Epilepsy Action Australia

E-360 E-newsletter

Edition 20

Feature 1: Weather conditions & epilepsy

Have you ever noticed that your seizures happen more often in relation to the weather? Well you are not alone. In Australia, many people report that their seizures are often related to hot weather conditions. Whilst this topic has not been studied in Australia, research in the northern hemisphere, limited studies have shown:

- that in spring, autumn and winter, *unstable* weather conditions cause an increase in seizures in almost half of the people with epilepsy they studied, and but only in 7 percent had an increase in seizures in summer[i].
- an increase in seizures in winter conditions - lower ambient temperatures, higher atmospheric pressure, higher humidity, and reduced sunlight exposure[ii].
- that low atmospheric pressure and high relative air humidity may also increase epileptic seizure risk[iii].
- that weather-dependent seizure risk may be heightened in people with less severe epilepsy, that is, those taking a single antiepileptic drug. However, these studies had an under-representation of people with severe epilepsy.

Obviously, as with many seizure triggers, this is individual for everyone and clearly the effect of weather on seizure risk is still not fully understood.

Seizure Triggers

Most epileptic seizures occur unexpectedly and independently of known risk factors. There are many risk factors identified, and we also call them triggers. People with epilepsy report weather to be a major risk factor for epileptic seizures. [iv]

Triggers are circumstances that can bring on a seizure in some people with epilepsy. They differ from person to person, but not all people with epilepsy have seizure triggers.

And what triggers one person's seizures might not affect someone else with epilepsy in the same way.

Some commonly reported seizure triggers also include:

- Missed medication
- Lack of sleep
- Physical fatigue and exhaustion
- Stress, excitement, emotional upset
- Menstruation and hormonal changes
- Illness or fever
- Poor diet
- Medications other than prescribed seizure medications
- Flickering lights or geometric patterns
- Alcohol or drug use

For some people, knowing their seizure triggers, means they may be able to avoid them and lessen the risk of having a seizure.

What's the difference between triggers and causes?

Triggers for seizures are not the same as causes for epilepsy. A trigger for someone to have their first seizure may be a stressful situation, but the underlying cause for that person to start having seizures may be quite different. Causes can be genetic or because of structural damage to the brain.

Research: Temperature induced seizures

The latest epilepsy research carried out by experts in the US has looked into the issue of temperature-induced seizures, which remains a problem for many people around the world. They found that inserting a mutation into the genes of fruit flies that was similar to those found in people who experience febrile seizures led to the flies also having seizures. These experts have discovered new insights into the issue of heat-related seizures.

"What happens is the mutant neural (nerve) channels don't open and close properly. This effect is amplified at high temperature and this changes the ability of neurons to generate

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the appropriate electrical signals, leading to hyperactivity in the brain circuits".

"With this knowledge, the next step is to use this model to look for drugs that might reduce or eliminate heat-induced seizures."[v]

Seizures and the heat

Whilst research related to weather and seizures has been limited, and based in the northern hemisphere, there is no scientific evidence that hot weather itself causes seizures to occur in people with epilepsy. In Australia it appears most people report that the heat, or becoming overheated, tends to increase the likelihood of seizures. Becoming severely overheated can cause seizures, but an average hot day is not in itself the culprit.

How heat may cause seizures

Obviously, heat can be a major contributor to dehydration. If someone is exposed to heat for a long period of time and does not drink enough fluid, this can cause dehydration which can increase the risk of a seizure in someone with epilepsy, sometimes later in the day. When fluid loss from the body (mostly perspiration) is greater than fluid intake, it causes a change in electrolytes – a drop in sodium (salt) and glucose (sugar) levels in the body. Ultimately, this can lead to low blood sugar levels (hypoglycemia) which can also trigger seizures for some people.

Not surprisingly, on the rare occasions when a person becomes severely overheated, they risk a higher chance of having a seizure (amongst other serious health issues). So, it is important for people with epilepsy to prevent becoming over-heated in the first place, which at its worst, can lead to heat exhaustion or heat stroke.

