotional investment

# **Physiotherapy**

In most cases, the first person to work with your child will be a paediatric physiotherapist, who will be concerned with problems relating to movement and posture. In the case of a child with hemiplegia, the specific aim of physiotherapy will be to make them as physically two-sided as possible. The physiotherapist may work on things like balance, weight-bearing on the affected side, with the aim of developing sensitivity in the affected hand. Your child's limbs may tend towards spasticity (increased muscle tone i.e. over-tightening of muscles), so the therapist will spend a lot of time stretching them. While your child is still very young, much of the therapy will be a question of doing things to them; as they grow, they will be encouraged to take a more active part in it themselves.

Make exercises fun and part of daily routine like teeth brushing.

We tried to do everything the physio told us but made it all lots of fun (and something he USUALLY! wanted to do). We feel this has given B the best start physically.

Of course, for maximum benefit, the exercises that the physiotherapist does with the child need to be practised every day, so an important part of their task is to teach you to do them at home, and also to integrate therapy techniques into everyday activities. You might, for example, encourage your child to reach with their affected hand when you are passing them toys or food, or remind them to use both hands when appropriate - holding a beaker, for instance.

Progress may seem slow, and you and your child will both get sick of the phrase 'both hands, please'! Try not to feel guilty if you seem to be getting nowhere — too much pushing can be counterproductive, and your child will work out for themselves whether a skill is useful or not.

Treatment may also include hydrotherapy (therapy in a special pool), since it is easier to exercise stiffer limbs in warm water.

The physiotherapist will also advise on special shoes or boots, or splints to help with standing and walking or with hand position. They can also tell you about specially adapted bikes and trikes.

# Occupational therapy

As children grow they acquire all sorts of **practical skills**. They learn self-help skills such as feeding and dressing themselves, using the potty and the toilet. Through play, they develop early learning skills - sorting objects, solving puzzles, drawing pictures etc.

Children with hemiplegia may take longer to acquire these skills, and this is where the occupational therapist (often shortened to OT) comes in.

The OT looks at your child's everyday life and devises ways of **minimising the effects of their hemiplegia**, both at home and at school.

This might mean changing their environment in some way — a special chair, cup or spoon can mean greater independence at mealtimes. Velcro fastenings might make dressing easier. And other bits of **specialised equipment** such as scissors and pens can also increase your child's independence and self-confidence (this is particularly important for left-handers).

The OT will advise you on **toys and activities** which will aid your child's development, both physically and cognitively. They might help hand eye co-ordination, for example, or encourage two-handed activities. Particular activities and toys might help the child develop the matching and sorting skills which will be important at school.

The OT is ideally placed to recognise **early signs** of difficulties which might later affect your child's school career. For example, some children with hemiplegia have problems with visual perception, i.e. how the brain organises the information coming in through the eyes. This might show as difficulty in, say, putting a puzzle together.

Other children have **visual field defects**, which means they cannot see what happens on one or both edges of their field of vision. Children's drawings are often a good way of discovering whether they have visual field defects. Although most children have their eyesight tested (visual acuity), most do not have their visual perception assessed. This is one of the roles of the paediatric OT, and of course the earlier problems like these are identified, the better.

The occupational therapist can come along to **pre-school or nursery** to advise staff how they can best help your child develop their potential. Other professionals that may need to be involved with your child include:

## Speech therapist

Speech therapy is concerned with every aspect of language. Speech therapists monitor both your child's understanding of language and their ability to use it in speech.

## Psychologist

A developmental or clinical psychologist will monitor and assess your child's cognitive development from time to time. They are particularly involved in assessing children before they go to nursery or school. Clinical psychologists are also helpful in dealing with problem behaviour.

# **Other Treatments**

Some children with hemiplegia may benefit from other forms of treatment. These include:

## Splinting

The physiotherapist or OT may suggest and design a splint to help keep your child's wrist, thumb or foot in its correct position.

#### Serial plastering

This works in much the same way as a splint to gradually move the affected limb into the correct position. The limb is usually plastered at regular intervals for several weeks at a time.

### Botulinum Toxin injections

These allow muscles to relax for a period of a few months, and when combined with other therapies such as splinting or serial casting and intensive physiotherapy they may have a lasting effect on a child's walking and posture.

#### ETA

If none of the above therapies are effective, the child may benefit from an operation to lengthen the Achilles tendon, enabling them to keep their heel on the floor.

# **Other Sources of Support and Information**

There are lots of local and national organisations that might be able to offer you help, advice and support. These include:

## • Portage Services <u>www.portage.org.uk</u>

Run by most local authorities. Portage workers are trained to work with parents and young children at home. Their role is to help the parents identify specific goals for their child and devise ways of achieving them. Parents can contact the LEA themselves or be referred by a health visitor or GP.

## Toy Libraries <u>www.natll.org.uk</u>

Provide an opportunity to borrow and try out a range of toys which might be useful. Specialist play advisors are sometimes available.

## National Disability Organisations

These organisations may well have groups in your area. There may also be local support groups for parents and carers. See HemiHelp's **Useful Names & Addresses** List.

#### Local Libraries

A good place to start. They may have a council one-stop shop providing information on all local services and state benefits. They may also offer Internet access and reference material.

## **Benefits**

Children with hemiplegia and their parents/carers may be able to access various benefits, tax credits and other financial help. See HemiHelp's **Benefits** information sheet for details.

Your child's hemiplegia will inevitably have an enormous effect on the whole family. Just as it is difficult for the professionals to predict how your child will develop, so will you be unable to predict how you are going to cope with all these new demands.

The best way to cope is to take each day as it comes and only take on as much as you can manage. You may feel that your whole life is given over to treatment and therapy of one sort or another, but you must take care not to become obsessed by this at the price of ordinary family life.

Remember, your child is a person, not a 'condition'. They need not just therapy, but ordinary play, stimulation and love.

Be patient, it may be a longer wait until each milestone is achieved, but there is a far greater sense of joy when it is reached.

Let them be a child first and a child with hemiplegia second.

Stay positive and your child will never stop surprising you.

HemiHelp has a wide range of information sheets on aspects of living with hemiplegia, as well as lists of **Equipment** and **Useful Names and Addresses**.

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

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