



GET THE KETTLE ON FOR EPILEPSY

November is epilepsy awareness month and this year to celebrate we're launching E-Tea – a great opportunity for our supporters to gather together with family, friends or colleagues for delicious treats, laughter, fun, fundraising, and to of course generate awareness of epilepsy.

Sign up to host a morning or afternoon tea and we'll send you a FREE goodie pack containing lots of delicious treats and baking supplies, as well as tea and coffee samples.

You'll also have access to information and resources to make your E-Tea event a great success – including posters, decorations, games, and checklists, etc.

A few cups of tea can help make a difference this November!

For more information or to register visit
www.epilepsy.org.au/support-us/fundraise-for-us/e-tea

Feature 1: Vaccination Safety

Medicine has advanced dramatically over the years. The development of vaccines set in motion an era of illness prevention unlike anything the world had ever seen. In fact, vaccinations are largely viewed as the most successful medical advancement in the history of public health. Yet some people question the safety of vaccines and raise issues. There are many sources of information available, some contradictory, so it can be confusing to gauge what is important for you. However, no matter what your choice, it is essential to be informed before you make that choice. Here we have put together some information to explain the benefits and issues surrounding vaccinations and to help you make an informed decision about vaccines and your child's health.

The Australian Academy of Science 2016ⁱ has a comprehensive section to answer your questions. Below is a summary of their information:

Are vaccines safe?

Vaccines are like other medicines, and can have side effects. However, all vaccines in use in Australia provide benefits that greatly outweigh their risks.

Most reactions from vaccination are minor

Most of the side effects that follow vaccination are minor and short-lived. The most common side effects for all vaccine types are local reactions at the injection site, such as redness or swelling, which occur within hours and are clearly caused by

the vaccine. More general reactions, such as fever or tiredness, can also occur after vaccination, but studies have shown that they are much less common than local reactions.

Local reactions are outward signs that the vaccine is working with the immune system to generate a protective response. The nature of these reactions varies, depending on the type of vaccine given.

So for example, if a person is given an *inactivated* vaccine, they almost always develop a fever within 24 to 48 hours—the time when the immune system is making an immediate response to the components of the vaccine. In contrast, when given a *live* attenuated vaccine (such as the MMR vaccine), the onset of fever is delayed for seven to 12 days because this is the time needed for the virus in the vaccine to multiply sufficiently to induce a protective response from the immune system.



Medical conditions with unknown causes have been incorrectly linked to particular vaccines. The most prominent example is the claimed link between the MMR vaccine and autism—a disease whose first clinical signs commonly occur in the second year of life, at a time when MMR vaccine is usually given. Many comprehensive studies subsequently ruled out

this suggested link by showing conclusively that rates of autism are the same among children who have and have not been vaccinated.

Allergic reactions

Do many people have serious allergic reactions to vaccines? Generally, the rate of severe allergic reactions following vaccination is

extremely low, between 0.02 and 4.52 per 100,000 doses. However, precautions should always be taken by people with a past history of reaction to a specific vaccine or a strong family history of allergic disease or reactions.

Injectable vaccines used in Australia do not contain detectable amounts of antibiotics such as penicillin or sulphonamides to which some people may be allergic. There have been some isolated reports of possible severe allergic reactions to the hepatitis B vaccine, but supporting evidence is incomplete and again, the benefits of receiving the vaccine far outweigh the multiple risks associated with hepatitis B infection.

Serious side effects from vaccines are extremely rare

Potentially serious side effects, such as transient febrile seizures, have been reported after vaccination. However, such severe side effects occur much less often with the vaccine than they would if a person caught the disease itself. About three in every 10,000 children who receive the MMR vaccine develop a fever high enough to cause short-lived seizures.

This is illustrated (Fig 1 below) in young children by comparing the frequency of adverse events from

Your child health nurse should provide you with a list of common reactions for each vaccination, and what to look out for if it is potentially serious.

Some symptoms coincide with, but are not caused by, vaccination

There have been studies showing that many common symptoms that occur after a vaccine are not always caused by the vaccine, but occur by chance at that time. Symptoms such as fever, rashes, irritability and nasal snuffles are common, especially among children. Consequently, it can be difficult to determine how many of these reactions are caused by a vaccine when the 'background rate' (how often it occurs anyway) in the same age group is unknown.

