

## Feature 1: Embracing and Enduring Change

Have you actively taken on board some resolutions, or have you seamlessly surfed the wave from 2018 into 2019?

Regardless of whether the New Year has fostered a sense of novelty and excitement or has left you blissfully still writing the date '2018,' the new year often brings with it some form of change. Changes can be overwhelming or insignificant, self-directed or a product of circumstance, but with the right approach, most change can be made manageable and positive. This article will identify some common types of and reactions to change, the impact it can have on seizures and provide some practical and adaptable strategies for enduring and embracing your new situation.

### Our response to change

The relationship between change and our response is often defined by how we perceive the situation. For instance, when we choose to make changes in our own life, we have made a conscious decision to alter the status quo in some shape or form, and thus are more likely to embrace it. When change is forced upon us, we still have the option to embrace it, but are more likely to resist the change or take the wait-and-see approach while we form an opinion.

Regardless of why the change occurs, an emotional and/or physical adaptation must occur. There is no 'normal' or 'right' response. You may disregard or not even care that the change or its consequences exist. Or you may feel angry or frustrated, sad or depressed, or overcome with a sense of relief or happiness. Your feelings about the change will likely shift, occasionally doubling-back as you familiarise yourself with the practical implications and more minute consequences of difference in your world. At some stage, you may even become curious and explore the nature of the change. Ideally, at some point, you come to accept the new status quo, or find a way to modify it again.

The nature of the change we face also influences our response and the practical measures we take to adjust. Some types of change are inherently more stressful than others and can take

longer to adjust to. Change on a more general scale, as result of moving houses, changing jobs, or schools, for example, requires different types of emotional and practical adaptation in comparison to more specific changes to your diet, your fitness regime or your circle of friends. Responses to change are multi-layered and specific to you reflecting the scope of variation that you are faced with.



### Change and epilepsy

Change can be especially relevant in the context of epilepsy as it can impact your seizures and vice versa.

Seizure activity can pose a range of secondary challenges, often related to memory, thinking and learning, or mental health that can add to the difficulties associated with adapting to change. Being

mindful of the influence of a new situation can help minimise the chances of change impacting on your epilepsy or sense of wellbeing;

### What you can do

- Maintain or improve your sleeping pattern: lack of sleep can be a seizure trigger for some people, so trying to maintain or improve your sleeping schedule during periods of transition can be extremely important for ongoing seizure management.
- Identifying sources of physical or emotional stress: change can be hard, and some level of stress is often unavoidable, but identifying sources of stress and actively seeking ways to reduce their impact can be beneficial for your overall mental and emotional wellbeing, as well as for seizure reduction.
- Alcohol and drug use: new situations, friends or environments may present different opportunities for drug and alcohol use, but these can have negative interactions with epilepsy medications. While some people can tolerate a reasonable amount of alcohol (usually no more than a couple of standard drinks is advised), it is important to note the influence these can have on seizure activity.
- Being consistent with medication and health precautions: keeping to your medication schedule and maintaining any

other precautionary steps you have in place is beneficial not just for reducing the likelihood and impact of seizures, but also for providing a sense of normalcy and comfort in the face of change, which can be reassuring regardless of whether you have epilepsy or not.

- Be aware of seizure triggers: if you have been diagnosed long enough to recognise your triggers, then you already have a leg up. If, however, you are still identifying what your seizure triggers are, introducing change can provide you with the challenge and opportunity to familiarise yourself with potential risks you were previously unaware of. The danger lies in not knowing whether something is a trigger until you are faced with it, so especially if you find yourself in a new setting or tackling dramatically different circumstances to your norm, keep an eye out for known triggers or anything that prompts any unusual or seizure-related feelings.
- Check out the EpiDiary app for help tracking your seizure activity, triggers, sleeping and medication schedules <https://epidiary.com/login-page.php?l=en-AU>

Some other helpful strategies when it comes to managing change and your health, regardless of whether you have epilepsy include;

