HemiHelp
For Children and Young People with Hemiplegia

nse The National Society for Epilepsy

An introduction to epilepsy for people with childhood hemiplegia

You may be reading this leaflet because your child or someone you know has hemiplegia. They may also have epilepsy, or you may have heard that epilepsy is common in people with hemiplegia. In this leaflet we look at what hemiplegia and epilepsy are, and why these conditions sometimes happen together.

Hemiplegia and epilepsy

Both hemiplegia and epilepsy are neurological conditions, which means they are conditions that are caused by something that goes wrong in the brain. Both conditions are relatively common, and epilepsy is common in people with hemiplegia. So why do the conditions sometimes happen together? To answer this, it is useful to know a bit about the brain and how it works.

The brain

Our brains are very complex, and control everything we do - our movement, consciousness, thoughts and emotions. The brain is made up of two halves, the left and right hemispheres. The right hemisphere controls the left side of our body, and the left hemisphere controls the right side of our body. Each hemisphere contains four different areas or lobes, and each lobe is responsible for something different. For example, the temporal lobe (at the side of the brain, above our ears) is responsible for our memory and emotions, and the occipital lobe (at the back of the brain) is responsible for our vision and what we see. Each hemisphere of the brain is made up of millions of brain cells, called neurones. Neurones are the cells that send and receive the messages (electrical signals) around our brain that tell our body what to do.

What is hemiplegia?

Hemiplegia (sometimes called hemiparesis) literally means paralysis of half of the body. When someone has hemiplegia ('hemi' means 'half' in Greek) it is because one of the hemispheres of their brain is damaged. We talk about a left or right hemiplegia, depending on the side affected.

About 1 in every 1,000 children has hemiplegia. In the majority of cases the damage to the brain happens before, during or soon after birth, when it is known as congenital hemiplegia. Some children, however, develop hemiplegia after a stroke (when a bleed or a blood clot damages part of the brain), an accident, a brain infection or tumour. This is called acquired hemiplegia. Some people develop hemiplegia in adulthood, again following illnesses such as a stroke, accident, infection or tumour.

Hemiplegia affects everyone differently but its most obvious result is a varying degree of weakness and lack of control in one side of the body (rather like someone who has had a stroke). Some children are only mildly affected, others more seriously; in some the leg is more badly affected than the arm, in others it is the arm which is more seriously affected. But in a majority of children the damage to their brain affects more than their limbs and movement.

Specific learning difficulties such as dyslexia, perceptual and concentration problems are common, as are emotional and behavioural problems. And hemiplegia can also cause medical problems such as visual impairment, speech difficulties and epilepsy.

Hemiplegia is a permanent condition, so it will not go away and it cannot be cured. But it is also non-progressive, which means it will not get any worse, and with help its effects may be reduced. When a child is diagnosed with hemiplegia, they are usually referred to a Child Development Centre, often within local hospitals. Here, different therapists work with the child to lessen the effects of the condition, strengthen the weakened side of the body, and develop the skills of the individual.

For more information about hemiplegia contact the **HemiHelp** helpline on 0845 123 2372 or visit www.hemihelp.org.uk

What is epilepsy?

Epilepsy is the tendency to have repeated epileptic seizures. Epileptic seizures happen when the way the brain normally works is temporarily disrupted (when the messages the brain sends to communicate with the rest of the body become disorganised). This disrupted activity can last from a couple of seconds to a few minutes, and can make the person's body do strange things. Many people (about 1 in 30) will have an epileptic seizure some time in their lives. But having one seizure does not mean you have epilepsy - epilepsy is the tendency to have repeated seizures and so is usually only diagnosed after two or more seizures. Nevertheless it is a common condition, affecting 1 in every 131 people.

An epileptic seizure is a sudden brief event that causes a change in a person's awareness of where they are or what they are doing, their behaviour or their feelings. What happens during a seizure depends on where in the brain the disrupted activity is, and how much of their brain is affected.

