

Fact Sheet 21

Being a teenager and having epilepsy

Becoming a teenager is often a difficult time in a person's life and the path to adulthood can be a tricky one. Teenagers will experience intense physical and emotional changes as a result of puberty. They will face parental, societal and school expectations, peer and social pressures, discovering new relationships, independence issues and they will be developing self-identity and self-esteem. In other words, it is a period of dramatic growth and personal development.

For teenagers with epilepsy, there can also be added stress as they seek peer acceptance and autonomy around their condition. Stigma is associated with poor psychological health and it is keenly felt by teenagers with epilepsy who are already grappling with discovering who they are, and their position in the world. Teenagers with epilepsy may also face challenges such as medication compliance, driving, drinking, taking drugs, and unplanned pregnancies.

A teenager's guide to living well with epilepsy:

Seek support from your family and friends to live well with your condition. Practise PEACE:

Participation, Encouragement, Acceptance, Comfort, Empowerment. A circle of caring and supportive friends can help you in your transition to adulthood as you live with epilepsy.

Participation: Epilepsy does not define who you are. Freely participate in safe activities that interest you whilst managing your epilepsy well. Take responsibility for keeping yourself safe by managing your seizure trigger(s) and regularly taking your medication.

Encouragement: To be who you want to be, within reason. Having epilepsy can potentially create employment and life challenges but it does not mean that you cannot be the person that you want to become. Take advantage of educational opportunities, learn a skill set and sell yourself. Keep focused on attaining goals for a positive future.

Acceptance: Telling your friends that you have epilepsy is entirely up to you but you may find them to be supportive and wanting to find out more about your condition so they can help you. If you experience any form of bullying, please seek help.

<https://www.youthline.co.nz/infozone/bullying/>

Everyone needs to feel safe in our society and it is important for your self-esteem that you feel accepted for having a condition that is actually not uncommon.

Comfort: You are not alone. Ask help from those around you regarding the various aspects of your epilepsy. Your epilepsy advisor can put you in touch with others your age. There is nothing like sharing your epilepsy stories to understand how to live positively.

Empowerment: Feel more confident and stronger in yourself by understanding your epilepsy condition. (<http://ewct.org.nz/what-is-epilepsy/> and <http://ewct.org.nz/epilepsy-types/>) Take responsibility for self and freely ask questions of your GP, neurologists or epilepsy advisor about aspects of epilepsy that may concern you. Knowledge is power!

2. Understand your emotions

It is not unusual for teenagers to feel angry or anxious about who they are, or about their life, and a teenager with epilepsy is no different. A teenager with epilepsy, however, may be anxious about the unpredictability of the seizures and how his/her medications affect him/her, and have concerns about relationships, feelings of social isolation or coping with other's fears and prejudices. A chat with a trusted adult may help, however. Epilepsy is not a mental illness, it is a neurological condition and so feelings of anger and anxiety are perfectly normal reactions to stress. However, some medications can cause mood changes. Seek medical help if you are aware of this happening, especially if you believe that you are depressed as a result of your anti-epileptic medications.

There is also the commonground.org.nz website where you can access information that will support you to manage the hard times and enjoy positive well-being as a teenager.

3. Have regular epilepsy check-ups

Once you have been seen by a neurologist, your GP (doctor) will take responsibility for your epilepsy condition with regard to prescribing your medications, making sure that your seizures are under control and that you are feeling well. It is important to find a GP with whom you can openly talk to about your epilepsy. Show the GP your seizure diary, if you are recording your seizures, and freely discuss your concerns if you have any. You are entitled to take a support person with you to any medical consultations, and to take notes.

- You are covered by the "Health and Disability Code of Rights" <http://www.hdc.org.nz/the-act--code/the-code-of-rights>
- You may wish to phone Healthline 0800 611 116 for free and confidential health advice
- Get your free seizure diary from your EWCT epilepsy advisor.

Understand your medication

Get to know your pharmacist well. He/she will provide free, confidential and professional advice to you about your anti-epileptic medication. Discuss possible side effects, how to take your medication properly, and possible interactions with other medicines such as the contraceptive pill, alcohol, recreational drugs or natural therapies that you may be taking.

Do not adjust or stop taking your medications except on the advice of your epilepsy specialist.

Make sure that you never run out of your medications. Plan around public holidays and travel. If you intend travelling take enough medications for your trip and a copy of your prescription. Seek advice from your pharmacist should you be taking an overseas trip. See our fact sheet on [epilepsy medication](#) for more information.

5. Understand your triggers

Some events or situations can lower the seizure threshold and make a person more vulnerable to seizures. If you learn which things may trigger your seizures, then you and your GP can learn to manage your epilepsy more effectively. Get a free copy of a seizure diary from your EWCT epilepsy advisor to help you to record your seizures.

Here are some common seizure triggers:

- Missed medications or medication change
- Tiredness or sleep deprivation
- Stress
- Alcohol and recreational drug use
- Feeling unwell
- Menstrual periods in women.

