

the flame

the newsletter of epilepsy queensland inc

Issue 3 - 2020

**I have epilepsy,
can I drive?**

Helen Whitehead

A legacy of care

MY EPILEPSY STORY
MOTIVATION THROUGH ADVERSITY



RENEE'S COLOUR CHALLENGE

Did you know some people with epilepsy lose their hair due to treatment, testing or surgery?

Purple Hero Renee invites you to join her "My Hair, I Care" everyday hero challenge which is encouraging people to shave, cut, or colour their hair with funds raised going to Epilepsy Queensland.

Renee says: "Personally I lost (my hair) due to a treatment I went through when I was in my late teens and it's only just finished growing back. This can destroy a person's confidence and identity." "I want to run the "My Hair, I Care" fundraiser in

honour of my own experience and those of my community, demonstrating solidarity through people altering their hair in our honour and raising money to help through Epilepsy Queensland Inc."

Renee writes more about her reasons for undertaking this challenge here: <https://bit.ly/Hairicare>

Thank you Renee and challenge recruits for your tireless efforts and advocacy for Queenslanders living with epilepsy. We can't wait to see your new looks!

ACMENA GROUP SUPPORT DURING TOUGH TIMES

Thank you to Acmena Group Pty Ltd which recently donated \$5,000 to Epilepsy Queensland to support our services for Queenslanders living with epilepsy. Each year, this Australian owned and operated engineering and management services provider generously donates to a number of charities supported by their team members. We were nominated by Ricky Clayton, whose wife was recently diagnosed with epilepsy.

"In January this year my wife had a seizure, which was frightening and definitely unexpected," said Ricky. "When we

tried to find out why this happened to her the doctors couldn't give us definitive answers and we realised how little we knew about the subject. That's why this year I decided to support Epilepsy Queensland, which helps to raise awareness and support people who suffer from the condition."

This support will help ensure more Queenslanders impacted by epilepsy will have access to our vital services such as the Epilepsy Helpline, training, information and support during these tough times.

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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 their discretion.

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



RESEARCH UPDATE

What is Deep Brain Stimulation (DBS) and how can it help treat epilepsy?

Thanks to its success in treating Parkinson's disease, Deep Brain Stimulation (DBS), which involves electrodes being implanted in the brain, is now being explored for other conditions, including epilepsy.

"In epilepsy it's often used to break up circuits," Professor Matthew Kiernan, co-director of the Brain and Mind Centre at the University of Sydney says. "It's like a lesion – like cutting out part of the scar that might be causing the epilepsy. If you put electrodes into that area and turn the stimulation rates up it sort of paralyses that part of the brain so the seizures don't occur anymore."

More than 160,000 people around the globe have been treated with DBS, however, in Australia the treatment is currently only approved and funded for the treatment of Parkinson's disease, essential tremor and dystonia.

DBS is approved, but not yet funded, for use in epilepsy and obsessive compulsive disorder (OCD).

The Mater Neurosciences Centre Brisbane is a public service and DBS is one of the neurological services they offer.

Find out more: <https://bit.ly/DBSnews>

Do you find music therapeutic for epilepsy?

A new Canadian clinical research study has found that a particular Mozart composition may reduce seizure frequency in patients with epilepsy.

The results of the research study, "The Rhyme and Rhythm of Music in Epilepsy," was recently published in the international journal *Epilepsia Open*. It looks at the effects of the Mozart melody, "Sonata for Two Pianos in D Major, K. 448" on reducing seizures, as compared to another auditory stimulus -- a scrambled version of the original Mozart composition, with similar mathematical features, but shuffled randomly and lacking any rhythmicity.

"In the past 15 to 20 years, we have learned a lot about how listening to one of Mozart's compositions in individuals with epilepsy appears to demonstrate a reduction in seizure frequency," says Dr. Marjan Rafiee, lead author on the study. "But, one of the questions that still needed to be answered was whether individuals would show a similar reduction in seizure frequency by listening to another auditory stimulus -- a control piece -- as compared to Mozart."

Whilst the sample size was too small to be applied to larger populations, the results were encouraging, with the next step to conduct larger studies with more patients, over a longer period of time.

You can read more about the study here: <https://bit.ly/2NdBla5>

Risks Around Epilepsy Medicines In Pregnancy

More than one in ten (11%) women in the UK who are currently taking the epilepsy medicine valproate are unaware of the possible risk of birth defects if taken in pregnancy. Furthermore, almost one in five (18%) don't know that, when taken in pregnancy, the medicine could also cause learning and developmental delays in children. These worrying figures come from a newly published survey by epilepsy charities Epilepsy Action in the UK, Epilepsy Society UK and Young Epilepsy.

For information about the UK survey visit:
<https://bit.ly/EpiPregnancy>

In Australia we are very fortunate to have the Australian Pregnancy Registry which has been monitoring women taking anti-epileptic medication during pregnancy for over 20 years.

