

the flame

the newsletter of epilepsy queensland inc

Issue 3 – 2018

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WITH A RARE CONDITION

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outside
the box**

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Getting Cheeky in Queensland



Are you starting on Fycompa?

Would you please consider being part of the Fycompa Patient Registry?

Registries are an important tool, recommended by health authorities world-wide, to obtain more in-depth, high quality information on the effectiveness and safety of a new drug. This registry will help your doctor understand and use your medication more effectively.

This registry is recruiting: Patients with refractory epilepsy who are being started on Fycompa (perampanel).

Patient involvement includes 3-monthly questionnaires on seizure severity, quality of life and side effects, by phone and mail, and keeping a daily seizure diary (over a 12-month period).

Contact:

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yvonne.gautam@health.qld.gov.au

News - Epilepsy drug Fycompa listed on PBS

If you live with generalised tonic-clonic seizures that are not controlled well with existing medication, there may be some good news on the horizon. Health Minister Greg Hunt MP has announced that epilepsy drug Perampanel (FYCOMPA) will be listed on the Pharmaceutical Benefits Scheme (PBS) from 1 August. This new PBS listing for FYCOMPA provides reimbursed treatment access to adult and adolescent patients (from 12 years of age) with idiopathic generalised epilepsy (IGE) experiencing primary generalised tonic-clonic (PGTC) seizures. This drug is also available to be added on to an existing medication for partial-onset seizures with or without secondarily generalized seizures in people over 12 years of age.

The change could mean a saving of \$5,000 per year. For more information contact our services team on 1300 852 853.

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EDITORIAL DISCRETION

Epilepsy Queensland welcomes you to share your stories for inclusion in Flame. However, the Editor is responsible for the content of Flame and for ensuring the integrity of all work that is published in it. The Editor is responsible for ensuring an appropriate balance of stories published and for taking reasonable care to ensure that no work is published that contains material that is unlawful, or otherwise objectionable, or that infringes any other person's copyright, right of privacy, or other rights.

The Editor reserves the right to edit or exclude stories from inclusion in Flame at his/her discretion.

The Flame is published quarterly by Epilepsy Queensland – www.epilepsyqueensland.com.au

NDIS UPDATE AND WORKSHOPS

Are
you
ready?

The NDIS is now live in Brisbane, the Gold Coast, Logan and Redlands. Epilepsy Queensland is hosting workshops suitable for people with epilepsy and their families, disability support workers, child care workers, teachers, nurses and medical or allied health professionals. Join us to learn more about NDIS eligibility and access, practical steps to prepare for the NDIS, plan implementation and Epilepsy Queensland's support and services.

Location: Epilepsy Queensland, Lvl 2, 411 Vulture Street, Woolloongabba

Date: Various dates available

- Monday 6 August 10.30 - 12.30pm
- Thursday 9 August 5.30 - 7.30pm
- Tuesday 4 September 5.30 - 7.30pm
- Thursday 6 September 10.30 - 12.30pm

If you are not able to attend these workshops, but are still interested in training opportunities or need further support, please contact us on the below details.

If you are receiving this on behalf of an organisation, we would greatly appreciate it if you could forward this to others in your organisation. Similarly, if you are part of any network, please feel free to share this information widely.

If you have any questions or to book, please do not hesitate to contact Leonie on 07 3435 5000 or ndis@epilepsyqueensland.com.au. RSVP is essential.

Looking forward to seeing you there



MY EPILEPSY STORY

NOT BAD FOR A WESTIE KID WITH A RARE CONDITION



For a bloke that's made his living inspiring teenagers to learn and winning over business executives with his charm and smarts, it's hard to imagine his start was marred by a condition that has sent him into seizures and, at times, has taken command of his faculties.

Luke Eisenhuth is part of an exclusive club. In childhood he was diagnosed with the rare condition of Landau Kleffner Syndrome. In this type of epilepsy the 'Broca's area' of the brain is switched off with the loss of the ability to use or understand spoken language.

His experience however, has been far from shadowy – he's managed to step out of the shadows and face the adversity head on.

Luke grew up in the South West Sydney suburb of Campbelltown and since his diagnosis at the age of four, he's been busily bursting the bubbles of this grim diagnoses.

