

Family

Fact Studies show that the mere diagnosis of epilepsy causes the most difficulty for the family.

Epilepsy affects not only the individual with epilepsy but also can have a great impact on all members of the family unit. People with epilepsy do not live in isolation. Many of the negative events experienced by children with epilepsy are likely to extend to all family members. As stress in the family increases, any pre-existing marital quarrels may be exasperated. Parents may become too attached to their child as they try to gain control over a condition which is often very unpredictable. Communication between family members may shut down since parents may withdraw emotionally in order to protect themselves from painful feelings. Parents should be aware of the potential complications which may result from their feelings while trying to deal with their child's condition. That way, parents can get help from support groups, counselling or other available resources.

When a child is diagnosed with epilepsy, parents may experience a number of consequences and the family may face many issues. Parents often find themselves dealing with feelings such as "I've lost my perfect child" and "My child will be different now." Parents may feel very vulnerable and experience anger, guilt, shock, denial and grief before finally accepting their child's disorder. Family members also may report feelings of depression, helplessness, frustration, low self-esteem, and high levels of stress. Family members may blame an individual in the family for causing the child's epilepsy: parents may blame themselves or their spouse; siblings often blame themselves. These difficulties may continue as the disorder progresses.

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 child 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 stigmas society attaches to epilepsy. These attitudes may include lowered expectations for the child with epilepsy, and the belief that the child must be protected. Parents' overcompensation in an effort to try to gain control over the unpredictability of the seizure disorder may lead to overprotectiveness. Studies show

that overprotectiveness or restrictive families are associated with poor adjustment and poor acceptance of epilepsy. Studies also show that children who perceive their parents as over-controlling are more depressed and have more behavioural problems. Overprotectiveness can also impede the child's emotional maturity and cause the child to become over-dependant on the family. The child may also lack social skills, act passively and be unable to make normal peer relationships.

When families are having difficulties coping with epilepsy, interventions are essential to improve the outcome for the entire family. Education helps to eliminate the stigmas associated with epilepsy and may help to improve family functioning. Information is an important component to help parents, the child and siblings come to terms with the diagnosis of epilepsy. However, many families report that they receive little advice from health care professionals when their child is initially diagnosed with epilepsy. Parents feel forced to seek out most information for themselves. Without accurate, clear information, children may experience inappropriate adjustment or maladjustment because of the way they feel about their disorder or the way they are treated. Studies show that when individuals know more about epilepsy, they respond more positively towards people with the disorder. Thus, educating people about epilepsy has a great beneficial impact on making their attitudes more positive towards people with the disorder.

The child with epilepsy may perceive the functioning of the family very differently from the way the rest of the family views it. If the child with epilepsy has additional difficulties, such as learning and/or physical disabilities, these in turn may put additional strain on the whole family. Remember that children also have to deal with the demanding task of growing up, which has its own stresses and strains on the family. Any negative effects of epilepsy may become intertwined with the process of growing up and lead to further negativity as the child matures. Thus, the effects of epilepsy are far reaching and can have negative effects on everyone who is involved with the child who has epilepsy.

Parents

Parenting is a very demanding job. Everyone needs time to themselves. This is especially important for parents of children with more intense medical challenges. If parents don't take time out for themselves, stresses will rise. Being chronically tired and burned out can make individuals more susceptible to illness. Parents must ensure that they set aside some time each week for themselves. It is essential: take time for a relaxing bath, go for a walk, or talk with friends. Social interactions with people in addition to the child-parent interaction are essential for **both** the child with epilepsy and the parents.

Many parents of children with epilepsy find themselves relying on family members to assist them with the care of their child. However, there may be other options available. Try to find a mature babysitter, or a daycare that deals with children with special needs. You may be able to find other parents of children with epilepsy who are willing to watch over your child, the favour being returned.

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.

