

Feature 1: Things you probably didn't know about medications

Most people take some form of supplement or medication, either regularly, as prescribed or when necessary, depending on the type of medication and what it is taken for. People with epilepsy take regular medication, so it is good to know a few things that can affect the medication or your seizures. Did you know:

Missing even one tablet can make a difference

Taking your medication as prescribed keeps it at constant levels in your blood. Missing a dose or a day can make it drop – how low depends on the type of medication as some are controlled release so their levels take longer to drop. Sometimes an imbalance like this can take the medication a few days to return to the therapeutic level. This increases the risk of seizures, so be diligent.

Some medications can interact with grapefruit juice

Grapefruit juice contains a chemical that can affect how medications are absorbed. This can cause you to either get too much or too little of what you need, which can be a seizure risk. A single glass of grapefruit juice is enough to increase the bioavailability of some drugs. If the juice is drunk over several days the effects are long-lasting, so simply separating the dose of medication and the ingestion of grapefruit juice does not prevent the interaction. For this reason, grapefruit juice should be avoided completely with certain drugs. With epilepsy one drug known to interact with grapefruit juice is carbamazepine (Tegretol).

Take them with or without food?

Food and its ingredients may have a significant effect on both the rate and extent of absorption of medication after taking them orally. Taking medication with food generally delays drug absorption. However, meals may have a variable effect on the extent of absorption - depending on the characteristics of the meal, the medication and its formulation. For most medicines, especially those used for chronic conditions, a delay in the onset of absorption is of no clinical consequence as long as the amount of drug absorbed is unaffected.



Some drugs have strict guidelines about when they should be taken in relation to meals. Your doctor and pharmacist will advise you whether or not it is important to take your medication with food.

** Note: Taking a medicine with a meal implies taking the dose within 30 minutes of a meal. Taking a medicine on an empty stomach implies taking the dose one hour before or two hours after a meal.*

They may lower your nutrient levels

Some antiepileptic drugs change metabolism and absorption of many vitamins and minerals. Therefore, people with epilepsy may be at higher risk of nutrient deficiency and its unwelcome effects. Before jumping the gun and taking vitamins and supplements though, speak to your doctor, ask for a blood test and take what you really need.

Growth spurts can make a difference to how much medication is needed

When children have a growth spurt or go through puberty, their medication may need to be reviewed as often the dose they were taking before the growth spurt is too low for their body needs. For this reason, seizures may occur around the time of growth spurts.

Medication changes may be needed as we age

Ageing can affect the way medicines are absorbed and used. For example, aged related changes in the digestive system can affect how fast medicines enter the bloodstream. Changes in body weight can influence the amount of medication needed and how long it stays in the body. The circulation system may slow down, which can affect how fast drugs get to the liver and kidneys. The liver and kidneys also may work more slowly affecting the way a drug breaks down and is removed from the body.

Because of these body changes, there is also a bigger risk of drug interactions for older adults. Drug-to-drug interactions happen when two or more medicines react with each other to cause unwanted effects. This kind of interaction can cause one

medicine to not work as well or even make one medicine stronger than it should be.

Don't lie down straight after taking your medication

Lying down immediately after you swallow a tablet slows its journey to your stomach. This may simply delay how long it takes to work, but some medications may irritate the lining of the oesophagus if they are in contact with it for too long.

Generic drugs aren't exactly the same as the original brand

A generic product is essentially the same as the original brand. Even though specific guidelines and tests are conducted to ensure the generic medications are the same, a slight degree of variation is allowed. This means that the generic product is not exactly the same as the original brand.

There are a few key differences:

- The most obvious differences are the tablets appearance and packaging.
- The formulation itself may not be exactly the same either. The non-active ingredients may differ – these include what is used as a filler, binder, coating or colouring.
- There are also minor differences in the active ingredient. These are very small because the generic preparation must be similar enough to the original to satisfy strict guidelines. The maximum variability between a generic and original medication is 10%.

Generic or brand formulations are both OK, but you need to stick to whatever brand you always take because even these small differences in antiepileptic medication can trigger seizures in some people who have epilepsy.

Changing your antiepileptic medication

If the doctor has prescribed antiepileptic medication changes, either a new drug or dosage changes, there is a good chance you will need to stop driving. Your doctor will advise you if you need to stop driving and for how long. When changing these medications, it can increase the risk for seizures, so it is a safety measure.

