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Epilepsy in Infants, Toddlers & Pre-School Children - Questions Parents and Carers Ask

What is Epilepsy?

Epilepsy is the tendency to have recurrent seizures. Recurrent is generally defined as two or more episodes. As many as 1 in 20 people will have a single isolated seizure at some point in their lives whereas 1 in 200 will subsequently be diagnosed with epilepsy. In children the rates are 1 in 100 having epilepsy. Of those diagnosed with epilepsy throughout the lifespan an estimated 30% have first seizures in the preschool years with 17% of those being in the first two years of life alone. So seizures are commonplace events in the early childhood years.

A seizure is a brief burst of excessive electrical activity within the brain which causes a range of symptoms which may be described as seizures. How the seizures are described depends on where they happen in the brain and how and whether they spread. There are two broad categories of seizure generalized and partial.

Generalised seizures affect the entire brain and consciousness is lost. Common forms are absences (previously known as petit mal) and tonic clonic (previously known as grand mal). Partial (focal) seizures affect localised areas of the brain. Symptoms vary and consciousness may be lost to a greater or lesser degree. Simple partial seizures occur when consciousness is retained (such as an aura or warning). Complex partial seizures involve confused behaviour , automatic behaviours , and memory being affected.

Seizure threshold: Describes the point at which a person can be triggered into having a seizure. Every person has a seizure threshold. For most people it is said to be "high" and therefore they are unlikely to experience seizures. For people with epilepsy it is "low" and they are more easily triggered in to having seizures.

How does the doctor decide that my child has epilepsy?

When a child has seizures their GP will discuss referral options with parents whereby children may be seen by a Paediatric Neurologist. As there are currently five posts nationally (4 in Dublin, 1 in Cork) this may involve a waiting period. Whether the child is started on treatment in advance of seeing the Neurologist is a matter for the GP and parents. Many parents express concern about putting a child on medication at this stage whilst others are concerned about ongoing seizures. A detailed history is important

when diagnosing epilepsy and there are many ways parents can be prepared to provide as much information as they can to the clinician.

What is the best way to record my child's seizures?

Keep a diary of all witnessed and suspected episodes. Describe what happened in as much detail as possible. Divide your account into before during and after .

Before (for the previous hours or day):

What was the child doing just prior?

(playing, sleeping, awake, watching TV etc), record any behavioural or mood changes that were notable prior to the seizure, had the child been unwell prior to this infections, fever, tiredness, on medication

Were they stressed or excited or "out of sorts" in some way?

Had their pattern of sleep or meals been disrupted lately?

Other factors to consider - recent travel, any changes and disruptions to routine

During:

Did the episode begin promptly or develop more gradually?

Did their behaviour indicate getting a warning? (eg. seeking comfort from parent)

Was consciousness lost or otherwise affected ? (confusion/ disorientation)

What happened to the child? - e.g. jerking movements of limbs, automatic behaviours such as wandering chewing, staring, blinking, eye movements, tremor, sounds.

Were both sides of body affected or one side?

Was bladder or bowel control lost?

Were they pale or flushed, agitated or unresponsive?

How long did this stage of the episode last? - try to time it as accurately as possible.

After:

Was the child sleepy?

How long did they need to sleep for?

Were they confused or disorientated?

Did they have any memory of the event?

Did they sustain injury?

Were they able to describe any part of the experience?

Video recording of seizures is a very useful method of capturing the episode. When we observe a seizure we are often emotionally affected by what we see and parents frequently recount feeling very distressed witnessing their child have a seizure. This can mean it is difficult to fully recall accurately what happened . Where seizures are likely to recur it is a good idea to have a VCR on standby ready to record the episode. Perhaps one parent can record the seizure this way whilst the other tends to the child. Rarely will the child have a seizure when they attend the clinic so having it on video gives the doctor an exact idea of what happened.

What Caused my Child's Epilepsy?

For many children no cause is identified. Where causes are known they range from genetic and inherited conditions, head injury, brain infections (meningitis/encephalitis), developmental brain disorders, birth injuries, cerebral palsy, hydrocephalus and more rarely tumours.

It is important to distinguish between causes of epilepsy such as brain injury and triggers for seizures such as high temperature.

What Tests and Investigations can we expect to Have?

EEG and Sleep EEG:

EEG -(electroencephalogram) or brainwave test is designed to pick up brainwave patterns using electrodes placed on the scalp. The person must lie still. These are attached to the EEG which gives a printout graph of the patterns detected from the selected areas. It is a painless procedure and takes about 30 minutes. Any abnormality that occurs during the recording can be read from the graph and this gives important information about the focus (location) and spread of seizures. However many people (60%) are not having abnormal brain activity or indeed clinical seizures whilst the test is being performed and may have a normal reading. A normal EEG result does not exclude a diagnosis of epilepsy. A sleep deprived EEG means the doctor may request the child to stay awake for longer the previous night or be woken earlier on the morning of the test so as to enhance the likelihood of obtaining abnormal rhythms connected with sleep deprivation.

CT or Computerised Tomography is a brain scan. The child must lie still again and the head area is scanned by a machine that is like a revolving drum. It is painless. The purpose of the scan is to rule out for structural abnormaities such as tumours, malformed veins, areas of calcification. Over 90% of people with epilepsy will have no such structural abnormalities which is good news.

MRI (Magnetic Resonance Imaging) is a more detailed scan where pictures are taken in slices across the brain so as to build up a composite picture of the brain and its deeper structures. Again the purpose is to rule out structural abnormalities which may be undetected or less well defined by the CT.

What is the Outlook for my Child? Will They Grow Out of Epilepsy?

For the majority of children the outlook is favourable as epilepsy is a treatable condition. Most childhood epilepsy is controllable with treatment and therefore may not persist beyond childhood. Whether a child is likely to "grow out" of having epilepsy depends on the kind of epilepsy they have. For most children it is more realistic to talk about controlling their epilepsy rather than curing it. Once a child is well controlled on medication for 2-3 years the doctor may discuss with parents the opti