

# Seizure Smart

## EPILEPSY FOR TEENS

Serving Australians with Seizures

### What's Epilepsy?

*Epilepsy is a tendency to have recurrent seizures. Having epilepsy usually means that you have had one or more seizures and are likely to have others if they are left untreated.*

Seizures are sudden, temporary changes in the normal activity of the brain. During a seizure the brain cells fire much faster and all at once - which can affect your level of consciousness, body movements and how you think or feel.

*Not all seizures are epilepsy. Seizures can happen because of a reaction to a strong medication or alcohol. Children can have seizures when ill with a high fever, or some people have seizures related to other sicknesses such as kidney failure. This is not epilepsy*

### Anyone can get epilepsy at any age.

***I have always hated being different and having to take pills and getting tired from pills as my body got used to dose changes. I told all of my friends, and am not embarrassed, but just wish it would go away....***

*This year, I decided to do a project on children and teenagers who have epilepsy. This has really helped me come to terms with my differences, and I feel a lot better hearing similar stories. I have learnt that you can make it through this, and that it isn't that bad, just be strong.*

***Dania 17yrs***

### What Causes It?

There are many causes of epilepsy, and a large number of people never find out why they have epilepsy. Some known causes are:

- ▶ *Injuries to the brain or head – such as a car accident or serious fall*
- ▶ *Lack of oxygen to the brain such as in a heart attack or drug overdose*
- ▶ *Strokes and brain haemorrhages*
- ▶ *Infections of the brain such as meningitis, encephalitis, or a brain abscess*
- ▶ *Some people inherit epilepsy.*

### What Triggers or 'Sets Off' Seizures?

The most common triggers of seizures in people who have epilepsy are:

**Lack of sleep or over-tiredness – Missing medication – Emotional or physical stress**

Other triggers include: being unwell – colds, flu' or vomiting and diarrhoea, low blood sugar and poor nutrition, flashing lights, hormonal changes in females, growth spurts in children and adolescents and many more.



***If I have learnt anything since my first seizure – it is that I must be totally honest with my doctor and generate trust...***

*Once, a doctor that had been treating me for only 6mths told me I needed to reduce my Dilantin dose. Because I had epilepsy for 15yrs and been seizure free for close to a year, I knew I needed a high therapeutic level of medication in order to be OK. The doctor was worried about my liver. I should have known better. I started to have seizures again. Fortunately, I was able to get my old neurologist back.*

***Sean 16yrs***

**Types of seizures:** Seizures are classified into two groups



**Partial** –*the seizures begin in a small region of the brain* – called the focus. 60% of people with epilepsy have partial seizures. **There are 2 types of partial seizures - Simple and Complex. It all depends on if your consciousness is changed or not.**

### ***Simple Partial Seizures***

- The person stays alert and aware of what is happening around them and too them - symptoms include nausea, changes in taste or smell, feeling afraid, de ja vu or sensations that are difficult to describe. Simple partial seizures are also termed an ‘aura’ or warning and are usually brief.

### ***Complex Partial Seizures***

- Consciousness or awareness is altered. The person may seem vague and stare blankly. They can also do things like fidget, fumble with clothing, chew, walk aimlessly, and other purposeless movements. Afterwards there is often confusion for a short time, tiredness, and little or no memory of the event.



**Generalised** –*these seizures start in the whole brain all at once.* The two most common types of generalised seizures are:

- ***Absence seizures***, which last a few seconds, the person suddenly stops what they are doing – stares, at times may roll the eyes upwards or blink – then just as quickly, continue on with what they were doing. These happen numerous times a day and are often thought to be daydreaming. The person is not aware of having these seizures. *These used to be called “petit-mal”.*
- ***Tonic-clonic seizures***, sometimes called “*convulsions*” or “*grand-mal*”. There is a sudden loss of consciousness followed by stiffening of all the muscles (tonic) for a few seconds. This may cause a fall or force the person to cry out. After this, there is rhythmic jerking of the muscles (clonic). This phase lasts from 1-3 minutes. During this seizure the person isn't breathing properly, so their colour becomes very pale sometimes blue-ish. The tongue or cheek may be bitten, so blood may come out of their mouth. Breathing is very heavy afterwards for a short time, and the person is often quite confused and very sleepy. Sometimes they may lose control of their bladder.

## **Living with epilepsy**

There are lots of reasons to care about your health - like feeling good, looking good, and getting stronger. Doing well in school, at work, in sports and other activities. Believe it or not, these can all be affected by your health!

*Living with epilepsy is not always rosy, but people with good seizure control lead normal lives – they are often more limited by the attitudes and misunderstanding of others than by the epilepsy itself. Just remember....*

Epilepsy is not necessarily a lifelong condition  
**Over 70% of people stop having seizures once they start medications**

*There are many different seizure types*

**Many people have never had a convulsive seizure**

Epilepsy is condition of the brain,  
NOT a mental, emotional  
or psychological problem

***Epilepsy should not be a barrier to success***

Living with epilepsy is more than just taking medications.

***Be positive - You can do anything you put your mind to.***

*A healthy, active life is also very important.*

***Your health begins with you!***

## Driving

Driving is a big deal for most young people – it provides a sense of freedom and independence. People with epilepsy usually can get their license if seizures are controlled. If you cannot drive... Catch a lift with a friend. Take the bus. Call a cab. Ride a bike. Walk. There are plenty of other ways to get around.