There are many types of seizures but we can divide them into two groups – generalised and partial (or focal) seizures. In generalised seizures the whole of the brain is affected by the seizure, and the person becomes unconscious and will not remember the seizure. Examples of these seizures include absences (in which the person briefly looks blank and loses awareness) and tonic clonic seizures (in which the person's body suddenly stiffens, they fall down and then their body shakes or convulses).

In partial seizures the seizure affects just part of the brain and the person may not lose consciousness, although they might become quite confused. What happens depends on where in the brain the seizure happens, and what this part of the brain normally does. For example, the person may get pins and needles in part of their body; they may get a strange taste in their mouth or a sudden feeling of fear; they may become very confused, or make strange movements with their arms or legs; or they may make strange noises or lip-smacking or chewing movements with their mouth.

What is the relationship between hemiplegia and epilepsy?

Both hemiplegia and epilepsy are conditions caused by a malformation or damage to the brain or a change in the way the brain works. In some people the brain damage that causes hemiplegia can also cause epilepsy. Statistics vary, but at least 20% (1 in 5) of children with hemiplegia also have epilepsy. In most children with both conditions, epilepsy starts before the age of 5, and the chances of developing epilepsy seem to reduce as the child gets older, especially after the age of 10.

Seizures and hemiplegia

As we saw previously, hemiplegia is caused by damage or malformation in one half of the brain. If the damage that has caused hemiplegia also causes the epilepsy, it is likely that the child will have partial seizures – that is, seizures that start in and affect just part of the brain. Partial seizures can vary, and although the person may not lose consciousness they may be confused. However, some children have generalised seizures and some have 'startle' seizures. Startle seizures happen in response to a shock or surprise, for example a sudden loud noise or by tripping or stumbling when walking.

What happens during this type of seizure varies but often it will include stiffening or posturing (making strange movements) of the arm or leg.

Some individuals have more difficult or complicated epilepsy, called epileptic encephalopathies. These are more severe types of epilepsy, with more serious effects. Epileptic encephalopathies can cause learning disabilities and can affect how well someone can think, understand and interact with the world around them.

How is epilepsy treated?

Most children with epilepsy, including those who also have hemiplegia, have their seizures treated with anti-epileptic drugs (AEDs). These drugs cannot cure epilepsy, but they work on the brain to try and stop seizures from happening. Which particular AED is used depends on the type of seizures the individual has because some AEDs work better for certain seizures. Around 70% of people can have their seizures controlled with AEDs.

When a child's epilepsy doesn't respond to AEDs and they continue to have seizures, brain surgery may be considered. Surgery is only carried out after extensive tests and if the child has partial seizures (that start in just part of the brain). The aim of surgery is to stop seizures occurring by removing or separating the part of the brain that causes the seizures. In most cases intelligence and skills will not be seriously affected, and the surgery can improve their life dramatically.

For more information about epilepsy contact **NSE**'s helpline on 01494 601 400 or visit www.epilepsysociety.org.uk

The impact of hemiplegia and epilepsy

Both hemiplegia and epilepsy are variable conditions that can affect people in different ways and to different degrees. Many of the effects of these conditions are physical, such as muscle or limb weakness, or seizures. However, there are often emotional effects of living with these conditions. Your child may have many different feelings about living with their condition. And as a parent of someone with hemiplegia and epilepsy you may experience many different emotions at different times too.

If you would like to talk to someone about how you or your child are coping with living with hemiplegia or epilepsy, or you have any questions about either condition, you might like to call our helplines (see below).

Useful Addresses

More information about hemiplegia is available from: **HemiHelp**
Helpline 0845 123 2372 (Monday – Friday 10am – 1pm) www.hemihelp.org.uk
Hemihelp produces over 30 information sheets about living with hemiplegia, including information on diagnosis, treatment, education, financial help, behaviour and day-to-day activities.

More information about epilepsy is available from: **National Society for Epilepsy**
Helpline 01494 601 400 (national call rate) (Monday - Friday 10am – 4pm) www.epilepsysociety.org.uk
NSE produces information leaflets on various issues around living with epilepsy including Seizures, What is it?, First aid, and Children and education.

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THE ROALD DAHL FOUNDATION

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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