"When I was 4 year of age, I completely and instantaneously lost my ability to speak."



"I was told I would never speak again, that I'd struggle to make it through mainstream school, and that I'd need special support."

It wasn't an easy path to tread, but Luke has managed to forge his own way through life.

"I suffered regularly from tonic-clonic and focal seizures, and I was on medication to control that right up until the end of Primary School."

"I experienced social anxiety as a kid, and had to deal with some exclusion, coupled with moderate learning difficulties, traits of autism; so, it wasn't easy..."

Just to confuse people more, Luke could sing even though he couldn't speak, due to the area of the brain affected.

"I guess you could say, the seizures were one thing – but once I regained speech, it came with a stutter and a high pitch – so, that was at another level. You can imagine how that goes down in the playground".

He feels his experience with epilepsy has shaped his success.

"From being told to never play contact sport, I went on to play professional rugby league. So, I've learned to take people telling me about my limitations with a grain of salt."

Since hanging up the footy boots, Luke took to education and business.

Epilepsy created a lot of fear for Luke, as it does for many people dealing with the condition and their families. For him, almost everything became affected by fear, yet time after time he has climbed all of the mountains life has placed in his path.

"My own experience in school and the teenage years wasn't an easy one, so I was really motivated to do what I could to make life easier for the next generation of kids."





He holds three tertiary qualifications and now focuses his energies to helping large corporates improve their cultures as a Business Education Manager for behaviour, motivation, strategy company Pragmatic Thinking.

"My job now is to help teams and businesses shift their mindsets and build their corporate cultures."

Still, Luke's focus hasn't narrowed to improving the lot of big companies. He remains committed to helping young people on their journeys in life.

"I know what it's like to do it tough, and I find happiness in educating people of all ages in dealing with tough times".

"I'm on the way to finishing my book. It's aimed at helping young people improve their mindsets through motivation and movement."

"The book touches on all spheres of wellbeing illustrating my unique view of life through the lens I have been 'lucky' enough to experience".

"I seriously believe everyone can relate to at least some part of my story, and some information will even surprise those closest to me"

Luke has not been in Queensland long, but after attending Epilepsy Queensland's Purple Day 2018 celebration in Brisbane, he has already established significant friendships.

"The colour purple itself represents a vast range of strong qualities, much like those who live with epilepsy. Again, like the colour purple, it represents the distinct uniqueness of the condition, and the specific symptoms the individual may face."

"Purple day is a perfect way to educate the significant impact epilepsy has on individuals and their families, and the link it has

to a range of neurological conditions. It simply achieves the most powerful movement- bringing people together."

Luke strongly believes Purple Day should not be the only time that we talk about epilepsy.

"I hope in the future we see more people who have experienced or live with epilepsy achieving highly and speaking of their condition. I would like to see epilepsy detached from the stigma of being a 'disability', or a condition that limits one's ability. In particular, for children and families to live with less fear, take educated risks and make more effort towards good health and a positive mindset."

"Personally, I want to continue to prove conditions such as epilepsy do not define a person, yet the person defines the condition."

Despite his successes in sports, education, and business, Luke maintains his trademark humility.

"It's not bad for a Westie kid with a rare condition"

If you would like to share your epilepsy story and help break down the myths and misconceptions of living with epilepsy visit: <http://bit.ly/ShareMyWhy> or contact us on pr@epilepsyqueensland.com.au.

Thinking outside the box

The Ninth Annual Queensland Epilepsy Symposium 'Thinking outside the box' is planned for 30 October 2018. Speakers from overseas, interstate and Queensland will provide opportunities to learn about a range of exciting developments in epilepsy under the banner, 'What's in the pipeline?'.

A key note speaker this year, is Sean Pittock Professor of Neurology, Mayo Clinic College of Medicine, who setup the Autoimmune Neurology Clinic at the Mayo Clinic, the first dedicated clinic of its type in the USA.

At the Epilepsy Queensland Symposium Professor Pittock will present on Autoimmune Epilepsy: From biomarker to cure.

It is believed that some forms of epilepsy may be autoimmune and caused by antibodies that attack different proteins in the brain. This form of epilepsy may not respond fully to standard antiepileptic drugs (AEDs) and might require a different treatment strategy. Knowing at the time of diagnosis whether a person's epilepsy is linked to autoimmunity would help to ensure they received the right treatment promptly.