Parents' Experiences

- ∅ Terror and confusion the first time they see their child have a seizure.
- ∅ Fear that their child will die during a seizure.
- ∅ Feelings of helplessness, fear, or panic when their child experiences a seizure. Feeling that they have no control during the seizure may cause parents to scream, cry, freeze or yell for help from onlookers.
- ∅ Feelings that they didn't handle the crisis adequately.
- ∅ Feelings of intense anxiety as to when seizures will occur and their future implications.
- ∅ A sense of loss of control as there are an increased number of medical appointments and changes in daily routines.

Tips for Parents

- ∅ Get information from your local epilepsy chapter.
- ∅ Talk to other parents who have children with epilepsy.
- ∅ Obtain counselling for you, your child, and/or the entire family.
- ∅ Find a support group for yourself, and/or your child.
- ∅ Encourage your child to actively share information with his/her friends about epilepsy.
- ∅ Encourage your child to spend some time alone with the doctor, asking questions and discussing any concerns.
- ∅ Help your child to identify emotions — anxiety, sadness, anger, disappointment, uncertainty, fear, frustration, guilt and worry — and to learn to deal with them appropriately.
- ∅ When planning family outings, create a back-up plan, should a seizure occur. Consider the following:
 - How can brothers and sisters help during and after a seizure?
 - How soon can your child resume activity after a seizure?
 - If not, who will tend to the child after the seizure, while other family members continue with their trip to park, birthday party, picnic, or camping?
 - Under what conditions would it be necessary to cancel or end an outing prematurely?

Talking to the Child about Epilepsy

It is very important for parents to inform their child about his/her epilepsy. The child may have no knowledge of the seizures if s/he is not conscious during them. How much parents tell their child depends on how much they think their child can handle. Generally, the younger the child is, the more satisfied s/he will be with a brief explanation of his/her seizures. However, as the child grows, it is likely that s/he will want more information. Books, diagrams and information from your local epilepsy chapter can help explain epilepsy to the child and help answer any of his/her questions or concerns. Parents may also want their child to speak to his/her doctor or counsellor for further information.

Parents should discuss what epilepsy is; triggers (what causes a seizure); what happens during a seizure; what

a person looks like during a seizure; how to manage epilepsy in terms of diet, lifestyle, medications and medical care; and how the child can tell others about his/her epilepsy. Parents should reassure their child that although some seizures look dramatic, the vast majority are painless for the person involved. Parents should also consider mentioning that it is extremely rare for anyone to die while having a seizure if they suspect that their child has fears about death. Children should also be encouraged to ask any questions and mention any concerns they have. The child should be encouraged to become more and more involved in managing his/her own epilepsy. This includes taking his/her own medication, researching epilepsy him/herself, becoming aware of his/her own triggers, and building his/her own relationships with medical professionals.

Siblings

When there is so much to attend to for the child with epilepsy, parents may tend to overlook the effects of seizures on siblings. These children may feel left out, jealous, scared or even responsible for their sibling's epilepsy. Siblings of children with epilepsy have also been found to be at an increased risk for psychosocial difficulties. These children may feel a great deal of jealousy toward the child with epilepsy who receives more attention from the parents. Siblings may have trouble adapting to their situation. They may feel overwhelmed by their complex feelings and thoughts about the demanding situation in which they find themselves. Siblings may also feel alienated from their parents or from the child with epilepsy. Siblings still need to contribute their fair share to the family. However, parents should acknowledge their feelings and deal with them accordingly.

Many of the negative feelings of siblings can be eliminated or reduced by providing them with reassurance and adequate information about epilepsy.

Siblings are also part of the process of socialization; the things that siblings do together provide a child with seizures a 'normal' experience. This is particularly important for the development of social skills. Siblings may play together at home or in the neighbourhood with other children. Siblings may also fight with each other. Siblings can help provide a "normal" environment for the child with epilepsy. This is especially important for the child with epilepsy who must develop his/her social skills, just like everyone else. Siblings should not be told to treat the child with epilepsy any differently because s/he has seizures. This may cause siblings to feel resentment toward the child with epilepsy.

Siblings as Care Givers

Remember that brothers and sisters play a significant role in the life of your child with epilepsy. Siblings who understand seizures and are not fearful of them can often be helpful by ensuring that other children do not overreact to a seizure and by calling a designated adult to assist the seizing child.