- Being mindful of your mental state: You can best tackle challenging or novel situations when you are aware and attentive. Irrational thinking and emotional challenges presented by depression or anxiety can greatly impact on your ability to cope with change. Having epilepsy or any chronic illness can significantly increase your risk of anxiety or depression, and it is especially important to be conscious of where you are at mentally and emotionally. If you are not feeling like you are in the right state of mind to cope with change, then if you can, maybe put it off until you are more able to cope.
- Listen to your body: Whether your body is sore from a new workout, conveying a hormonal change or warning of fatigue, listen and respond to your body and its needs to maximise your mental and physical adjustment to new stimuli.
- Reframe your thoughts: If you are struggling to embrace change, try looking at it from a



different perspective. Look for the positive aspects of the change, re-assess how severe the negative implications really are, consider if there is a way you can make it work for you, and put it in perspective. For instance, if you've ended up with a new boss at work, challenge yourself to identify anything positive they bring to the table – a more inclusive management style or a flexible perspective of your job description. If you're not enjoying the new boss, ask yourself why and how bad the situation really is – are the new team meetings really that dreadful, or was your previous boss just so great that it's hard to let go? Can you find a way for the change to benefit you – could you use the opportunity to develop a better working relationship with upper management, or is there something you can learn from this person? Lastly, consider just how much of an impact the change has on your overall existence – is this a person you must interact with for more than a few hours out of every week? Are they dramatically changing anything else in your workplace?

Of course, facing change head on can be challenging, and sometimes a little bit of help can go a long way in facilitating your adjustment. Talking to your friends or family may provide you the valuable insight and support you need. Some other tools that may help include

- E-quip <https://www.epilepsy.org.au/how-we-can-help/online-toolsresources/> - a service for teenagers and young adults aimed at helping you along in the chaotic world of dating, depression, studying, working and so much more
- Neuro Wellbeing via the eCentreClinic <https://www.ecentreclinic.org/> - for brief courses that provide information on and teach practical skills for managing some of the cognitive and emotional challenges presented by epilepsy and other neurological conditions
- MyEpilepsyTeam <https://www.myepilepsyteam.com/> - an online platform that puts you in touch with a wider community of people with Epilepsy who can relate to the unique challenges you face, provide support and practical insight for managing whatever change life throws your way

Have a look at 7 Tips for Dealing with Change <https://au.reachout.com/articles/7-tips-for-dealing-with-change>

## Feature 2: Prepare for severe weather events

Unexpected or severe weather can happen anytime, in any part of the country. From bushfires, storm damage or floods, we all may be in the path of a nature-related emergency at some time. Thinking and planning ahead can lessen the damage and even save lives. If you or a loved one lives with epilepsy or any chronic health condition, here are some things to think about, beyond food and shelter, to help you stay safe.

### Have a Plan for Emergencies

Your family may not be together if a disaster strikes, so work out how you'll contact one another and reconnect if separated. If appropriate, establish a family meeting place that's familiar and easy to find. Depending on the type of weather emergency you are expected to experience, it is important to plan ahead whether you are going to stay or leave.

How will you receive early emergency alerts and warnings? Find out local services or Apps (such as Country Fire Service) for your area and connect with them to be contacted with alerts.

### Consider specific needs in your household.

As you prepare your plan tailor your plans and supplies to your specific daily living needs and responsibilities. Keep in mind some these factors when developing your plan:

- Different ages of people within your household – are there children at school or childcare?
- Responsibilities for helping others
- Locations frequently visited
- Medical needs including prescriptions and equipment
- Disabilities or access and functional needs including devices and equipment
- Pets or service animals

### Medication supplies

Always keep enough medication or have back up of medication, especially in seasons and locations where you are more likely to endure an emergency such as a cyclone or bushfire. If you are aware of an impending storm or natural event and you are running out of medication, don't wait. Contact your doctor or pharmacy to stock up.



