

Self-management is when someone with a chronic disease takes an active role to help manage their own illness. It includes things such as making healthy lifestyle choices and informed decisions about treatment, and actively monitoring and managing symptoms.

These practical tips may help you to better manage your seizures and gain more control of your life.



Medications

Antiepileptic medications do not cure epilepsy, but they can control seizures. Up to 70% of people with epilepsy who take their medications as prescribed do not have seizures. Many people with epilepsy have memory problems to some degree, so to help you remember to take your medications every day, some practical tips are suggested below:

Try to make it part of your daily routine like taking your medications at meal times.	Put your medications in a safe, visible place as a reminder.
Set a watch, phone or alarm clock to remind you.	Use a chart or calendar and tick when you have taken your medications.
Consider using a pillbox or ask your pharmacist to pack your medications into a pill pack. These usually have the day and time you are supposed to take the tablets.	Ask someone to remind you.

Other medications, including over-the-counter medications may interfere with how antiepileptic medications are absorbed, or make you more prone to having seizures. Speak to your doctor before taking any new medications.

There are also many different **brands and generic medications** on the market for epilepsy and your pharmacist may offer you one of these as an alternative.

Be aware that a generic product may not be exactly the same as the original brand and the non-active ingredients may differ - these include fillers, binders, coating or colouring. While specific guidelines and tests are conducted to make sure the generic medications are the same, a slight degree of variation is allowed. These slight variations may affect seizure control. Even a minor variation in blood levels of an anti-epileptic medication can lead to a higher risk of seizures - or possibly toxic side-effects for some people taking doses that already border on toxicity. The slightest change can make the difference between a medication not working, a medication working well, or being too strong.

Whether you are changing from brand to generic, generic to brand or generic to generic, this may increase your risk of seizures. So if your medication is working, continue with it - do not switch brands without discussing with your neurologist or prescribing doctor. Generics sometimes have a different name, different packaging, different tablets, and are often slightly cheaper.

Sickness such as vomiting and diarrhoea (which may also be side effects of antiepileptic medications) can affect reduce how much of your medication is absorbed so may trigger seizures. Also imbalances in your body's fluid and electrolytes can occur due to dehydration increase the chance of seizures.

Complementary therapies and supplements

Many people believe that alternative or complementary therapies, such as herbal remedies, are safe because they are derived from natural sources, but this isn't always true. Some of these therapies can act on the body as potently as any conventional medication, and unwanted side effects can occur. While most of herbal therapies and supplements are relatively safe in recommended doses, incorrect doses can be dangerous. They may also interact or "clash" with your antiepileptic medication.

Some people with epilepsy have reported having seizures after taking herbal and homoeopathic medicines or supplements. Substances known to possibly increase seizure frequency include Gingko Biloba, St John's Wort and Evening Primrose Oil. Gingko and St John's Wort may reduce the effectiveness of antiepileptic medications.

Other herbal products that have been reported to cause seizures in isolated cases include: ephedra, ginseng, borage, and essential oils such as eucalyptus, fennel, hyssop, pennyroyal, rosemary, sage, savin, tansy, thuja, turpentine, and wormwood. The exact mechanism of how these drugs may induce seizures is not known.

Talk to your doctor before taking any of these substances or herbal medicines as these may interfere with the metabolism of antiepileptic medications.

Check with your doctor before taking any other medications or supplements and always report unwanted side effects or medication reactions to your doctor or pharmacist immediately.

Other substances that can affect seizures

Caffeine is a stimulant found in coffee, tea, chocolate, many soft drinks, high energy drinks, some supplements and medications, including some diet pills, antihistamines and decongestants. Excessive amounts of caffeine can cause an increase in seizures in some people. In addition, caffeine may interfere with antiepileptic medications, and affect sleep patterns



Guarana is a natural caffeine source and a stimulant. It is a common ingredient in high energy drinks and herbal 'weight loss' teas and can combine with adrenaline to produce an even stronger stimulant effect.

