EPILEPSY ACTION AUSTRALIA

E-360 E-newsletter

Edition 3

FEATURE 1: EPILEPSY PRODUCTS

There are an increasing number of products, resources and tools available to people with medical conditions, including people with epilepsy, which can be used to improve quality of life and/or help take more control over their disease. With today's technological advances, there is also a lot more information and easier access to find and buy products. Here we take you through some more recently available products. This is by no means an exhaustive list and to find more products go to: http://www.epilepsy.org.au/resources/epilepsyproducts

Devices currently on the market:

Seizure sensor
This state of the art epilepsy sensor monitors the user's vital signs including heart rate and breathing patterns to detect a range of epileptic seizures. The sensor eliminates the need for carers to make physical checks, promoting independence and dignity. http://www.tunstallhealthcare.com.au/solutions/epilepsy-sensor

Nikki G's Temperature Control Clothing
Developed by an Australian mum, the temperature control clothing whilst caring for her little girl Nikki, who had great difficulty controlling her own body temperature. Using a fabric developed for NASA, the technology is able to provide both heat if a persons temperature drops too low, or take heat away when the body temperature starts to rise. There are many products for adults and children. http://www.nikkigs.com.au/

Cooling Vests
There are many different products on the market. It is best to investigate what type of cooling vest or clothing suits your needs. Some Australian companies that sell cooling products and vests are:

Arctic Heat http://www.arcticheat.com.au/

Cool Down Australia http://www.icevests.com.au/

Personal Cooling Products http://www.coolhats.com.au/pg_cool_vest.php

Silver Eagle Outfitters Australia http://www.coolweave.com.au/vests.htm

Recording EEG through the ear
Electroencephalography (EEG) is used as an inexpensive way to record electrical signals in the brain. Though it would be useful to run these recordings for long periods of time, it usually isn't practical.

Now engineers at Imperial College in London have developed an EEG device that can be worn inside the ear, like a hearing aid. They say the device will allow EEGs to be recorded for several days at a time; this would allow doctors to monitor patients who have regularly recurring problems like seizures or sleep disorders. http://www.technologyreview.com/news/518356/device-could-spot-seizures-by-reading-brainwaves-through-the-ear/

Independent Living Centres Australia
This is a great website for products and technology of all types to assist people with health conditions. The range is broad and includes alarms, alerting devices, watches, helmets, medication boxes, aids for physical disability and safety products. To see the range go to http://ilcaustralia.org.au/search_category_paths

NEW SMART WATCHES

Today there are many different devices that identify when you're having a seizure and call for help. For example, there are a number of smartwatches - a wristwatch-like monitor that detects shaking motions, changes in heart rate and other signs. The watch sends a warning signal to your recipient of choice - family members or a caregiver for instance.

Embrace Watch
Embrace is a smartwatch that looks great on anyone. It can track your activity, stress and overall balance. It is designed to bring a better lifestyle to people that live with epilepsy: they get an alert when an unusual event happens, like a convulsive seizure, warning them and their loved ones. https://www.empatica.com/embrace-watch-epilepsy-monitor

Apple Epiwatch
The Apple Watch has a potential to be used for improving health and fitness. And now, thanks to a new study from the Johns Hopkins University School of Medicine, the watch is being used for the first time as a tool to help people diagnosed with epilepsy.

EpiWatch, an app the school recently launched, will be the first to take advantage of the sensors in Apple's wearable device for a medical study. It can directly measure limb movement while also monitoring the blood flow of someone in the throes of a seizure. The watch's multiple sensors make it far easier to collect all of that information and look at it together. http://www.bendbulletin.com/health/3613546-151/apple-watch-could-predict-seizures-thanks-to-johns

APPS

There are a wide range of mobile applications (apps) available for the everyday care of people with epilepsy. Those apps include seizure diaries as well as medication trackers with reminders to take the next dose. Apps are available to answer any question people with epilepsy might have and to remind doctors about drug interactions to watch out for. There are also Apps that turn your smartphone into a seizure detection system. It sends a report of your health and your GPS location to a family member or friend when you have a seizure. Some of these include:

EpDetect

Uses advanced signal processing to detect epileptic seizures. It runs on most mobile phones that support SMS messaging, movement detection and GPS position location. Epdetect can monitor the movement of a person while the phone is in their pocket or worn on a belt. The software will differentiate the movements associated with epilepsy from normal movement. When a seizure is detected it will warn the person that it is about to send an SMS message to a carer, in the case of a false alarm the person will be able to cancel the SMS alert. The SMS message contains time, GPS coordinates and a short message, allowing the carer to raise the alarm and take action or call an ambulance. When the person recovers they press a button to cancel the alarm, which will initiate an end of emergency SMS message. http://www.epdetect.com/

SeizAlarm

SeizAlarm is a user-friendly iPhone and Apple Watch app which allow people with seizure disorders to alert emergency contacts automatically when seizure-like motion is detected or manually if they need immediate help or think they might need help soon. Help is always just a button press away. For further information go to http://www.seizalarm.com/

Seizure Log by Seizure Tracker

Founded by parents of a child with epilepsy, App users can time and videotape seizures simultaneously in this revolutionary and simple-to-use application. When you stop the video and timer, it immediately creates an event log that is stored in a seizure library. You can edit the event at any time to add additional details about triggers, seizure description and what happened afterward. You can also use this app to log seizures without videos attached. https://itunes.apple.com/au/app/seizure-log/id410716391?mt=8

My Epilepsy Diary

This is an app for the self-management of seizures and epilepsy. It helps to track your epilepsy as it has options to add your medical history, seizures, medication and other symptoms or experiences. It can remind you about appointments, tests or medications. You can now allow your doctor or health provider to access the diary also, so he/she can monitor your epilepsy and observe any patterns with your seizures. This can improve communication between you and your doctor, and consequently management of your epilepsy. Go to https://www.epilepsy.org.au/myepilepsydiary

Epilepsy Society UK
Epilepsy Society's new smartphone app for Android and iPhone, with seizure diary and first aid information, is an interactive way to help you to manage your epilepsy via your phone. Find out more about the app and how to download.
http://www.epilepsysociety.org.uk/free-epilepsy-smartphone-app#.VnTAmbiGSko

MEDICAL JEWELLERY

The medical alert bracelet is a much lower-tech option that's been around for many years. It contains important emergency information about your condition. Information like the type of epilepsy you have and your medications help medical personnel know how to treat you in case you can't speak for yourself.

Whilst there are many traditional bracelets and necklaces on the market, for something more unique and personal try Etsy https://www.etsy.com/market/medical_alert

Road ID
Initially developed for outdoor athletes - joggers, cyclists, or triathletes - in the event of an accident on the road this medical ID not only looks good but it could save a life. Available in many different colours and styles. It's not just a piece of gear - it's peace of mind. There is also a Road ID app and other products on the site.
http://www.roadid.com/

BOOKS

Stacey Chillemi
Stacey Chillemi has written more than 20 books on a wide variety of subjects, from the challenges of living with epilepsy, positive thinking, alternative medicine, health, creative writing and poetry. Her books about epilepsy are for consumers and she has also written some childrens books about epilepsy to explain the disease to children.
http://www.staceychillemi.com/

Falling Down Funny – Mark Hawkins
In this brave and very funny account, Mark Hawkins gives a glimpse into what it's like to live with epilepsy and seizures, and to do so while succeeding in a career in the public eye. This is a very engaging book that will make you laugh but also make you think. A must read for anyone who knows and loves someone with epilepsy. Can be bought as a hardcopy or ebook on several sites
https://www.goodreads.com/book/show/18599556-falling-down-funny

Kevins Pyramid Calendar 2016
Kevin's Pyramids is a collection of stained glass that was created over a period of eight years by Trish Barnes as she grieved the loss of her son, Kevin Andrew Mateczun. Proceeds are donated to the Epilepsy Foundation USA with the intention to raise $50,000 to benefit new therapies, awareness and research in epilepsy.
https://epilepsyfoundation.four51ordercloud.com/epilepsyfoundation/product/KPC758

To see the beautiful pyramids go to http://www.kevinspyramids.com/

Stories for parents to explain their epilepsy
Epilepsy Action UK has written two story books for parents with epilepsy to explain the condition to their child. They are downloadable from their website
https://www.epilepsy.org.uk/info/parents-explain-epilepsy

UPCOMING DEVICES AND TECHNOLOGY

Predicting seizures

In the past, it was believed seizures occurred at random and couldn't be predicted. But it has been discovered that there is a series of readable events in the brain (sometimes heart rate and breathing) leading up to a seizure.