Safety surveillance systems in countries like Australia require health care providers to report adverse events that occur following vaccination regardless of the cause.

the MMR vaccine with the frequency of adverse events with measles itself.

Figure 1: Severe complications due to MMR vaccine and measles among 1 million children aged under 5 years.ⁱⁱ

MMR vaccine	Measles
Uncommon complications	
300 children have seizures	10,000 children have seizures or convulsions induced by fever
Rare complications	
26 children have a temporary tendency to bruise or bleed more easily (thrombocytopenia)	330 children develop thrombocytopenia
Very rare complications	
Up to four children get a severe allergic reaction (anaphylaxis). This is readily treated with complete recovery	No anaphylaxis cases
No children will get subacute sclerosing panencephalitis (SSPE). SSPE causes progressive brain damage and death	10 children get SSPE several years later
Uncertain; a maximum of one child may develop inflammation of the brain (encephalitis). Encephalitis from any reason may result in permanent brain damage or death	2000 children may develop encephalitis

<https://www.science.org.au/learning/general-audience/science-booklets/science-immunisation/4-are-vaccines-safe>

Newer vaccines

The frequency of side effects associated with some earlier vaccine preparations (no longer in use in Australia) was higher than with the current generation of vaccines.

Is vaccination during pregnancy safe, and if so for what diseases?

It is safe to give *inactivated* vaccines in pregnancy. The rates of side effects among pregnant women are similar to those in the general population, and no link has been established between vaccination with inactivated vaccines in pregnancy and birth

defects. The use of inactivated vaccines in pregnancy is often encouraged for conditions such as influenza, which affects pregnant women or their babies more frequently and severely than the general population. This is because vaccination during pregnancy not only protects the mother against infection, but also provides protection to the unborn baby as a result of transfer of maternal antibodies.

Live attenuated vaccines, such as MMR or varicella vaccines, are not recommended during pregnancy, as the live viruses could in theory be transmitted from pregnant mother to their foetus. However, there is no evidence of an increased incidence of birth defects in children whose mothers inadvertently received live attenuated vaccines while pregnant.

Go to the Australian Academy of Science for more comprehensive information regarding this:

<https://www.science.org.au/learning/general-audience/science-booklets/science-immunisation>

Should people with epilepsy be vaccinated?

The Australian Immunisation Handbook 10th Edition, 2016 states that stable neurological conditions (such as epilepsy) are not a reason to avoid giving any vaccines, including pertussis (whooping cough) even if there is a family history of seizures or epilepsy. Febrile seizures, a relatively common response to fever in young children, can occur at a low rate following immunisation however a history of febrile seizure due to any cause is not a reason to avoid future vaccines.

Side effects and genetic predispositionⁱⁱⁱ

Increasing concerns and controversy about vaccine unwanted side effects and reactions have been raised and threaten the public health successes attributable to them.

People react differently to medications and vaccines. Individual responses to a vaccine are determined by a host of known and unknown factors, including:

- individual characteristics (age, gender, race, medical condition, etc.),
- the quality and quantity of vaccine antigen(s),
- the number of doses administered,
- route of immunisation,
- and genetics.

In medicine, right across the board, there has been increasing knowledge about genetic predisposition. This is also the case for a genetic predisposition to susceptibility to severe allergic reactions. Advances in genetic testing will ultimately lead to the ability to predict such unwanted effects and reactions, or to design new vaccine approaches that lessens or eliminate serious vaccine-related reactions.

Although a lot of work has gone into understanding genetic susceptibility to infectious diseases, attention now needs to turn toward genetic susceptibility to vaccine-related unwanted effects. Researchers have a theory that adverse reactions and events may not be random, but may in fact be, in part, genetically predetermined.

Genetic testing

There is a growing trend to perform genetic testing on families to assess current medical problems and to predict future health risks. It has been theorised that genetic defects that impair detoxification and antioxidant function in the body may increase the risk of severe vaccine reactions.

With current and future technology advances, we can better understand individual genetic variations in vaccine response. This knowledge will help create a new model for vaccine safety and is critical to understanding and preventing serious adverse vaccine-related events, developing the next generation of vaccines, and improving public confidence in vaccine safety.