Sometimes though, people report seizures due to *changes* in weather (or environment). For instance, if a person enters a hot environment from a cold environment this could potentially trigger a seizure; however, the opposite remains true as well.

How to protect yourself from the heat

If hot weather or becoming overheated is a trigger for your seizures it does not mean that you must sit in front of the air conditioner all summer. It means that sensible preventative measures can be taken in order to ensure a happy and safe summer.

A few suggestions to help:

1. When inside, keep the house at a temperature that is cool enough to be comfortable. The air conditioner temperature ideally should be set at 24 degrees Celsius. Try not have it too cool as this creates a large difference between the inside and outside temperature.
2. Don't let the house heat up before cooling it down. Keep the air conditioner on a constant temperature all day.
3. Good full thickness or blackout curtains, or tinted windows are another way to keep the house cooler.
4. Ceiling fans and free-standing fans work as a good method to circulate the air as well, and in high humidity, sometimes are more effective in keeping you cool.
5. Why not plant some good shade trees or bushes in your yard?
6. Seek shade when going outdoors when you can. If you have to walk, do so on the shady side of the street. If you are taking the children to a park or playground, source one with good shade or plenty of trees. Try not to be in direct sunlight for lengthy periods.
7. Stay hydrated. Take a water bottle with you and drink regularly.
8. Wear light cotton clothing and avoid synthetics in the heat. Synthetic clothes make you sweat more and make you feel hotter. Cotton is the coolest type of clothing to wear and "breathes" better. It goes without saying that wearing a hat is also a good idea.
9. Young children and seniors have more difficult time regulating body temperature. So monitoring their time in the heat is recommended. Give the kids some down time with a food break, or instigate water play such as water pistols, sprinklers or water balloons.
10. Topamax (topiramate) can decrease perspiration, which is the body's natural way of staying cool. Be aware of this if you take Topamax.
11. If you have to spend a hot day outdoors then make sure take it easy and don't over exert yourself.

Ultimately, it is important to spend time both indoors and outdoors in the summer. We all need a bit of sunshine. Just be prepared and take appropriate measures to ensure you or your family don't get overheated or sunburnt.

If you think your seizures may be weather related

What you can do:

1. Keep a diary of seizures; when they occur and the circumstances in which they occur. Patterns can emerge for some people. This may take months to recognise, particularly if they are associated with weather changes.
2. If you think your seizures are weather related, look at adjusting your environment at home (and preferably work) so you are less likely to have a seizure. This may even mean getting an air conditioner for your bedroom.
3. A domestic weather station (they vary considerably in price) may be worth considering so you can record the conditions on the days you have seizures to see if there are patterns.
4. Take precautions in unfavourable weather conditions for you.

Many people with epilepsy find that their seizures are triggered by various things, including temperature or barometric changes, certain lights and sounds, hormones and even sleep.

Regardless of the cause, if heat is a seizure trigger for you, use caution in hot weather to reduce your risk of seizures.

For more information go to:

Prepare your home for summer:
https://www.redfin.com/blog/2016/06/how-to-prep-your-home-to-avoid-summer-hazards.html
Heat induced illness – First Aid:
https://www.health.nsw.gov.au/environment/factsheets/Pages/heat-related-illness.aspx
https://www.cdc.gov/niosh/mining/UserFiles/works/pdfs/2017-128.pdf
Products that can help keep you cool:
Cooling Vests https://www.icevests.com.au/
Nikki G temperature controlled clothing
https://www.nikkigs.com.au/
Cooling towels https://runnerclick.com/10-best-cooling-towels-reviewed/
Cooling scarves https://gadgets-reviews.com/review/223-best-cooling-bandanas-wraps-scarves.html

Feature 2: Taking healthcare from the hospital to the home

Are you worried about seizures, fainting spells or blackouts?

Seizures can be sporadic, unpredictable and sometimes difficult to diagnose or determine if they are actually seizures, making diagnosis difficult in some cases, especially in young children where it is difficult to get a quality EEG recording. Getting a diagnosis of epilepsy can take some time and involve several repeated electroencephalograms (EEG's).

