

How will epilepsy affect our family?

Siblings

Sibling love and rivalry are normal. The reaction to siblings to your child with epilepsy will depend on age and developmental stage, but will rely mainly on your reaction to your child's epilepsy and to your children.

There is always an impact on siblings whose brother or sister has a disability, this can be very positive if it is handled appropriately. Brothers and sisters can become stronger, more empathetic and more caring adults.

Siblings can help provide a more 'normal' social environment for the child with epilepsy.

Siblings feelings

Left out, neglected, jealous and resentful: of the time and attention you give to your child with epilepsy.

Scared: that their sibling may die during a seizure and scared of managing the seizure.

Responsible for their sibling and the epilepsy.

Guilt that they don't have epilepsy and that they may in some way have caused it.

Overwhelmed and anxious with feelings and thoughts about situations that arise and being able to cope the epilepsy.

Parents should discuss and help deal with these feelings.

Tips to Help Siblings

- Be sure to spend time one-on-one with each child.
- Explain what epilepsy is. Take time to talk with your other children about epilepsy. Siblings who understand seizures and are not fearful of them can help by ensuring that other children do not overreact to a seizure.
- 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.
- Explain that epilepsy is not contagious.
- Give them information about how to explain seizures to their friends.
- Include brothers and sisters in the care of your child with epilepsy: this can help them to feel useful, but do not expect them to supervise the child with epilepsy, this gives them too much responsibility for a child.
- Fighting with brothers and sisters is 'normal'. Don't tell your other children to treat your child with epilepsy differently.

Grandparents

Are more likely to have misunderstandings about epilepsy, because of the values and attitudes of their generation. They may be set in their ideas of the disorder and may be unwilling to accept and discuss it. Grandparents may be afraid to look after the child with epilepsy.

- Try discussing your child's epilepsy with grandparents. Explain what they will need to do if the child has a seizure. 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.
- Get them to spend more time with your family, this may give them the opportunity to witness a seizure and they will become more confident in handling seizures themselves. This may not be possible if the child's seizures are infrequent.

Other people

You may be afraid that friends, neighbours and relatives will react badly to the news that your child has epilepsy. Negative reactions are most likely when people are afraid or don't know what epilepsy involves. Openness and honesty are the best ways to combat any stigma surrounding epilepsy and you will probably find that most people are sympathetic and supportive if they know how they can help.

Books, videos and advice are available from local epilepsy associations.

References:

- Pollard,R.,Chapman,D.(2002) *Epifile – An Epilepsy Management Manual*. Melbourne: Epilepsy Australia
Website of EpilepsyOntario <http://epilepsyontario.org/faqs/P-T/stages.html> Posted 17th May 2001
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