Professor Terence J. O'Brien, MB, BS, MD, FRACP, FRCPE, FAHMS, FAES, is The Van Cleef Roet Professor of Medicine (Neurology) and Head, Departments of Neuroscience, Monash University and Director of Neurology and Deputy Director of Research, Alfred Health

He is a specialist in neurology and clinical pharmacology, with particular expertise in epilepsy and neurodegenerative diseases, neuropharmacology and in-vivo imaging in animal models and humans. He did his clinical and research training at St. Vincent's and Royal Melbourne Hospitals in Melbourne, and then the Mayo Clinic, Rochester, Minnesota, USA (1995-1998). He leads a large translational research team undertaking both basic studies and clinical studies focused on developing improved treatments for people with epilepsy and related brain diseases, including traumatic brain injury, dementias and brain tumours. Prof O'Brien will

be covering: "Disease modifying therapies for epilepsy: making the dream a reality."

Along with other medical professionals, Professor Glenn King, who is the group leader, Chemistry and Structural Biology Division and Investigator at the Centre of Pain Research at University of Qld, will be presenting: 'Can venomous animals help us develop precision medicines for epilepsy?'

Professor King's research team uses the complex chemical arsenals of venomous animals to develop drugs to treat epilepsy, chronic pain, and stroke. His laboratory at the University of Queensland maintains the largest collection of venoms in the world, comprising more than 600 venoms from ants, assassin bugs, caterpillars, centipedes, scorpions, and spiders. Professor King has published 3 books, 19 book chapters, and more than 230 peer-reviewed articles in international scientific journals.

Nervous system disorders, like pain, epilepsy, and stroke remain some of the world's most serious health problems. Epilepsy, stroke, and pain have two significant things in common. Firstly, an overactive or mutated ion channel influences the disease, and secondly, we need good treatments to address them. Professor King is exploring the venoms of spiders, centipedes, and scorpions to find novel peptides that can inhibit or activate ion channels. These have potential to become drugs for nervous system disorders.





Other presenters include Professor David Reutens from the Royal Brisbane and Women's Hospital Comprehensive Epilepsy Service and the Centre for Advanced Imaging, University of Queensland, talking about Seizure Detection Devices. Mr Peter Jones, Australia's first Epilepsy Nurse Practitioner will share his

journey so far in his new role. Stay tuned for other details about the symposium and the diverse range of presenters.

For more information and to book your tickets visit:
<http://bit.ly/EpilepsySymposium>

Ninth Annual
Queensland Epilepsy Symposium
 Thinking **outside** the **box !**
 Save the date
 Tuesday 30 October 2018
 State Library of Queensland
 Join us for some stimulating dialogue...
www.epilepsyqueensland.com.au
 Bookings essential!

Spark NeuroCare

Epilepsy Queensland has withdrawn from the next phase of the Spark NeuroCare partnership.

We've valued the opportunity to trial a different service framework with partners MS Queensland, MNDQA, Huntington's Queensland, MND and Me, and Youngcare. Epilepsy Queensland's recent consultations and planning

have helped determine our future pathways to best respond to the needs of people with epilepsy and their families, and it is in this context that we've decided not to participate in the next phase of Spark NeuroCare.

We sincerely thank MS Queensland and partners for their support for Spark NeuroCare.

30 minutes with...

Jo

Adams



What is the exact title of your role?

I am Founder and Head Cheeky Neuron Handler at The Cheeky Neurons

Where do you currently work & how long have you been working there?

I am currently working full time at The Cheeky Neurons- an epilepsy awareness project that I started in 2017 while studying.

Where else have you worked or studied in your life?

My education and work has always been driven by my fascination with the brain and behavior! Through my early studies I ultimately became a neuroscientist and I was involved in research that ranged from studying brain cells in culture to cognitive testing in dementia facilities. I spent over 10 years teaching psychology and neuroscience at Monash University and Monash College, which I loved. Then in 2016, I decided to run away and join the circus – the Science Circus that is! I spent 2017 as a touring presenter with the Shell Questacon Science Circus while studying a Masters of Science Communication (Outreach) at The Australian National University in Canberra. It was during this time that The Cheeky Neurons were born – combining my love of neuroscience with my love of craft and my passion for ending the stigma associated with neurological disorders.