The Royal Brisbane and Women's Hospital epilepsy and women's clinic consulted with Epilepsy Queensland on the sodium valproate and women information, guidelines, checklist and consent form. This information is vital to assist woman to make informed decisions on their epilepsy treatment in conjunction with their health practitioners. We are grateful to Dr Cecillie Lander and Dr Lata Vadlamudi for their leadership in this important area of epilepsy care, and for revising our fact sheets.

For the latest Queensland specific information and fact sheets:
<http://bit.ly/EpiFertility>

For the Epilepsy Society of Australia guidelines on Valproate and Women, go to <https://bit.ly/ESAwomen>

The Metro North Comprehensive Epilepsy Service based at Royal Brisbane and Women's Hospital offers specialist outpatient clinics including rapid assessment and treatment of patients over 14 years of age and a specialised service for women with epilepsy.



MOTIVATION THROUGH ADVERSITY



MY EPILEPSY STORY WITH SIMON MCQUILLAN

Simon McQuillan is no stranger to adversity. Diagnosed with epilepsy at the age of 18, Simon hit rock bottom in his early twenties. He was dealing with anxiety and depression that he believes were a side effect of epilepsy medication. At 20, he flipped his car after a seizure behind the wheel, severing parts of his fingers. His treatment plan was changed and things were going well for a while, until Simon was coward punched when on a night out. After this, his seizures changed and increased and Simon had to stop working.

Simon explains: "I had gone from being healthy, working in mining and had everything all lined up. In six months, I lost everything and had to move back in with my folks. I had next to no social life and had lost contact with most of my friends and was unemployed for 5 years."

At 24, Simon was left feeling as if he was out of options, so when his neurologist suggested epilepsy surgery, he jumped at the idea.

"I had gone from being someone who was extroverted and then couldn't work, so I was not worried about the risk of surgery. I didn't care because I couldn't do anything, I had a speech impediment and had no quality of life. I had nothing to lose, either way at least it was a chance."

Simon was one for the first people to undergo this surgery in Brisbane: "I had temporal lobe lobotomy surgery, about 18 months before Wally Lewis. It was a similar operation, but I had it in Brisbane. It was my only option. I was lucky the surgeon was moving from Sydney to Brisbane in about six months. They had to set up some of the equipment first, but I was one of the first ones in Brisbane to have that surgery done."

The surgery changed Simon's life. It was a hard recovery, but he went from feeling as if things were hopeless, to being back to his motivated self.

"I went from having 40 seizures a week to pretty much nothing. They gave me a 60 percent chance of success due to position of the epilepsy focus (where the seizures start in the brain). They told me within two months I should be okay, but I found I had to rest up for six months. After that, I got a basic job working in a cold room. Within 12 months, I had saved up for a house of my own and a holiday to reward myself. My seizures are now mostly under control, but it has changed and now I can get seizures due to stress, heat and lack of rest. They are at nighttime when I am tired during sleep."

Despite these major improvements in Simon's life, there was still one aspect that was not fulfilled. Epilepsy had an impact on Simon's self confidence and he didn't date for about 10 years.

To connect with others impacted by epilepsy
or share your story contact Epilepsy
Queensland on 1300 852 853 or
epilepsy@epilepsyqueensland.com.au.

"Dating and meeting people was the biggest challenge. When it really started to set in, my self-esteem was knocked for a sixer. Why would someone be interested in me with my current issues?"

He made the brave decision to go on reality TV show "Married at First Sight" hoping to find love. Simon's down-to-earth outlook on life meant he was a fan favourite on season three. The whole country was rooting for Simon and his bride Alene Khatcherian. Unfortunately, the pair were not able to make the relationship work, but Simon was grateful to be matched with a caring partner in a difficult situation.

"When I was on Married at First Sight I let them know what had held me back with dating came down to social issues with my health. I was my own worst enemy. I was lucky to be matched with someone who was understanding and of all things, a nurse. I was having seizures on our honeymoon at nighttime and she would pick me up off the floor and help me back to bed. In the morning, she would let me know what had happened. No matter who you are, everyone is susceptible to health issues," he explains.

Simon believes the conditions on the show were a trigger for seizures.

"It was really full on. Sometimes the filming would be until 2-3am. I would not have access to medication on time or meals at the same time. We would have meals at ridiculous hours. I said to them if I was working in a factory there would be access to first aid or a nurse. One day we filmed until 3am and they wanted to start filming again at 6am. I told them, I won't be there, and I am happy for you to tear up the contract. I advocated for proper breaks and a nurse onsite. Things would be a bit better for a day, then they would go back to the same thing," he said.

Simon's family and friends have been a wonderful source of support, but over the years, he has suffered discrimination and stigma in the workplace.

