Epilepsy - lifestyle issues

Summary

- Epilepsy is different from person to person, and its impact will depend on the type of epilepsy and the unique lifestyle of each person.
- Learn about your own type of epilepsy so that you can make informed decisions about your lifestyle.

Epilepsy is a common condition of the brain in which a person has a tendency to have recurrent unprovoked seizures.

Many people with epilepsy and their families worry how epilepsy will affect day-to-day life. Just as epilepsy is different from one person to the next, managing and coping with the condition is different for everyone.

Having unpredictable seizures can certainly have an impact on your lifestyle. For some people this impact is minor, while others may need to make larger lifestyle changes.

Understand your epilepsy diagnosis

Getting a diagnosis of epilepsy can be a shock. It may take you some time to adjust, and may affect your physical, emotional and mental health. These can be challenging times, especially when working out the best treatment for your seizures.

Understanding your epilepsy means you can take a more active role in managing it with your doctor. If you have any concerns, discuss them with your doctor, so you can work together to find a treatment program that suits you.

It is likely that your diagnosis may lead to some unavoidable life changes. These may range from a change in your mode of transport, to adapting your job role or lifestyle habits so that they suit your health.

There are many online support groups for people with epilepsy, where you can share experiences and ask questions. It can really help to know there are other people who are going through similar issues.

Epilepsy seizure triggers

Some people with epilepsy may notice a link between certain situations and seizures. Activities or circumstances that increase the risk of a seizure happening are called seizure triggers.

Some commonly reported seizure triggers related to lifestyle include:

- lack of sleep
- overexertion or physical fatigue
- physical or emotional stress
- heat
- alcohol and other drug use.

These triggers are not the same for everyone and it may take some time to recognise your own triggers, especially if your seizures are infrequent. A good way to find out is to keep a diary of your seizures, and what was happening before you had each of them.

Although reducing your exposure to triggers may be helpful, it is important not to restrict your activities to the point where your interests and fun are excluded and you’re not enjoying life. Precautions should be sensible with a balance between risk and restrictions.
Driving and epilepsy
If you have a seizure while you are driving, it could cause a serious accident. It is dangerous for you, other road users and pedestrians.

When you are first diagnosed with epilepsy your licence will be suspended for a period determined by your neurologist. The length of this period will depend on things such as:

- what caused your seizure
- what type of seizure you had
- if you have epilepsy, and if so, what type.

In accordance with Australia’s driver licensing authorities (VicRoads in Victoria), people with epilepsy can drive as long as they meet certain criteria and their seizures are controlled. If you do not meet the required criteria, your license will not be renewed, or you may be issued with a conditional licence.

In most cases, people who have had a seizure are required by law to notify the Driving License Authority (DLA) in their state or territory and stop driving until a medical report is supplied. The DLA will consider the advice of your doctor, but will always make the final decision about your licence status.

Many people can return safely to driving once their seizures have become controlled, but the length of time a person must wait varies depending on their seizure circumstances.

Epilepsy and sports
Exercise can lead to improved physical and psychological health outcomes for everybody, including people with epilepsy, so don’t let epilepsy prevent you from participating in sporting activities.

Seizures during sports activity are rare – around two per cent of people with epilepsy have seizures that are triggered by exercise. Most sports activities should be safe as long as you avoid overexertion, dehydration, and low blood sugar levels. As a precaution, let people such as your coach, team manager and team mates know what to do if you do have a seizure.

Some sports are riskier than others for people living with epilepsy, especially if their seizures aren’t fully controlled. It is best to assess this risk on an individual basis. Talk to your health professional about which sporting activities you want to do, and the level of risk involved to you and others. Activities may be able to be adapted, or additional safety precautions put in place, to reduce the risk to an acceptable level.

Read more about epilepsy and sporting activities.

Epilepsy and travel
If you plan to travel overseas, it is a good idea to plan ahead and consider anything that may affect seizures during your trip. There are many things to think about, but some main points include:

- Take a letter from your doctor confirming your diagnosis and treatment.
- Pack more medication than you think you will need. Always keep your medications in their original containers showing your details.
- Take your prescriptions with you, and keep them on your person, or in your hand luggage.
- Keep supplies in different bags so if one gets lost, you still have some medication with you.
- Make sure the medication is available in your country of destination just in case you lose it all.
- Try to have a stopover if your flight is lengthy to lessen the sleep disruption.
- Avoid drinking water or eating salads in countries where the water is not considered safe to drink. Even brushing your teeth with bottled water is advisable in these countries. Vomiting and diarrhoea can reduce the absorption of your medication and cause seizures.
- Choose your travel insurance carefully, as insurance companies vary in the way they assess cover and in the charges that apply when you have a pre-existing medical condition. It is a good idea to carefully read their Product Disclosure Statement. The Chronic Illness Alliance has useful information about travel insurance for people with chronic disorders.

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Epilepsy and alcohol

Alcohol and anti-epileptic medications usually don’t mix well. Anti-epileptic medications can increase the effects of alcohol, making you feel intoxicated faster. Alcohol may also reduce the effectiveness of your medication, making seizures more likely.

