



How to Help Brothers and Sisters of Children with Epilepsy

Many children with epilepsy and their families go through a period of adjustment at some point after the diagnosis. Most families settle down with a new routine and adjust well. What is less appreciated is the stress felt by the brothers and sisters (siblings) of some children with epilepsy.

Why some siblings find adjustment challenging?

Behavioural difficulties occur more commonly in children with epilepsy: One-quarter of children with uncomplicated epilepsy and just over half of children with complicated epilepsy will demonstrate difficulties in their social-emotional functioning. These types of difficulties can complicate their interactions with their siblings and make parenting more difficult.

Anxiety is common in adolescents with epilepsy and depression is often not recognized and not treated. In addition, epilepsy often carries a certain degree of stigma. If there is fear of stigmatization, this complicates socialization and other family activities.

Siblings observe the difficulties experienced by the child with epilepsy and by their parent's adjustment to the situation. If coping with epilepsy is a burden for the parents and child, the sibling(s) are often affected by such stress.

Studies suggest that the parents devote less time and stimulation to siblings especially at the time of the initial diagnosis and particularly in children with complicated epilepsy. This is particularly true for siblings under nine years of age, who often report feeling left out.

Sibling(s) of Children with Epilepsy

It is common for children to be scared when they see a brother or sister have a seizure. Fear of their sibling becoming injured or even dying during a seizure is common, particularly when the sibling is under 12 years of age. Not knowing what to do if their sibling has another seizure can be an added stress.

Siblings can sometimes be treated like surrogate parents by friends, relatives, and even schoolteachers who see the family as a unit and frequently approach the sibling for information or support. This can place undue stress on the child. Although some siblings have good coping strategies, are mature and become resilient following the diagnosis, it is important that the sibling(s) have a chance to enjoy their own childhood and not become surrogate parents.

Siblings may also feel obligated to protect their brother or sister if there is teasing or bullying. Siblings may also be concerned that people may make fun of them because of their sibling's seizures.

Parental Perception and Attitudes: Risks and Strength

When there are differences in how each parent sees the epilepsy, this can add stress to marital relationship and the effectiveness of problem solving within the family. This can occur because only one parent has met



with the physician and has received teaching about epilepsy. A study on families of children with epilepsy demonstrated that when one parent has unresolved issues related to the diagnosis of epilepsy, the other parent perceived less cohesion and affection in the marriage. Thus, how parents cope with a child with epilepsy can affect not only the adjustment made by the child with epilepsy but also by the siblings.

How the parent reacts to the siblings can be very important. Family studies suggest that the parents sometimes develop unrealistic expectations for siblings, which can increase the overall stress level. Parental over control and negative criticism have been shown to result in higher levels of depression, impulsiveness, and home and school behaviour problems in the siblings. In contrast, a positive relationship between the parents and a positive relationship between the parents and the children has a very beneficial effect. In one study, maternal warmth was significantly related to lower levels of antisocial behaviour and somatic complaints.

The diagnosis of epilepsy can have a marked effect on some parents of children with epilepsy. Between 20 and 30% of mothers have clinically significant symptoms of stress or become depressed in the first year after the diagnosis. Less is known about fathers but they can also be markedly affected. Parents often report high levels of depression, anger, guilt, helplessness, and frustration. It is important for parents to recognize these stresses and to obtain some help with them. This will help them cope more effectively and will also help the child with epilepsy and the other children adapt better to the diagnosis.

Tips for Management

- It is important that both parents receive education and counselling about epilepsy and its impact on the child. Lack of understanding and misinformation results in unnecessary fears and is a major cause of the stigma associated with epilepsy.
- Siblings should also have the opportunity to learn about epilepsy. This will help them cope by reducing their fears and exposing common myths about epilepsy.
- Parents allocating a period of one-on-one time with siblings at regular intervals will add to the sense of support they feel and to their own ability to cope.
- The family should advocate for early assessment whenever academic, behavioural, affective, and social issues become a concern.
- Parents should ask schools, friends and relatives not to put the sibling in the surrogate parent role. This will help to protect the siblings from unnecessary burdens.
- Parents should advocate for the child with epilepsy and acts as a role model for the siblings to be assertive and independent without having to be their sibling's protector.
- It is important for parents to have realistic expectations for their child with epilepsy and also for the siblings.
- If the parents or siblings experience difficulty coping, the family should approach a professional for counselling and education or find appropriate resources.

Approved for circulation on November 2007 (ah)

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