



**Epilepsy Ireland**  
**249 Crumlin Road, Dublin 12**  
**Tel: 01- 4557500**  
**Email: [info@epilepsy.ie](mailto:info@epilepsy.ie) Web: [www.epilepsy.ie](http://www.epilepsy.ie)**

## **PARENTING YOUNG PEOPLE WITH EPILEPSY**

The teenage years are a time of physical and emotional change, a time of striving for increased independence, testing of boundaries, a time of turbulence in which issues of identity come to the fore. For all teens and their parents there can be heightened levels of conflict as rules are tested and perhaps renegotiated. It's as though the volume is turned up on a teen's emotional life. Teens feel their emotions more intensely both the highs and lows and can change feelings states more rapidly, which can lead to confusion and conflict in the family. It is not uncommon for parents to say that their teen's moods and behaviour affect everyone in the house. Teens can be swept along on a tide of their emotions unable to keep a balanced view of what is happening. Things may be described in terms of extremes, or all-or-nothing terms. The middle ground can easily elude a teen who sees things only in black or white terms. Parents can help maintain stability and security by holding the middle ground and keeping perspective. Parental concerns increase in the teen years. Even with the most open and mature of teens there can be parental anxiety about peer influences and safety outside the home. Parents will need to consider discussing topics they may feel uncomfortable raising with their teen such as alcohol, sex, street drugs. Keeping the lines of communication open is essential to building a trusting relationship where you're teen knows they can rely on you for support.

When epilepsy features in a teen's life it can add to further challenges for the whole family. If the teen had epilepsy since childhood this may have been already been absorbed into the family's way of doing things. Parents may be used to taking the lead regarding administering medication, making appointments and arrangements, sourcing information and support. Now the teen may want to express their own views on how epilepsy affects them and take more responsibility. The need to belong and to be the same as everyone else in the teen years is very strong - so when a teen develops epilepsy for the first time they may feel it sets them apart from their peers in some way and this may lead to feelings of isolation. While striving for a separate identity is a persistent theme in adolescence many young people resist feeling different to their peers. When epilepsy develops it may be perceived as a potential barrier to belonging to the wider social group in particular if activities need to be curtailed.

Increasing independence brings its own challenges and with it comes increasing responsibility. Parents will need to gauge what level of independence and responsibility their teen can handle. Teens need to know that negotiating these boundaries and demonstrating they can be trusted are key to persuading parents they can handle their greater independence. Parents may wonder can they trust their teen to take the medication regularly without being constantly reminded. Parents may worry whether their teen will get enough sleep at the sleepover, become too stressed about exams or take alcohol at a party.

Some teens are open and adjust easily taking epilepsy in their stride. They are often comfortable with disclosing their epilepsy and explaining to friends what needs to be done. For such teens epilepsy does not have to control their lives. For others however the experience may be very different. Epilepsy may exacerbate or trigger problems of low self esteem, poor coping and isolation. Parents can support their teen by being available to talk when they are ready to and by

being aware of the emotional aspects of epilepsy. For some teens epilepsy can lead to a sense of frustration with ongoing seizures, a sense of life on hold and a sense of injustice. Depression is common in epilepsy and parents can help by being alert to the signs of depression in their teen. As with every other issue that affects teens and teens with epilepsy alike communication is key to being able to be available and supportive.

Overprotection can occur where parents are reluctant to foster appropriate independence in teens. Teens need to learn to take responsibility for those aspects they can manage, such as using a pill dispenser to manage medication, maintaining regular sleep patterns, and learning stress management techniques. Parents can support them sourcing the information they need to make decisions in the future about education, careers, living independently and community support groups.

### **Safety:**

When out and about ID jewelry such as the Epi-Alert bracelet helps explain to the public and first responders that the person has epilepsy. If a teen is reluctant to wear such ID at least ensure they have an ICE (In Case of Emergency) number programmed into their phone or carry an ID card which explains what to do. At home epilepsy alarms help detect seizures in the house and in bed. The safety guidelines that apply to people with epilepsy will apply in the same way but may need to be negotiated with a teen especially where issues of privacy and dignity are concerned such as showering with the door unlocked.

### **Lifestyle:**

Teens need support and guidance to understand how lifestyle affects seizures. Lack of sleep, skipped meals, stress, alcohol and high caffeine energy drinks can increase the risk of seizures. Lifestyle issues are within the persons control but only if they are aware of the impact.

### **Education:**

Most teens wish epilepsy will not have learning difficulties though for some epilepsy and its treatment can lead to memory and concentration issues which can affect performance. Parents can help by explaining their teen's needs to the school or suggesting a school talk. Brainwave resources such as Teachers Packs will provide the school with templates for school policy. Teens need to be included in as many appropriate activities as possible under supervision. Undue restrictions lead to feelings of isolation and resentment. The emphasis should be on trying to find ways to include rather than exclude the young person. Brainwave has heard reports of teens being excluded from computing, sports, field trips and school tours, Gaisce Awards and even practical subjects. Every case deserves to be assessed on an individual basis to see if such restrictions are warranted and advice from the neurologist can establish what is safe for the young person. State exams are a concern for young people and parents alike especially with regard to having a seizure in the exam. Reasonable Accommodations may be obtained which allows use of a separate room and extra time if a seizure occurs (see [www.examinations.ie](http://www.examinations.ie)). The DARE programme is a supplementary access route to college for students with disabilities who can enter 3<sup>rd</sup> level on a reduced points basis (see [www.accesscollege.ie](http://www.accesscollege.ie))

Career choices can be affected by having epilepsy but perhaps not as much as is often assumed. While becoming an airline pilot or public transport driver is not an option many other careers options will depend on the degree of control of seizures. Someone with epilepsy which is not

controlled may find it harder to enter professions associated with higher risks to themselves or others. Working with machinery, sharp tools, open circuits, on heights or at sea, supervising children or vulnerable persons and construction are some areas where seizures potentially pose risks on health and safety grounds. However when a person's seizures are fully controlled their career options widen. Every case needs to be assessed individually and advice from the neurologist should be factored in to the career decision. As epilepsy is unpredictable it is wise to consider what contingencies can be built in to a career choice if seizures return - can the person be redeployed or is there flexibility in the role to accommodate them.

Peers have a huge influence on all teenagers and so it is with young people with epilepsy too. Not every young person has the resilience to resist the pressure to conform. Parents may worry that their teen will try to fit in with their friends by engaging in risky behavior and developing negative attitudes. Parents can help by supporting their teen to value their wellbeing and feel able to express concerns about peer pressure. They can tell their teen that genuine friends will not pressure them into doing something that puts them at risk. Of course many friends of young people with epilepsy have proven to be exceptionally supportive and mature and Brainwave has heard inspirational accounts of how friends have responded. Young people have expressed this consistently at youth conferences organised by Brainwave. Young people need to be supported to attend youth events such as this where they can meet and talk with other young people who have epilepsy, and youth events are always open to friends, siblings boyfriends/girlfriends of young people also.

Leisure and sport activities need to be decided upon on an individual basis, blanket restrictions are unhelpful. The emphasis needs to be on encouraging young people to partake in leisure and sport activities that are safe for them to do under supervision

Relationships and dating are a natural feature of the adolescent years and issues will arise for some teens with epilepsy regarding disclosure and dealing with other people's perceptions of epilepsy. Young people will need accurate and appropriate information about birth control, folic acid for girls and fertility.

Support for parents and young people is available through Brainwave's network of offices throughout Ireland on an individual & group basis. Remember we also run special youth events such as youth conferences regionally. Young people and parents can also link to online support through Brainwave's Facebook and twitter pages.