

## (19) Parents: Epilepsy and behaviour

Changes in behaviour can sometimes be observed in a child following a diagnosis of epilepsy. This could be:

- \* psychological, ie the child may struggle coming to terms with possible restrictions in their life
- \* connected with seizure activity
- \* caused by side effects of medication

To help identify the cause of your child's change in behaviour, consider the following:

- \* Did your child's change in mood come about after a change in medication or dosage?
- \* Does your child's mood or behaviour change every time after taking their drugs, regardless of what your child is doing?
- \* Does your child's behaviour change also at school or just at home with you?
- \* Is your child's behaviour difficult all the time?
- \* Is it usually a response to your child not getting their own way?

Is there something else going on in your child's life, not connected to the epilepsy, which may be upsetting? It could be starting a new school, moving house, a bereavement or the loss of a pet.

### Seizure activity

A change in behaviour can sometimes be linked to seizure activity in the brain. There may not be an obvious or predictable reason for your child's seizure to you but when you get to know the pattern of behaviour you may be able to associate it with seizure activity in the brain. Changes like this will normally settle once seizures are brought under control or once the seizure has run its course.

## Side effects of anti-epileptic drugs

A change in behaviour may result from anti-epileptic drugs' side effects. These range from mood swings, irritability or increased activity, drowsiness, tiredness or lack of concentration. Your child's appetite may also be affected causing either an increase or a loss in appetite. All of this can make a child vulnerable to mood changes. It can be more difficult for a child, especially one who might have a learning disability, to understand and communicate what they feel so they can often express distress or anxiety through difficult behaviour.

Your child's doctor or epilepsy specialist nurse will want to rule out side effects of medication. Even if the behaviour is caused by a medication side effect, it can still be addressed.

## Psychological causes

It can be difficult for anyone to come to terms with an epilepsy diagnosis and seizures. A child may be finding it tough to deal with the way their life may have changed and will not like possible restrictions. A child may also worry about having a seizure in front of others especially if their parents are worried about this.

## Parent's own reaction to epilepsy

Parents often become anxious and may relax normal routine and the setting of boundaries. This can unsettle a child as their parents' reaction is one of the most important factors in how well a child adapts. Establishing a predictable routine and using consistent and calm parenting practices will reassure a child.

Be aware of the impact the diagnosis has on you. Watching your child have a seizure, especially a tonic-clonic seizure, can be a distressing and traumatic event. You may feel frightened, helpless, and even believe at that point your child is going to die. It may take some time to get over this initial trauma. In the beginning you may feel overprotective and fearful of witnessing another seizure.

## Allowing yourself to grieve

Coming to terms with your child's epilepsy and / or special needs can be like going through a grieving process. You may recognise some of the following stages which are common in the grieving process:

**Shock** – you are unable to take in what is being said

**Denial** – this cannot be true, the doctors must be wrong

**Anger** – it is not fair, why me?

**Grief** – you may feel sad, vulnerable, depressed or experience a sense of loss

**Acceptance** – you come to terms with it and move forward.

Everyone deals with grief in a different way. Not everyone will go through these stages in this order.

## Discipline

Parents may find it difficult or may be reluctant to discipline their child, especially if they believe that their child's behaviour is linked to seizures or medication. They may also fear that disciplining their child may provoke a seizure.

Considering how to set boundaries and establishing a routine and structure are the most difficult but important roles for all parents. No child is born knowing how to manage their behavior; it is something they will have to learn. Any parent faced with a screaming baby or a toddler's tantrum will recognise this. In order for a child to learn how to manage their behaviour a parent will need to teach them how. This is no different for a child with epilepsy. However, the challenges parents with a child who has a long-term condition and / or complex needs can be greater, which require consideration and support.

## Changing a child's behaviour

In order to change your child's behaviour it is important to recognise and acknowledge the impact your child's epilepsy has on you, and how you react to their behaviour. Acknowledging this will turn your attention to how this may affect the way you discipline your child.