"When I first was diagnosed, I was scared for years to say anything about it because of the stigma, in particular, in the workplace. I would not say anything about it until I was comfortable in the job. One time I was going for a job and I mentioned to the supervisor I had previously worked with a couple of years before, that I can't drive anymore, but I can catch the train. He passed the message onto the employer and suddenly there wasn't a job. People were afraid thinking I was going to be a liability. So, I made sure I didn't tell until I had the job," Simon explained.

While Simon has an easygoing nature, once his seizures were under control, his motivation was undeniable. He found ways around challenges in the workplace by investing money from a mine redundancy to start his own business.

"I started buying and selling cattle and invested in a business selling accessories for vehicles and trucks I have designed. I manufacture and send them all around Australia, New Zealand and other places overseas. I also drive a truck for Coles one night a week which is a great change mentally and socially."

Simon would like to see others give people living with epilepsy and other conditions a fair go, whether it be in relationships or in the workplace.

"People need to realise there is a real person underneath that shield. If you see barriers put up it might be because they are worried about what you think. They have so much to offer. You should not judge a book by its cover," he shares.

These days Simon rarely has seizures and credits his continued improvement to medicinal cannabis. When speaking openly about this change to his treatment, Simon has faced some criticism, but is keen to explain that it contains no THC and it is prescribed. He would like to see the barriers broken down for people living with epilepsy that medicinal cannabis may assist.

He shares "I am now using medicinal cannabis. I did a lot of research before commencing this treatment. The application process was a pain and there has been a number of glitches in availability. The product that I was using would become unavailable, so I would have to use a different product and it would not quite work the same. I've been on that for seven months now. Affordability at \$500 for 20ml is ridiculous. Most people can't afford that cost, but I am lucky."

Simon is happy to be a mentor to others impacted by epilepsy and encourages people to reach out for connection and support from their local epilepsy organisation.

"I found Epilepsy Queensland on social media many years ago. Recently I have been following the stories people have been sharing and I thought I could share mine too. I went to the Woolloongabba office about 10 years ago and was given a lot of information to read."

Simon encourages people to also give what they can.

"What have you got to lose? The next person you could be assisting could be your cousin who has only just found out they have epilepsy. It could be a friend who has had it for years, but you have not discovered. My brother has epilepsy and my cousin was diagnosed in late twenties. I also have an Auntie through marriage who has epilepsy. One in every 20 will have epilepsy and other similar conditions. It won't kill you to give and the research can go so far."



ASK AN EDUCATOR I HAVE EPILEPSY, CAN I DRIVE?

Having a diagnosis of epilepsy may impact your driving status. It is important to discuss transport and driving guidelines with your GP or neurologist.

At Epilepsy Queensland, we understand the challenges and concerns relating to a change in driving status, even if this is on a temporary basis. Not driving may make people feel a loss of independence, that you can't go where you want, when you want or that you are dependent on others.

A number of health conditions, including epilepsy and seizure disorders, can impair a person's ability to drive safely. As seizures can cause loss or impairment of awareness and loss of motor control, the risks associated with driving are increased. Driver health and fitness to drive is imperative to road safety, not only for the drivers themselves but for the safety of passengers, pedestrians and other drivers.

Your first seizure

Following a first seizure, the Australian recommendation is a driving ban for a minimum of six months for private vehicle licence holders.

It is good medical practice for any person with initial seizures to be referred to a specialist, for accurate diagnosis of the specific epilepsy syndrome so that appropriate treatment can begin and all the risks associated with epilepsy, including driving, can be explained.

With regard to licensing, the treating doctor/general practitioner may liaise with the driver licensing authority (Department of Transport in Queensland) about whether the criteria are met for driving a private vehicle, but only a specialist may do so for a commercial vehicle driver.

According to the Queensland Department of Health, a conditional licence may be considered by the driver licensing authority subject to at least annual review, taking into account information provided by the treating doctor as to whether the following criteria are met:

- There have been no seizures for at least 12 months; and
- The person follows medical advice, including adherence to medication if prescribed or recommended.

There are certain situations associated with a lower risk of a seizure-related crash whereby driving may be resumed after a shorter period of seizure freedom. However, this is at the

discretion of your treating specialist. An annual review still applies and you must abide by all medical treatment and advice.

Circumstances under which an exception to a 12 month driving ban may made include:

- First seizure (requires 6 months of seizure freedom unless the seizure results in a motor vehicle accident)
- Epilepsy treated for the first time (requires 6 months seizure freedom)
- Seizures only in sleep
- Seizures in a person previously well controlled.

Your responsibilities as a driver

Assessing Fitness to Drive, a joint publication of Austroads and the National Transport Commission (NTC), details the medical standards for driver licensing for use by health professionals and driver licensing authorities. Under section 6.2.2 the responsibilities of licence holders living with epilepsy are explained.

