Teenage Epilepsy

At a time when young people are facing huge adjustments, epilepsy can cause particular challenges. Sound information, careful management, and understanding from parents and teachers can help.

Today, young people face greater challenges on their journey from childhood to adulthood amid the ever-changing demands of this fast-paced and technologically driven world. Explicit images, cultural and social trends all shape the adults they are destined to become.

Many people often discover an underlying resilience and creativity in themselves, while parents wonder and sometimes despair at the multitude of influences and challenges facing their teens during this time of rapid physical change. Young people are also questioning if their experiences are normal and how they compare to their friends and peers, not wanting to be different or singled out.

Being a teenager … with epilepsy

Adolescence often creates its own issues: among them physical changes, experimentation, exploring relationships, trying to fit in with the new social ‘norms’ of the adolescent world, and first experiences from dating to driving.

As teens seek their place in the world, their attitude towards having a health condition like epilepsy can affect their whole experience. Sometimes just thinking negatively about epilepsy can lead to denial and taking risks with medication and drinking alcohol, plus the possibility of depression and impacts on achievement at school.

This highlights the need for teens and their families and friends to really understand the condition. Most get through adolescence despite the obstacles with the support of people they are close to, from friends and mentors to family.

When teens push the boundaries

Australian society links socialising and relaxing with drinking and alcohol, reinforced by television advertising and social media.

These images also impress on children and teens that being sexy and cool is the ‘norm’, increasing pressures to conform. Reports indicate that at some stage about 40% of teens will try alcohol. Some doctors say people with epilepsy should avoid alcohol altogether; others believe a small amount (one standard drink) will usually do no harm.

To make an informed rather than random choice about this, it important teens realise that:

1. Seizures related to binge-drinking are more common than with the use of any other substance.
2. Alcohol doesn’t mix well with epilepsy medication and can:
   a) stop seizure medications reaching the right level in the blood;
   b) increase the unwanted effects of medication.
3. Some epilepsy medications can worsen the effects of alcohol, so people feel drunk after a small amount of alcohol and have a more severe hangover.
4. Binge-drinking can trigger seizures by unbalancing the body’s fluid and electrolytes through either dehydration or over-hydration.
5. Drinking alcohol, especially binge-drinking, can cause seizures or make some seizures worse. Also partying and drinking often leads to late nights, lost sleep, missed meals and forgotten medications – all of which are common seizure triggers.

Missing a dose, taking extra medication or changing the time of taking antiepileptic medications before drinking will not prevent these effects – and may cause extra side-effects or seizures.

**TIPS: Make an informed decision. If you know you are going to have a late night, sleep in or rest beforehand. Over-lifes should stick to light beer or low alcohol drinks – if you do drink. Try having a soft drink every second drink, or at least when you buy the round.**

Drugs other than alcohol and tobacco

Teenagers tend to have greater exposure and knowledge of over-the-counter and street drugs than their parents through media, rave parties and music culture, their peers and the internet. Health campaigns have also raised awareness of these drugs.

Some teens will experiment to fit in or as a means of escape. They need to know that no illicit or street drugs are gentle or without side-effects. No rules control which ingredients they contain. They can be ‘cut’ or ‘bulk’d using substances such as Ajav, Panadol, salt, plaster and even rat poison.

Many such drugs, especially stimulants like cocaine, ‘crack’, angel dust (PCP), ecstasy and speed (amphetamine), can cause seizures. It is not known exactly how they may interact with epilepsy medication.

Some teens will also incorrectly take medications kept at home such as analgesics, antihistamines and decongestants. This can be dangerous.

As with drinking alcohol, drug-taking is usually associated with reduced sleep, partying hard, dehydration and eating badly, which alone can trigger seizures.

The decision to try illicit or street drugs or abuse over-the-counter medications is a personal one that affects the whole family not just the teen. Before taking that first step, teens need to understand the risks, including that of triggering seizures.

**TIPS: As a teen approaches driving age, it’s time to see the doctor for a review. If the last seizure was several years ago, talk about reducing and eventually stopping medications with the doctor at least six months to a year before it’s time to apply for a licence. If the seizures are not well-controlled, this may be a good opportunity for further exploration and possible changes to the treatment plan.**

Other concerns

**Dating:** Everyone worries about dates and dating, with or without epilepsy. A major concern for many teens with epilepsy is whether to tell their date or boyfriend/girlfriend about their epilepsy and when. It’s common to feel stressed about this and sometimes avoid dating and relationships. Most choose to tell a future partner early, but usually wait until trust and openness have developed in the relationship.