As an example, your child asks for sweets, and you refuse as it is nearly tea-time. Your child continues to whine, demands sweets but you stay firm. Your child then becomes increasingly demanding and starts to throw a tantrum; you finally give in and hand over the sweets for a quiet life. Your child has learnt that by making increasing demands and throwing tantrums, they will get what they want. On the other hand, by being consistent and setting clear limits, your child will very quickly learn that if mum / dad say 'no', they mean 'no', and your child will stop this kind of behaviour.

By teaching your child to manage their behaviour, this helps keep them safe and makes them feel secure. It also teaches them self-control, how to respect other people, and helps them to become responsible adults.

Children with epilepsy often feel more vulnerable and out of control because of their seizures. If you do not set limits on your child's behaviour, you give your child a level of power and freedom which they cannot handle or know what to do with. This can increase their vulnerability.

It helps to remind yourself that discipline is not about dominating or controlling a child. To discipline your child in an effective way, follow these three steps:

**Communicate clearly** – make eye contact, check the tone of your voice (which should be friendly and controlled). Make sure that any instructions can be understood by your child and explain why a certain type of behaviour is unacceptable. It helps to check that your child has understood what you have said by asking them to repeat this back to you.

**Try to be consistent** – try not to have too many rules but agree on the important ones, such as not hitting anyone. Parents need to give the same message consistently as children often may try to play one off against the other.

**Rewarding and praising** – both are great motivators and do not need to cost anything. Praise should be related to the specific behaviour you are hoping to encourage. Telling others about your child's good behaviour when your child can overhear you can also increase the positive effect. The best reward you can give your child is your time.

Some children respond better to set routines whereas others may react more positively to being given a choice.

## Containing a child's behaviour

If your child has difficulty in communicating their needs, it may be more difficult to detect any patterns or find out what is triggering their behaviour. Ask yourself:

**What happened before the behaviour?** For example, your child had a fizzy drink.

**What did your child do?** For example, your child became increasingly agitated, hyperactive or uncontrollable.

**What happened next?** For example, your child was sent to their room, and broke their new toy.

If you start to think about what might cause a certain type of behaviour (apart from not getting their own way), you may be able to anticipate and avoid those situations or triggers which provoked the outburst.

## Parenting classes and parent support groups

Some parents may find it helpful to share their experiences with others in similar situations. A parent support group, or even a closed facebook group, is a good way to do this. If your child's behavior is particularly challenging and you want to get some expert advice on how to deal with this, a parenting class may be another option.

Your health visitor, GP surgery or epilepsy specialist nurse may have details of such groups or classes in your area.

## Onset of puberty

The combination of epilepsy, hormones and anti-epileptic drugs can be powerful and can result in more complex behaviour issues. Seizure patterns and frequency may change in some children as they approach and go through puberty.

A child approaching adolescence will also probably become more sensitive about how others view them and may find it more difficult to cope with seizures. It is also a time when your child will want more independence.

Youth groups can support a young person through the challenges of growing up and making balanced decisions about their epilepsy. Our Edinburgh and Glasgow youth groups cater for children / young people aged 11-19. Both groups are involved in a wide range of social activities. Contact our helpline 0808 800 2200 for more information.

There is more about transitioning into adulthood in our Parent's factsheet 'No 21 Transition into young adulthood'.

## Further information

The following sources can provide you with further parent-specific information and support:

- \* **Kids Behaviour** [www.kidsbehaviour.co.uk](http://www.kidsbehaviour.co.uk) - information on how to manage behaviour, useful case studies and an online expert advice service
- \* **Parent Network Scotland** [www.parentnetworkscotland.org.uk](http://www.parentnetworkscotland.org.uk) - classes and courses for parents. Contact them on 0141 948 0022
- \* **Parenting across Scotland** [www.parentingacrossscotland.org](http://www.parentingacrossscotland.org) - information and support for parents. Contact them on 0131 313 8816
- \* **ParentLine Scotland, 08000 28 22 33**, [www.children1st.org.uk](http://www.children1st.org.uk) a free and confidential telephone helpline for anyone who cares for a child in Scotland
- \* **The Relationship Helpline 0808 802 2088** – [www.thespark.co.uk](http://www.thespark.co.uk) - a free, confidential and accessible telephone and online counselling service offering support to people in Scotland who are experiencing relationship difficulties