What do you think is the most exciting/important change in the epilepsy education sector and why?

I think it's great that people are talking more about epilepsy and schools are actively promoting epilepsy awareness. There's a greater recognition from teachers and schools that even when there is no seizure activity, students with epilepsy might still be affected by their condition. While I know that there is some way to go before we reach universal epilepsy awareness in schools, this is a really positive shift in the classroom as students affected by epilepsy aren't so readily left behind.

What do you feel the main challenges are for a child living with epilepsy?

Kids with epilepsy and their families are still confronted by huge amounts of stigma. I've heard some awful tales from families about the discrimination that they have faced - it's truly heart wrenching! Like all stigma, this is largely based on a lack of understanding about epilepsy specifically, and the brain more generally. We learn about

the rest of the body in primary school – most six year olds can tell you something about how the heart and lungs function - yet the brain remains a mystery. This means that kids affected by epilepsy are in an environment where their peers don't have the ability to understand their condition. This coupled with fundamental human traits like fearing things we don't understand and seeking quick and easy information (even if it's misguided), can mean that kids affected by epilepsy face significant discrimination from their peers that stems from the stigma that prevails in the community at large.

Tell us about your experience with epilepsy education and why you are so passionate about raising awareness and understanding of epilepsy.

I have always been passionate about tackling the stigma that surrounds both neurological and psychological conditions. I've seen this stigma directed at people close to me and I'm determined to be part of the solution.

Since the inception of the Cheeky Neurons project, something that I have seen repeatedly is that children are fascinated by the brain and have a great capacity to learn about it when information is pitched at their level. Not only that, they love telling other people about what they have learned – so knowledge can spread pretty fast when it's in the hands of children!

What do you love about your job?

I recently had a wonderful experience with a young girl who created her own Cheeky Neuron character at an event I attended, and proceeded to tell her mum all about neurons, how they work, and how sometimes they can be a bit cheeky. Her mother thanked me emotionally; telling me that she herself had epilepsy but hadn't told her children because she wasn't sure how! They left that event talking openly about the brain, neurons and epilepsy and the door was open for the family to talk about how epilepsy affected them. Having experiences like that are what I love about my job. Knowing that I have made life with epilepsy a bit easier for that family is just so rewarding!

Where would you most like to travel?

This is a really hard question – I want to travel everywhere! However, if I was to plan my next trip it would probably be to Hawaii. I am fascinated by volcanoes and there's very few places on Earth that you can witness their power quite like you can there.

What is your favourite food?

Home-grown tomatoes from my vege patch!



Getting Cheeky in Queensland

We enjoyed a beautiful sunny winter's day for Little Poss' Birthday Party at the Community Place at Stafford. There were so many fun things to do, new friends to meet and nothing beats the delicious cupcakes and cuddles with Little Poss.

We were thrilled to have Jo and the Cheeky Neurons as our special guests all the way from Canberra. Little Poss' party was the start of their tour of South East Queensland generously supported by Inspiring Australia Queensland and Moggill Mt Crosby Lions Club. Jo makes explaining epilepsy fun and crafty as she takes children through creating their own Cheeky Neuron while talking about Nix and Nellie's adventures in the brain. After the workshop, they can take their Cheeky Neuron home, making it easier to have a conversation about epilepsy with their friends.



Jo and the Cheeky Neurons appeared at Queensland Museum during Brisbane's Out of the Box Festival, Darling Point Special School and Noosa Civic shopping center on the Sunshine Coast. These events raised fantastic awareness, helping to build understanding of epilepsy, particularly amongst younger children.

Find out more about Jo and the Cheeky Neurons in our 30 minutes with story.

To Join the Little Poss Club and be the first to hear about our events and services for families visit: <http://bit.ly/EQchildren>

Describe your most embarrassing moment?

It wasn't 'embarrassing' at the time, but a moment that has stuck with me and drives me to this day happened when I was about 14 years old. I was in central Melbourne with friends and we saw an elderly woman struggling on an escalator and calling out for help. I distinctly remember looking around to see what everyone else was doing, and when the people around me did nothing, I also did nothing to help! I have felt deep regret and personal embarrassment about that day ever since.