Reasons to discuss vaccination with an expert^{iv}

Vaccination is not a one size fits all model. For your own reasons, you may have some concerns or hesitations to vaccinate your child. Here are some circumstances which might prompt you to discuss

vaccination with your doctor or child health nurse to help you make an informed choice:

1. If your child or siblings has had a severe vaccine reaction already
2. If you have had a severe reaction
3. If more distant relatives have had a severe reaction. Reactions that occur in grandparents, aunts and uncles, or cousins are less of a concern as the genetic risks are not as closely shared. However, parents can and should discuss this with their doctor
4. If your child has any medical or chronic conditions. Children with any chronic medical condition or temporary moderate to severe condition can discuss with a doctor whether or not that condition warrants temporary or permanent exemption from vaccination
5. If there is a family history of severe medical conditions. There is a growing body of research which is finding a small link between vaccination and increased risk of autoimmune disease. Families with lupus, rheumatoid arthritis, celiac disease, fibromyalgia, multiple sclerosis, type I diabetes, and other autoimmune conditions can discuss this with their doctor. Families with neurodevelopmental or psychiatric conditions should also discuss this with their doctor. The greater the number of familial diseases, and the closer in the family they occur to the child in question, the more likely the relevance
6. If there are genetic abnormalities in a family. A genetic test, conducted before vaccinating, could alert you to a heightened risk of vaccine injury for your child.

Febrile Seizures^v

What are Febrile Seizures?

Febrile seizures are convulsions or seizures in infants or small children that are brought on by a fever. Mostly the child will lose consciousness and have rhythmic jerking for less than two minutes, some can be as brief as a few seconds.

Occasionally, the seizure may cause the child to become rigid or have twitches in only one part of the body. Sometimes a febrile seizure may last for more than 15 minutes.

Approximately one in every 25 children will have at least one febrile seizure. They usually occur in children between the ages of 6 months and 5 years, peaking in the second year of life. The older a child is when the first febrile seizure occurs, the less likely that child is to have more. A few factors appear to increase a child's risk of having recurrent febrile seizures, including young age (less than 18 months) when the first seizure happens and having immediate family members with a history of febrile seizures.

Febrile seizures and vaccination^{vi}

In a Danish study of a total of 537,171 children, 17 986 children developed febrile seizures at least once. 439 251 of these children (82%) received Measles, Mumps and Rubella (MMR) vaccination and 973 of the above febrile seizures occurred within 2 weeks of MMR vaccination. They concluded that the MMR vaccination was associated with a brief increased rate of febrile seizures but the risk difference was small, even in high-risk children. The long-term rate of epilepsy was not increased in children who had febrile seizures following vaccination compared with children who had febrile seizures of a different cause such as illness.

Is there any treatment?

A child who has a febrile seizure usually doesn't need to be hospitalised. If the seizure is prolonged or is accompanied by a serious infection, or if the source of the infection cannot be determined, a doctor may recommend that the child be hospitalised for observation. Prolonged daily use of antiepileptic medications is usually not recommended because of their potential for unwanted side effects. Children especially prone to febrile seizures may be treated with medication when they have a fever to lower the fever and the

risk of having another febrile seizure, but sometimes the seizure can be the first sign of a fever.

What is the prognosis?

The vast majority of febrile seizures are short and harmless. There is no evidence that short febrile seizures cause brain damage and the vast majority children who experience febrile seizures do not go on to develop epilepsy.

Multiple or prolonged febrile seizures pose a higher risk for developing epilepsy. So when the prolonged febrile seizure that lasts longer than 15 minutes, or the febrile seizures are focal affecting only one part of the body, or if the child experiences seizures that reoccur within 24 hours, the risk is increased.



Why vaccines can cause seizures, read more... <http://sciencenordic.com/breakthrough-why-mmr-vaccine-can-give-children-febrile-seizures>

Conclusion

Modern vaccines provide high levels of protection against an increasing number of diseases and the symptoms, disability and death that can occur from them. Most of the arguments against vaccination appeal to parents' understandable deep-seated concerns for the health of their children, particularly very young babies. Serious reactions to vaccines can happen but are rare, however, some people may have a genetic predisposition for these serious reactions to occur. It is always important to understand any health intervention to make the right choice for you. If you have any concerns, speak to your doctor or child health nurse for more information.

