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Explaining Epilepsy to a Child

How to explain to your child about his/her seizures (and why you should)

Small children can have very vivid imaginations. Indeed pixies, giants and other strange creatures may appear quite real to lots of imaginative children.

Although most childhood fantasies are a lot of fun and quite harmless, it is possible for a child to frighten him/her self with what he/she makes up. Scary fantasies often arise when a child is anxious about something he/she doesn't understand, but luckily they tend to disappear when a proper explanation of the real situation is given.

In the same way, we often overlook the fact that a child with epilepsy is likely to make up fantasies about his/her seizures unless they are properly explained to him/her. Parents usually receive explanations from the doctor, but often he/she is considered "Too young to understand".

From the child's point of view it must be very confusing. He/she becomes sick. He/she is taken to a doctor. Strange people in a hospital place wires on his/her head. Afterwards he/she has to take medicine every day. Even a very young child will probably realise that something in his/her head is involved, and if his/her parents seem upset and anxious (as will likely be the case) he/she may feel that it is serious.

If the child is not given an explanation of what is going on and why he/she has to take medicine, he/she is left to make up his/her own reasons. Under these circumstances it is quite possible that what he/she imagines may be far worse than the truth.

Cases have been reported in which children associated seizures with death, with broken or missing brains, and with punishment for being bad. These may be extreme cases, but they do demonstrate how a child can misunderstand his/her condition, and become very anxious indeed about him/her self. So it is important that children with epilepsy should be given a factual explanation about seizures, which they can understand. This will help to prevent undue anxiety, and will lead to a better acceptance of the condition and of its treatment.

Explaining seizures to a very young child who doesn't know much about his/her own body or how it works can be quite difficult. We think the description given by a seven year old named Peter, of his own seizures would be helpful even for very young children: -

"It's like when you are watching TV and the picture gets all blurry and fuzzy for a minute and then goes back on again OK. That's what it's like to me."

You can add that this happens to lots of people, children and grown-ups, and the medicine you take helps you keep your picture clear.

An older child can be given a more detailed explanation along the following lines: -

Our brain, which is inside our head controls everything we do, walking, talking, seeing, hearing, and even sleeping. Everyone has a little bit of electricity in his or her brain, and this electricity helps the brain send messages to our body to tell it what to do.

Sometimes people make too much electricity in their brain and the messages get all mixed up. That's what is happening when you have a seizure. It's a bit like the way static can make the picture on the TV set go all fuzzy, or disappear for a minute.

The tablets you take help to stop the electricity increasing so that you won't have a seizure so often. Lots of people, both children and grown ups, have this problem with too much electricity, and they all take tablets to keep in order.

Some children think by taking extra amounts of medication it will give them better seizure control, or even cure their epilepsy. Sometimes children get the idea that taking more than the usual dose of medicine will work better than the standard dose. This can be a dangerous belief if the child decides to act on it.

It is suggested that parents should find out as much as they can about their child's condition, since he/she's bound to want to know a lot more as he/she gets older. Parents of children who have epilepsy can help their children understand why they take medication by explaining that: -

Epilepsy medicine works best when you take a little bit at a time. Just like the doctor said.

Taking lots of medicine at once wouldn't make you better; it would probably make you sick.

Epilepsy medicines sometimes take a while to work, and some people still have a few seizures even though they are taking their medication.

Some books, which are particularly useful for children are listed below.

What Difference Does it Make to Danny?

Helen Young- suitable for ages 9-12 years old, available through bookshops.

Epilepsy - The Detective Story

Peter Rogan- Suitable for age's 7-12 years old, available from I.E.A.