The person:

- must continue to take anti-epileptic medication regularly as prescribed
- should get adequate sleep and not drive when sleep-deprived
- should avoid circumstances, or the use of substances (e.g. excessive alcohol), that are known to increase the risk of seizures

If a person refuses to follow a treating doctor's recommendation to take anti-epileptic medication, it is likely the person will be assessed as not fit to drive.

Consequences of not reporting a medical condition that may impact safe driving

Further describing a driver's role and responsibilities, Austroads advises drivers may be liable at common law if they continue to drive knowing that they have a condition that is likely to adversely affect safe driving. Drivers should be aware that there may be long-term financial, insurance and legal consequences





where there is failure to report an impairment to their driver licensing authority.

Options for travel assistance

If your condition prohibits the use of public transport, you may be eligible for the following supports.

Taxi Subsidy Scheme

For people with severe disabilities who are unable to use other forms of subsidised public transport, the Taxi Subsidy Scheme (TSS), under the National Disability Insurance Scheme (NDIS) may provide a co-contribution of up to \$25 per trip for those eligible. The scheme was due to end on June 30, 2019, however, the Queensland and Commonwealth Governments have dedicated funding to ensure the scheme can be accessed by NDIS participants until 31 October 2021.

Find more information under "Taxi Subsidy Scheme and Lift Payment" at the Queensland Government website www.qld.gov.au

Mobility allowance

Where a person experiences a disability, illness or injury that means they cannot use public transport, they may be eligible for a mobility allowance payment to assist with travel costs for work, study or job seeking.

Read more under "Mobility Allowance" at Services Australia's website www.servicesaustralia.gov.au/

For more information visit the Epilepsy Queensland website: <https://bit.ly/EpiDriving>

The above information has been abstracted from the following references:

Services Australia - <https://www.servicesaustralia.gov.au/>

individuals/services/centrelink/mobility-allowance

Austroads - <https://austroads.com.au>

Queensland Government - <https://www.qld.gov.au/transport/licensing/update/medical/fitness>

Queensland Government Department of Health - <https://www.epilepsyqueensland.com.au/wp-content/uploads/Driving-and-epilepsy-QH.pdf>

ASSISTANT HEALTH MINISTER VISITS TO HEAR IMPACT OF EPILEPSY

We were pleased to welcome Assistant Minister for Health, Nikki Boyd MP who visited our Woolloongabba Office to hear more about the impact of our services on Queenslanders living with epilepsy.

Epilepsy Queensland is grateful to receive Queensland Health funding to assist us to support people living with epilepsy through our Helpline, counselling, training and online communities.

We look forward to continuing to work with the Queensland Government to continue to get the best outcomes for people living with epilepsy and their family members.





HELEN WHITEHEAD A LEGACY OF CARE

To say Helen Whitehead has lived the mission of Epilepsy Queensland would be an understatement. In the 28 years she has spent as CEO of Epilepsy Queensland, she has helped to optimise the lives of Queenslanders living with epilepsy and bring epilepsy out of the shadows. It is with sadness that we advise Helen has resigned from Epilepsy Queensland.

Helen has been a major part of achieving the Epilepsy Queensland mission forged 50 years ago by a group of parents, people living with epilepsy, health professionals and educators. In that time the lives of hundreds of thousands of people have been touched by our services.

Helen is known for the signature splash of purple in her hair in line with the awareness colour for epilepsy. She will, however, also be remembered for was cultivating a culture of care and support amongst team members, volunteers and the members of our epilepsy community. A community where people matter and staff support and get to know people and their needs as individuals.

From the beginning, Helen set about raising awareness and understanding of epilepsy, to help reduce stigma and discrimination. The “Shadows of Discrimination” study was the first of its kind in Queensland and clearly demonstrated the impact of misconceptions and stigma on the lives of people with epilepsy.

Helen was instrumental in engaging ambassadors for the cause with lived experience of epilepsy themselves or as a family member to share their stories in the media, advertisements and our publications. In 2009, the team helped to usher in our main awareness campaign as Epilepsy Queensland brought Purple Day to Australia.

Wayne Bennett was the first “celebrity” to step forward and publicly support Epilepsy Queensland’s awareness and fundraising. The Brisbane Broncos became valued partners for many years. Early supporters who were generous in their time and contribution to Epilepsy Queensland included Hugo Weaving, George Gregan, Susie O’Neill, Pat and Louise Rafter.

Wally Lewis accepted Helen's invitation to become Patron in 2009, and this heralded a new era for epilepsy in Queensland. Wally Lewis recently said of Helen, "When you're first involved with epilepsy and told all about it, you're not quite sure what path you are going to follow. You need some assistance and precious advice that comes from the people at Epilepsy Queensland. Helen Whitehead is the CEO at Epilepsy Queensland. She ensures they provide wonderful assistance to everybody that requires it. After working with Helen for over 11 years as Patron of Epilepsy Queensland, I have only respected her even more."

