



Alternating hemiplegia in children

This leaflet explains about alternating hemiplegia in children and how it can be managed.

What is alternating hemiplegia?

Alternating hemiplegia is a rare condition where a child has episodes of weakness affecting one side of the body. This weakness can affect all the muscles on the affected side, not just those in the limbs. After an episode, the weakness improves, but will recur during the next episode. Alternating hemiplegia is a variable condition that affects children to differing degrees and in a variety of ways. This can make it a difficult condition to diagnose and manage but much expertise has been gained in recent years.

What are the symptoms of alternating hemiplegia?

A major feature of alternating hemiplegia is variation within a day and over longer periods.

As well as the one-sided weakness described above, other symptoms are associated with the condition. The bulbar region, which controls swallowing, speaking and feeding, may also be affected during episodes. This may be serious enough for the child to need a stay in hospital, particularly if he or she is having breathing difficulties or dehydration due to feeding problems.

Children can have other long-term problems, such as learning difficulties, behaviour problems and movement disorders, such as spasticity, dystonia and dyspraxia. These tend to be fairly constant throughout and do not come and go like the episodes of weakness. Significant problems with speech, feeding and breathing also occur during and in between episodes. Epilepsy is also present in about half of children with alternating hemiplegia. Seizures are completely different from the episodes of weakness but may happen at the same time.

How is alternating hemiplegia diagnosed?

The main problem with diagnosis is that the condition is extremely rare and symptoms come and go over time. As a result, the condition may be misdiagnosed in the early stages.

There is no specific diagnostic test and doctors tend to diagnose it by looking at a child's history and symptoms. In many children, diagnosis takes a long time and may have involved many different specialist doctors. Once a diagnosis has been made, a multidisciplinary team, including both specialist and local doctors, are best placed to manage affected children.

What causes alternating hemiplegia?

We do not know what causes alternating hemiplegia to develop but we do know that it is a very rare condition, affecting about one in every million children. Symptoms usually appear before a child is four years old and then come and go over time.

What treatments are available?

While there is no 'cure' for alternating hemiplegia, we have learnt a lot about both preventing episodes, treating episodes when they occur and managing epilepsy. The following sections explain further about each of these.

Preventing episodes

In about half of children, there seems to be a 'trigger' for episodes of weakness. These vary from child to child and include exposure to cold, emotional stress, tiredness, bathing, high temperatures and respiratory infections. While avoiding these triggers may reduce the risk of an episode, it can also have a negative effect on family life, so a balance between prevention and normality needs to be reached after discussion with the team. Anti-seizure medicines have been used in the past to prevent episodes but these do not work very well. Other medicines have also been tried, for instance, anti-migraine medicines, but these are not used very often. Flunarizine, a calcium channel blocker, has been used widely, although it rarely stops episodes completely. However, it does seem to reduce the severity of episodes and how

long they last. Some parents also reported that episodes happen less often.

Treating episodes

In many children there is a 'warning sign' of an impending episode, which may include tiredness, yawning and appearing exhausted. Sleep seems to reduce symptoms of weakness, so we recommend that the child get to sleep as soon after these warning signs as possible. Several types of medicine can help, such as buccal midazolam and melatonin. Please see our information sheets for further information. Some children complain of pain or seem to be in pain during episodes, so use paracetamol or ibuprofen as pain relief. The ability to feed during an episode will vary. The first 15 to 20 minutes after waking are usually when problems are minimal so this is the time to give food, and particularly drink. Assessment of feeding problems can be difficult outside of an episode. Swallow scans can be useful but may need to be arranged at short notice when an episode occurs. Some children need to be admitted to hospital during an episode, but this depends on the severity of their symptoms. It is necessary to have an arrangement with the local hospital where the child is admitted when the family feels it is necessary. Specific issues that might need an admission include feeding difficulties causing dehydration, breathing problems and concerns about chest infections or seizures. On rare occasions, a child may need to be admitted to the intensive care unit, usually due to chest infections or breathing problems, as these are the main life-threatening features of alternating hemiplegia.

Managing epilepsy

Epileptic seizures are usually different to the symptoms of an episode of weakness. There seem to be two types of seizure affecting these children: minor motor jerking in one part of the body (epilepsia partialis continua) and/or more generalised seizures that last for five minutes or more (status epilepticus). Many children are resistant to commonly used epilepsy medicines and their use should be balanced against possible side effects.

Treatment plans

A plan of treatment agreed by the family and medical team can be invaluable. This may include descriptions of the different episodes experienced by the child and expected treatment for each of them. This may make part of an 'information file' kept by the family containing important information for the child and a history of his or her condition.

What is the outlook for children with alternating hemiplegia?

The variation in function in between and during episodes needs to be understood by all involved with the child. For example, a child may be able to walk reasonably well for some of the time, but need a wheelchair or buggy sometimes, often with little warning.

While it is not a progressive disease, it seems that episodes of weakness may get worse over time and recovery may become slower.

Is there a support group?

The following organisation can offer support and advice:

Alternating Hemiplegia Support Group
80 London Road
Datchet
Slough SL3 9LQ
Tel: 01753 546268

Notes