**Remember, it may not always be like this.**

**TIP: #1** *As you get closer driving age, it may be worth having your epilepsy reviewed. If you have had no seizures for at least 2 years, talk to the doctor about lowering and eventually stopping medications a good 6 months or a year before getting your license.*

**Tip: #2** *If your seizures are not controlled, this may be a good time for further review and possible changes in the treatment plan.*

**TIP: #3** *Taking your medication and keeping yourself healthy really helps with seizure control. Seizure control will help you get your license.*

## School

**Sometimes** people with epilepsy have problems with attention, concentration and memory. **Find out what your school or university offers to help - and identify your strengths and how you learn best.**

**Sometimes** parents or teacher may have expectations that are above or below your ability. **Doing the best you can is the best plan.**

**Sometimes** it is just a different environment or teaching technique that is needed to help you learn, or understanding how you learn best.

**Epilepsy should not be a barrier to education and achievement.**

***I was pretty scared when I was diagnosed. I thought I wouldn't be able to go to university any more.... This was one of my first questions. My doctor said, "of course you can"... I felt so relieved. I realise now, you can do anything you put your mind to.***  
***Jenni 19yrs***

## Sleep

***Getting a good night's sleep is important.***

Sleep deprivation isn't ideal. If you're a student or ever gone without many ZZZ for a number of days you know the feeling. It not only can trigger seizures, but also causes a perfectly sane person to seem temporarily loopy and even the most coordinated person becomes a complete clutz. *The physical effects of little sleep are very real and cause a lot of stress to the body.*

## Medication

*Taking medication not only controls seizures, but helps you get on with all of the above – and life. The less you have seizures, the less interruption in your daily life.*

## Family

Sometimes we love them, sometimes times we hate them, but let's face it, without them, life wouldn't be the same.

## Friends

Friends are important at any age, but when you are growing up, they are the people you can most relate to and feel comfortable with. Sometimes friends feel like the bond that holds everything together in your life.

*Most friends are understanding about epilepsy. Often their biggest fear is not knowing what to do.*

If you tell them how you feel, my guess is that they've felt the same way about a different situation. Just knowing that others understand improves your ability to cope.

**A true friend will listen, understand and help when they can.**

## Feelings

Being a teen isn't fun all the time - especially when the pressure of things becomes too much to handle. With epilepsy, there may be extra things to deal with or worry about.

**Feeling sad sometimes and having mood swings is normal for many teenagers, but feeling sad and depressed for a long time is not.** These are signs of depression, especially if they last for more than 2 weeks:

- ▶ *Changes in eating or sleeping habits*
- ▶ *Sadness that won't go away*
- ▶ *Losing interest in what used to be fun or interesting*
- ▶ *No longer hanging out with friends*
- ▶ *Loss of energy or motivation*
- ▶ *Drop in grades at school*
- ▶ *Thoughts of harming or killing yourself*
- ▶ *Anger and rage*
- ▶ *Using drugs or alcohol to "forget" about problems*
- ▶ *Over-reaction to criticism*
- ▶ *Lack of concentration or forgetfulness*
- ▶ *Aches and pains that don't get better with treatment*

**Find someone you can talk to about your worries.** Maybe a teacher, parent, relative, older brother or sister, coach, friend, someone you can trust. *Don't struggle alone - let it out.* If you need confidential help - try calling a help line or visiting your school counsellor or doctor. **Talking about your feelings is often the first step in getting help and feeling better.**

## Sports

*Whether you are a sports person or not any type of physical exercise - big or small - has some sort of benefit.* With epilepsy, you can do and play sports just like everyone else. If your seizures are not well controlled it is not advisable to do water sports such as scuba diving or swim alone, or sports at heights such as rock-climbing or skydiving. Otherwise, get going - however you can.



## Relationships

Most teenagers worry about dating, whether or not they have epilepsy. Dates are scary enough as it is, let alone having to worry about other things like having a seizure! *Everyone who has been on a date knows the fear of being rejected!* It causes a lot of worry and feeling awkward. Rejection is part of dating and relationships. No one is spared. There are so many reasons for rejection... Anyway, it is a good idea to talk about your epilepsy with someone you are dating regularly, but it is fair enough to wait until the relationship feels comfortable.

## Life

### Take each day as it comes...

When there's a lot going on, worrying about the future can be scary. Thinking about it usually makes it worse and we often feel that everything will merely continue on a downwards slide.

Sometimes there's enough to deal with today to be concerned with looking ahead.

Deal with each day as it comes and do the best you can. When thoughts of a scary future creep in, think to yourself "just one day at a time...". It's not an easy thing, however it's worth giving it a go.

### A simple message...

- ◆ Believe in yourself
- ◆ Believe in your dreams, rights and abilities – but also be realistic
- ◆ Do things that make you happy
- ◆ Keep or develop interests and hobbies
- ◆ Make sure you are seen as a person first. You are not your illness. You are a person with interests, feelings, strengths, and weaknesses, who also has epilepsy.
- ◆ Tell your friends it's still OK to be invited out socially and do everyday things
- ◆ Talk to others with epilepsy, or similar issues. They may have their own ways of coping with problems that may help you.
- ◆ You are allowed to have bad days. Everybody does. Remember that bad days will eventually be followed by better days
- ◆ Try to think of life as a challenge and not as impossible. **Never lose hope.**
- ◆ Use humour to break the ice when other people are uncomfortable
- ◆ Don't forget to have fun and laugh
- ◆ Learn to accept help from people without feeling guilty or inadequate
- ◆ Let people know when you want to make your own decisions
- ◆ Fight the myths about epilepsy. Educate your close friends and teachers.

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