6. Driving

Most teenagers want to learn to drive in New Zealand, and it is possible to do so in many cases, even if you have been diagnosed with epilepsy. In most situations, epilepsy treatment with medications should not prevent you from driving, but it is essential you seek the support of your GP or epilepsy specialist because there are strict regulations regarding driving with epilepsy in New Zealand.

See our driving and epilepsy fact sheet for more information.

7. School

Staff at schools are obliged to take into account the fact that you have epilepsy when understanding your social, emotional, academic and physical needs. Having epilepsy can be challenging and so encouragement and positive interactions at school are important for your general wellbeing.

If you're a teacher please see 'How to help a student' fact sheet for more information.

8. Tertiary education

Make yourself known to the disability co-ordinator who will be able to provide you with a support system in your classes, should you need it. Most students require strategies to handle the stress around assignments and so managing your stress levels are likely to be important to avoid having seizures.

Know your seizure trigger(s) and practise good seizure management, even if it means having plenty of rest and sleep, a good diet, cutting back on your caffeine intake and avoiding alcohol. This is easier said than done, when the work is piling up, but you may have to negotiate extra time for completion of work, or in exams, from time-to-time. Unless you make it known that you need help, then your disability co-ordinator will not know how to help you. At this stage in your life, you are considered an adult and so personal care and responsibility are expected.

9. Applying for a job

On many job application forms you are asked to disclose if you have a disability or health condition that could affect your ability to work. If there is no specific question on the application form, then there is no need to reveal it. Take a look at this website that clarifies when, and how, to disclose your health condition.

<https://www.workwise.org.nz/uploads/files/resources/Sharing-personal-information.pdf>

Some employers are reluctant to hire people with epilepsy because of their fear and prejudice, but there is no reason why your condition (if your seizures are well controlled) should be held against you when applying for jobs. You could ask your GP to write a letter of support for you. Most people do not understand what epilepsy is, and that it is a spectrum of disorders with at least 40 different types of seizures and with varying degrees of severity.

Most people with epilepsy (at least 70%) are well controlled with medications and they work in a wide variety of jobs where their epilepsy does not impact on their safety or the safety of others. Do your own research about a job that potentially suits your qualities, your qualifications, interests and skills, and at the same time consider your epilepsy condition. Complete the “careers quest quiz” if you need inspiration in choosing a career.

<https://www.careers.govt.nz/tools/careerquest/>

Some jobs have known occupational hazards that would pose even greater risks to people with epilepsy, and you would automatically be barred from applying for them. Use your common sense when applying for jobs. Be positive and seek help in finding employment. Most people find jobs through word of mouth and so sell yourself.

You could try organisations such as Workbridge that help people with disabilities find employment. Check out the Young Person’s Resource Centre <http://www.ywrc.org.nz/> and know your employment rights.

10. If you have a job

If you have not disclosed that you have epilepsy, it may be useful to do so just in case you have a seizure at work. Let your colleagues know what sort of seizures you have and devise an action plan so that everyone knows how to help you should you have one.

You may need to have a conversation with your boss to discuss why you need some time off now and then for a neurology appointment or to recover from a seizure. It is about being reasonable and fair. Employers and employees are governed by the “Health and Safety in Employment” Act and reasonable care must be taken to ensure everyone’s safety, including yours.

If you have concerns about your employment, you may wish to contact the Young Person’s Resource Centre: <http://www.ywrc.org.nz/>

11. Partying

Most teenagers want to go out and have a good time with their friends but be aware that a lack of sleep and drinking alcohol may increase your seizure activity the following day. Both alcohol and recreational drugs will interfere with your medications, and so you will very likely experience an increase in seizure activity. Continue to take your medications anyway. If you are driving, you risk losing your licence should you have a seizure, and so you may wish to become your group’s ‘safety driver’ and enjoy the night out with a clear head!

On medical grounds, it is best to avoid drinking alcohol and taking (non-prescribed) drugs when you have epilepsy.

For general advice and information on drinking and taking drugs please see <http://www.commonground.org.nz/common-issues/the-hard-stuff/>

12. Forming relationships

It is often during this time that teenagers start to learn about, and experience romantic relationships with others. It can be a time of intense and emotional feelings and anyone involved in a relationship is likely to experience rejection at some time or another. Being rejected is not unique to people living with epilepsy.

As a teenager with epilepsy, there is no need to disclose that you have the condition in an early relationship until a feeling of trust has been established. Once you feel confident about the relationship developing into a positive one, then it is best to tell your ‘partner’ about your epilepsy. Good relationships are built on trust and so openness about your epilepsy is important.

People with epilepsy can generally enjoy the same sexual feelings and pleasure as everyone else. Having sex does not normally bring on a seizure but the anxiety about your sexual performance may. Some anti-epileptic drugs (AEDs) can possibly lower your sex drive.