Include brothers and sisters in the care of your child with epilepsy. This can help them to feel useful, and can

also be a welcome support to you as parents. It is important to note that placing responsibility on the sibling to supervise a child with seizures is not recommended. This places the sibling in a parental role and is too much responsibility for a child. Brothers and sisters need to feel included in helping their brother/sister manage the disorder but should not feel responsible for managing it.

Tips to Help Siblings

- ♫ Explain what epilepsy is and is not.
- ♫ Explain that the child with epilepsy will not die from seizures.
- ♫ Explain to the siblings that they did not cause their brother/sister to have epilepsy.
- ♫ Be aware that brothers and sisters may fear catching epilepsy, can believe the myths and stereotypes held by school mates, and may have a difficult time coping with ridicule, teasing and ignorance. Parents' understanding and response to their child's seizures provide a model for siblings to follow.
- ♫ Take time to talk with your other children about epilepsy. When siblings have someone to talk to, this can increase their ability to cope and ease any frustration they feel about their sibling's epilepsy.
- ♫ Be sure to spend time one-on-one with each child. Brothers and sisters are aware of the extra time that parents spend with their child with seizures, and do feel left out.
- ♫ Give them information about how to explain seizures to their friends.
- ♫ Give your child with epilepsy responsibilities, duties and privileges as you do your other children in the family.
- ♫ Don't give in to your child for fear s/he will have a seizure. Some children may threaten with a temper tantrum that parents often fear may lead to a seizure. Treat your child with epilepsy the same as you do your other children.
- ♫ Don't limit play opportunities between your child with epilepsy and their brothers and sisters. Any precautions for brothers and sisters will usually apply to your child with epilepsy: for example, no child should ever swim alone. (You should have already spoken to your child's doctor about any special precautions.)
- ♫ Try to have another caregiver present from time to time to help the child with epilepsy, should s/he have a seizure.

Grandparents

People of earlier generations are more likely to have misunderstandings and stereotypes regarding epilepsy. They may be set in their ideas and opinions of the disorder and may be unwilling to accept it in the way parents feel they should. Parents should try to explain to grandparents what epilepsy is so that they can better understand it. They may even want to invite grandparents to attend one of their child's medical appointments so that they can meet the doctors and learn more.

Grandparents may be afraid to take care of their grandchild if they feel that they won't be able to manage the child should s/he have a seizure. While this is understandable, there are things that parents can do to help grandparents feel more confident in their abilities to help the child having a seizure. Parents should explain to them what they will need to do if the child has a seizure. If the grandparents spend time with the parents and witness them during a seizure, they will probably be more confident in handling a seizure themselves. Of course, this may not be possible, especially if the child's seizures are very infrequent. Still, a good description of what the child's seizures look like will let grandparents know what to expect and will help prepare them to deal with a seizure, should one occur.

Babysitters and Other Caregivers

For a child with well controlled epilepsy, a competent babysitter should be able to manage quite well. However, it can be very difficult to find a babysitter/caregiver for a child whose epilepsy is not well controlled. This is no surprise, since helping a child manage a seizure is a great responsibility. Regardless of the child's level of control, parents should ensure that the babysitter/caregiver is confident and content in dealing with the child who has epilepsy.

Whether or not the child's epilepsy is well controlled, parents should leave clear instructions regarding general care of the child, what to do in the event of a seizure, where they can be reached, and the physician's phone number and/or other emergency medical phone numbers.

Information for Caregivers

- ∅ A clear explanation of what epilepsy is.
It is important to note that epilepsy is not contagious, and that it is not a mental illness.
- ∅ A list of the medications the child is taking (including the dosages), who should administer it, and when it should be administered.
Also mention any pertinent side effects which the child may experience.
- ∅ A description of the type of epilepsy the child has, any auras the child experiences, what a seizure looks like, and the frequency of seizures.
- ∅ How to administer first aid to the child experiencing a seizure, both during and following the seizure.
- ∅ Any other relevant information, including emergency phone numbers.