It wasn't until I studied social psychology at university that I began to understand my behaviour. It's called 'the bystander effect' and pretty much everyone will succumb to it at some stage in their lives. I also learned that you can counteract the bystander effect by stepping forward when others don't – being what my hero Philip Zimbardo calls an 'everyday hero'.

What/who is your favourite book/author?

My favourite book is Fahrenheit 451 by Ray Bradbury, and my favorite author is Douglas Adams.

Who would you like to meet?

This list is almost endless, but it's heavily populated by inspiring women especially those who were pioneers in STEM (Science Technology Engineering and Maths). I'd say a top candidate would have to be Florence Nightingale. She famously founded the first school of nursing and helped many wounded soldiers through their darkest hours and for that alone she is a hero. But, she also used statistics and clever communication to convince legislators to make real changes to hygiene practices, which contributed to saving countless lives!

What genres of music do you like listening to/favourite song?

I listen to a range of music, but I love my hard rock!

Do you have any interesting hobbies you would like to tell us about?

I'm what's known as a spinner & hooker - I spin my own yarn and I crochet it into all kinds of things (even Nellie the Cheeky Neuron is made from hand-spun yarn). I also love to play board games with my husband and friends and we regularly attend board-gaming conventions all over Australia.

What do you feel would greatly improve epilepsy care currently in Australia?

I believe that we need to get to a stage when open, everyday conversations about neurological conditions like epilepsy are commonplace. You'll often read statements along the lines of "everyone knows someone with epilepsy, but they might not know it" which really highlight how people with epilepsy often don't feel able to be open about their condition. I've met some brave people who are willing to stand up and talk about their experience of epilepsy, but it's far from the norm, and I can understand why. I believe that by having everyday conversations about the brain and epilepsy, we can contribute to normalizing those conversations and increasing general knowledge about the brain. This will have a hugely positive impact on people with epilepsy and other neurological disorders in the long term.



Who will you walk, run or wheel for?

Epilepsy Queensland is excited to be entering a team in Bridge to Brisbane for our third year in a row. We are inviting everyone touched by epilepsy who enjoys either a challenge, or a leisurely stroll along the scenic Brisbane River, to join Team EpilepsyQLD for this iconic day.

Whether it is personal, or in honour of someone you love, there is so much to gain from participating in this event while raising funds and awareness to help Queenslanders living with epilepsy.

With 5km or 10km options, Bridge to Brisbane is for all ages, abilities and fitness levels, for those serious about achieving their fitness goals or those out to have fun!

Meet and connect

Come alone, or get your family, friends or colleagues together. Past participants have shared with us that events, like Bridge to Brisbane, are a great way to connect with others living with epilepsy. So why not join Team EpilepsyQLD or create your own team?

Step up for epilepsy and start fundraising today. We'll be with you every step of the way!

A dedicated Fundraising Coach will be available to offer you tips and suggestions on how to maximise your fundraising. Raise over \$100 to go into the draw for a great prize!

To register or for more information visit
www.epilepsyqueensland.com.au/team-epilepsyqld today!

Get your organisation/company involved!

In addition to the above fantastic benefits, your organisation/ company's participation will see your brand shared in Epilepsy Queensland's communications and all the goodness that comes from team bonding.

Increase your team's fundraising impact:

- Encourage friendly department competition
- Match \$ for \$ what your team raises
- Sponsor your team by paying their Bridge to Brisbane registration
- Share Epilepsy Queensland's message with your clients and customers.

Alternatively, your organisation/company can be involved by sponsoring Team EpilepsyQLD.

Can't make it to Brisbane?

What about joining Team EpilepsyQLD in our Virtual Run/Walk for Epilepsy? Challenge yourself to run, walk, wheel or ride the 5-10km distance of the Bridge to Brisbane from the comfort of your hometown, in your own time, while raising funds for Epilepsy Queensland.

For more information on fundraising or joining Team EpilepsyQLD email Lisa at fundraising@epilepsyqueensland.com.au or phone 07 3435 5000.

