Fact Sheet 34

Epilepsy and Wellness

Epilepsy is a complex neurological condition that can affect the quality of life for each individual living with it. However, with education and support it may be possible to improve the way in which those with the condition are able to live well.

Once an epilepsy diagnosis has been made, and a treatment plan has been developed, then the next phase is about living well and improving quality of life. You can do this with managing the things that you can control for yourself, for example by taking your medications correctly, sleeping well, controlling your stress levels, and eating healthily. In a nutshell, managing your epilepsy and living well is about taking control and being empowered to live a good life despite coping with a condition that is complex and sometimes challenging to manage medically. Here are some strategies to help you to live well (extracted mainly from EWCT's book "Understanding and Managing Epilepsy – an Introductory Guide" by M. Lowe and D.J. Lowe. See https://ewct.org.nz/product/understanding-and-managing-epilepsy-an-introductory-guide/).

A. Find yourself a good GP

Once your neurologist has your epilepsy under control you will discharged from their care and you will be looked after by your GP. It is really important, therefore, that you find a GP who you can relate to since managing epilepsy can sometimes require a lot of patience, and trust, in order for things to go well. It is preferable to see the same GP for each visit because that person will know your history and be aware of specific personal circumstances relating to your condition. Appointments to see your GP are often limited to 15 minutes and so make the most of that time (or ask for a double appointment).

Take along your seizure diary. It provides a record of your seizures and possible comments, or concerns, about medication side effects, seizure triggers, sleep, anxiety, mood, etc. Be prepared with your list of questions and ask someone to go with you if you are in need of support. Sometimes that extra pair of ears is needed to understand and remember what is being said. If you need to see a neurologist again to review your medications, or to discuss major issues associated with your epilepsy, ask your GP to refer you to the neurology department at the hospital. Remember to attend all GP and hospital appointments. If you cannot go to your appointments, please let the receptionists know in advance so that another person can take your place.

B. Find yourself a good pharmacist

Pharmacists can support you by providing sound information about your medications, how to take them correctly, and by offering a range of other advice to help you manage your condition in an

C.Regularly take your medications

Taking medications correctly will become an important part of your daily routine. Having a 'steady state' of ASM in your blood at all times helps to prevent seizures from happening. It is recommended that ASMs are taken routinely, twelve hours apart, for example at 7 am and again at 7 pm. Sometimes you may forget to take your medications (and that is very normal). Use the guide in the box below to help you decide what to do if you forget your medications.

- If you take medications once a day: take the forgotten dose as soon as you remember it.
- If you take medications twice a day: take the forgotten dose if you remember within six hours after it was due. If you forget altogether, just take the next dose at the due time.
- If you miss a dose, do not take twice as much at the next dose time as this larger dose may cause side effects.

When you collect your ASM medications from the pharmacist, please make sure that they are the ones that you have been prescribed. Receiving the wrong medications can lead to side effects or break-through seizures. A single break-through seizure can have an impact on your ability to drive, your employment, your wellbeing and, in some cases, it increases your risk of injury or harm. ASMs have the potential to increase, or decrease the blood levels of other medications that you may be taking (such as antidepressants, birth control pills, blood thinners, etc). Make sure that your GP and pharmacist have a complete list of the prescription, and also any over-the counter medications that you are taking, so that they can check for potential medication interactions. Have your medicines organised in blister packs or sachets by your pharmacist if you need support to enable you to regularly take your medications. Alternatively, you can manage the ASMs yourself by putting them in a weekly pill container. These options take away the guess work of remembering whether or not you have taken your medications on any given day.

If you are having problems with your medications, do not give up. It can take a long time to find the right medications, or combinations of medications, that can work for you. Voice any concerns about your side effects with your GP, pharmacist, or neurologist, and ask them to explain how to take your medication correctly. Medications can be changed, if they are not working, or the dose can be 'tweaked' − but remember that all changes are to be made by your medical professional and not by yourself.

D.Use your seizure diary

A seizure diary, whether in book form or as an app on your phone, is a really useful way of keeping a record of your seizures and their manifestation.