Frequently asked questions about immunisation:

<http://immunise.health.gov.au/internet/immunise/publications.nsf/Content/frequently-asked-questions>

Further reading:

Australian Immunisation Handbook
<http://www.immunise.health.gov.au/internet/immunise/publishing.nsf/Content/news-20160109>
 Australian Vaccination Skeptics Network
<https://avn.org.au/>
 Fact File Immunisation
<http://www.abc.net.au/health/library/stories/2003/05/22/1918384.htm>
 Facts and myths about vaccination
<http://www.nhs.uk/Conditions/vaccinations/Pages/myths-truths-kids-vaccines.aspx>
 The vaccination debate
<http://www.naturalhealthmag.com.au/content/vaccination-debate>

Sources:

- i <https://www.science.org.au/learning/general-audience/science-booklets/science-immunisation/4-are-vaccines-safe>
- ii Sources: Plotkin, S.A., Orenstein, W.A., and Offit, P.A. eds. (2007). Vaccine. 5th edition. Saunders Elsevier. Institute of Medicine. (2012) Adverse effects of vaccines: evidence and causality. Washington, D.C.: The National Academies Press. Barlow, W.E., et al. (2001) The risk of seizures after receipt of whole-cell pertussis or measles, mumps, and rubella vaccine. *N Engl J Med* 345 (9), 656–61. Mantadakis, E., Farmaki E., and Buchanan, G.R. (2010) Thrombocytopenic purpura after measles–mumps–rubella vaccination: a systematic review of the literature and guidance for management. *J Pediatr* 156 (4), 623–8. Perry, R.T., and Halsey, N.A. (2004) The clinical significance of measles: a review. *J Infect Dis* 189 Suppl 1: S4–16. Centres for Disease Control and Prevention. (2011) Measles. In: Atkinson W, Wolfe C, Hamborsky J, editors. *Epidemiology and prevention of vaccine-preventable diseases*. 12th ed. Washington, D.C.: Public Health Foundation.
- iii <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2843136/>
- iv <http://drjaygordon.com/vaccinations/dr-bob-sears-explains-the-new-vaccine-law-better-than-anyone.html>
- v http://www.ninds.nih.gov/disorders/febrile_seizures/febrile_seizures.htm
- vi <http://jama.jamanetwork.com/article.aspx?articleid=199117>

Feature 2: Supplements in Epilepsy

Complementary therapies

Complementary therapies are therapies used together with conventional medical treatments with the aim to help improve a person's health and wellbeing. They are practices intended to treat the whole person, not just the symptoms of their disease. A wide range of treatments are under the umbrella term of complementary therapy. For example, acupuncture, aromatherapy, neurobiofeedback, supplements and vitamins, traditional Chinese medicine, herbal medicine, yoga, meditation and massage. These treatments are sometimes known collectively as 'complementary and alternative medicine' (CAM).ⁱ

People may have a number of reasons for choosing a complementary therapy or other approaches to enhance their health. There are also people who use CAM because of their cultural traditions and beliefs. Studies show that the most frequent users of complementary therapies include well-educated women, high-income earners and people with chronic conditions.ⁱⁱ

The number of Australians who use complementary medicines or consult with complementary therapists is on the rise with more than half the population using supplements or other complementary medicines each year. Some experts say it could be as high as 80 per cent. A studyⁱⁱⁱ in 2005 surveyed 400 patients attending epilepsy clinics in the UK. Thirty-four percent had used or were using CAMs; the majority had not told their doctor. The majority of people in this study did not use CAMs for their epilepsy but for general health purposes. Most people stated that CAMs had little or no effect on seizure frequency or severity.

Because of the number and diversity of CAMs available, this article will focus on supplements.

What are supplements?^{iv}

Supplements is a broad term describing a wide range of complementary medicine products. These may include herbs, vitamins, minerals, nutritional supplements and homoeopathic medicines. At some stage, most of us have taken supplements in our lifetime.