**Other dating issues:** Teens often feel ready for an intimate relationship long before their parents expect, and can be unsure of how this could affect their emotional and psychological wellbeing, especially given potential complications of sexually transmitted infections or pregnancy. It’s vital to address any concerns or questions early to avoid difficulties at a later date.

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Hannah’s story

Epilepsy has affected Hannah, with impacts ranging from not feeling as confident as she might, to schoolwork difficulties. Accessing support has helped. “Hannah didn’t like feeling out of control,” says her mum, Nikki. Normally vibrant, the 16-year-old can be exhausted for up to two days after seizures she has had during her sleep since age 6, and “epilepsy has dramatically impacted her schooling, her self-esteem.” She’s sometimes experienced loneliness and teasing. Over the years, she and her family have received support from Epilepsy Action Australia. At Family Camps, Nikki says: “We met other people with epilepsy and saw they can work around it.” Meanwhile on Youth Camps, Hannah conquered fears safely during supervised adventure activities like a giant swing that built her confidence. “I wanted to meet people my own age with epilepsy,” says Hannah. “My family supports me but they don’t really know what it’s like to have epilepsy. It was really nice to be around people who were facing the same issues, to feel like a normal person.”

Hannah’s health deteriorated recently. Told her seizures were caused by congenital Lyme Disease (a condition debated by doctors in Australia), Hannah is now undergoing therapy including treatment with antibiotics in the US. Her health and seizures are slowly improving.

Whether or not your teen is already in an intimate relationship, they need to know that:

1. Some antiepileptic medications interfere with the contraceptive pill. It’s important to discuss this with the doctor prescribing either the medication or the contraceptive pill. Using extra protection such as condoms or intrauterine devices (IUDs) can prevent unplanned pregnancy.

2. People with epilepsy generally have normal sex lives. No evidence suggests seizures are more likely to happen during sex; in fact it’s quite rare. Occasionally, seizures may be more likely during or just after physical effort and intense emotional experiences. When this happens, some modifications to activity and timing may be needed.

3. Some people may have difficulties because of fear of seizures, their medication, seizure types or issues like depression.

4. Planning for the future; remember that most people with epilepsy are fertile and have perfectly healthy children. Having said that, epilepsy, its treatment, and other related disorders may affect fertility and reproduction. Men with epilepsy may have slightly reduced fertility, possibly linked to epilepsy medication and hormonal changes relating to seizure control. Women with epilepsy may have higher infertility rates due to medications and irregular menstrual periods.

Education and learning: Learning, language and memory can be challenging for people with epilepsy, according to one new study. Teens and their parents and teachers can decide strategies for improving learning by first understanding the facts that may affect it in the first place. These include:

1. The cause of the epilepsy – for example a particular brain characteristic.
2. Drugs used for epilepsy – these can affect tasks surrounding learning like processing information and memory.
3. Epileptic activity in the brain, whether or not a seizure occurs.
4. The type, regularity and severity of seizures being experienced.
5. Stress, anxiety, depression.
6. Tiredness, general health, lack of sleep.
7. Alcohol and other drugs.
8. Bullying is an issue for many teens, not just those with epilepsy. It can lead to issues with learning, self-esteem, stress, depression and anxiety. A number of services are available for help with bullying. The website http://www.bullyingnow.org.au/ is a great resource for students, parents and teachers, created and managed by Australian educational authorities. The National Centre Against Bullying (http://www.ncab.org.au/) is a peak advice body that provides a 24/7 Kids Helpline service on 1505 50 180. The not-for-profit organisation Reach Out Australia (http://au.reachout.com/) offers advice, fact sheets and safe online forums for teens to talk over issues.

TIPS: If school staff know of the teenager’s seizure disorder and any related challenges, they are more likely to understand and assist with difficulties around learning. Parents can create a supportive environment that encourages a teen’s learning, for example helping them at home, or hiring a tutor.4

Emotional wellbeing: Adolescents often find epilepsy difficult, emotionally and socially. They may feel anxious, depressed, isolated, judged or embarrassed, making it harder to be confident, independent and emotionally stable. If their activities are limited due to epilepsy, their sense of being different can increase frustrations and worry. Teens can also fear having seizures, especially in front of other people. Sometimes they prefer to keep their condition a secret.5 These issues can be relieved by encouragement and understanding from family and friends (see ‘Ricky’s story’), and by activities that build their sense of confidence, courage and belonging, such as attending Epilepsy Action Australia’s Youth Camps (see ‘Hannah’s story’).