The aim of your seizure diary is to record:

- What your seizure looks like
- How often your seizures occur (frequency)
- The medications that you are taking

- The side effects that you are experiencing from your medications
- Events or situations that may be triggering your seizures (e.g. exam cramming, partying).

These details are known as the history around the seizure. You need to ask others who have seen your seizures to help you describe them fully and accurately. Please take time to carefully record your seizure types so that others may help you with managing your epilepsy successfully. Remember to note anything that you did that was unusual (e.g. forgetting to take your medication, poor sleep, excess alcohol, recreational drug taking). You may have to think back 24 hours before the seizure took place to get a clear picture. By using a seizure diary, it helps you to understand your epilepsy better. In some cases, if you understand your seizure trigger, then you may be able to change or modify situations or behaviour to prevent seizures from happening again. (You can obtain a free epilepsy seizure diary from your EWCT epilepsy advisor.)

E.Sleep well

Having good, regular sleep is helpful for your general wellbeing. It helps your body to heal itself, for the brain to forge new connections, and memory retention. Poor sleep, on the other hand, can affect your overall health and make you prone to medical conditions such as obesity, heart problems, heart disease, high blood pressure, and diabetes. People living with epilepsy can experience poor sleep. This poor sleep can make seizures more likely to occur during the day. For others, sleep seizures can occur at night. They are linked to the different stages of sleep.

- **Stage 1 non-REM**: This lasts for only a few minutes. Breathing, heart rate, and brain waves begin to slow. (REM = rapid eye movement.)
- **Stage 2 non-REM**: This stage occurs before the body enters deep sleep. The muscles relax even more, and body temperature drops.
- **Stage 3 non-REM**: A person needs to reach this stage of deep sleep to feel rested, and it lasts longer in the first half of the night. Breathing and heart rate slow to their lowest levels.
- **REM sleep**: Within 90 minutes of falling asleep, a person enters REM sleep. The brain becomes more active, maximum dreaming occurs, and the arms and legs become temporarily paralysed.

If the body does not go through these stages several times a night, a person may wake feeling fatigued and unfocussed. Keep a sleep-seizure diary to record what is happening in your life and discuss any concerns that you have with your GP or neurologist. Be aware that sleep may be affected by the ASMs that you are taking and this is also worth mentioning.

Achieving healthy sleep routines becomes an important strategy in living well with epilepsy. How can this be achieved? Know that sleep routines may start several hours before you actually go to bed. Once you are in bed, on average, it should take you between 10 to 20 minutes to fall asleep.

- Avoid the temptation of having a late afternoon/early evening cup of coffee/tea or other caffeinated drink. It is believed that caffeine should be avoided for at least six hours before you go to bed.
- Avoid eating too late into the evening.
- Avoid exercise too late in the day. Try more relaxing activities instead.
- Go to bed at the same time each night, even on weekends and holidays.
- Likewise, wake up at the same time each morning, even on weekends and holidays. These nighttime and daytime routines help us to remember to take our medications on time. We will even function better during the day.
- Make sure that your sleep environment is quiet, dark, and safe especially if you are prone to having seizures during sleep.
- Turn off all your electronics such as phones, tablets, computers etc an hour or so before going to bed. The 'blue light' from these devises interferes with the production of our melatonin, the hormone which controls our sleep/wake cycles, and makes it harder for us to fall, and stay, asleep.

The National Sleep Foundation (NSF) in the United States of America recommends that people of different ages get the following amounts of sleep every 24 hours:

- **newborns (0–3 months)**: 14–17 hours
- **infants (4–11 months)**: 12–15 hours
- **toddlers (1–2 years)**: 11–14 hours
- **preschoolers (3–5 years)**: 10–13 hours
- **school-age children (6–13 years)**: 9–11 hours
- **teenagers (14–17 years)**: 8–10 hours
- **younger adults (18–25 years)**: 7–9 hours
- **adults (26–64 years)**: 7–9 hours
- **older adults (65 years and above)**: 7–8 hours

F. Manage your stress

When you are living with stress it can affect your entire well-being. You may find yourself struggling emotionally and physically or experiencing problems managing normal every day events. Little things can suddenly loom into feelings of helplessness and, when you have epilepsy, these can suddenly mean more seizures. Stress is a well-known seizure trigger and so managing your stress becomes an important life-skill to master if you are to avoid having them. No, or few, seizures definitely improves your overall quality of life.

