



BC Epilepsy Society



FAMILY

DAY



BC Family Day is Monday, February 13

Tips for families of children living with epilepsy

Epilepsy affects not only the individual with epilepsy, but also can have a great impact on all members of the family unit.

After a child has several seizures and a diagnosis of epilepsy is made, parents often experience a sense of disbelief, feelings of fear or worry, which is normal and understandable.

There are many factors that influence how epilepsy may affect people's lives. The age of the child, the type and severity of the disorder, the functioning of the child prior to the diagnosis, their temperament, the availability of information and access to support services, are some of the factors that may play a role. The struggle of dealing with epilepsy, often starts with the first seizure and continues long past when seizure control has been obtained.

Seizures by nature are unpredictable. When there is a child with seizures in the family, there are specific things which must happen regarding the management of the seizure disorder. For example, there are doctor's appointments to attend and medications to be given. Another interruption to daily routine is the care required when a child has a seizure. As well, parents may be called into the school to pick up their child because of a seizure. In this way, family routines are disrupted, outings are sometimes cancelled and plans for special one-to-one time with siblings may be postponed.

For young people who are in school, it may mean simply missing hours and days of schoolwork, or it may mean taking time off altogether, or having to make changes in their school curriculum. For those who work, it may mean missing work, losing income, giving up their job, putting their career plans on hold, or making new types of career choices.

The family environment is very important in the course of epilepsy and may influence both the severity and the impact of the condition. If family members' attitudes towards epilepsy are negative, the individual with epilepsy will be affected negatively, which in turn will negatively affect the family unit and its functioning. Negative attitudes toward epilepsy may result from the stigma's society attaches to epilepsy. These attitudes may include lowered expectations for the child with epilepsy, or the belief that the individual must be protected. In many cases, family members also report feelings of depression, helplessness, frustration, low self-esteem and high levels of stress.

When families are having difficulties coping with epilepsy, interventions are essential to improve the outcome for the entire family. Education helps to

eliminate the stigma's associated with epilepsy and may help to improve family functioning. Information is an important component to help parents, siblings, children and adults come to terms with the diagnosis of epilepsy.

Here are few coping strategies for families and individuals living with epilepsy:

- **Communication:** One of the best ways of dealing with the challenges of having a child with epilepsy is keeping the lines of communication open. Speak to your family and close relatives about how you are feeling. Talk to your children about epilepsy and seizures, and solicit their opinions or concerns. Especially, for children with epilepsy let them know that it's okay to be confused or frustrated at times, and that he or she can talk to you about feelings.
- **Self-Care:** Parents or caregivers need to pay attention to their own well-being, so they have enough energy to take care of their loved ones. They must attend to their own physical needs - nutrition, exercise, sleep and rest. It is imperative to find out what works to keep you calm and relaxed. For some it may be listening to music, reading a good book, for others it may be going for a walk. Whatever works for you, you must make the time to look after your physical needs. Don't feel guilty about taking the time to enjoy yourself. It is important to rejuvenate yourself, in order to be able to give to others. Finding a safe place to talk, cry and vent your feelings or dilemmas is crucial.
- **Contact the BC Epilepsy Society:** who can offer you support and information and help you meet other parents/individuals who have gone through what you are experiencing. Learn as much about epilepsy as you can. This knowledge will often go a long way toward making you feel more comfortable and in control.
- **Join a Support Group:** Being a part of a support group often helps people cope with epilepsy. Whether you are a parent of a child with epilepsy, or an individual who lives with epilepsy, it is important to find people in a similar situation and form a support group to share your experiences. Listening to others in a similar situation breaks the isolation. It provides an opportunity to learn from others and support others. You may gain an insight into your own ways of coping, when you listen to others deal with similar situations.

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