A survey^v in 2007 showed the most commonly used supplements in the general population include fish oil/krill oil, sports nutrition products (glucosamine, protein powders), Echinacea, flaxseed and ginseng, as well as calming and sleeping products.

When someone has epilepsy

For people with epilepsy, the most frequently taken supplements reported were ginseng, Ginkgo biloba and St Johns Wort. These extracts are generally used for symptoms of anxiety, depression and memory deficits – often seen in people with epilepsy. However, whilst all three have been reported to have beneficial effects on seizures, each has also been reported to aggravate seizures as well. Ginkgo and St Johns Wort may interact with some antiepileptic drugs. Error! Bookmark not defined.

Some factors to consider if you have epilepsy and thinking about taking supplements are:^{vi}

- Herbal sedatives (kava, valerian, chamomile, passionflower) may increase the effects of antiepileptic medications, increasing their sedative and negative effects on cognition (attention, concentration, learning and memory).
- There have been reports of seizures being exacerbated when herbal stimulants containing ephedrine (ephedra or ma huang) and caffeine (cocoa, coffee, tea, maté, guarana, cola or kola) are taken, especially when taken in combination.
- Ginkgo and ginseng may also exacerbate seizures although the evidence for this is anecdotal and uncertain.
- St. John's wort has the potential to alter antiepileptic medication metabolism and the seizure threshold.



- The essential oils of a number of plants contain epileptogenic compounds.
- There is mixed evidence for evening primrose and borage lowering the seizure threshold.

Many people think because they are vitamins or “natural” that they are safe. But this is not always the case, and they can have side effects just like any other medication. The reality is that most of us take supplements based on trust. We often don't know what ingredients they contain, where they come from or whether they are even effective for our condition.

Because research related to CAMs and epilepsy is sparse, education of both health care providers and patients is the best way to avoid unintentional and unnecessary unwanted reactions to supplements and herbal medicines. Speak to a qualified CAM practitioner and also your own specialist before embarking on taking any supplements.

The effectiveness of many supplements for control of seizures cannot be accurately measured from available studies. However, people typically report overall benefits in well-being. At worst, supplements can be dangerous. But for most, there's little reliable evidence about how well they work— and they are not closely regulated for safety and effectiveness. Supplements and complementary medicines contain what the Therapeutic Goods Association (TGA) considers low-risk ingredients and therefore receive less checking than higher risk products.

Mixing poorly with existing medications

You should always talk to your doctor before starting any supplements. Some people don't think about it or feel the need to tell their doctor, but it is best to discuss it in case there are any reasons you aren't aware of specific effects of some supplements. If you experience any problems after starting supplements, then the doctor will be aware of what you are taking and possibly correlate it with any positive or negative responses.

Regulation of complementary medicines^{vii}

Under Australian law, every complementary medicine is assessed for the safety and quality of its ingredients, but not always for efficacy (how well it works). Only the complementary medicines that are deemed 'high risk' are assessed for efficacy. The Therapeutic Goods Administration is a federal government department that regulates all medicines in Australia, including complementary medicines. The TGA considers as complementary medicines:

- Medicinal products that contain herbs, certain vitamins or minerals
- Nutritional supplements
- Homoeopathic medicines
- Certain aromatherapy products
- Traditional medicines such as traditional Chinese medicines, ayurvedic medicines and Australian Indigenous medicines.

TIPS

1. Buy Australian-made complementary medicines

Buying supplements or medicines online, particularly from overseas, can be risky, as the chances of receiving forged products are real.

Supplements sold on the internet aren't likely to have been evaluated by the TGA, meaning there is even less guarantee that the product contains what it says it does, whether it contains unlisted, illegal or dangerous ingredients, or whether it is contaminated with toxic heavy metals such as lead, mercury or arsenic. Error! Bookmark not defined.

Complementary medicines made in Australia are subject to strict product safety and quality regulations. This may not be the case in other countries. **Look for Australian-made products that are marked:**

- a. *'Listed Aust R'* – this means the product is considered low risk and has been assessed for safety and quality.
- b. *'Registered Aust R'*, this means the product is considered higher risk and has been

assessed for safety, quality and how well it works. The TGA assesses efficacy and safety by looking at data that are required to be provided by the manufacturer.