Any substance that is considered a stimulant should be avoided or taken with care and moderation, as they are more likely to increase the risk of seizures. It's hard to know exactly how much caffeine is a problem, as its effects on the body vary from person to person. The rough guideline for the average person is to drink (or eat) less than 600 mg per day – around four cups of strong coffee, or five or six cups of tea¹. This would probably be less for someone with epilepsy. So limit your intake to two or three drinks at most.

Avoid large amounts of caffeine or switch to decaffeinated drinks.

There is much debate and controversy over the effects of artificial sweeteners. Opinions differ about their effects on health. Despite this, a number of people, including some with epilepsy, still think that the sweetener affects their health. If you use it, the best test is to try eliminating it from your diet, keep a diary and see if your health, or epilepsy, improves.

Grapefruit and Seville oranges may impact seizure control. There are substances in grapefruit that can interfere with the way the body absorbs and breaks down certain medications, increasing or decreasing levels of the dose in the bloodstream. One of the medications affected is Carbamazepine [Tegretol].

¹ <http://www.abc.net.au/health/library/stories/2006/04/27/1829125.htm>

To minimise the risk of adverse effects caused by grapefruit:

- **DO NOT** drink grapefruit juice or eat grapefruit in any form if taking Carbamazepine (Tegretol, Tegretol CR or Teril) until you have talked with your doctor or pharmacist.
- Avoid taking any medication with grapefruit juice until you discuss with your doctor or pharmacist.
- Read the labels on foods and natural health products to make sure they do not contain grapefruit or Seville oranges.



Lifestyle

Triggers are events or circumstances that make people with epilepsy more likely to have a seizure. **Identifying known seizure triggers and trying to avoid them is important for gaining better control of your seizures.** Avoiding seizure triggers can be difficult sometimes, so it is important to weigh up the risks and look at overall quality of life.

Common seizure triggers are; missed medications, fatigue, sleep deprivation and stress. Examples of some more individual triggers include:

- Flashing lights or changes in geometrical patterns (photosensitivity)
- Fever, colds or infections
- Extreme heat or cold, or sudden change in atmospheric temperature
- Low blood sugar and poor nutrition
- Hormonal fluctuations in females
- Change in sleep states (many people with epilepsy have only ever had seizures whilst asleep)
- Drug toxicity (too much antiepileptic medication or other medications)
- Medication interactions
- Emotional stress or anxiety
- Boredom
- Dehydration and over hydration
- Physical exhaustion
- Sudden shock or extreme pain
- Sudden loud noise

Sleeping

Lack of sleep is a common trigger for seizures. How much sleep each person needs is individual, but keeping to a regular bedtime and getting a full night's sleep (7-8 hours) as often as possible will be beneficial for someone with epilepsy.

People with epilepsy should not feel they need an excessive amount of sleep. Constant tiredness and sleepiness may be a sign that medications need adjusting. If you suffer from sleeplessness or overtiredness discuss the possible reasons with your doctor.

Drugs and alcohol

There are individual differences in the effect that alcohol has on seizures. Some people with epilepsy are more affected than others. Excessive alcohol intake is known to increase a person's risk of seizures. Alcohol and recreational drugs can interfere with the metabolism of antiepileptic medications in the liver and also contribute to dehydration.

These are a few important points regarding drugs and alcohol:

1. Most people with epilepsy can enjoy a social drink; however some medications used in seizure management do not mix well with alcohol. Always check with your doctor or pharmacist first.

