

Psychosocial Effects of Epilepsy

Fact Many people report that the most frightening thing about seizures is their unpredictability.

Children with epilepsy must learn to live with epilepsy. Epilepsy is a chronic disorder and may have the same types of effects on children as would a chronic disease. Epilepsy is episodic; in other words, no one can predict when a seizure will occur. Therefore, it may be even more difficult to adapt to epilepsy than to other more predictable chronic conditions. Even a child whose epilepsy is well controlled with medication may still be fearful about having another seizure, especially in the presence of peers.

Quality of Life

It is not enough to treat only the medical aspects of the child's seizure disorder. The psychosocial, emotional and physical components of the child's life must all be considered as well. Research shows that parents may interfere with their child's healthy psychosocial adjustment by being overprotective, rejecting, or having low expectations of him/her. Children with epilepsy can attain a high quality of life. Parents who know when to let their children have their own freedom, who accept and support their children as they are, and who encourage their children to have new experiences can greatly assist their children in attaining the skills which will help them to have fulfilling lives.

Stigma of Epilepsy

Research shows that the attitudes of others about epilepsy has more impact on people than does epilepsy itself. Attitudes toward people with an invisible impairment, such as epilepsy, are generally less positive than towards those with a visible impairment. The social stigmas associated with epilepsy can be very detrimental to children with epilepsy. Children are often very self-conscious about their appearance and it may be very difficult for them to deal with having even brief seizures in public. Children fear being viewed as "different."

A newly diagnosed child's perceptions of the disorder largely depend on the parents' reactions to it. How the child's parents deal with the disorder, rather than the severity or frequency of the child's seizures, determines how well the child adapts to the disorder. Instill confidence in the child by praising what s/he can do. Allow your child to make choices to foster independence. Do not isolate the child, saying "It's for your own good." All children deserve the same opportunities. All children need to learn how to take reasonable risks. Facing fear and failure is a valuable learning experience necessary for a child to grow and mature.

Disclosure

The social stigma of epilepsy is experienced sooner or later by both children and adults. Many people feel anxious about the prospect of having to deal with a person who has epilepsy. To help build your child's self esteem, you should encourage openness. Secrecy reinforces the idea that epilepsy may be something shameful. Secrecy interferes with acceptance and can erode a child's feelings of self-worth. A straightforward approach to dealing with epilepsy may appear to be difficult initially but will be more helpful in the long run. Coping with uncertainty is part of having seizures. Taking an active role in understanding your child's seizures and how to deal with them can help make the uncertainty more manageable.

The decision whether or not to tell others about a child's epilepsy depends on many factors. Before you tell anyone outside of the family about your child's condition, you should discuss it with your child. Ensure that your child understands why it is necessary to disclose his/her condition. It is probably not necessary to tell everyone about your child's condition, so discuss with your child who you are going to give this information to. Allow your child to play a role in deciding who to tell about his/her condition.

As a general guideline, you should consider informing people of your child's epilepsy once s/he has had more than one seizure. This is especially important when the seizures are frequent and when the child's medication causes side effects. Informing others of your child's epilepsy will allow them to be prepared in the event of a seizure. If the child's friends seem understanding, the decision to tell them about the child's epilepsy may be easier. However, it is never easy to predict how others will react. While you may be fearful that other people will dwell on the disorder and blow it out of proportion, it is important for your child's safety that other people are informed. Use your own judgement in deciding what to tell others, remembering that openness is preferable.

Advantages of Disclosure

- ∩ Helps others understand your child's condition.
- ∩ Enables others to learn how to help your child during and after a seizure.

Disadvantages of Disclosure

- ∩ Focuses the attention of others on just one component of the child's life: epilepsy.

Perceptions of the child as a whole may be diminished, with epilepsy assuming a disproportionate share of the child's identity.

Children and Self-Esteem

Self-esteem may be the single most important attribute for a child to develop. For children with epilepsy, developing self-esteem can be a challenge, as society often holds negative attitudes toward epilepsy.