Show your support and donate to TeamEpilepsyQLD online <http://bit.ly/TeamEpilepsyQLD>

Be Seizure First Aid Aware



Kos Sclavos (Board Member) and Wally Lewis (Patron) getting ready for the September Sizzle

One in 10 people will have a seizure during their lifetime. With this in mind, our aim is for one person in every household to know seizure first aid. Epilepsy Queensland have a range of resources available for work home or school. Download them from our website or order online. www.epilepsyqueensland.com.au/first-aid

During the month of September we will be sharing tips and stories about seizure first aid on Facebook. Please share our posts or your own posts about your experience with seizure first aid. www.facebook.com/EpilepsyQueensland

September Sizzle for Seizure First Aid

Host your own September Sizzle to raise awareness of Seizure First Aid. Join with us by hosting a sausage sizzle or other event (Breakfast, BBQ, Dinner Party Morning/ Afternoon Tea) to raise vital funds to increase awareness and understanding of seizure first aid.

1. **Sign up for September Sizzle** - Host your own sizzle from backyard BBQ to black tie, at work, school or your home. www.epilepsyqueensland.com.au/sizzle
2. **Be a Seizure First Aid Hero** – share your story to raise funds and awareness of seizure first aid. www.everydayhero.com.au/event/septembersizzle18
3. **Celebrate your birthday for seizure first aid** – Are you celebrating your birthday or a special occasion in September? Ask your family and friends to donate to Epilepsy Queensland in lieu of gifts. Set up your celebration page at: www.everydayhero.com.au/event/celebrateforepilepsy
4. **Buy/sell merchandise** - visit our online shop, download and return an order form or purchase from a participating pharmacy or location near you. www.epilepsyqueensland.com.au/little-poss-appeal.
5. **Donate online** - make a secure online tax deductible donation. Visit www.epilepsyqueensland.com.au/donate.

Contact Us

So what are you waiting for?

Register today for the September Sizzle activity of your choice or contact us for further information.

Phone: 07 3435 5000 or 1300 852 853 (outside Brisbane)

Email: fundraising@epilepsyqueensland.com.au

Website: www.epilepsyqueensland.com.au/sizzle

**Buy
tickets**



Play for Purpose is a new charity lottery where you can support your favourite charity - including Epilepsy Queensland!

By joining together, Play for Purpose are able to offer a 1 in 19 chance of winning a fabulous prize - drawn on 27 September 2018.

Total value of all 11,105 prizes is over \$1,000,000!!

Tickets are only \$25 with \$15 from each ticket sold via the below link going to Epilepsy Queensland to help people living with epilepsy.

Why not play for a purpose today?

Visit: <http://bit.ly/eqraffle>

**OR call us on 07 3435 5000 with
your credit card details and we can
purchase the tickets on your behalf.**



Celebrating our volunteers

National Volunteer Week (21–27 May 2018) celebrates and acknowledges the generous contribution of volunteers. Epilepsy Queensland's volunteers give their time and expertise to assist us in our mission to optimise the lives of Queenslanders living with epilepsy and help bring epilepsy out of the shadows.

Volunteers assist with tasks and projects across our organisation from putting together our mailouts to marketing, education, events, fundraising, awareness, support groups and our board. During National Volunteer Week we hosted an afternoon tea to say a huge thank you.

Volunteering Australia's theme for National Volunteer Week was: Give a little. Change a lot.

According to Volunteering Australia: "This years' theme represents the millions of volunteers who make a profound impact in their communities and on society, through giving a little time."

We would sincerely like to thank all of the volunteers from across Queensland who create change for people living with epilepsy through their generous contributions.

If you are interested in volunteering for Epilepsy Queensland please contact Jenna on 1300 852 853 or email epilepsy@epilepsyqueensland.com.au.



GIVE A LITTLE. CHANGE A LOT.

NATIONAL VOLUNTEER WEEK | 21-27 May 2018 | #NVW2018



NVW
NATIONAL VOLUNTEER WEEK
Give a little. Change a lot.



SMART EVERYDAY TECHNOLOGIES

Q: I have seen people using wearable seizure monitors and using other smart devices around the home. What technologies can I use to help manage my epilepsy?