Sometimes an accurate diagnosis may require several days in hospital with video-EEG monitoring simply waiting for seizures to occur. It's uncomfortable, inconvenient, has a long wait-list and is costly to the medical system. Seer medical have developed an at home video-EEG (and ECG) service.

Seer Medical

If you think you or your child may be experiencing episodes that may be seizures, fainting spells or blackouts, Seer's at-home brain and heart monitoring service can help you get the right diagnosis and enable you to take control of your life. Seer offer bulk-billed, at home long term video EEG (and ECG) monitoring.

Seer monitor people just like you, all across Australia, every day. People who suffer undiagnosed episodes, people who want to confirm a recent diagnosis and people with epilepsy who want to explore their medication options.

How it works

Seer's at-home week-long video EEG-ECG monitoring service is for diagnosing unexplained or unpredictable events, testing the effectiveness of medications, or establishing whether people with epilepsy are safe to drive.

Who benefits?

Episodes that may be monitored can include seizures, fainting / syncope, psychogenic non-epileptic seizures, panic attacks, unusual sleep related episodes, narcolepsy, sudden collapse, transient ischemic attack, migraine and other sporadic conditions.

People who particularly benefit include people:
• who live in rural / regional areas;
• who are unlikely to commit to a stay in hospital;
• with a psychiatric / behavioural co-morbidity (e.g. depression, anxiety);
• with an addiction (cigarettes, alcohol etc);
• from a non-English-speaking background or with English as a second language;
• that require care or assistance such as

elderly patients, disabled patients or patients with other special needs;
• who are transitioning to adult hospital;
• who are single parents;
• with pets.

How do I get a booking?

1. All you need is a referral from your doctor.
2. Following a referral, you will be contacted by the Seer team to confirm an appointment for fitting the monitoring system at a Seer clinic.
3. Seer provide instructions on what to expect and how to prepare, via email or by post.
4. Appointments to fit the monitoring system take approximately one hour.
5. You then return home for monitoring where we record ambulatory video EEG-ECG for 7 days (maximum 10 days).
6. You use an App to report any episodes of interest.
7. At the end of the monitoring period, you will return to the Seer clinic, where they remove the equipment. This appointment typically takes half an hour.
8. The data is then analysed and a diagnostic report is prepared.
9. The data is interpreted and concluded by highly-regarded neurologists Prof Mark Cook, Dr Gabriel Dabscheck, or A/Prof Wendyl D'Souza or other renowned neurologists (or cardiologists).

The testing is fully bulk-billed, so you have no out-of-pocket expenses with a valid Medicare card. We are also a pre-approved TAC provider if you have a TAC claim.

Currently Seer are only operating in NSW, Queensland, Tasmania and Victoria, but have plans to expand further across Australia in the very near future. For more about this service; Call Seer on 0400 626 186 or email info@seermedical.com. Website: https://www.seermedical.com/

In the News – The latest on epilepsy

A Mind Unravelled: A Memoir.
The compelling story of an acclaimed journalist and New York Times bestselling author's ongoing struggle with epilepsy—his torturous decision to keep his condition a secret to avoid discrimination, and his ensuing decades-long battle to not only survive, but to thrive. To view the book, go to: https://www.amazon.com/Mind-Unraveled-Memoir-Kurt-Eichenwald/dp/0399593624

Early life seizures and autism.
Early-life seizures prematurely switch on key synapses in the brain that may contribute to further neurodevelopmental delay in children with autism and other intellectual disabilities, suggests a new study. Read more at https://www.sciencedaily.com/releases/2018/05/180529132005.htm

New screening tool for people with epilepsy and obstructive sleep apnoea.
Researchers have developed a tool to help neurologists screen for obstructive sleep apnoea in people with epilepsy whose seizures can be increased by sleep. Read more at https://www.sciencedaily.com/releases/2018/09/180927105625.htm

Nocturnal Monitoring May Reduce SUDEP in Severe Epilepsy.
Monitoring people with severe epilepsy in residential care facilities during the night was associated with a much lower rate of sudden unexplained death in epilepsy (SUDEP), a new study found. Read more at https://www.medscape.com/viewarticle/903503?src=wnl_edit_tpal&uac=265499PT&impID=1772281&faf=1#vp_1