Over-the-counter medicines

Common over-the-counter medicines include pain relievers, laxatives, cough and cold products, and antacids. Some over-the-counter medicines however, can affect the way prescription medicines work or are used by the body. Always ask your doctor about over-the-counter medicines you take and when you are purchasing them at the chemist, speak to the on-site pharmacist first about interactions.

Don't store your medication in the bathroom

The bathroom is often a damp atmosphere and the additional moisture may affect the stability of the medication and possibly reduce its effectiveness. It is best to store them in a cool, dry and dark place, where the temperature and atmosphere is stable. Don't forget to keep them out of reach of children.

Don't mess with the medication

Don't chew, crush or break capsules or tablets or mix with a liquid unless instructed. Your body could absorb some long-acting medications too quickly if you chew or crush them. Other medications may be ineffective or could irritate your gut or make you sick. If a tablet needs to be crushed, then it may be worthwhile looking at different forms of the medication, such as a syrup form.

Don't keep old medications

Monitor prescription and over-the-counter "used by" dates and throw away expired ones. Some drugs may become ineffective or toxic after the due date, while others simply lose their potency. Dispose of old medications safely through the Return Unwanted Medicines scheme <http://www.returnmed.com.au/>

Check your mouthwash

If you do use mouthwash, it's a good idea to be aware of what is in it. While each mouthwash may be slightly different, most will include the following:

- Alcohol: or other antimicrobial agents to help kill bacteria and other germs that contribute to tooth decay and bad breath.
- Detergents: to help dislodge and remove food debris and loose plaque
- Flavours: and colours that improve the look and taste.
- Preservatives: that prevent growth of bacteria in the mouthwash
- Water: to dissolve the other ingredients
- Some include fluoride to help make teeth more resistant to acid attacks, and defend against tooth decay.

While these ingredients are only in your mouth for 30 seconds or less, it's probably wise not to use them straight after taking medication.

Further information

NPS Medicine wise <https://www.nps.org.au/>
Medicine Line 1300 MEDICINE (1300 633 424) Mon-Fri 9-5pm

Mouthwash - See more at:
<https://www.nationaldentalcare.com.au/does-mouthwash-work/#sthash.11719kQn.dpuf>

Vitamin and Minerals
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4928610/>

Over the counter medications
<https://www.medicalnewstoday.com/articles/16181.php>

Nutritional supplements, foods, and epilepsy: Is there a relationship?
<https://onlinelibrary.wiley.com/doi/full/10.1111/j.1528-1167.2008.01678.x>

Feature 2: Exciting new partnership with HealthMatch

Epilepsy Action Australia has joined forces with HealthMatch – a clinical trial matching platform, designed to make accessing clinical trials much easier for patients.

HealthMatch is a free service and aims to dramatically accelerate patient recruitment to clinical trials, with the intention to faster progress life-saving medical treatment onto the market.



By employing innovative technology, HealthMatch are able to match patients to clinical trials in a matter of minutes. You have to complete a once-off questionnaire to create your medical profile, which you can do yourself or with the help of your doctor, then your medical data is used to filter your eligible trials. (You can delete your medical profile at any time).

HealthMatch will constantly search for appropriate trials based on your medical profile. As new trials are created, they automatically check them for suitability. When a match has been found, you will be notified. You can then review your options and apply via your HealthMatch trial dashboard. When you have been accepted to a trial, HealthMatch will put you in direct contact with the trial group.

By simplifying the currently complex trial search process, HealthMatch put the metaphorical steering wheel back in the

hands of the patient. They don't just filter trials. They determine actual eligibility.

“At HealthMatch we believe that all patients should have access to every treatment option available to them. This includes clinical trials, which give patients access to new potential cures and medical breakthroughs.

This is why at HealthMatch we have developed a mobile app that allows patients to find clinical trials in the fastest and simplest way possible. A simple tool that matches patients in real-time to clinical trials tailored to their profile.

It's never been easier to take control of your own health and ensure you have access to the latest advances in medicine.”

What is a Clinical Trial?

A clinical trial is a scientific study, or an organised test of medication and new treatment options involving patient and healthy volunteers. Clinical trials confirm whether medicines are safe and effective to introduce as new treatments for a particular disease or condition.

Clinical trials may also be used to determine whether an existing medicine can be safely and effectively used for other diseases and/or conditions.

Who runs a clinical trial?

Each clinical trial is led by a doctor. The clinical trial team includes doctors and nurses as well as pharmacists and other health care professionals. The clinical trial team are responsible for checking the health of the participants at the beginning of the trial, monitoring them during the trial, and staying in touch with them for a period of time after the clinical trial has been completed.