These products are manufactured in a laboratory licensed by the TGA.

2. Avoid the temptation to self-diagnose and self-medicate.

Always speak to an expert in the field and also discuss with your doctor.

3. Remember supplements do have side-effects and do mix with other medications.

Just because they come from a plant or claim to be 'natural' does not mean they are free of unwanted effects. Find out what the side-effects of your supplements may be (just like you would for a medication) and what effect any supplementation can have on your antiepileptic drugs.

4. Don't rely solely on supplements to meet your nutritional needs.

Try to improve your diet and lifestyle as well.

5. Always consult with your doctor before taking a complementary medicine or embarking on a complementary therapy.

It's important to ask about both potential benefits and potential harms of any therapy.

6. You must keep your health team informed of any complementary medicines you are taking to ensure you are using all your medicines safely.

Monitoring your condition, treatment and lifestyle is important in gaining the best possible outcome for you.

7. Never stop taking prescribed medications, or change the dose without the knowledge and approval of your doctor.

It's too risky.

Regulation of complementary therapists

In Australia, state governments regulate complementary therapists. This means that the laws differ from state to state. For example:

- The complementary therapy industry in Australia is largely self-regulated.
- Most complementary therapists are affiliated with a professional association. Membership may require that therapists maintain a certain standard of care. However, membership is usually voluntary, which means there is no legal obligation.
- In Victoria, acupuncturists, Chinese medicine practitioners and Chinese herbal medicine practitioners are legally obliged to register with the Chinese Medicine Registration Board.
- Across Australia, police, the courts or a health review board may investigate the activities of a complementary therapist in the case of misconduct.

Risks

Complementary therapies can cause harm if used incorrectly or by someone for whom they are unsuitable. For example:

- Poor standard of care – without regulation, there is no legal requirement that a complementary therapist is qualified, trained or experienced. A dodgy therapist can inflict harm on a person
- Indirect harm – relying on complementary therapies alone may delay a person's diagnosis and medical treatment. In the case of serious illnesses, such as cancer, a delay can lead to serious complications or death
- Side effects – complementary medicines can cause unwanted and potentially dangerous side effects.
- Drug interactions – complementary medicines can interact with over-the-counter and prescription drugs. For example, ginkgo and chamomile may increase the risk of bleeding in people who take anticoagulant medicines such as warfarin and anti-inflammatory medicines such as aspirin.

- Financial harm – you are wasting your money if the complementary medicine isn't effective or appropriate. The TGA and the Australian Competition and Consumer Commission (ACCC) have strict guidelines on claims made by companies. However, there is no protection under Australian law if the product is bought from overseas.

How to choose a complementary therapy practitioner

Error! Bookmark not defined.

Some suggestions on finding a reputable practitioner include:

- Contact the professional association for your chosen therapy and ask for a list of members in your area
- Ask your doctor for a referral
- Ask your friends for word-of-mouth recommendations
- During the first visit with your practitioner, ask about their training and qualifications
- Find out if the practitioner has experience in dealing with people with similar conditions
- Be very cautious about any practitioner who advises you to abandon your conventional medical treatment
- Enquire about costs and if there is any reimbursement from your health insurance

Summary

Supplementation is a choice made by many, and can have beneficial effects, but you have to think of supplements as a type of medicine because they have effects and side effects like any other medication. By all means take supplements, this is not meant to be a deterrent; if you have deficiencies, if they make you feel better or if the doctor advises so, but just do your homework about what you are taking and how it can affect you (and possibly seizures). Make an informed decision and preferably purchase something that manufactured in Australia.

<http://www.ncbi.nlm.nih.gov/pubmed/16822357>

Abstract

<http://link.springer.com/article/10.1007/s11910-006-0029-4> Abstract with links

four Corners report "Supplements and Safety"
<http://www.abc.net.au/4corners/stories/2016/05/16/4460291.htm>
<https://www.tga.gov.au/complementary-medicines>
 TGA Complementary medicines regulations and guidelines
<http://bmccomplementaltermmed.biomedcentral.com/articles/10.1186/1472-6882-10-58>
<http://www.ice-epilepsy.org/alternative-therapy.html>

Sources:

ⁱ<https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/complementary-therapies-safety-and-legal-issues>

ⁱⁱ<https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/complementary-therapies>

ⁱⁱⁱ<http://www.sciencedirect.com/science/article/pii/S1525505004003087>

^{iv}<http://www.abc.net.au/news/health/supplements-what-you-need-to-know/7408972>

^vEkstein, D., and Schachter, S.C. Natural Products in Epilepsy – the Present Situation and Perspectives for the Future. *Pharmaceuticals* 2010, 3, 1426-1445.