As a psychologist and speech pathologist, Helen recognised the profound psychosocial impact of epilepsy. To provide support for people with epilepsy and their families, Helen built a team of professionals with diverse skills including teaching, counselling, nursing, human services, public health, communications, fundraising and the arts. We gained a reputation for consistently punching above our weight as creative projects coordinated by Carol Sugden both empowered people with epilepsy and their families, as well as raised awareness in the community.

The "Shadows of Discrimination" study demanded that we become proactive in raising awareness about epilepsy to reduce stigma, and we started this with children, where we could make the greatest lasting difference. With Anne Little, our mascot Little Poss was conceived in 1993 to help remove the stigma of epilepsy amongst children in schools. The books "And Down Went Poss" and "Poss's School Days" were written to help children understand how to be a good friend to people living with epilepsy. These books and the "Little Poss Show" that visited kindergartens, preschools and schools, were considered very innovative. In 1994 this was enhanced by the World of Trivia Program in schools to increase awareness and raise funds for the program. It was through World of Trivia that we met one of our longest supporters, Andrew Barnes as a student, who remains with Epilepsy Queensland as a board member and key advocate today.

Helen also brought Epilepsy Queensland into the digital age with our first website in 1998 giving people ready access to evidence-based information in their own homes. In 1999 our Little Poss website won the Cable & Wireless Award for best not-for-profit website for children in the world.

Helen has been a strong advocate to Government for support for people living with epilepsy and funding for EQI so we could deliver our services.

Along with staff and board members, she has developed a strong reputation for EQI by networking with healthcare workers, neurologists, educators, government departments and researchers for the best results for people living with epilepsy. While seminars and workshops have always been one of our activities, the "Thinking outside the box" symposia have made cutting edge research accessible to the Queensland epilepsy community.

Helen says "It's been such a privilege to work at Epilepsy Queensland, honouring and carrying on the legacy of the Kemp family and other founding members who originally fought so hard for the rights of people living with epilepsy". She pays special tribute to Jan Taylor, Louise Foley and Fergus Pollock for their decades of dedicated service on the Board.

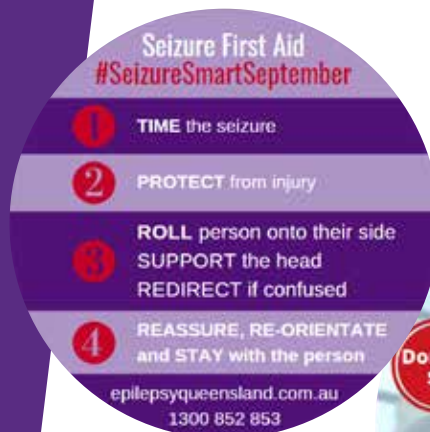
Helen's time has seen many advances in treatments and our organisation's efforts have made a difference, providing information and support to people in tough times. Until we have a cure for all types of epilepsies, our battle continues to ensure every Queenslanders has access to these vital supports and we end the stigma associated with living with epilepsy.

Epilepsy Queensland Chairman Sam Bryce shares "As a person living with epilepsy and parent to a child who is also affected by the condition, I will be ever grateful to Helen for all of her efforts. As Chairperson of Epilepsy Queensland, I have every faith that the team will carry on her legacy and will continue to evolve and provide the vital supports needed for all those impacted by epilepsy."

"I am also grateful for the involvement and support of all of our members and supporters. It is always an honour to hear your stories of living with epilepsy and see the support everyone has for each other in our community. My best wishes go out to Helen," Sam said.



Be Seizure First Aid Smart



One in 10 people will have a seizure during their lifetime regardless of whether they have epilepsy. A seizure can happen to anyone, and don't always look the same. 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. <https://bit.ly/EpiFirstAid>

During the month of September, we will be sharing tips and stories about seizure first aid on Facebook, Instagram, Twitter, YouTube and Linked In. Please share our posts or your own posts about your experience with seizure first aid.

www.facebook.com/EpilepsyQueensland,

www.twitter.com/epilepsyqld,

www.instagram.com/epilepsyqld, www.linkedin.com/company/epilepsy-queensland

<http://bit.ly/EQIYouTube>

Does your workplace or school need understanding epilepsy and seizure first aid training? Contact us for training options via Zoom, in your workplace or self-paced online webinars.

Join us! Here are some ways you can support our seizure first aid campaign.