It is important for adults to focus on what is within their control. Parents can instill feelings of self-acceptance and self-worth within their children. In order to help your child develop self-esteem, you must accept and acknowledge your child's feelings. (This also means that parents must come to acknowledge and accept their own feelings. Shame develops when parents tell their child not to feel a certain way, or when they find their child's emotions unacceptable.) In accepting and acknowledging your child's feelings as important, valid and valuable, you will help to create an open environment for discussion, which may help you to address any future problems.

For a child with a chronic disorder such as epilepsy, the development of self-esteem may be a great challenge. At times, your child may struggle with a low self image and increased feelings of anxiety and loss of control due to the unpredictable nature of seizures.

Just as parents have a multitude of concerns about their child's seizures, the child may also be coping with a myriad of feelings, including fear, embarrassment, anger, denial and anxiety. These feelings may come or go, and may fluctuate in duration and intensity. Uncertainty about when a seizure will occur, fear of death, fear of medical tests, fear that kids will tease are feelings that can follow some children into adult years.

Your child's self image, in large part, is affected by the reactions of family, friends and involved medical professionals. As a parent, you may be able to educate others. Inform family and friends that the seizures are a temporary interruption to your child's day. It is important for others to understand that your child is a child first, who simply happens to have seizures.

It is likely that your child will also need to combat inaccurate societal beliefs and unfair stereotypes about epilepsy. Learning to cope with these stereotypes may become one of the greatest challenges in your child's life. Often, epilepsy only becomes an illness when seen through the eyes of others. Equipping your child with correct information and the vocabulary to answer questions from the public will be immensely helpful.

If parents are comfortable with their child's seizure disorder, it will help their child to be more comfortable with the disorder. If parents are ashamed of or anxious about their child's epilepsy, then their child will be ashamed or anxious too. Fostering self acceptance, self-confidence and self worth helps to prepare your child to deal with his/her own feelings and the attitudes of others.

Sharing information about epilepsy in words that your child understands will help to remove some of the mystery surrounding the seizures. If there is a greater understanding, it may be easier for your child to accept his/her epilepsy. Concealing information about epilepsy in an attempt to protect a child is not helpful. Children often fill in the blanks with misinformation which can create unfounded concerns. Don't assume that, because a child asks no questions, epilepsy is not a concern for him/her.

The following tips may assist parents in developing their child's self-esteem.

- ♫ Seizures are only one aspect of your child's life: focus on everything that your child has to offer.
- ♫ Do talk about epilepsy with your child. Tell your child the truth about epilepsy and its possible implications. What you tell should depend on the child's age, sophistication and level of understanding.
- ♫ Ensure that your child understands that the seizures are not his/her fault.
- ♫ Treat your child the same as you would had they not had epilepsy. Try to not overprotect your child. Overprotection signals to a child that s/he is not capable and should not be independent.
- ♫ Encourage and support your child to learn, explore and experience new situations in order to develop a sense of confidence in his/her own abilities.
- ♫ Point out the characteristics of your child that make him/her special and unique.
- ♫ Encourage your child to love him/herself.
- ♫ Tell your child that you love him/her. Don't assume that s/he knows it. This will also help to teach your child that it is acceptable and desirable to communicate feelings openly.
- ♫ Listen carefully to your child's thoughts and ideas so that s/he knows that what s/he says and feels is important, heard and valued.
- ♫ Have realistic expectations of your child. Unattainable goals will only frustrate both yourself and your child and will lead to feelings of failure. However, lowered expectations may communicate a lack of confidence in the child.
- ♫ Let your child take responsibility for his/her actions. Encourage him/her to play an active part in the management of his/her seizures.
- ♫ Never use labels such as "epileptic", "stupid", "lazy", "clumsy" to describe your child.
- ♫ Respect your child's need for privacy.
- ♫ Be a positive role model for your child.
- ♫ Because your child may have concerns about being different, it may be important to reinforce a sense of belonging within the family. It is also important to help him/her to find ways to explain his/her epilepsy to others.
- ♫ Keep in mind that it takes time to develop a positive self-image and feelings of self-worth.

Psychosocial Effects of Epilepsy on Parents

A single seizure — especially the child's first seizure — usually has its greatest effects on the parent, not the child. Parents concerns include:

- Can I let my child play alone? What if s/he has a seizure?
- What will my child's friends think? What about their parents?
- Will other people take responsibility for watching my child? Should I let them?
- Will my child's teachers treat him/her the same as everyone else?