^{vi}<http://www.sciencedirect.com/science/article/pii/S1525505001902811>

^{vii}<https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/complementary-therapies-safety-and-legal-issues>

**In the News –
 The latest on
 epilepsy**



Seizures may one day be warded off by a sports drink

Melbourne researchers think they might've found the key to preventing epilepsy after a head injury. They're looking into whether the drug could one day be put into sports drinks, for athletes playing contact or dangerous sports. Read more...
<http://www.abc.net.au/news/2016-07-12/could-epileptic-seizures-one-day-be-warded-off-by/7588662>



Many kids with epilepsy have other health problems

Nearly 80 percent of children who have epilepsy also have other health conditions, such as digestive troubles and attention-deficit/hyperactivity disorder. Parents should be aware of the increased risk of [other] problems for their children. Read more...
<http://medicalxpress.com/news/2016-08-kids-epilepsy-health-problems.html>

Having a relative with epilepsy may increase your risk of a diagnosis of autism



Having a first-degree relative with epilepsy may increase a person's risk of being diagnosed with autism. Read more...
<https://www.aan.com/PressRoom/Home/PressRelease/1472>

Queensland medicinal cannabis trials to commence

Queensland will finally begin administering British pharmaceutical company GW Pharma's pure CBD extract, Epidiolex, to children with acute cases of epilepsy by the end of the year. Read more...
<http://www.marijuana.com/blog/news/2016/07/australia-to-conduct-groundbreaking-medical-marijuana-trial/>

Fertility treatment link to epilepsy of genetic origin

Parental infertility or fertility treatment may be linked to a type of epilepsy called idiopathic generalised epilepsy, which is thought to have a genetic cause. Read more...
<http://www.neurologytimes.com/epilepsy-and-seizure/fertility-treatment-epilepsy-genetic-origin?GUID=E96F8A20-8B81-4455-B4FC-4F93CEE1DD68&XGUID=&rememberme=1&ts=02072016>

Novel inhibitory brain receptor may be mechanism for remission of epilepsy in adolescence

More than half of children with epilepsy outgrow their seizures, yet the reasons why this remission is unknown. Read more...
<https://www.sciencedaily.com/releases/2016/08/160826083817.htm>



Q&As – Our service providers answer your questions

Q: My son has recently had a sleep deprived EEG after a generalised seizure. The report said there was potentially epileptogenic activity from a right centro-temporal focus. He has been put on medication. Does this mean he has epilepsy or just has seizures?

A: I expect if your son has been medicated, then the neurologist or treating doctor has made the decision that more seizures are likely to happen if he is not (medicated). Epilepsy is a tendency to have recurring seizures, and if your son had a seizure without any known provocation or cause, then the doctor has more than likely made a diagnosis of epilepsy. It would be worthwhile asking your doctor to explain the EEG results and if your son has been diagnosed with a specific type of epilepsy.

Q. What are 'first-' and 'second- line' antiepileptic drugs?

A: Antiepileptic drugs (AEDs) are medications licensed for use in controlling seizures. 'First-line' and 'second-line' refers to the order AEDs are selected, and used for the treatment of epilepsy.

First-line AEDs are the medications that are usually considered first when starting epilepsy treatment. They tend to be used on their own as monotherapy. They include medications such as sodium valproate and carbamazepine. Which one is chosen depends on the type of seizures the person experiences.



Second-line AEDs are medications that are usually taken alongside first-line AEDs which is referred to as adjunctive therapy or polytherapy. They include AEDs such as topiramate and gabapentin. Second-line AEDs also include medications

that were used as first-line treatments but are generally, no longer considered as a first treatment option.

However, as treatment with AEDs is always individualised, in some cases the neurologist may use his specialist knowledge and decide to put someone on monotherapy with a second-line rather than first-line drug.