One way to pinpoint these events is with electroencephalography (EEG) measuring the electrical activity in the brain. Among other things, EEG is currently used to diagnose epilepsy, but researchers are discovering that it also can be used to identify abnormal patterns in brain behaviour before a seizure occurs.

Small, portable EEG devices have been developed that can be worn comfortably and monitor someone 24 hours a day.

The tools scientists are studying to predict seizures detect abnormal brain waves or changes in nervous system measurements—like heart rate and breathing. Then they use mathematical formulas to calculate the odds of having a seizure.
Here are a few ideas being tested for predicting seizures.

Wristband

Researchers at Massachusetts Institute of Technology (MIT) are working on a wristband that measures skin conductance—how easily an electrical current travels through the skin. Conductance is a measure of how much you're sweating and this conductance spikes just before someone has a seizure. The device can tell how severe a seizure is, and it may eventually be able to predict one.

Smartphone App

There are already smartphone apps to help you track your seizures and follow how well your medication is working. Now there are smartphone apps in development that will predict seizures. One product, called *Dialog*, could help people with epilepsy get a better handle on their condition.
http://www.dezeen.com/2014/03/14/epilepsy-aid-uses-wearable-technology-to-predict-seizures/

Dialog is made up of a small bracelet that you wear on your wrist, or a patch that you stick on your skin. The device continually records your temperature, pulse rate, and hydration level, and communicates these measures to the app using Bluetooth technology.

By analysing the data, the app alerts you to a possible seizure so you can take actions to prevent it. It also collects data during the seizure to give you more insight into your condition.

Other Seizure Prediction Devices

Researchers have been studying an implanted device that monitors brain activity to localise when a seizure might occur. An Australian study tested a device that consisted of a unit implanted in the chest with electrodes running to the brain. The unit sends out a signal to a handheld device, which flashes red if a seizure is imminent. In the study, the device accurately predicted a seizure about 65 percent of the time. Researchers say more studies are needed to figure out who might be the best candidates for this device.

The Future of Epilepsy Prediction

Current wearable devices can call for help while you're having a seizure, but they can't tell you whether you're about to have one. These new products being developed might one day be able to predict a seizure before it happens. This warning system will help people with epilepsy avoid potentially dangerous or distressing situations. They might even be able to avoid a seizure entirely.

It's important to remember that all of these technologies are still being investigated. It may be several years before an accurate seizure prediction product is available. For now, your best option is to follow the treatment plan your doctor recommends.

WHAT YOU CAN DO

If you have used a product that has helped and you feel will help others feel free to email us on epilepsy@epilepsy.org.au or call 1300 37 45 37 to let us know the details so they can be passed on to others.

FOR MORE PRODUCTS

Go to our website http://www.epilepsy.org.au/resources/epilepsyproducts
http://www.healthline.com/health/bracelets-and-devices-epilepsy#TheFutureofPrediction4

IN THE NEWS
THE LATEST ON EPILEPSY

Will we be able to predict medication resistance for people with epilepsy?
A new study has shed light on potential predictive factors that could be used to help identify people with epilepsy who are at risk of experiencing medication resistance – or poor seizure control despite trying a number of medications. Research at the University of Saskatchewan in Canada, aimed to identify these risk factors, which – if identifiable – would allow patients to receive earlier treatment and more individually tailored treatment plans. For more information go to: http://www.epilepsyresearch.org.uk/drug-resistance-predictors-for-epilepsy-patients-highlighted/

New brain imaging technique helps identify epilepsy focus.
Researchers at the University of Pennsylvania have developed a non-invasive brain imaging technique for people whose epilepsy symptoms do not respond to medication and who would otherwise be poor candidates for seizure-relieving surgeries. The imaging technique, known as glutamate chemical exchange saturation transfer (GluCEST), is a new specialised imaging technique that can trace the location of seizures that are not detected with conventional MRI or PET. For more information go to: http://www.nibib.nih.gov/news-events/newsroom/new-brain-imaging-technique-identifies-previously-undetected-epileptic-seizure