### Have an emergency kit ready

Keep important documents, including your medication scripts and your seizure management plan, current and accessible so you can grab it in an emergency. A **seizure first aid poster** <https://www.epilepsy.org.au/about-epilepsy/first-aid/> may also be a good idea. Make sure you have a list of your medications, important documents, and, if possible, a supply of medication with

you at all times in a water tight bag or container.

Keep your battery-operated radio and torch in this kit as well and have a store of an emergency supply of non-perishable food and water.

There are a number of online emergency plan checklists available in your state. Have a look at the **Red Cross checklist** [https://www.redcross.org.au/campaigns/prepare/prepare-get-packing?gclid=EAlaIqobChMI4ZfZnZ-m4AIVih0rCh2MuAjzEAMYASAAEqJCN\\_D\\_BwE](https://www.redcross.org.au/campaigns/prepare/prepare-get-packing?gclid=EAlaIqobChMI4ZfZnZ-m4AIVih0rCh2MuAjzEAMYASAAEqJCN_D_BwE)

### Charge phones and devices

Keep your phone and any electronic devices charged that you may need for reminders and contact with family and emergency response. Think about purchasing a mobile power bank (portable phone charger) for extra charge when the power is out.

### Communication - include others

Talk about your plan to family, neighbours and friends. Discuss:

- potential emergencies with all household residents. For example, bushfires, severe storms and flooding
- how you plan to respond to each potential disaster
- what to do during power outages and if a personal injury occurs
- household roles during each emergency situation

Have flexibility in your plan as things don't always go as planned. Check in with family or friends on a regular basis. If you are alone, consider staying with someone temporarily or use a shelter.

### Stay informed

Listen to the weather and know your total fire bans. Check radio, website, social media and news updates. Make sure you have a battery-operated radio if there is a power blackout. Subscribe to any local warning apps or calls.

## Where to access warnings

There are many ways for you to access warning information. The Bureau of Meteorology often give warnings well in advance:

- internet - [Bureau of Meteorology website](#)
- radio - tune into your local station
- television - watch out for televised weather updates
- BOMs [telephone weather service](#)

## Know when to leave and where to go.

Know what to do and where to go to stay safe. Make sure you know local evacuation routes and check with your local emergency preparedness authorities or shelters about their policies for pets and animals.

Before you evacuate, remind your family or other household members of your central contact point in case you get separated. Make sure each household member has important phone numbers with them.

You must have a plan B if it becomes too dangerous to leave or you are unable to drive. Expect the unexpected and be prepared for several possibilities.



### Services to contact if you are affected

Life threatening emergencies (Police/Fire/Ambulance) - **000** (mobiles 000 and 112)

State Emergency Services (SES) - **132 500**

Red Cross Register. Find. Reunite. system - once you have registered, it will help your friends and family locate you. The system

can be accessed during a disaster by:

- visiting the [Australian Red Cross website](#)
- phoning the Australian Red Cross on 1800 100 188
- visiting an evacuation centre

## In the News – The latest on epilepsy

### Seizures that worsen during pregnancy is related to seizure type

<https://www.neurologylive.com/conferences/aes-2018/seizure-worsening-pregnancy-postpartum-influenced-epilepsy-type>



Women with focal epilepsy, particularly frontal lobe epilepsy, have higher rates of seizure worsening during pregnancy compared to women with generalised epilepsy.

### Acid reflux could cause death during seizures

<https://www.purdue.edu/newsroom/releases/2019/Q1/acid-reflux-could-cause-death-during-epileptic-seizures,-study-finds.html>

Recent research suggests that obstructive spasm of the larynx resulting in cessation in breathing may be a mechanism in sudden unexpected death in epilepsy (SUDEP).

### Concussions may contribute to the development of epilepsy <https://www.newswise.com/articles/fralin-biomedical-research-institute-scientists-link-concussions-to-seizures-development-of-epilepsy>

The development of epilepsy triggered by mild traumatic brain injury (concussion) may be related to an abnormal response from specific brain cells, which change to form scars.