Why be part of a clinical trial?

New interventions that help people to live longer, have less pain or be free of disability are only possible because of the willingness of people to be involved in clinical trials. Both healthy people and those diagnosed with a disease or condition are needed to help find new ways to diagnose, prevent, treat or cure disease and disability.

By taking part in a clinical trial, you can contribute to the advancement of scientific knowledge and, in some cases, to improved health for yourself or others with the same disease or condition.

Australia conducts internationally recognised high-quality clinical trials. Australian clinical researchers have a wealth of knowledge and expertise that is helping to improve health care both in Australia and around the world. Clinical research also improves our health care service by improving patient care practices.

Like any volunteer work, clinical trials can also be a way to give back to the community.

People with epilepsy may decide to participate in clinical trials to contribute to better understanding of, or better treatment or a potential cure for epilepsy. In some cases, clinical trials can provide access to new interventions before they are widely available.

Trials also offer the hope of developing better interventions or tests for a particular disease or condition, so that even if a trial does not provide a benefit for you, it may provide benefits for others in the future.

As a patient participant, even when you receive the highest quality care, you may also benefit from additional support and attention provided by clinical trial staff who understand your disease or condition.

There are a number of possible advantages of participating in clinical trials. These can include:

- Gaining early access to new medicines not otherwise available;
- Obtaining the clinical trial medicine at no cost, at least during the trial;
- Receiving extensive medical care associated with the clinical trial; and
- Contributing to the development of future life-saving or life-enhancing treatments.

Participation in clinical trials is not, however, without its downsides. For example:

- There may be side effects from the trial medicine;
- The trial medicine may not work;
- You may be placed in the control or reference group and not receiving the trial medicine until after the clinical trial has finished; and

- You may need to visit the hospital or doctor's room more frequently or stay there longer.

Are all clinical trials the same?

There are four different types of clinical trials, each one associated with a different phase in the development of a new medicine or treatment:

- Phase I clinical trials involve the first administration of the medicine to humans, usually to small numbers of healthy volunteers. Phase I clinical trials determine the safety of the medicine, how it works and how well it is tolerated. These clinical trials also identify preferred routes of administration (eg. tablet, liquid or injection) and help determine the appropriate doses for later studies.
- Phase II clinical trials are normally the first trials of the medicine in patients suffering from the condition for which the medicine is intended. The principal aim of these clinical trials is to determine effectiveness and safety. These clinical trials are undertaken in a small number of closely supervised patients and conducted by researchers regarded as specialists in the particular disease or condition and its treatment.
- Phase III clinical trials involve greater numbers of patients and are undertaken for the purpose of determining whether the medicine gives clinical benefit in the disease/s for which effectiveness was demonstrated in Phase II clinical trials. They also determine the nature and likelihood of any side effects. Phase III clinical trials are undertaken if the Phase II clinical trials indicate the medicine has potential benefit that outweighs the hazards.
- Phase IV clinical trials are those clinical trials undertaken after the medicine has been approved for treatment of a particular disease. Phase IV clinical trials are undertaken to compare a new medicine to a wider range of existing medicines/therapies. Such clinical trials are used to establish where, in the range of treatment options, the new medicine is best used.
- Phase IV clinical trials are also undertaken to further investigate the use of the medicine in the normal clinical setting of the disease, as this may differ quite markedly from the conditions under which the other clinical trials were conducted. This includes post marketing surveillance studies.

Register your interest as a participant in future clinical trials with Health Match and read more [here](https://www.epilepsy.org.au/research/participate-in-research/)

<https://www.epilepsy.org.au/research/participate-in-research/>

In the News – The latest on epilepsy

New research could help predict seizures before they happen

A new study has found a pattern of molecules that appear in the blood before a seizure happens. This discovery may lead to the development of an early warning system, which would enable people with epilepsy to know when they are at risk of having a seizure. Read more

https://neurosciencenews.com/seizure-prediction-14206/?utm_source=feedburner&utm_medium=feed&utm_campaign=Feed%3A+neuroscience-rss-feeds-neuroscience-news+%28Neuroscience+News+Updates%29

New building for research

Tech giant IBM and Melbourne University will establish a \$10 million artificial intelligence centre, focused on using the technology to solve some of healthcare's most challenging problems, including epilepsy. Read more

<https://www.afr.com/technology/technology-companies/ibm-invests-10-million-in-melbourne-uni-ai-centre-20190606-p51va7?fbclid=IwAR1XKtLqzTck7f7txqp2Yof2NhzqICcCxClxBoBEouqjUXeiQGSsk-BhjJo>