Antiepileptic drug clearance changes during pregnancy.
During pregnancy, the numerous physiological changes a woman's body undergoes can alter the way medications are metabolised, the rate at which they are cleared, and their overall effectiveness. Read more at https://medicalxpress.com/news/2018-10-dose-antiepileptic-drug-clearance-pregnancy.html

Unintended pregnancy common in women with epilepsy.
More than half of all pregnancies in women with epilepsy are unintended and associated with premature birth. Read more at https://www.neurologyadvisor.com/epilepsy/unintended-pregnancy-rates-in-women-with-epilepsy/article/807978/

Unplanned pregnancy in women with epilepsy may double miscarriage risk.
In women with epilepsy, spontaneous miscarriage is twice as common in unintended pregnancies as in planned pregnancies. Read more at https://www.mdlinx.com/neurology/top-medical-news/article/2018/10/16/7546993/

Q&As – Our service providers answer your questions

Q: I've been told I have focal seizures. Are these silent seizures?
A: With a focal seizure, the seizure activity stays in one part of the brain. Therefore, you tend to have localised (focal) symptoms which appear quite subtle in some people. Different parts of the brain control different functions and depending upon which areas of the brain are affected will determine the outward signs of the seizure activity.

Two main types of focal seizures include:

1. Focal aware seizures
   In this type of seizure, you do not lose consciousness or awareness. They may involve muscular jerks or strange sensations in one part of the body. Or you may hear, see, smell, or taste odd sensations. Some people develop pins and needles in one part of the body. These seizures are usually very brief lasting just a few seconds, but sometimes minutes. These can lead onto focal impaired awareness seizures or tonic clonic seizures.
2. Focal impaired awareness seizures
   During this type of focal seizure, you are not aware of your surroundings or what you are doing. In effect, you have a partial loss of consciousness or awareness. Symptoms vary greatly but can include confusion, wandering, fidgeting, vocal sounds or confused language and chewing or lip smacking. These can also lead on to tonic clonic seizures.

Some people may call these seizures silent seizures, but this is not a recognised name for focal seizures. They were previously called partial seizures.

Q: How is nocturnal epilepsy treated? I am having seizures when I am asleep.
A: Nocturnal seizures are treated with medication like other types of epilepsy. The dosages of medication may be higher in the evening than during the day, and usually the medication is in the form of controlled release tablets, which means they release the medication slowly to keep the blood levels stable overnight.

Any form of epilepsy where the seizures are not controlled should be reviewed by a neurologist, and medication doses or the medication type may need to be changed. Two in three people will get good seizure control with medication. If, after a good trial of medications, the seizures are still not controlled other forms of treatment such as surgery or vagus nerve stimulation may be considered especially if the seizures are affecting quality of life.

Q: I was wondering what the chances are of a small bright light source near my work space causing a seizure?
A: We all find flickering lights or some colours or patterns irritating or difficult to look at to some degree however some people with epilepsy have seizures triggered by flashing or flickering lights, or by certain geometric shapes or patterns. People who have these seizures are diagnosed with photosensitive epilepsy.

Photosensitive epilepsy is a type of epilepsy we call reflex epilepsy and is seen in less than 5% of people with epilepsy. Medication can help gain seizure control.

Our modern environment is a rich source of potentially seizure-triggering visual stimuli. New potentially provocative sources turn-up now and then unexpectedly.

Whether or not a photosensitive seizure happens is also influenced by:

- whether the eyes are open, closed or closing at the time of the stimulation
- the speed or flicker of the flashing light or movement of the geometrical pattern
- the contrast and brightness of the stimuli – in general, with brighter stimuli and strong contrasts in colour, the more likely seizures will be induced
- how long the stimulation goes for – a seizure is more likely to occur with longer exposure
- the colour of the flicker (if any) – red flicker is more provocative and colour oscillating from red to blue
- how large and close the screen is – the larger and closer someone is, the more "field of view" it takes up and is more likely to trigger a seizure.