Parents often go through a variety of stages after finding out that their child has epilepsy. The first emotion most people experience is fear. Parents fear the unknown most of all. Because epilepsy is episodic, there is no way of knowing when or if another seizure will occur. Grief is the next emotion that parents often feel. Parents grieve for the child they think is no longer the same as before, for the effects they think epilepsy will have, and for how epilepsy will interfere with all of their lives. Parents need to put their grief into perspective. Finding support groups and other resources can help parents accept their child's condition. Eventually, grieving must come to an end and parents must find a more productive way to deal with epilepsy. Following grief, parents are often angry. They often wonder, "Why did my child get epilepsy?" They may feel anger towards the medical staff for not doing/knowing more. Anger is not a productive emotion; instead parents should try to discuss their feelings or ideas with others. It is important to realize that having these feelings is normal and that they will usually pass with time.

It is very important to remember that your child is still the same child after a diagnosis of epilepsy: you should treat your child the same and try not to provide too much extra attention. Extra attention can harm one's personality development and can also affect the functioning of the entire family unit, including sibling relationships.

Many people believe that the single biggest issue for parents raising children with epilepsy is overprotection. The effects of overprotection on children can be serious and long lasting. They may include dependency, hypochondria, low self-esteem, underachievement and immaturity. Parents should not let their anxiety about epilepsy control their life or that of their child. Parents should be a bit more cautious but should not let the fear of another seizure run your life.

Tips for Parents

- ∅ Discuss epilepsy with all of the family members.
- ∅ Encourage your children to ask questions.
- ∅ Treat the child with epilepsy as much as possible as you did before the diagnosis.
- ∅ Avoid making the siblings constant caretakers of the child with epilepsy.
- ∅ Allow your child to participate in the same activities as before being diagnosed with epilepsy, but make necessary changes to avoid unnecessary risks (wearing a helmet).
- ∅ Meet with your child's teachers to discuss your child's epilepsy.
- ∅ You may want to encourage your child's teacher to discuss epilepsy with the class, to make the other students aware of your child's seizures.
- ∅ Meet with any other coaches or instructors with whom your child interacts to ensure they know the proper first aid in dealing with epilepsy. You may also want to consider discussing the psychosocial effects that epilepsy may have on your child.
- ∅ Don't shortchange your child's future.
- ∅ Be honest with your child. The child should know that other people know s/he has epilepsy. Secrets can make the child feel ashamed — that something is "wrong."
- ∅ Give your child responsibilities appropriate for his/her age.
- ∅ Explain which restrictions apply to the child with epilepsy but limit the number of restrictions to those which are necessary.

Psychosocial Effects of Epilepsy on Children

Children may also go through the same emotional stages as their parents. Children may fear dying, fear losing control, fear the unpredictability of the disorder. Children also grieve, as they may be forced to change what they once could do. Therefore, it is important that when restrictions are put in place, parents find other activities that the child can engage in safely. It may be helpful for children with epilepsy to meet other children with epilepsy. For all children, self-esteem is crucial in their accepting themselves as they are. Parents who tell their child that the child's medication is a vitamin, or just something that is good for them, have not accepted their child's epilepsy and are not allowing their child to begin to accept the disorder. Parents are encouraged to let their children be responsible for taking their own medication (still with supervision of the younger child) so that the child feels that they can take control of their epilepsy. Do not focus on your child's limitations; rather, concentrate on what your child is capable of doing. Teachers can be very helpful in informing parents of any changes in the performance or personality of their child (such as side effects related to drug toxicity).

Children are extremely motivated towards successful adjustment. The behavioural difficulties that children with epilepsy tend to experience are generally a result of the frightening, helpless and traumatic state in which children with epilepsy often find themselves. Seizures are often experienced as attacking and threatening, which in turn heightens the child's feelings of vulnerability. Having to deal with the unpredictable, attacking nature of seizures is often an extremely frightening and tense experience for children. Children with epilepsy may feel vulnerable about their bodies and fragile about their well being. While children with epilepsy may exhibit differences in their physical and neurological development, they must still achieve the same emotional and physical milestones as all other children.