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2. Heavy or binge drinking is not recommended. Not only the drinking can increase the risk of seizures but also late nights, missed meals, forgetting medications and poor sleep, can trigger seizures as well.
3. Both alcohol and many antiepileptic medications are metabolised by the liver. Chronic and excessive consumption of alcohol can cause liver problems that may alter the effectiveness of antiepileptic medications.
4. Some drugs or substances, such as alcohol, caffeine, nicotine and various prescribed and over-the-counter medications, are legal. Although they are legal, there are laws that restrict their availability, quality and price. Taken incorrectly or in large amounts may increase the risk of seizures.
5. Many illicit recreational drugs, especially stimulants such as cocaine, 'crack', ecstasy and speed [amphetamines] plus illicit synthetic drugs have the potential to cause seizures and it is uncertain what interactions these, or any illegal drugs, may have with any prescription medications.
 - a. These drugs are illegal. This means they cannot be subject to quality [or price] controls. A person using illegal drugs can never be sure of how strong the drug is, or what is actually in it. Different batches of an illegally manufactured drug may have different amounts of the drug and other unidentified additives. It is very risky for someone with epilepsy to take these drugs.
6. Federal and state laws provide penalties for possessing, using, making, selling or driving under the influence of illicit drugs. Penalties can include fines, imprisonment and disqualification from driving.
7. If you have concerns regarding alcohol or other drugs that you think are affecting your seizure control, discuss these with your doctor.



Most people with epilepsy agree that taking their medication regularly and simply being careful with lifestyle minimises their chance of having a seizure.

Recognise and respond to stress

Some stressors cannot be avoided but our response to them can change how they impact on our health. Identifying the causes of stress and finding practical solutions is important for everyone. People react differently to stress, and not all stress-management techniques work for all people.

Here are some known stress-reduction techniques:

- Muscle relaxation exercises
- Breathing techniques
- Yoga / Meditation
- Effective time-management
- Music
- Reading
- Exercise and sport
- Hobbies and crafts
- Avoiding stressful situations or people as much as possible
- Good support networks



Contact the local council or community health centre for classes or call Epilepsy Action Australia for information on programs aimed at enhancing social networks and providing support.

If stress is having a significant impact on your life, discuss any concerns with a professional such as a nurse, psychologist or counsellor.

Keep a seizure diary

Seizure diaries can help to identify seizure triggers, and provide a good overview of seizure frequency and presentation.

Your seizure diary needs to include:

- Date and time of seizures
- If you were asleep or awake
- Description or type of seizure
- What happened before, during and after the seizure, if known
- Medication taken and missed that day, including medication for other conditions
- Any possible seizure triggers
- General health and energy level leading up to the seizures
- Menstrual cycle for women

Keeping a seizure diary is a good way to identify possible triggers.

Our Services and Tools

My Epilepsy Diary

Epilepsy Action Australia has an online seizure diary My Epilepsy Diary that can be accessed on our website.

My Epilepsy Diary is a personal electronic diary to help you keep track of your epilepsy - putting you in control of your information and helping you keep an accurate account of your seizures, triggers and medications. All the above details and more can be added, plus reminders can be set up. You can access your diary anywhere, anytime, using your computer or smart phone.

E-Quip - a resource for youth

Equip is a self-paced online tool to assist young people with epilepsy to cope with the psychological, social and lifestyle demands of living with epilepsy.

Psychosocial Wellbeing for Adults Living with Epilepsy

A resource for adults living with epilepsy.

Join a program

A variety of programs encourage self-management through:

- Techniques to deal with issues such as frustration, fatigue, pain and isolation
- Appropriate exercise for maintaining and improving strength, flexibility, and endurance
- Appropriate use of medications
- Communicating effectively with family, friends, and health professionals
- Nutrition
- How to evaluate new treatments

Self-management is now encouraged in many aspects of healthcare, and with ready access to so much information people are now more likely to be involved in their own health decisions.

References/Further Reading

1. Comprehensive Epilepsy Centre <http://epilepsy.med.nyu.edu/diagnosis-treatment/alternative-therapies#sthash.AkLovKMT.dpbs>
2. Epilepsy Ontario <http://epilepsyontario.org/alternative-medicine/> Expert Patients UK <http://www.patient.co.uk/doctor/expert-patients>.
3. Australian Drug Info Clearinghouse <http://www.druginfo.adf.org.au/drug-facts/drugs-the-facts#sthash.FTZTjvr.dpuf>

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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.