1. Be a one in 10 Hero – Are you or someone you love impacted by seizures? Join our 1 in 10 challenge and do one thing related to the number 10 every day for 10 days. It could be 10 push-ups, a 10 minute run, read or meditate for 10 minutes, walk or ride 10 kilometres or your own personal 1 in 10 challenge. The challenge starts at the conclusion of Seizure Smart September between 1/10/20 and 10/10/20. Share your story to raise funds and awareness of seizure first aid. www.everydayhero.com.au/event/onein10
2. Purchase a Seizure Smart awareness token - During September selected pharmacies, schools and other retailers will be helping to promote seizure first aid awareness and raise funds for our seizure first aid education, training and awareness programs. Seizures are not rare and

broader community understanding of basic seizure first aid could save lives.

Anyone can get involved by stocking our Seizure Smart September \$2 tokens (pictured) and displaying seizure first aid educational posters. The token contains basic seizure first aid information, so people who purchase them can either take them home or the retailer or school can display them to show their support.

3. Be a digital ambassador – share your seizure first aid or epilepsy story. Contact us on pr@epilepsyqueensland.com.au and we will guide you. Write or make a video of your own story and share on social media or we will send you some questions and put it together. Through people allowing us to share their stories on Facebook, Instagram, Twitter, our website and member magazine we are helping others to know they are not alone or isolated in their experiences with epilepsy and seizures.
4. Donate online - make a secure online tax-deductible donation. Visit www.epilepsyqueensland.com.au/donate.

Contact Us

If you would like us to share your seizure first aid story through social media or local media or if you would like further information or resources please contact us on:

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

Email: pr@epilepsyqueensland.com.au

Website: www.epilepsyqueensland.com.au



Seizure First Aid



TIME the seizure

PROTECT from injury

ROLL onto side if unconscious

SUPPORT head if seated

REDIRECT if confused

REASSURE and re-orientate

STAY with the person

DO NOT restrain

DO NOT put anything in mouth

DO NOT give any food or drink until recovered

**CALL AN
AMBULANCE
000**

or 112 for mobile phones

- As per management plan
- Seizure longer than 5 minutes
- Second seizure follows
- Seizure occurs in water
- Person is eating or drinking
- Person's first seizure



**YOUR
FEEDBACK
MATTERS!**

EPILEPSY QUEENSLAND SURVEY RESULTS 2020

Introduction

Every few years Epilepsy Queensland conducts a survey of financial members, supporters, and people who have received our services to gather data on needs and how well Epilepsy Queensland is meeting these needs.

The survey was advertised in our e-news, Flame and on our website and was available online, through Survey Monkey from January to February 2020. There was also the option of going through the survey with a staff member over the phone or face-to-face. Thank you to everyone who provided feedback.

Respondents

Eighty-six people responded online, none through alternative means. Epilepsy had been in most of these people's lives for over 10 years. The majority of people completing the survey were female (69%), 29% were male and 2% did not specify. No respondents identified as an Aboriginal or Torres Strait Islander person, and 95% spoke English as their first language.

Most of the sample was aged over 45 years. Respondents were more likely to have contact with Epilepsy Queensland once every few months or less frequently. The majority prefer their communications with Epilepsy Queensland to be via digital formats rather than face-to-face or via the phone. Most popular communications in order of preference were via email, eNewsletters, our website and social media.

They identified their relationship with epilepsy as follows:

Type of respondent	%
Person with epilepsy	46
Family member, spouse or parent	32
Employer of person with epilepsy	1
Teacher/Disability/Health worker	16
Other	5

Table 1 Breakdown of survey respondents

What is Epilepsy Queensland good at?

services excellent Providing information info training etc
advice helpful support Symposium epilepsy
awareness information sure Providing people
communication Helping

People talked about how we provided good support, that we were helpful, good listeners, a sounding board, friendly, welcoming, and patient. "You answer my questions without making me feel like an idiot". Some mentioned that we were especially helpful for people who are newly diagnosed. "You understand my story", and "you make me feel like I'm not different to others" was another theme.

There were also extensive mentions of our quality information services – "you can answer things on the spot", or "better than my GP". Epilepsy Queensland's ability to provide up to date information on a wide range of topics was appreciated. Information resources, the Flame, social media and our website were specifically identified. The publication of people's own stories was especially appreciated.

A number of people talked about Epilepsy Queensland's commitment to bring epilepsy out into the open. Our awareness work is appreciated. We were also seen to be a good advocate to government, with good government relations.

Training was also identified as something we are good at, as well as our annual Symposium.

Most important activities for Epilepsy Queensland

Sixteen activities were listed and respondents were asked to rate how important they were to them. These are the top five.

1. Information to help me understand epilepsy
2. Educating the community about epilepsy and reducing stigma
3. Information about new research and treatment
4. Support and counselling
5. Connecting and referring me to other services for special help

What actions have we taken in response to the survey?