Having epilepsy can create an enormous challenge for the child developing adaptive behaviour. Children work very hard to make a positive adjustment to epilepsy. However, having to deal with seizures as part of their everyday development has the potential to traumatize children. Despite the best efforts of parents, physicians, counsellors, etc., the child may feel so overwhelmed that their psychosocial development is affected. When trying to cope with the disruption of epilepsy, the child may experience behavioural and emotional (psychosocial) difficulties. Even when seizures are controlled, some children still have these difficulties. Warning signs, especially when seen in combination, may indicate that your child is having

trouble dealing with epilepsy. These warning signs may include hyperactivity, depression, confusion, disorganized speech, inability to listen to and comply with directions, and lack of pleasure.

Children with epilepsy often tend to have more difficulties in school. Usually, this is not a direct result of epilepsy but due to the consequences of fear and anxiety which children with epilepsy experience. Many children with epilepsy do not have learning problems.

The information and explanations that parents give to their children act to buffer their child's experiences and build the foundation of their future awareness. Complications can occur when children's feelings are not acknowledged or comforted. Parents must not allow their feelings to make things worse by preventing their child from engaging in various experiences or having independence. Establishing routines for doctors visits, taking medications, having EEGs, etc., can help the child accept and deal with having epilepsy. In middle childhood and early adolescence, children have new concerns regarding their medical condition: these may require the child to gain a new level of knowledge and understanding about epilepsy and how it will impact on their life as they grow. Older children often need to sort through their feelings about epilepsy before they can move on and accept their condition. It is important for parents to tell their child exactly what their condition involves, especially as children become older, so that they can accept having epilepsy. Distortions of reality will affect your child's development of autonomy (feelings of control over one's own life) and sense of self-competence. As children grow up, they may experience feelings of unfairness, pessimism, anger, dismay, depression and unhappiness as they try to achieve independence and self-respect.

Tips

- ▷ Set limits for all children. Keep limits brief, few in number and consistent.
- ▷ Try to follow the same rules that you expect your children to follow. You are an important role model for your children.
- ▷ Try to keep the rules consistent for all of your children whenever possible, but make modifications as necessary.
- ▷ Ensure that the "punishment fits the crime" when you enforce rules.
- ▷ Ensure that you discuss the reasons for the rules.

Depression in Children

Depression is quite common in children who have epilepsy. It may be a side effect of medication, or it may be caused by other factors including stress, major disappointment, or a chemical imbalance in the body. Depression can have a major impact on your child's life. It is important for parents and teachers to be aware of the possibility that the child with epilepsy may experience depression. This should not be surprising since the diagnosis of epilepsy can be quite overwhelming for a child. The child who is depressed is unlikely to talk to others about how they are feeling. Look for the following signs which may indicate the child is depressed.

- ▷ **Emotional Changes.** The child may exhibit a troubled and unhappy state of mind. The child may feel unhappy, worried, guilty, angry, fearful, helpless, lonely or rejected. The child may even contemplate suicide. Look for the usually happy and active child who suddenly becomes quiet and withdrawn.
- ▷ **Intellectual Changes.** The child may exhibit trouble concentrating or may experience chronic negative thoughts. Look for the child who was a good student, but suddenly receives bad marks.
- ▷ **Physical Changes.** The child may complain of headaches, or aches and pains. The child may also appear to be unmotivated, with a lack of energy and sleepy all of the time. The child may also develop eating problems.
- ▷ **Behavioural Changes.** The child may withdraw from interacting with others. The child may cry easily and display angry or aggressive behaviour. The child may not want to interact with friends, play or take part in fun activities that s/he used to enjoy.

If any of the above signs are noticed, the child should be encouraged to discuss his/her feelings with his/her parents, another caregiver or another trusted individual. If these warning signs are noticed by a teacher, the teacher should report them to the child's parents. A school counsellor may be able to help. Professional medical help should also be sought. It is important for the child's physician to determine whether there is a physical cause for the child's headaches, aches and pains, sleepiness, etc.

Depression is treatable and it can be overcome.