Dietary treatment for epilepsy. Therapeutic means uncovered.
Scientists from Royal Holloway, University of London and University College London (UCL) have identified how a specific diet can be used to help treat people with poorly controlled epilepsy. The research team have identified a specific fatty acid, decanoic acid, provided in the ketogenic diet that has potent anti-epileptic effects. For more information go to: http://www.neuroscientistnews.com/clinical-updates/drug-resistant-epilepsy-diet-therapeutic-mechanism-uncovered

Long term use of anti-epileptic drugs may affect balance.
Antiepileptic medication use appears to be associated with poor balance control, but it is not clear if these effects are related to epilepsy itself or its treatment. For more information go to: http://www.pharmaceutical-journal.com/news-and-analysis/research-briefing/long-term-antiepileptic-drug-use-may-impair-balance/20200113.article

Cannabis-based drug to be made available to NSW children with epilepsy
A small number of children with drug-resistant epilepsy will soon be able to access a new cannabis-based drug in New South Wales which is showing promise in relieving the symptoms.
The pharmaceutical drug, Epidolex, is still in a trial phase and has not yet received full approval from authorities, but the Government has now set the date of March for a compassionate access scheme to begin. Last year, the NSW Government approached the company that makes the drug, the UK's GW Pharmaceuticals, to see if trials could be arranged in NSW.

Pru Goward, the Minister for Medical Research, said the scheme was great news for families who had children with the *condition*. "These families are desperate," Ms Goward told the ABC.
GW pharmaceuticals said the drug, which had been trialled internationally, could be administered without the psychoactive effects or "high" of smoking marijuana.
Current medication used to treat epilepsy can leave children to deal with unwanted *side effects* that also impacts quality of life.
The use of Epidolex is part of $3.5 million batch of trials announced by the NSW Government in partnership with GW Pharmaceuticals, which includes a world-first trial of another drug, CBDV, or cannabidivarin.
New South Wales is also conducting a medicinal marijuana trial for adults with a terminal illness - the Terminal Illness Cannabis Scheme.
Ms Goward said that should the drug be approved, she was confident it would be available for use in Australia within three years.
The compassionate access scheme will start in March.
See more at: http://www.australiaplus.com/international/2016-01-24/cannabisbased-drug-to-be-made-available-to-nsw-children-with-epilepsy/1539199#sthash.035Stx80.dpuf

Q&As
OUR SERVICE PROVIDERS ANSWER YOUR QUESTIONS

Q. I have a child who waves an open hand in front of her face when outside and our GP mentioned it could be a form of epilepsy. Do you have any information about this?

A: There is a rare type of epilepsy where children demonstrate this behaviour called Sunflower Syndrome. It is a form of what we call *reflex epilepsy*. The waving of the open hand in front of the eyes induces photosensitive seizures which may present as absence seizures (brief periods of staring) or myoclonic seizures (sudden muscle jerks). If the stimulus is long enough, they may develop into a tonic clonic seizure. In some cases of photosensitive seizures, children may be drawn to the television or things like a screen door to elicit seizures.

There are many different types of reflex epilepsies, and overall, they are usually easy to manage with medication, and by avoiding the provoking stimuli. However, if this child is self-inducing, you may have to seek advice on strategies to lessen or stop this behaviour. Not all children with this syndrome will require medication especially if no significant seizures have been witnessed or you feel they are not affecting quality of life or schooling.

For more information on self-induced seizures click here: http://www.epilepsy.com/information/professionals/about-epilepsy-seizures/reflex-seizures-and-related-epileptic-syndromes-2
For more detailed information on reflex epilepsies click here: http://www.ncbi.nlm.nih.gov/books/NBK2596/
To view video examples of Sunflower Syndrome click here: https://www.youtube.com/watch?v=wVYTstTC1Wg&app=desktop

Q: My 13 year old daughter has been diagnosed with absence epilepsy and before starting medication she actually wants to try a dietary method, because she's read about it as a treatment. I was wondering if anyone has tried a low carb diet as treatment and was it effective?

