Adjusting and coping as a parent

Epilepsy is a disorder of brain function that involves recurring seizures. About 4% of the population will have epilepsy at some stage of their life and it presents as unique to every person. It is characterised by seizures, which can range from short episodes of loss of attention to intense convulsions.

Being told that your child has epilepsy is likely to be very confronting. You may experience strong feelings of shock, fear, guilt and sadness, perhaps mixed with a little relief that you now have an explanation as to what has been happening for your child. These strong feelings will be useful in fuelling you to make the changes needed to help your family cope well with epilepsy.

Along with strong emotions, a diagnosis of epilepsy is likely to bring up many questions. You may want to understand more about epilepsy in general, so that you can answer your child’s questions and better manage the impact that epilepsy might have on them, as well as on the rest of the family.

The diagnosis may also challenge your personal views about your child, yourself, and your hopes and dreams for the future. Most parents find that they adjust in time, and that their child’s epilepsy becomes just one of the many issues that are part of the daily life of every family.

Adjustment takes time

Even though your feelings might seem overwhelming now, they will subside with time. You can help this process by talking about your feelings and thoughts with a trusted friend or family member.
The importance of managing anxiety

One of the most challenging aspects of epilepsy is the worry that it brings with it. Every member of the family is likely to be feeling more anxious as a result of the new diagnosis, making coping with the diagnosis more difficult. Research shows that children tend to take their cue from their parents about what is worth being anxious about, and what is not (Cohen, 2013). One useful way of helping your child, and other members of the family, therefore, is to take steps to manage your own anxiety well. (See the Self-care section for ideas on how to this.) Another way to help your child is to show your support by asking about any worries, and gently challenging anxious thoughts as they arise, while providing comfort.

Consider the balance between safety and overprotection

Your first instinct may be to do all in your power to protect your child, especially if he/she is experiencing generalised tonic-clonic seizures. Although this is natural, it is important to be wary of overprotection, as this can have long-term negative consequences for your child, his/her siblings, and yourself. The whole family may miss out on activities because of fear of what might happen, causing your child to feel ashamed, or unfairly singled out.

Consequently, it is useful to realistically estimate the risks involved in any activity, and perhaps to substitute a safer activity for a more risky one. For example, swimming may involve too much risk for your child, but playing soccer may be an acceptable substitute, especially when the associated physical and social benefits are taken into account. Finding an acceptable balance between your child’s safety and his/her independence takes good communication and flexibility, but your child will benefit as a result (Carlton-Ford et al., 1995).

Involving others

Other people can be an important source of comfort and support while you are adjusting to your child’s diagnosis, as well as a resource for the safety and protection of your child when you are not there. It can be reassuring to talk to family members and friends, as well as professionals in your community such as your child’s school nurse or the family GP.

You might be concerned that, if other people find out that your child has epilepsy, he/she may be treated unfairly, or even rejected. Perhaps you could test this out by picking one trusted person to tell about the diagnosis, and seeing how they react to the news.

If you do meet with any negative reactions, they may be caused by ignorance. One way to support your child over the long-term is to do what you can to educate the people surrounding them about epilepsy.

Self-care

Although your main focus will naturally be on your child, it is essential for his/her welfare that you give some thought to your own needs. It will be easier for you to maintain your emotional balance if you are able to schedule some time to do the things that you enjoy. Regular exercise, for example, can be a way of replenishing yourself, physically and mentally. It is also important for you to maintain your connections to other people. Contact with other parents via local organisations or on-line forums can be both informative and supportive, while sharing your worries with close friends can help you cope. The process of adjustment will happen more quickly and easily if you look after yourself as well as others.

References