Q: Within a short amount of time of starting Epilim (sodium valproate) I gained a lot of weight ... and today, still struggle with weight control. I have heard taking amino acids (Carnitine) for weight loss may help but not sure if they are safe?



A: I'm sorry to hear you have gained so much weight whilst taking Valproate. It is an unfortunate side effect of what is otherwise a very effective anti-epileptic drug.

There is a study regarding Carnitine, a substance found naturally in the body, and weight loss whilst taking Valproate
<http://www.ncbi.nlm.nih.gov/pubmed/17042889>.

Unfortunately it was proven to not be significant in helping with weight loss. However, overall, the people taking it lost more weight than the people not taking it but in science terms, it wasn't a significant amount more.

By all means speak to your doctor or get a referral to a good dietician to discuss this or other options, but if you continue to struggle with your weight and are unhappy about this then it might be best to discuss a potential change in medication with your doctor.

Q. Which antiepileptic drugs reduce bone density? Is this only a risk for people on particularly high doses?

A: There are many factors that can affect bone density, which consequently can increase the risk of fractures. Antiepileptic drugs are just one factor, and genes, age, gender (hormones), lifestyle (activity), other medical conditions, Vitamin D and calcium levels are some others that can affect bone density. Generally there is more than one factor involved.

Many AEDs are known to affect bone density. There is currently no research that has reported dose as a contributing factor. I would expect though if you are on a high dosage of one or more medications, there is more likelihood of unwanted side-effects such as dizziness, double vision and unsteadiness – all of which can increase the risk of falls.

A study of people over fifty taking AEDs documented:
<http://www.sciencedaily.com/releases/2011/01/110164748.htm>

“Most antiepileptic drugs are associated with an increased likelihood of non-traumatic fracture in individuals aged 50 years or older....The likelihood of fractures was highest for persons taking phenytoin followed by carbamazepine, other, phenobarbital, gabapentin and clonazepam. The only antiepileptic drug not associated with an increased likelihood of fracture was valproic acid (Epilim).”

The greatest risk of fracture was found in people who were taking more than one AED.

Q: I have been seizure free for several years until recently, experiencing some focal seizures. I also have an ongoing twitch in my left upper eyelid. It doesn't coincide with my focal seizures, but I was wondering if it could be a different type of seizure?

A: Eyelid twitching is common, usually a benign self-limiting spasm often triggered by lack of sleep, fatigue, excessive caffeine or alcohol. If the spasm involves other parts of your face, or your eyelid closes completely as in a winking motion, it could be related to the epilepsy or other neurological

condition and is worth mentioning to your doctor.
<http://www.healthline.com/health/eyelid-twitch#Overview1>

Sometimes low magnesium levels are thought to contribute to eyelid twitching, so you may like to ask your doctor this as well.
<http://www.allaboutvision.com/conditions/eye-twitching.htm>

It should go away on its own, but may happen again in the future.

Taking Action – What's happening at Epilepsy Action

MyEpilepsyKey

Epilepsy Action is pleased to announce the launch of *MyEpilepsyKey*. When plugged into a computer the Key provides access to education, information, interactive resources and service programs that will assist you to more effectively self-manage epilepsy.

The keys are available in all JB Hi-Fi stores across the country until the end of November. The keys are FREE of charge, just ask a JB Hi-Fi staff member for yours today.

To find out more information about the Key, please visit www.epilepsy.org.au/myepilepsykey.

MyEpilepsyKey is proudly supported by






Do you need Seizure First Aid training?

Epilepsy Action provides professional training in Seizure First Aid across the country to schools, child care centres, organisations and businesses. If you

would like to arrange for training please contact us on epilepsy@epilepsy.org.au or phone 1300 37 45 37.

Become a Member!

Consider becoming a member of Epilepsy Action and for only \$75 for a year, have access to a range of benefits available to you as part of our program including but not limited to: have a direct say in the governance of the organisation, continued access to our innovative and ever expanding collection of online resources and self-management tools, and free access to our online "Epilepsy Essentials" education course.

For more information about our membership program or to join, please visit www.epilepsy.org.au/membership or phone 1300 37 45 37.