1. We have new affordable online learning modules available and we are also doing our monthly and ad hoc Understanding Epilepsy and Administration of Midazolam workshops via Zoom
2. We launched our new website with new and updated information in March 2020. Online support chat is now available on our website and social media.
3. We've reviewed many of our fact sheets to ensure all of the information we provide you is up to date
4. A new swimming safety/ seizure first aid poster will be launched during Seizure Smart September
5. Direct debit is now available for membership
6. Purple Day merchandise will be reviewed
7. Providing the option for digital communications while still maintaining our face-to-face, phone and mailed support. More resources invested in our digital communication and online community.

If you have further feedback please contact us on 1300 852 853 or epilepsy@epilepsyqueensland.com.au.

SEVEN EPILEPSY WARRIORS READY TO SOAR



We are excited to announce that our Purple Month event iFLY for Epilepsy has been rescheduled for September. Join our troupe of high flyers with this fantastic opportunity to fundraise and experience indoor skydiving. Launch your fundraising here to raise a minimum of \$300 for Epilepsy Queensland, and join us at iFLY Chermside on 5 September.

iFLY are proud to empower people to soar beyond their own expectations. They are experienced at ensuring people of all abilities can fly.

One of our fantastic flyers is Mia Whittall who is nine years old and lives with epilepsy. Mia was three years old when her parents found her in bed having her first tonic clonic seizure.

Mum Shannon said: "Her Dad travelled with her to hospital in the ambulance and I followed shortly after in the family car, expecting to find her in a room in emergency resting with the reassurance it was a one-off event. I hoped it was just something that happens to kids sometimes. I did not expect to find her in resuscitation with two doctors and a nurse monitoring her."

Two weeks later, EEG monitoring showed a type of epilepsy that mainly occurs during sleep. They waited before trying medication but she had a few more seizures while in bed in quick succession which meant it was necessary to try a medication.

"While it kept the seizures mostly away, we didn't like what it did to her. So we phased out the medication when she was five years old. We thought we had made the right decision. She has not had a tonic clonic seizure since and we thought she had grown out of it," Shannon shared.

In 2017, she had another EEG to rule out any seizure activity before starting a non-epilepsy

related medication. The paediatrician called as soon as she received the results as Mia was having constant seizure activity. Mia's parents were advised to start medication that day and they did.

"We had no idea that this activity was constant and affecting her so much. She would fall over multiple times in a running race, we thought "she has long legs, she is just clumsy", we would ask her to put her shoes on, she would forget in two seconds, we thought she was just forgetful. She was also having outbursts in class. We didn't realise it was from her brain constantly hitting the reset button and she was confused and didn't understand what was being taught," Shannon said.

Her family were happy to share: "Mia is now under the care of one of Brisbane's top neurologists and the improvements are obvious. She can now focus at school and at home. She runs without falling over and her quality of life has improved greatly. We have spoken to Mia about her condition and with support from Epilepsy Queensland, she understands her condition and wants more people to know about it. This year she did a PowerPoint presentation to her Principal about hosting a Purple Day fundraiser which has been delayed due to COVID-19. We are hoping to do it in September. She also set up an Everyday Hero page raising money for Epilepsy Queensland to participate in iFLY for Epilepsy. Mia was really excited to raise over \$1600."

Mia and her parents are looking forward to meeting more families at iFLY. She shares: "We were sad when many things were cancelled due to COVID-19 and can't wait to meet everyone in the epilepsy community in Queensland at the next Purple Day event."



To join Mia and our other flyers contact our fundraising team on 1300 852 853 or visit <https://bit.ly/EQiFLY> to register.



VALE JACK CAMERON

We are deeply saddened by the recent loss of a young member of our epilepsy community, Jack Cameron, along with 16-year-old Archie Gouldson. Our thoughts are with Jack's loving parents Nick and Sarah, older sisters Georgia, Jemma and Meg and everyone touched by this tragic loss.

To say Jack Cameron was an extraordinary young man is an understatement. At the tender age of 10 years and 10 months, the country boy from Ardno, Mount Abundance (near Roma) was a sports champion. He excelled at Rugby League, swimming, tennis and running.

James Nason wrote in a Beef Central article: "Jack sent a huge NRL crowd at Suncorp Stadium into raptures of delight last year when he carved up the field playing for the Carnarvon Cubs in a pre-game match ahead of a Broncos game. His spectacular try was captured on the big screen and unleashed wild cheers around the crowd with every replay."

The article continues "Earlier this year he qualified to compete in the Queensland Schools State Swimming Championships at Chandler in Brisbane, before COVID-19 forced its cancellation. Who knows what may have eventuated, but the times he was clocking in training had placed him in strong contention for a top-three finish."

"Jack also had his eye on a record closer to home as well – he was training to break the Roma and District Schools under 11s 800 metre record this year, a mark set some 36 years ago, by none other than his father Nick," James writes.

The article further explains his sporting prowess was paralleled by his abilities on the farm. "He was already capable of mustering on his own and was raising his own herd of more than 100 poddies he had rescued in drought. Jack was also breeding up his own goat herd and was showing early entrepreneurial skills by selling manure to local gardeners in Roma."