World-first trial offers hope for epilepsy sufferers

A trial of deep brain stimulation therapy at the Austin Hospital Melbourne for people with Lennox-Gastaut syndrome, a complex epilepsy syndrome that typically appears in childhood. Read more

<http://www.austin.org.au/news/worldfirsttrialoffersepilepsyhope/>

Sydney led research aims to improve quality of life

The Deputy Director of the Sydney University's Nano Institute and his team are working on technology that aims to achieve real-time monitoring and processing of brain-signals with the goal of predicting oncoming seizures. Read more

<https://www.news.com.au/technology/innovation/inventions/sydney-led-research-aims-to-bring-back-portion-of-life-for-people-with-epilepsy/news-story/b37cfcf802e359a2a1a638aa48dcfcae>

Many people with subtle seizures don't get diagnosed for years

Professor Jacqueline French explains the dangers of delayed diagnosis.



<https://www.neurologylive.com/conferences/aan-2019/jacqueline-french-dangers-delayed-diagnosis-epilepsy>

SUDEP Action wins award for life-saving epilepsy tools

Judges commented that the 'outstanding winner' of the category were two free lifesaving epilepsy safety tools; the digital app EpSMon for people with epilepsy, and the clinician tool, the SUDEP and Seizure Safety Checklist. Read more:

<https://www.oxfordmail.co.uk/news/17623039.sudep-action-win-bmi-award-for-life-saving-epilepsy-tools/>

Vagus nerve stimulation (VNS) effective in treatment of epilepsy and comorbid depression.

While well established in the independent treatment of epilepsy and depression, findings indicate vagus nerve stimulation (VNS) may also be effective in the treatment of medication-resistant epilepsy and comorbid depression. Read more:

<https://www.neurologyadvisor.com/topics/epilepsy/vagus-nerve-stimulation-beneficial-in-epilepsy-and-comorbid-depression/>

Q&As – Our service providers answer your questions

Q: I have terrible memory problems and have heard that Ginkgo can help with memory loss. Will it affect my seizures?

A: Ginkgo biloba is promoted as a treatment for a variety of ailments including memory loss and dementia, poor concentration and mood, but studies haven't confirmed that Ginkgo biloba extract prevents memory loss or slows the progression of cognitive decline. Some studies have shown modest improvements, but most haven't confirmed it is useful in improving memory. Apart from this, there is growing evidence that Ginkgo may increase the risk of seizures in people with epilepsy and could reduce the effectiveness of anti-epileptic drugs. Ginkgo may be found in other herbal products so it is

important to check ingredients before taking any new product. It is not recommended people with epilepsy take Ginkgo Biloba.

<https://www.acs.org/content/acs/en/pressroom/presspacs/2010/acs-presspac-april-14-2010/ginkgo-herbal-medicines-may-increase-seizures-in-people-with-epiy.html>
<https://www.mayoclinic.org/diseases-conditions/alzheimers-disease/expert-answers/ginkgo-biloba-memory-loss/faq-20058119>

Q: I'm hoping to train my puppy to be a seizure response dog. Am I legally allowed to bring him with me in public places whilst I'm training him?

A: It's great that you are hoping to train your dog in this manner. Unfortunately, unless you go through the proper channels (using a service/assistant dog organisation) he will not be allowed on public transport or in shops unless he is wearing the appropriate coat. To have a Certified Public Access Dog you must have a diagnosed disability that an Assistance Dog can be trained to do specific tasks to assist this person. The trained tasks must be able to assist that person to live a more independent life and to help that person to be able to be more inclusive in the community. There are many assistance dogs organisations. This is one organisation, but be aware there are different rules in each state <http://www.dogandcatboard.com.au/accreditation-of-disability-dogs> If you contact a relevant organisation in your state, they will be able to explain how it works.



Q: Do you have any information on the Modified Atkins Diet?

A: The Modified Atkins diet (MAD) is a combination of the classic Ketogenic Diet, and the Atkins diet. The Atkins diet was created by Dr. Robert C. Atkins at John Hopkins Hospital in 1972, and limits carbohydrates while allowing for as much protein as the eater desires. The MAD, on the other hand, discourages too much protein, with an emphasis on high fat foods. The modified Atkins diet is much easier to follow and was designed to offer a less restrictive (than the Ketogenic Diet) dietary treatment, primarily for teenagers and adults. Unlike the Ketogenic Diet, the MAD:

- Has no fluid or calorie restriction or limitation.
- Although fats are strongly encouraged, they are not weighed and measured. Most people will consume plenty of dairy and oils.