### Device implanted in brain reduces seizures dramatically

<http://expressdigest.com/hope-for-epileptics-as-scientists-discover-device-implanted-in-the-brain-cuts-seizures-by-93/>

Animal studies have shown when the device was implanted in the brains of rats with epilepsy, they experienced 75 per cent fewer seizures after just two weeks.

### Distinguishing between epileptic seizures and psychogenic non-epileptic seizures (PNES)

<https://www.prnewswire.com/news-releases/at-aes-2018-cognizance-biomarkers-unveils-data-showing-it-can-accurately-distinguish-between-epileptic-and-psychogenic-nonepileptic-seizures-300758814.html>

A new biomarker-based blood test has the potential to revolutionise the diagnosis of epilepsy and distinguish between epileptic seizures and PNES.

### New childrens video about epilepsy and sports: 'Stella Starfish wants to play Sports!'

<https://www.youtube.com/watch?v=U0SK7wWYP4o&feature=youtu.be>

Stella the starfish loves to play football but is worried because she has epilepsy. Campi the Seahorse lives with epilepsy too, and he has an idea to help Stella learn more about epilepsy and playing sport.

## Q&As – Our service providers answer your questions



**Q: I have had no seizures for about 4 ½ years, but last week I had 3 in one day. What could be the reason for this? I did miss my medication the day before, but it seems like 3 seizures is a bit extreme for only missing one dose.**

A: It sounds like you may need to have your medication and dose reviewed. The most likely explanation for the increase in seizures – is that your medication dose is right on the margin of maintaining seizure control and may need some slight adjustments. This could explain you being sensitive to missing just one dose.

People can take a medication for a long time and it works well, then suddenly the seizures return or increase in frequency for no apparent reason. These are often called “breakthrough seizures” and can sometimes happen due to external circumstances. So, take a look at your recent happenings as sometimes your environment – such as additional stress, poor sleep or poor diet, being unwell – may increase the risk of seizures as well.

There are many reasons why seizures can increase, and it is a good idea to make an appointment with your doctor to discuss the possible reasons, and what to do.

**Q: I have recently started weaning off one epilepsy medication and introducing another. It has been a pretty bad experience and I'm suffering from a lot of dizziness and blurred vision. Is this from starting the new medication or stopping the old?**

A: Changing antiepileptic medication is different for each person. Just like starting a new medication, stopping one should be the same. You don't simply stop one and take another - there is usually a period where you are taking both medications together. This protects you from seizures until the new drug takes effect

In both situations the process should be slow and increments or reductions should be a small amount at a time. People tolerate different amounts, but the dizziness is bad, then possibly this process needs to go more slowly. Some people

start or phase out medications over a few weeks to lessen the unwanted side effects.

It will be difficult to tell what is causing the effects, but if they continue for several weeks, then they are more likely to be the side effects of the new medication. You may need to be monitored during this process and watch for and record any seizures. From start to finish, switching medications can take several weeks.

You should contact your neurologist. In the interim your local pharmacist may be able to help or call Medicines Line 1300 633 424

See our Factsheet: Medical Management of Epilepsy  
<https://www.epilepsy.org.au/wp-content/uploads/2017/08/Factsheet-Medical-Management-of-Epilepsy.pdf>

**Q: Are there are any precautions someone I should take when travelling with a VNS. Does it set the metal detectors off?**

A: If you have a VNS implanted, there are some environmental hazards you need to be aware of. Being close to certain types of equipment can affect the generator. Here is a list of equipment you should be aware of:

