

Parents and Carers

Research has shown that one of the greatest variables that determine social adjustment, academic success and the psychological well-being of children with epilepsy is the response of their family and friends. How a family copes with the diagnosis can have a greater effect on the child's reaction and behaviour than the severity and frequency of seizures. Although epilepsy is a complex condition, it is manageable and there are several things you can do to improve your child's adjustment.

- **Educate yourself**

To enable your child to be well-adjusted following an epilepsy diagnosis, it is important for you to be well-informed, as your thoughts, feelings and behaviour can be projected onto your child. If you are anxious, they will be too. You can improve your knowledge through researching epilepsy, asking questions and seeking advice. There are many different types of epilepsy and one person's experience may differ from another's. Learn about the particular type of epilepsy your child has so you have a good knowledge and can educate your child. Understand what your child's diagnosis is and what it is not.

- **Educate your child**

Provide your child with open and honest information about their epilepsy and try to answer questions they may have. This will decrease feelings of anxiety, fear, anger, loss or low self-esteem. It will also avoid confusion and help them feel empowered. Help your child complete their Personal Profile sheet so they feel included in the process. Use age appropriate language to help your child understand that epilepsy is not contagious and that there is no-one to blame.

- **Present epilepsy in a matter-of-fact manner**

To avoid creating fear, talk about epilepsy in a balanced and matter of fact manner. Use language that prevents your child from viewing epilepsy in a negative way. Make it comparable to other health conditions such as asthma or food allergies. For example, some children may have asthma attacks from time to time and need a puffer. After they have had the puffer, they recover. Seizures are typically brief episodes and after your child has a seizure they will recover too.

- **Epilepsy is only a small part of your child's identity**

Epilepsy is a condition your child has which does not define them. Just as a child with the flu is not known as 'a child with the flu', your child should not be defined as 'a child with epilepsy'. Epilepsy is part of your child's life and can be managed, but the impact of it does not need to be exaggerated. Your child should have the opportunity to develop and experience the world the same way as other children do. Emphasising and reminding them of their talents and interests will increase motivation and promote a sense of belonging.



- **Promote cautionary behaviour only when necessary**

For anybody diagnosed with epilepsy, caution is sometimes warranted. However, this should not be exaggerated as it can stifle independence and may result in behavioural and emotional difficulties. Expect the same level of responsibility and discipline from your child as you would from any child their age. Age and disease-adapted physical activity and sports have been shown to be beneficial for children living with epilepsy. Let your child swim, ride bikes and play sports if they are able to do so. Inclusion in age appropriate behaviour and activities is vital for the development of a healthy and happy child.

- **Socialise with others who have epilepsy**

Just as your family is a great support for your child, it is extremely beneficial for them to share their knowledge and experiences with other children who have epilepsy. Organisations such as Epilepsy Queensland provide support programs and services aimed at helping people with epilepsy adjust to their new diagnosis.

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