If you find the light is irritating, or makes you feel you may have a seizure, then speak to your boss and see if you can move to a different location at work, or ask if the light can be removed or dimmed. Also, some people with photosensitive epilepsy benefit from wearing tinted glasses such as the Zeiss Z1 blue lens glasses.

Q: Can I drink coffee if I have epilepsy? I heard it might cause seizures.

A: Coffee contains caffeine which is a stimulant found in a variety of foods and beverages, such as soft drinks, high energy drinks, tea, coffee, and chocolate. It can also be found in some supplements and medications, including some diet pills, antihistamines and decongestants. Be aware that some high energy and soft drinks contain more caffeine than a strong coffee.

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.
Some stimulant drinks or high energy drinks have other substances, like guarana. 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 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 coffee, or five or six cups of tea. This would probably be less for someone with epilepsy. So limit your coffee intake to two or three cups a day at most. If you also drink soft drink, this should be included in this quota.

Taking Action – What's happening at Epilepsy Action

GREAT CHRISTMAS PRESENT IDEA!

Our bears are getting ready for Christmas… will one of them be under your tree?

Every bear purchased helps us to provide more services and support to those impacted by epilepsy around Australia. Order before 16th December to have your bear in time for Christmas. Visit **https://www.epilepsy.org.au/get-involved/buy-merchandise/** to buy.

EXPRESSIONS OF INTEREST FOR YOUNG ADULT EVENT

Epilepsy Action Australia are happy to announce that expressions of interests are now open for a place at the Ya Me Event 2019.

Are you a young adult (aged 18-25)? Do you have epilepsy?

The YA Me event has been designed to provide young adults with epilepsy information and guidance on a variety of topics including employment, relationships, mental health and self-management.
Interested?

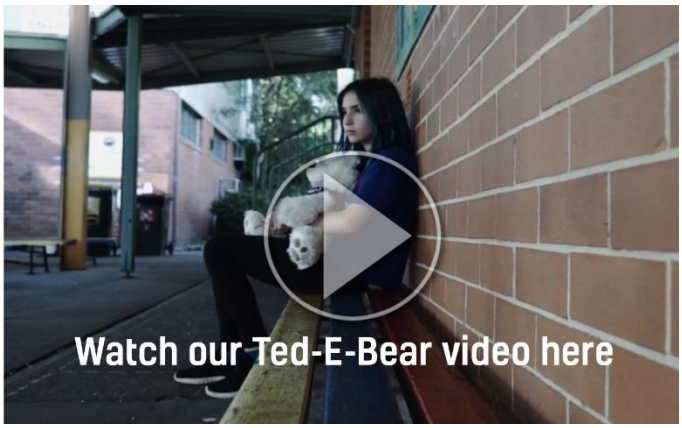
When - Saturday 2nd February to Sunday 3rd February
Where - Urban Camp Melbourne
Cost - The total cost of the program is $50pp, with accommodation and meals provided, however attendees will be asked to arrange their own transport to and from the venue.

Want to know more?
Email **epilepsy@epilepsy.org.au.** Want to express your interest in attending? **Please complete this survey: https://www.surveymonkey.com/r/YA_ME_EVENT_EOI**

Places are limited so please express your interest before 30th November.

SUPPORT OUR CHRISTMAS APPEAL

Visit **https://www.epilepsy.org.au/donation/make-a-donation/** to make a donation and bring comfort and joy this Christmas.



Have a look at the comfort our little Ted-E-Bears can bring to young children living with epilepsy. Video link is **https://vimeo.com/301547476/81c565fa6d**

[i] https://www.ncbi.nlm.nih.gov/pubmed/22212986

[ii] https://www.sciencedirect.com/science/article/pii/S1525505018301768

[iii] https://onlinelibrary.wiley.com/doi/pdf/10.1111/epi.13776

[iv] https://onlinelibrary.wiley.com/doi/pdf/10.1111/epi.13776

[v] https://www.epilepsyresearch.org.uk/epilepsy-research-reveals-details-of-temperature-induced-seizures/