A: What is smart technology? The world of smart technology is rapidly changing, which is just one reason why it is vital to keep up to date with technology options. Smart technologies are connected devices which offer us a range of sensing capabilities, remote monitoring and automatic responses. They are used to enable safety, home control and automation, health and wellness, connect you to help and support, and manage everyday life. This article describes some of the SMART technologies that can enable you to live independently and provide peace of mind.

Getting help when you need it

Personal Response Systems (PRS or PERS): if you are unwell or need assistance, it's important to have a reliable way to call for help. There are a range of technologies to call for help. These systems allow you to send an alert or stay in contact with someone when you need support. The system provides an alert button which you can wear around your neck as a pendant, or a watch strap.

You can choose the kind of system that work best for your individual situation. Some devices work within the home whilst others enable you to access support and stay in touch when you are out and about in the community.

Devices can either be 'unmonitored', allowing you to connect with your friends and family when you need help, or can connect directly to a monitoring or emergency call centre. There are benefits to either system so it's worth thinking through the options and deciding which will meet your needs.

Seizure detectors: There are a range of devices that can detect seizure activity – monitors, alarms, wearable devices and smart watches, and safety sensors that can detect movement, heart rate, breathing patterns or sounds that are associated with seizures. Some devices can be placed around the home, for instance a seizure mat can be placed on surfaces or on the

bed to monitor activity overnight while you sleep. Others are wearable and can be worn everywhere you go, depending on where and when you need to monitor your seizures.

Some Smart watches are designed to detect unusual movement or heart rate patterns and send an alert to friends or family as soon as a seizure is detected. These Smart watch devices may also offer additional features like falls detection, medication reminders or GPS location within the same device.

There are apps which can be downloaded onto a smart watch, which are being designed and evaluated for their ability to detect activity which is linked to seizures.

Falls detectors: if you are at risk of falling during a seizure, there are also devices which detect a fall and send alerts to your support network.

An activity (or inactivity) monitoring system can also be set up to identify if there is movement or lack of movement around the home for a predefined period. For example after a fall, the system will first ask if you are OK and if you don't respond it will send an emergency call or alert asking for assistance.

Getting around the community

Safe walking and staying in touch: Many people use location and tracking devices to help stay safe and keep in touch outside the home or getting around the community. Many devices have an SOS button which you can use at any time if you feel unwell or need to call for help. These devices identify your location and send details to your contacts. Your family or support network can also locate you if they have concerns. These kinds of technologies come in different forms so that you can choose the one that fits your needs and lifestyle.

Managing everyday life

There are a number of smart everyday technologies that help with managing your everyday life. For instance, there are apps for smart phones which can help with reminders to take medication. There are also apps to help manage your epilepsy and keep track of seizures, monitor side effects or organise your

medical appointments through a digital 'diary'.

Medication reminder devices can also help with managing a good medication routine. These can come in the form of watches that can be used anywhere you go, or smart pill organisers which can be used within the home. Simple apps on a smart phone can also help to keep you organised and on top of your daily medication routine. Smart technologies are often most effective when you have a good back-up plan, and a clear plan of action in case of emergency.

Support and protection

You can also find a range of low-tech options like supportive gear or protective wear in case of a fall. Some people find that extra support while walking can help ease anxiety in particular situations where they are fearful. While not a solution for everyone, supports like walk belts can provide support partners with extra grip to provide support or assistance, or help make some transfers easier. This can provide an extra degree of reassurance when used in conjunction with safe person-handling techniques. Seek advice from a health professional for a suitable solution for you.

Protective wear can also offer some reassurance and protection during activity or falls. There are a range of headwear offering varying levels of protection from hard helmets to soft padded caps and beanies.

Things to consider

To work effectively for you, these smart devices need to be reliably worn or used and may need regular charging, updates or management.

Different designs can make a huge difference to your experience of wearing or using a device. Think about the

features that will make a device comfortable, wearable and easy for you to use.

Some devices will have an ongoing cost associated with the service or system used. Ask your provider about the costs involved and the kind of telephone or internet connection services required.

Looking for support with assistive technology?

You can find out more about the range of smart options and devices at www.ilcaustralia.org.au

To discuss your individual needs in selecting and managing these and other devices, you can contact one of the national assistive technology services.

https://ilcaustralia.org.au/contact_us

LifeTec can help you explore possibilities of assistive technology and choose solutions that fit your needs.