Most adults with epilepsy can tolerate a small amount of alcohol (one to two standard drinks), but some people find they cannot tolerate it at all. If you find alcohol is a seizure trigger for you, then it is best to avoid it.

Excessive or ‘binge’ drinking is not recommended. This style of drinking is often associated with late nights, sleep deprivation, missed meals and forgotten medications, all of which can trigger seizures.

Ask your doctor about the interaction of alcohol with the medication you have been prescribed.

Read more about alcohol and epilepsy.

Epilepsy and flashing lights (photosensitive epilepsy)

Many people mistakenly believe that everyone with epilepsy has seizures triggered by flashing lights, television or video games (photosensitivity). In fact, this is quite uncommon – only about five percent of people with epilepsy have this response. Photosensitivity can also be triggered by natural light sources, such as sunlight reflections off water, or flickering between trees.

Medication can effectively control some seizures. Wearing wrap-around polaroid sunglasses, commercially available Z1 blue lenses, or patching one eye can also help some people.

Photosensitive seizures should not prevent you carrying out most normal daily work and leisure activities.

Epilepsy and stress

Many people with epilepsy report a strong link between stress and seizures, with stress being a common seizure trigger. However, a diagnosis of epilepsy may bring with it many potential stresses as well, many of which are long term (chronic). Sources of stress for people with epilepsy may include:

- seizures, and their unpredictability
- the type of seizure – focal seizures often involve unusual behaviours that many people would not recognise as epilepsy. These behaviours may be mistaken as intoxication, inappropriate behaviour or mental health problems and can cause embarrassment
- the risk of injury
- medication side effects
- teasing, bullying or social isolation
- employment difficulties and associated financial difficulties
- stigma of epilepsy
- in some cases, reduced independence.

Chronic stress may lead to increased seizures, which may consequently exacerbate the stress.

Stress has been demonstrated to have wide-ranging detrimental effects on health, but it is a normal part of life. It is important to recognise your own signs and symptoms of stress and to use strategies that you find helpful to manage your stress levels.

Epilepsy and relationships

It is common for people with chronic health conditions, such as epilepsy, to experience some challenges and fears with their relationships, especially when forming new relationships. This is particularly the case if people have experienced negative reactions to their epilepsy in the past.

Be open about your condition to the people close to you so they know what you are going through. Educating the most important people in your life about your condition is a major step to successful and happy relationships.
Epilepsy and intimate relationships

Juggling an intimate relationship and a chronic condition requires patience and commitment from both partners. If you feel that you need some help, don’t be afraid to seek relationship support. Taking a proactive approach to improving the health of your relationship can have positive health outcomes for you and your loved one.

Epilepsy should not stop you from having an intimate relationship. In some cases, your epilepsy or medication may affect your desire for sex. This is usually manageable, so see your doctor or neurologist and get a referral to the right professional.

Epilepsy medication and contraception

Some antiepileptic medications and hormonal contraceptives may affect each other’s effectiveness. If used in combination, this can lead to loss of seizure control, medication toxicity or an unplanned pregnancy. This does not mean that women with epilepsy cannot use hormonal contraception, but it does mean that they may need to use one that is suited to their antiepileptic medication.

Your doctor, neurologist or gynaecologist can help you decide what is the best form of contraception for you.

Epilepsy and pregnancy

Planning your pregnancy is very important if you have epilepsy. Speak to your neurologist before starting a pregnancy, so you can aim to have the best seizure control on the lowest effective dose of the right medication. By working with your doctor you can lessen any risks to you and your baby.

While antiepileptic medications can increase the risk of birth defects, most babies (over 94 per cent) exposed to these medications in utero are born healthy.

Medication can often be reduced well before falling pregnant, but most women need to stay on some medication because seizures during pregnancy can also be harmful to the developing baby. Folate supplements will usually be recommended to help protect your baby against neural tube defects (spina bifida).

If you have an unplanned pregnancy, do not stop your medication as this could provoke seizures. Contact your neurologist immediately.

Some forms of epilepsy are caused by genetic abnormalities but often the risk of passing on epilepsy to your child is low. People with a strong family history of epilepsy are at greatest risk of developing epilepsy. This is a complex topic that is best discussed with your doctor or a genetic counsellor.

Epilepsy and general well being

If you or your child have been diagnosed with epilepsy, it is not unusual to feel some anxiety, sadness or concern about your situation – this is a very normal reaction.

Whatever your age, you may be wondering how best to manage this new challenge. Learning as much as you can about your epilepsy may help you to feel more confident about managing the condition. A wide range of information and support is available.

Where to get help

- Your GP (doctor)
- Neurologist
- Epilepsy Action Australia Tel: 1300 37 45 37
- Epilepsy Action Australia have produced animated seizure first-aid videos aimed at both adults and children.
- The Epilepsy Nurse Line is a phone and email service to support people living with epilepsy and their families. The Epilepsy Nurse Line is available from 9am to 5pm, seven days a week in all Australian states and territories. Tel. 1300 EPILEPSY (37 45 37) or email epilepsy@epilepsy.org.au
- Epilepsy Foundation Victoria, Information Line: 1300 761 487 or (03) 8809 0600

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