Some AEDs can interfere with the contraceptive pill and some women with epilepsy may fall pregnant because of this interference. At other times the contraceptive pill may interact with the AEDs by reducing the amount of AED in the blood, therefore resulting in more seizures. Bleeding between periods is a sign that the contraceptive pill is not providing enough protection against an unplanned pregnancy. Professional advice on AEDs and contraceptive use is essential.

13. Becoming a mother

Pregnancies should be planned, at least a year in advance, as this enables the neurologists to review your anti-epileptic medication. Some AEDs can affect the development of the unborn baby and so specialist advice and support are essential at least 3-6 months before starting a family. Most babies are born healthy to mothers who are taking AEDs.

AEDs affect your body's ability to absorb folic acid and so it is advisable that you take higher-than-usual doses to prevent nervous system defects such as spina bifida in your developing baby. Iodine supplements are also recommended. Your specialist will prescribe an AED that gives you best seizure control whilst protecting your baby from its side effects. Any risks will be kept to a minimum. The effect of being pregnant is unpredictable in all women. Some may experience an increase in their seizures whilst others can have a decrease.

Read practical advice for new mothers in our '[epilepsy and motherhood](#)' fact sheet.

14. Quality of life

There are certain factors that will improve your quality of life. How well you live with epilepsy is dependent on a number of things.

Accepting that you have epilepsy does not come easily for some but it is important that you come to terms with having this condition. Epilepsy is one of a number of medical disorders that can affect anyone in life. It is complex and requires the medical and professional support of your neurology specialists. Patience is often required when finding a suitable medication and epilepsy management plan. Do not get disheartened but think of your long-term goals in life and work towards them.

Taking responsibility for your epilepsy management which involves taking your medications regularly and knowing your seizure triggers. The idea behind doing this is to reduce having seizures and the risk of injury (and in some cases potentially death) as a result of them.

The impact of your seizures could also result in absenteeism at work, study or social activities, or even the loss of your driver's licence, if you have one. Be encouraged to learn that at least 70% of people with epilepsy have excellent control of their seizures through taking their medications.

Go easy on alcohol, recreational drugs and smoking. Preferably avoid them altogether. For general information on this topic see: <http://www.commonground.org.nz/common-issues/the-hard-stuff/alcohol-and-cigarettes/>

Understand the importance of sleep in seizure management. The lack of sleep and missed doses of medications are common causes of increased seizure frequency.

Take advantage of your mobile phone and what it has to offer. It can be used to help you with remembering tasks, when to take your medications, accessing help, keeping you in touch

Many phones can connect you with the internet for valuable information on epilepsy. Under your contacts list, have an ICE number (in case of an emergency), for quick access.

The downside of having a mobile phone is the dependency one can have with it. It is fun to have contact with your friends but make your last text message at night several hours before you go to sleep. Having a mobile phone can also create distractions and sometimes lead to cyber bullying which in turn creates stress. Stress is a known seizure trigger.

Don't let the computer replace human contact. It is important not to withdraw from family and friends and into the world of computer games when you have epilepsy. A lack of human contact is unhealthy psychologically. People with epilepsy can face social isolation and it is important for you that you do not allow that to happen. You need to place value on real events happening in your life and take responsibility for them.

Late night computer sessions will also hack into your much needed sleep time. This lack of sleep and missed medications will cause an increase in your seizures.

Stay fit and healthy. Consider engaging in physical activity such as jogging, gym work, or in a team sport. Get those natural endorphins whizzing around your body and feel good emotionally and physically. It is possible you may be able to participate in a range of sporting activities. Take a look at our [Epilepsy and Sports](#) fact sheet to see which activities best suit a person with epilepsy. Use your common sense when choosing a physical activity and protect yourself and those around you should you need their help in the event of a seizure happening. Let someone in your team/gym/swimming club etc. know that you have epilepsy. Put in place a simple seizure action plan.

Start to develop your own independence. Know that you can put things in place that will help you to build your confidence.

- Wear a medic alert bracelet or necklace for identity <https://www.medicalert.co.nz/>
- Join St John as a member. It is cheaper this way than having to pay for each ambulance ride, should one be called for you. <http://www.stjohn.org.nz/>
- Put in place some safety measures for yourself, especially if you are going flatting Say, "If I had a seizure now, what would happen to me?" Take a look at <http://ewct.org.nz/safety-in-the-home/> and <http://ewct.org.nz/safe-cooking-strategies-people-epilepsy/>
- Set an alarm to remind you about taking your medication.
- Allow people around you to understand how you want to be treated should you have a seizure and tell them how you generally feel afterwards. Communication is the key to your autonomy and in developing a positive self-esteem.

Seek help at any time from your GP, neurologist, parent, counsellor, a trusted friend or adult. It is well recognised that the transition into adulthood can be a tricky one.

For more information on epilepsy, please go to <http://ewct.org.nz>