Ph: 1300 543 383 www.lifetec.org.au

Epilepsy Queensland can also help you find the right devices and assistive technologies. If you are considering the NDIS, funding may be available for assistive devices. Contact Epilepsy Queensland's team on 1300 852 853 to discuss.



IS YOUR MEMBERSHIP DUE FOR RENEWAL?

Your subscription to "the flame" is just one of the benefits of Epilepsy Queensland membership. To continue receiving your quarterly copy, we ask you to renew your membership. If you have not already renewed your membership prior to the end of the financial year, or if you are not sure if your membership is due, contact us on 07 3435 5000.

As a valued member and important part of our family of loyal supporters, you will also receive:

- Free (daytime in-house) workshops in Brisbane and the Gold Coast for members who have epilepsy and their immediate families
- Discounts on publications, regional workshops, seminars and special events

- An invitation to attend special events including the Annual General Meeting and Awards Ceremony
- Contribute to greater access to epilepsy services, support, policy, research and awareness initiatives.

To join or renew your membership today return the enclosed form or contact us on:

Phone: 07 3435 5000 or 1300 852 853 (outside Brisbane)

Email: member@epilepsyqueensland.com.au

Your continued support is important to us - Together we CAN make a difference!

2018

DIARY DATES

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|--|---|
| 26 August | Bridge to Brisbane Join team EpilepsyQld and raise awareness and funds for Queenslanders living with epilepsy |
| 1-30 September | September Sizzle One in 10 people will have a seizure during their lifetime. With this in mind, our aim is for one person in every household to know seizure first aid. Get involved by hosting a sausage sizzle or other event to raise vital funds to increase awareness and understanding of seizure first aid. Find out more: http://bit.ly/EQsizzle |
| 1-30 September | Little Poss Appeal Help us sell our range of cute merchandise including pens, Poss badges and awareness wristbands - plus gorgeous plush possums. This is a simple yet meaningful and fun way to not only raise funds but also increases community awareness, both of which are of enormous benefit to people living with epilepsy. |
| 30 October | Queensland Epilepsy Symposium Epilepsy Queensland has proudly presented Queensland's Epilepsy Symposium since 2010. The Symposium has presentations that will be of interest to anyone with a connection to epilepsy whether you are a person with epilepsy, a family member, a health professional or care worker. More information on speakers and topics coming soon. Register your interest today by contacting Epilepsy Queensland on 07 3435 5000 or services@epilepsyqueensland.com.au . |
| 16 August, 13 September 18 October (9:30am and 6pm) 15 November | Understanding Epilepsy Workshops (Woolloongabba) For Disability Support Workers, Child Care Workers, Nurses, Allied Health Professionals, Volunteers, People with Epilepsy and their Families |
| 5 September 14 November | Understanding Epilepsy Workshops (Gold Coast) For Families, People with Epilepsy, Carers, Child Care Workers, Teachers, Nurses and Allied Health Professionals |
| 4 September (5:30pm - 7:30pm) 6 September (10:30am-12:30pm) | NDIS information sessions (Woolloongabba) Sign up for one of our free workshops to find out more about the NDIS including eligibility and access, practical steps to prepare, plan implementation and how Epilepsy Queensland can help with every step of the NDIS journey |
| Informally First Saturday of the Month Formally – 1 September, 3 November | Brisbane Adult Support Group Meeting |
| 29 August, 26 September, 24 October, 28 November, 19 December | Adult Social Group Ipswich |
| Please call 07 3435 5000 for further information on any of the above events | |



ANNIVERSARY
CELEBRATION

WE'RE TURNING 50 NEXT YEAR!

We want your help to celebrate 50 years of supporting people living with epilepsy in Queensland.

- Share your story – tell us about your connection to Epilepsy Queensland, help us bring epilepsy out of the shadows and break down the myths and misconceptions of living with epilepsy. Let us know your significant birthday or anniversary in 2019.
- Have your say- help shape our future by being a part of one of our consumer focus groups.
- How we celebrate – tell us the events, projects and services you would like to see.
- Be a part of the celebrations – register to host your own event or be a part of one of ours.