- Antitheft devices, airport security systems, and other metal detectors —should not affect the generator or be affected by it. *As a precaution, however, move through them at a steady pace; do not linger in the area and stay at least 40 centimetres away from such equipment.*
- Electronic Article Surveillance (EAS) System tag deactivators — *The tag deactivators found in many retail stores can interfere with VNS Therapy when it is used near the generator. It can cause accidental activations or stop pulses. Stay at least 60 centimetres away from tag deactivators to avoid potential interference.*
- Devices with strong electromagnetic fields — *Electrical or electromechanical devices with a strong static or pulsing magnetic field can cause the generator to start suddenly. Such devices may include strong magnets, tablet computers and their covers, hair clippers, vibrators, antitheft tag deactivators, and loudspeakers. Keep this type of equipment at least 20 centimetres away from your chest. If your generator stops while you are in a strong electromagnetic field,*

move away from the source so the device may return to regular operation.

- Transmitting devices — Properly operating electrical ignition systems and power transmission lines should not affect the generator. *Sources with high energy levels, such as transmitting antennas, may interfere with the device.* Keep at least 2 metres away from any equipment that interferes with your device.
- Pacemaker Warning signs — Talk to your doctor before going into places that have Pacemaker Warning signs.

Devices that shouldn't affect the generator:

- Small appliances — Properly operating microwave ovens and other small electrical appliances, such as toasters, hair dryers, and electric shavers, should not affect the generator.
- Mobile phones — can affect some implanted cardiac defibrillators and pacemakers, but tests to date show that they do not affect the VNS generator.



It is worth asking your doctor to write a letter to carry while travelling that explains the VNS device and magnets. Wands used during security checks could affect the VNS device or the magnet could trigger a security alarm.

Other tips:

- Keep your magnet in a different pocket or on your belt buckle, away from your wallet.
- If you use a computer often, don't wear the magnet on your wrist – wear it on your belt buckle or put it on the floor when you are working at the computer.
- Don't put the magnet on top of a television, stereo, or other electronic device.
- Don't enter rooms or places that have strong electronic or magnetic fields or that have warnings for people with pacemakers or other implanted devices.

For more extensive information go to:

<https://us.livanova.cyberonics.com/patient-resources>

## Taking Action – What's happening at Epilepsy Action



### THE COUNTDOWN TO PURPLE DAY 2019 IS ON!

Mark **Tuesday 26<sup>th</sup> March** in your calendar but get set to celebrate all throughout the month of March!

Purple Day is in its 11<sup>th</sup> year and is a global initiative dedicated to raising epilepsy awareness.

We are so excited to see what all our wonderful supporters, schools, groups and communities will be

getting up to in March!

There are so many ways to get involved...

- Host your own fundraising event <https://www.epilepsy.org.au/fundraising-for-purple-day/>
- Get your school involved <https://www.epilepsy.org.au/purple-day-for-schools/>
- Buy our merchandise <https://www.epilepsy.org.au/get-involved/buy-merchandise/>
- Make a donation <https://www.epilepsy.org.au/donation/make-a-donation/>

Contact our Purple Day Team on 1300 37 45 37 or email [epilepsy@epilepsy.org.au](mailto:epilepsy@epilepsy.org.au) to get involved.

### IS YOUR SCHOOL SEIZURE SMART?

Epilepsy Action Australia is offering a Purple Day special 10% discount for schools undertaking our Epilepsy Essentials course.

It's just **3 simple steps** to become a certified Seizure Smart School:

1. Teachers and support staff trained in epilepsy awareness
2. Have seizure management plans in place for all students with epilepsy
3. Hold a Purple Day fundraiser through our [website](#)



**Share this link** with your school today so they can be a certified Seizure Smart School. <https://www.epilepsy.org.au/seizure-smart-schools/>

***YOUR OPINION MATTERS***

Epilepsy Action is canvassing our consumers to understand the types of information you would like to read in future newsletters. Could you please spare a few minutes to complete the survey by clicking here:



[https://www.surveymonkey.com/r/E360Newsletter\\_Survey2019](https://www.surveymonkey.com/r/E360Newsletter_Survey2019).

Have your say.