- There are no restrictions on proteins. Typically, 35 percent of calories for a person on the MAD come from protein.
- Foods are not weighed and measured, but carbohydrate counts are monitored
- It is started outside of the hospital and the person does not need to fast before starting the diet.
- Foods can be eaten more freely in restaurants and outside the home, and families can follow it as well.

It has shown to be effective in improving seizure control in approximately 45 percent of people who have trailed it. Please remember that no diet should be tried without speaking to your neurologist.

Q: Are nocturnal seizures easier to treat than daytime seizures?

A: Nocturnal seizures, like other forms of epilepsy, can be controlled with medication. Also, like other types of epilepsy, there is about a 30 percent chance that they will not be fully controlled. It depends a lot on the type of epilepsy that is causing the nocturnal seizures. Some types of epilepsy are easier to control than others.

So nocturnal epilepsy is treated like other forms of epilepsy and medication is the first line of management, but there are also many things people can do themselves to help control their seizures.

A few things which many people report help with their seizures:

- A healthy diet and lifestyle
- Getting enough sleep (it can be difficult to have a good quality sleep if a seizure occurs)
- Managing stress
- Restricting caffeine and alcohol
- Understanding what may trigger the seizures

There are risks with having seizures at night, especially if you sleep alone. Nocturnal seizures can be a risk factor for seizure related death. Read more here about reducing your risk.

<https://www.epilepsy.org.au/epilepsy-and-risk-taking-action-against-risk/>

Q: I get worried I may have a seizure when I go out and I'm finding this very restrictive and going out less often.

A: Many people have times where they feel stressed or anxious when under pressure, but these feelings usually pass once the stressor or stressful situation has gone away or been removed. Anxiety is when these anxious feelings don't subside. It is when they are ongoing and present without any reason or cause. It makes it hard to cope with daily life. When someone experiences anxiety, these feelings cannot be easily controlled. People with epilepsy are twice as likely to experience an anxiety disorder as the general population. Seizures by their very nature are unpredictable and it is this unpredictability and the possible loss of control during seizures that people with epilepsy fear. Anxiety about having seizures, particularly in public, is very common. Things you can do yourself are:

- Learn to manage stress in your life (there are many apps and tools that can help)
- Learn meditation or physical relaxation techniques
- Be healthy and active, avoid alcohol, caffeine and too much sugar
- Learn to replace negative self talk with coping self talk.

Seek professional help if:

- the fear and anxiety about having seizures occurs frequently or all the time.
- your seizures are well controlled, but the anxiety remains.
- you are isolating yourself from your friends, family and community.
- you think that the anxiety is related to antiepileptic medications.

Have a look at our Seizure Anxiety Factsheet if you want to read more. <https://www.epilepsy.org.au/wp-content/uploads/2017/08/Fact-Sheet-Seizure-Anxiety.pdf>

Taking Action – What's happening at Epilepsy Action

FIRST AID FOR SEIZURES

Seizures mostly run their own course but there are a few things that can help, like keeping the person safe and timing the seizure – particularly protecting the head from injury. It is crucial that during a seizure the person not restrained in any way nothing is put in their mouth. Always make sure someone stays with the person.



Epilepsy Action has several resources to help spread the word about seizure first aid. Have you checked out our **First Aid videos** yet you can view them here:

<https://www.epilepsy.org.au/about-epilepsy/first-aid/>? Or you can download an **A3 First Aid for Seizures poster here** to post up at home, school or the office also found here: <https://www.epilepsy.org.au/about-epilepsy/first-aid/>

ONLINE RESOURCES FOR TEENAGERS

Did you know Epilepsy Action has developed a number of educational resources to help increase knowledge about epilepsy and how to improve seizure control and quality of life.

E-quip: Developed for teenagers and young adults, this resource covers topics, such as dating, depression, study and work matters and has a number of videos featuring young Australians discussing their personal experiences. Visit <https://www.epilepsy.org.au/e-quip-an-epilepsy-resource-for-youth/>

rEaction: This resource is also aimed at youth with a focus on increasing epilepsy awareness for friends and peers of people with epilepsy. Issues covered include epilepsy in relation to: alcohol and drugs, fatigue, lack of sleep, stress, bullying, dating, puberty, birth control, playing sport, driving, study and school. Visit:

<https://www.epilepsy.org.au/reaction/>