Management choices

Which drugs are best: Teens will be more involved in following their doctor’s orders and achieve the best possible seizure control if their medicines are easy to take (for example, doses are taken just once or twice daily) and if they have fewer unwanted side-effects.

To help teens, it is important when prescribing that doctors consider side-effects such as extreme drowsiness (which can affect learning), weight gain (affecting confidence and fertility/contraceptive issues). It can also help if parents remind teens that taking their medications as instructed can help them reach goals like getting their driver’s licence. This is because if they become seizure-free on medication, they have a better chance of becoming seizure-free without medication.

Telling other people: Often people only tell those close to them about their epilepsy. But sometimes seizures in public places like at school or work need explaining. For teens, giving a reason like ‘blackouts’ can seem easier, but even this is beneficial to share your condition with other people in your life. Epilepsy Action Australia’s Epilepsy Educators can advise on what to say and when, so disclosure is a more positive experience. Information sessions in schools (for teachers and/or students) and workplaces can also raise awareness and understanding.

Call 1300 37 45 37 for information.

Parents

Seizures can be overwhelming for parents. Common worries include learning impacts; reactions from family members and other people; and whether they need to restrict what their child does.6 Being overprotective is tempting but it benefits children more if they gradually take responsibility for their epilepsy themselves, for example by managing their own medicines, or tracking their seizures along with sleep, stress levels and other habits for a few months and noting any changes. This helps them feel more in control, which is an important step towards becoming an adult. Informing a teen about their epilepsy empowers them to begin making sensible lifestyle choices and prepare for the future. Try being supportive rather than forceful, to boost your child’s confidence. It may help parents to remember that many teens with epilepsy become independent adults.

Getting help

While medical information about seizures is readily available, information about managing epilepsy is less easy to come by. Ask Epilepsy Action Australia (telephone 1300 37 45 37) about support networks aimed at teens, young children and parents. As mentioned above, these include camps designed for teens with epilepsy to meet other situations, build self-confidence and develop healthy coping behaviours.

Fortunately many people can help – and all you have to do is ask.

• Employment agencies can help with finding work.

• Schools and universities offer extra support or time for people who need it.

• Organisations like Epilepsy Action Australia assist in understanding epilepsy and meeting others with epilepsy.

• Friends and family can provide understanding and encouragement.

What now?

Epilepsy, like any chronic condition, has its challenges. These include making lifestyle adjustments; managing any emotional and behavioural impacts; building independence and quality of life; and dealing with other people’s responses to epilepsy.

Teens and parents may be reassured that:

• As they reach puberty, many children grow out of seizures, especially with some seizure types, for example absences.

• Epilepsy medications have improved tremendously in the past few years, with fewer side-effects and increased seizure control. Now most people need only take one or two drugs.

• Information and epilepsy support services are more widely available in the community. The effects of epilepsy vary greatly. For children entering their teens with good self-esteem, a sense of independence and supportive friends and family, the impact of epilepsy is often minimal. It is important to realise that everyone is different, and what is right is what works best for you. And remember: whether you are a parent or a teen, epilepsy need not control your life or define who you are.

Livewire is an online community for 10 to 21-year-olds living with a chronic health condition, with separate communities for siblings and parents. Visit http://www.livewire.org.au.

Ricky’s story

Year 12 student Ricky has had seizures since he was 18 months old. “Just remembering small things” is his biggest challenge. “If my teacher says I have something due today, I have to blank out my head and that affects my school work,” says Ricky, who hopes to become a chef. He believes getting his driver’s licence will help him with work and being more independent. Seizures free for nearly six months, he’s now undergoing review by his neurologist and applying to the Roads & Traffic Authority. When he does have a seizure, “for two seconds I blank out. I think, ‘What just happened?’ I feel paranoid and confused and wonder if other people saw.” Ricky hasn’t told his friends about epilepsy but hopes to one day, and says “my friends and my family encourage me to do that so I really want to do my parents inspire me. All the good and bad things that might happen, they’re there.”