

What is 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 brain activity. During a seizure the brain cells fire much faster and all at once. This can affect your level of consciousness, body movements, behaviour and how you think or feel.

Seizures can also happen because of a reaction to head injury, serious illness, drugs or alcohol. Young children can have seizures when they are ill with a high fever. **These seizures are not diagnosed as epilepsy.**



Anyone can develop epilepsy at any age.

What causes epilepsy?

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

- Traumatic injuries to the brain or head, such as in a car accident or serious fall.
- Lack of oxygen to the brain. For instance this could happen at birth, from drowning or a drug overdose.
- Strokes and brain haemorrhages.
- Infections of the brain such as meningitis, encephalitis or a brain abscess.
- Some people are born with or inherit epilepsy.

What triggers or 'sets off' seizures?

The most common things that make seizures more likely to occur in people with epilepsy are:

- Lack of sleep or over-tiredness
- Missing medication
- Emotional or physical stress
- Other triggers include being unwell such as having colds, flu or vomiting and diarrhoea; not eating well and poor nutrition; flashing lights; hormonal changes in females, growth spurts in children and adolescents and many more.

Types of seizures

Seizures are classified into two groups:

1) FOCAL SEIZURES:

Focal seizures begin in a small part of the brain. Approximately 60% of people with epilepsy have focal seizures. They are divided into two groups, depending if your consciousness is changed or not.

- **Focal seizures with no loss of awareness**

The person stays alert and aware of what is happening around them and too them. Symptoms can include nausea, butterflies in the stomach, changes in taste or smell, hallucinations, fear, de ja vu or sensations or feelings that are difficult to describe. These seizures are brief can also be called an 'aura' or warning because they can happen before a more severe seizure.



- **Focal seizures with change in awareness and behaviour**

(focal seizure - formerly complex partial seizure)

Consciousness or awareness is altered. The person may seem vague, confused and stare blankly. They can also do things like fidget, fumble with clothing, chew, walk aimlessly and carry out repetitive or purposeless movements. They can last from 1-3 minutes and afterwards they are often confused for a short time, tired with little or no memory of what happened during the seizure.

2) GENERALISED SEIZURES:

These seizures involve both sides of the brain. The two most common types of generalised seizures are:

- **Absence seizures**

These last a few seconds, the person suddenly stops what they are doing – stare, at times may roll the eyes upwards or blink – then just as quickly, continue on with what they were doing. These can happen many times a day and are often thought to be daydreaming. They are extremely brief and the person is not usually aware of having these seizures.

- **Tonic-clonic seizures**

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 they may look very pale sometimes blue-ish. They may bite their tongue or cheek, 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

Life with epilepsy is not always easy, but people with good seizure control can lead a full and active life. Other people's attitudes and misunderstanding of epilepsy can be more upsetting than 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
- Most people with epilepsy 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 a very important part of managing your epilepsy



Driving

Driving is a big deal for most young people. It can provide a sense of freedom and independence. People with epilepsy can often get their driver's licence if seizures are controlled.

Some advice about getting your driver's licence:

1. As you get closer to driving age, it may be worth having your epilepsy reviewed. If you have had no seizures for at least 2 years, talk to your doctor about weaning off medications a good 6 to 12 months before getting your licence.
2. If your seizures are not controlled, this may be a good time for further review and possible changes in the treatment plan.
3. Taking your medication and keeping yourself healthy really helps with seizure control. Seizure control will help you get your licence.
4. Check the Roads and Traffic Authority website for guidelines for driving <http://www.austroads.com.au/drivers-vehicles/assessing-fitness-to-drive>

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.



Education

Some people with epilepsy can have difficulties with attention, concentration and memory. Find out what your school or university offers to help - there are many ways they can support you or provide provisions.

Parents or teachers may have expectations that are above or below your ability. Sometimes a different environment or teaching technique is all that is needed to help you learn or understand how you learn best.

Epilepsy should not be a barrier to education and achievement.

Sleep

Getting a good night's sleep is important. If you are a student, or you have ever gone without sleep for a number of days, you will know that lack of sleep can create challenges. The physical effects are very real and cause a lot of stress to the body. Sleep deprivation is a common trigger for seizures. It can stop anyone from performing at a capable level. Try to plan ahead if you have exams or assignments so you don't have to do all-nighters. Also with social events, think of having a nap before going out.

Medication

Taking medication not only controls seizures, but helps you get on with all of the above - and with life. The less you have seizures, the less interruption you experience in your daily life. If you are unhappy with the effects of your medication, it is a good idea to discuss this with your doctor - there are many different antiepileptic medications, and it is just a matter of finding the one right for you.

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. If you don't tell any of your friends about your epilepsy, then they probably won't understand a lot of things that are happening with you. If you do, then they should respect your choices, for instance not binge drinking, and not pressure you to do things you don't want to do. Most friends are understanding. Often their biggest fear is not knowing what to do.

If you tell them how you feel, there is a good chance they have felt the same way about a different situation. Just knowing that others understand can help you to cope. A true friend will not leave you but listen, understand and help when they can.

Feelings

Being a teenager isn't fun all the time - especially when the pressures you are going through become 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 some 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 to you.
- No longer hanging out with your friends.
- Loss of energy or motivation.
- Drop in grades at school.
- Thoughts of harming or killing yourself.
- Anger and rage.
- Using illegal 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.

It may help to talk to a teacher, parent, relative, older brother or sister, coach, friend, or someone you can trust. Don't struggle alone. If you need confidential help, try calling a helpline, visiting your school counsellor, doctor or call us and ask to speak to an epilepsy nurse.



Lifeline Australia 13 11 14

Kids Helpline 1800 55 1800

Headspace 1800 650 890

Talking about your feelings is often the first step in getting help and feeling better.

Sports

Whether you are a sporty person or not, any type of physical exercise - big or small - has some benefit. People with epilepsy can play most sports just like everyone else. If your seizures are not well controlled it is advisable to avoid water sports such as scuba-diving and swimming alone, or sports at heights such as skydiving or free rockclimbing. Otherwise, get into it - however, you can.

Relationships

Most people, including 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.

You may wonder when to tell someone about your epilepsy. Each situation is difficult, but when a relationship feels comfortable, and you trust the person, it may be an opportunity to talk about your epilepsy with the person you see regularly.

Everyone who has been on a date has felt the fear of being rejected, which is a very normal. If someone rejects you because you have epilepsy, then they are not worth seeing.

Tips to remember

- Believe in yourself and do things that make you happy.
- Believe in your dreams, rights and abilities.
- Keep or develop interests and hobbies.
- Make sure you are seen as a person first. You are not an epileptic. You are a person with interests, feelings, strengths, and weaknesses, who also has epilepsy.
- Tell your friends it's still okay 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. You have to have bad days to appreciate the good ones.
- 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.
- 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 family, close friends and teachers.

References:

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<http://www.adolescenthealth.org>

<http://www.tribalwell.org.au>

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This information is given to provide accurate, general information about epilepsy. Medical information and knowledge changes rapidly and you should consult your doctor for more detailed information. This is not medical advice and you should not make any medication or treatment changes without consulting your doctor.