We all have our own ways of managing stress but here are a few coping strategies that have been proven to be effective for most people.

- Assess your life stressors. What are they and when do they happen? Keep a record of how you are feeling because this may help you to process what is actually going on in your life. By identifying the problem, you may find better ways of coping.

- Try to avoid people or situations that are causing you to feel stressed. If that is impossible, could you think about changing your approach and your reactions? You may have to seek help from a counsellor to help you. If your stress is work-related then please seek professional employment advice. Your epilepsy advisor can also help if the problem is associated with epilepsy.
- Set aside sometime in your day to completely relax. You may wish to read a book, meditate, listen to music, or do some art. It is your choice.
- Practice a breathing technique. Many of these ideas are found on the internet when you google the words 'breathing techniques for stress relief'. Even simply counting to 10 slowly can help when you are feeling overwhelmed.
- Use positive thinking techniques that help you to see a situation in a different light. Quite often 'silver linings' can be found in stressful situations.
- Have a daily routine to help you to manage the demands on your time. Set priorities in your life, pace yourself, and avoid procrastination.
- Build exercise into your daily routine. Exercise has proven health benefits for stress levels, mood, sleep, and overall health. Choose an activity that you enjoy doing. Go outside and connect with nature!
- Connect with family/whānau and friends. Join a support group or club.
- Seek help from a member of your epilepsy team, GP, or counsellor if you are finding your stress too difficult to manage. They understand how epilepsy can affect your life and are available to help you.

G. Take care of your mental health

It is not uncommon for people with epilepsy to experience depression, anxiety, or to sometimes feel suicidal. Some people may even develop personality disorders and psychosis. In fact, it is so common, that the overall rate of people with epilepsy experiencing a mood disorder is 25-50% higher than that of the general population. Depression can be mild, moderate, or severe. It can be a single episode, a chronic recurrent issue, or a life-long illness but, regardless of this fact, there is hope in it being treatable.

There is a relationship between epilepsy and mood disorders. The reasons for this relationship may be because of one or more of the following situations.

1. The part of the brain which is affecting certain seizure types is also affecting mood. The more severe the seizure, the more severe the mood.
2. It is occurring as part of a person's seizure pattern. Some people may feel a sense of hopelessness hours, or even days, before a seizure (pre-ictal). This feeling usually resolves after the seizure. Others may experience sadness, fear, anxiety and a sense of hopelessness, or suicide, during a focal-aware seizure, and this feeling is called ictal depression. A low mood following a seizure is called post-ictal depression. People can become tearful, experience a sense of hopelessness, become irritable, have sleep problems, or even experience suicidal thoughts. These feelings can last for 12 to 24 hours after the seizure.
3. Some anti-seizure medications can have a negative effect on mood.

4. Finding the right anti-seizure medications to stop seizures from occurring can take some time. This delay creates uncertainty in a person's mind and he or she may feel vulnerable, anxious, or depressed.
5. Living with a condition that is episodic can be unsettling, and people can live in a state of amber alert – not knowing when a seizure is going to happen.
6. Living with a chronic condition can lead to negative feelings of sadness, anxiety, embarrassment, and even anger.
7. Epilepsy is a challenging condition. People with epilepsy are often stigmatised in society despite laws aimed to protect the rights of people living with a disability. People with epilepsy can have issues around employment, education, transport, housing, finances, and social isolation etc (see https://ewct.org.nz/living-challenges-epilepsy/). Facing ongoing difficulties in life can cause a sense of hopelessness which can lead to depression and sometimes suicide.
8. Other events that effect mood such as divorce, the death of a loved one, etc. If you are unsure of how depressed, or anxious you are, ask yourself how often the following statements feel true (or use a questionnaire for anxiety and depression):
    - Everything is a struggle
    - Nothing I do is right
    - I feel guilty
    - I would be better off dead
    - I feel frustrated
    - I have difficulty finding pleasure