Jack was diagnosed with epilepsy at the age of two. It was controlled by medication and he continued to be seizure-free until his tragic passing. Two of Jack's older sisters are also living with epilepsy.

Jack touched so many people's lives and was an amazing friend. The family set up a tribute page to Jack to allow people to share their memories of this exceptional young man and make a donation to support Epilepsy Queensland in lieu of sending flowers. We have been overwhelmed by the support of the community for the Cameron Family and Epilepsy Queensland. There has been \$239 470.73 in donations now received on the Everyday Hero page <https://bit.ly/JackLastGift>.

Epilepsy Queensland Chairman Sam Bryce said: "This is the largest single fundraiser in the history of our organisation. Jack's Last Gift will be a lasting legacy in memory of Jack. He was a remarkable young man who will be missed by many people."

"We are sincerely appreciative of the Cameron family for wanting to make a difference for other people impacted by epilepsy at a time of such tragedy when we should be caring for them. Jack's Last Gift has been an opportunity for people to show their support for the family and share their memories of Jack," Mr. Bryce said.

He continues "The money raised will create a lasting legacy for Jack enabling us to assist many more families such as the Cameron's impacted by epilepsy. More than 200,000 Queenslanders will be diagnosed with epilepsy in their lifetime. The impacts of epilepsy vary from person to person and can affect the whole family. The donations will enable us to provide vital help through our Epilepsy Helpline, training in schools and workplaces, counselling for families newly diagnosed with epilepsy, advocacy and community awareness. We will be seeking input from the Cameron family to ensure Jack's legacy is honoured in the best possible way."

Thank you to everyone who have contributed to making Jack's Last Gift a reality.

2020

DIARY DATES

1-30 September

Seizure Smart September

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. During the month of September we will be sharing tips and stories about seizure first aid on Facebook, Instagram, Twitter, You Tube and Linked In. Visit your local participating Pharmacy for a Seizure Smart September Awareness token. Find out more: <https://bit.ly/EpiFirstAid>

1-10 October

1 in 10 Heroes

Are you or someone you love impacted by seizures? Join our 1 in 10 challenge and do one thing related to the number 10 every day for 10 days. It could be 10 push-ups, a 10 minute run, walking or riding 10 kilometres or your own personal 1 in 10 challenge. The challenge starts at the conclusion of Seizure Smart September between 1/10/20 and 10/10/20. Share your story to raise funds and awareness of seizure first aid. www.everydayhero.com.au/event/onein10

13 August
10 September
15 October
19 November

Understanding Epilepsy Workshops (via Zoom)

For Disability Support Workers, Child Care Workers, Nurses, Allied Health Professionals, Volunteers, People with Epilepsy and their Families

1 August, 5 September, 3 October,
7 November

Brisbane Adult Support Group Meeting (Online via Zoom)

31 July, 7 August, 14 August, 21
August, 28 August

Social Group – epilepsy crew (Online via Zoom)
South East Queensland – 1pm
Regional Queensland – 4pm

Please call 07 3435 5000 for further information on any of the above events

Epilepsy Queensland thanks McCabe Curwood Pty Ltd for their pro bono legal support.

A new mental health directory has been launched in Charters Towers to assist people to find help when they most need it. The guide was developed by a local mental health strategy group comprising of members of the community and service providers.

EQI participants were Project Coordinator, Dianne Rogers, and our Services Development Officer, Leonie Hogarth, who explains that the project was about opening doors and connecting the community. 'Opening Doors and Connecting Community' became the central theme for the project, as many people shared their experiences of not knowing how or where to access information and had experienced too many 'wrong doors' and were experiencing exclusion and frustrations.

"Epilepsy Queensland became involved when we received a grant from the National Disability Insurance Agency's Information, Linkages, and Capacity Building Grants Program," she says. The grant focuses on investigating how people in regional and remote areas access information about

supports and services available to enhance health and wellbeing. The learnings of this pilot project, will be applicable amongst other regional and remote communities.

"It was all about how do people in regional and remote communities access information about what's out there," Leonie explains.

Charters Towers Mayor, Frank Beveridge launched the directory to a gathering at the Indoors Sports Centre and hard copies will be available at selected locations across Charters Towers, including the Excelsior Library, Charters Towers hospital, Charters Towers Regional Council chambers, GP surgeries and Prospect Community Services.

This initiative demonstrates Epilepsy Queensland's commitment and efforts to extend our services into regional parts of Queensland to reach and support more people impacted by epilepsy.

Stay tuned for upcoming information on an online community directory linking residents to community, health and disability services in Charters Towers and Hinchinbrook Shire.

MENTAL HEALTH STRATEGY GROUP MEMBER AND COVER ARTIST EARL ROBINSON.