A: Over the years, there has been an increasing interest and practice of dietary options for people with epilepsy, particularly people who struggle to get seizure control with medications. These include the Ketogenic Diet, Modified Atkins Diet, and the Low Glycaemic Index treatment (LGIT). Both the ketogenic and modified Atkins diet focus on high fat, high protein and low carbohydrate intake, whereas the LGIT focuses on carbohydrates that have a low Glycaemic Index (GI).

The John Hopkins Childrens Centre in the US has reported that two high-fat diets — the classic ketogenic and a modified version of the Atkins — can reduce and, in some cases, completely eliminate seizures in children with absence epilepsy. "Our group at Johns Hopkins has found that children with absence (early or more classic age of onset) do well on ketogenic diets…" About a third of people treated with either of these diets experienced at least 50 percent fewer seizures, and almost 10% showed as high as 90 percent improvement.

For an overview of the three diets click here http://www.epilepsy.com/learn/treating-seizures-and-epilepsy/dietary-therapies

There are also many books on dietary therapies. This one, "Fighting Back with Fat", written by Erin Whitmer and Jeanne Riether is written by two mothers of children who were on dietary therapy for their epilepsy (ketogenic and modified Atkins diets, respectively). It is a candid, honest accounting of life on the ketogenic diet, especially during the initial few weeks. Full of practical tips and advice, it is a helpful guide for any family considering starting these treatments. $18.66 plus shipping at www.amazon.com

> However, your daughter may find that using a special diet long-term is not practical because they are quite restrictive and hard work to follow. Most people eventually stop the diet because of the culinary and social restrictions.
>
> Speak to your daughters neurologist and possibly a dietician about these options.
>
> http://www.hopkinschildrens.org/High-Fat-Diets-Effectively-Treat-Absence-Epilepsy.aspx
> http://www.medicalnewstoday.com/articles/284596.php

Q: I've been diagnosed with temporal lobe epilepsy, but not yet taking medication. I've always enjoyed swimming and want to continue it, but my family think it's too dangerous at the moment. What should I do?

A: A diagnosis of epilepsy does not mean that you have to give up doing the things you enjoy. With a few safety strategies put in place you will able to continue swimming. It is important to initially be aware of your own seizure patterns and triggers to help you develop strategies to reduce how often your seizures happen. Of course, seizures may happen, but over time, you will most likely learn what situations or circumstances you are more likely to have a seizure and try and avoid swimming at these times.

For instance, if you've had a late night or are extremely stressed (although exercise does help stress), or just feeling unwell. If you are having a bad run of seizures one week, then it may be best to skip swimming that week.

Your family are rightly concerned about the risk of your seizures happening in water and the risk of drowning. It is important to never swim alone, always have a friend with you who can recognise your seizures and knows what to do if you have a seizure in the water. Swim where there are lifeguards on duty and tell them before you go in.

Ultimately, no one can make this decision but you. It's about using some common sense. If you take steps to improve your safety in the pool, then swimming is a good exercise to keep up.

TAKING ACTION!
What's happening at Epilepsy Action

It's that time of year again where we gear up to go **PURPLE**! We would love for you to be involved! This year Easter Saturday coincides with the ninth international Purple Day on March 26, dedicated to raising awareness of epilepsy. We are so excited to announce that we will be working with Australia's largest multi-food franchisor, Retail Food Group, who is proudly sponsoring Purple Day 2016! Retail Food Group's extensive franchise network includes brands such as Donut King, Brumby's Bakery, Michel's Patisserie, Gloria Jean's Coffees, Pizza Capers and Crust Gourmet Pizza Bar. RFG will support the Purple Day campaign through a variety of activities across its network. Thank you Retail Food Group!

EPILEPSY ACTION
AUSTRALIA

RETAILFOODGROUP
STRENGTH IN BRANDS

Brumby's BAKERY
Michel's PATISSERIE
PIZZA CAPERS GOURMET KITCHEN
Gloria Jean's COFFEES
donutking
crust Gourmet Pizza Bar

ART FOR EPILEPSY

We are thrilled that over 40 artists have created or donated a beautiful art piece for Epilepsy Action's Art for Epilepsy Auction.

The auction kicks off on 14th February, closing on Purple Day (March 26th). Visit www.artforepilepsy.com.au to join the exclusive pre-notification list. Happy Bidding!