If you can tick the box for one, or more, unhappy thoughts then it is best to seek help. Numerous organisations and websites provide questionnaires and offer avenues of support, including:

- www.depression.org.nz
- www.sparx.org.nz
- www.beyondblue.org.au
- www.lifeline.org.nz
- www.youthline.co.nz
- www.health.govt.nz

Most often anti-depressants and psychotherapy treatments, such as cognitive behavioural therapy, are used to successfully treat depression and anxiety when you have epilepsy.

H.Eat well

A good balanced diet from different food groups helps the body, and brain, to remain healthy. Most of our nutrition and daily calories should come from fresh fruits, fresh vegetables, whole grains, legumes, nuts and lean proteins and with ample sources of B6, B12, and folate.

There are no specific foods that generally trigger seizures but individuals may say that they cannot eat certain foods containing monosodium glutamate (MSG) or artificial sweeteners and colourings. Others will avoid certain foods if they believe them to trigger seizures. Grapefruit juice does not trigger seizures but it can interfere with medication levels associated with the Tegretol brand, and increase the side effects of certain ASMs. Ask your medical professional for advice if these concerns apply to you.

Drinks containing caffeine, such as coffee, tea, and energy drinks, have a stimulating effect on the central nervous system. How this stimulation affects people living with epilepsy and their anti-seizure medications is unclear. Some reports suggest that caffeine can increase the possibility of seizures occurring in some people.

Alcohol can make epilepsy medication less effective or make the side effects of medication worse. You could ask your GP or pharmacist if you are unsure.

Drink plenty of fresh water to avoid dehydration.

You may opt to use a specialized diet such as the ketogenic diet or gluten-free diet (if you have celiac disease and epilepsy) to control seizures. Please consult your neurologist and dietitian to help with this choice.

For more information see our fact sheet on epilepsy and diets.
https://ewct.org.nz/epilepsy-and-diets/

I. Exercise

Participation in exercise and sport is important for general health and emotional well-being. It can improve fitness levels, help with weight loss, increase aerobic and working capacity, and reduce stress. Choose an activity that you enjoy doing, but bear in mind that some sports and activities require a sensible level of health and safety precautions. Avoid activities that involves the possibility of head injuries, or serious injury because of a loss of consciousness. Activities where there is no bodily contact with the ground, or in water, are best to be avoided.

Here are some tips on how to exercise safely when you live with epilepsy:

- Seek medical clearance from your doctor first
- Avoid triggers of seizures such as stress, fatigue, and anxiety
- Take medications and stay well hydrated
- Ensure exercise is stopped if you feel faint, dizzy, or nauseous
- Wear a medic alert bracelet (see below) if training alone so that people will be able to know you have epilepsy
- Carry a mobile phone with an emergency number listed (in case of an emergency – ICE), when out exercising alone – for example, biking, running, or walking. Let people know where you are going.

J.Manage your seizure triggers:

A seizure trigger is an event or situation that can lower your seizure threshold and make a person more vulnerable to seizures. If you learn which things or situations may trigger your seizures then you can learn to manage your epilepsy. Common seizure triggers are:

- Missed medication
- Medication change
- Tiredness or sleep deprivation

- Caffeine/alcohol/drugs
- Stress (physical/mental/emotional)
- Illness and high temperature
- Missed meals/diet change
- Sensory stimulation, e.g. taste, smell, vision
- Menstrual periods in women (especially flashing lights)
- Atmospheric conditions
- Hormonal changes
- Feeling too hot/cold
- Being bored/thinking too hard
- Sleep apnoea
- Having a headache/migraine
- Hyperventilation
- Individual triggers