

# the flame

the newsletter of epilepsy queensland inc

Issue 4 – 2018



**NDIS  
Advocacy profile**

**Staying safe  
in the water**

**MY EPILEPSY STORY**  
**MY YEAR OF YES**

**LENDLEASE CHARITY GOLF DAY – A  
VITAL SUPPORT FOR QUEENSLANDERS  
LIVING WITH EPILEPSY**





## North Queensland update

### Improving access to disability information and supports in the Charters Towers Region, Hinchinbrook Shire and Cardwell Township.

What information and resources do people with a disability, families and carers need in order to access services in the Charters Towers Region, Hinchinbrook Shire and Cardwell Township?

This important project funded by the National Disability Insurance Agency is seeking information from local residents.

- How do you currently access information and services?
- What barriers do you face in accessing information and services?

- What would assist you to access information and resources in your community?

Expected outcomes:

- Learn more about available supports
- Have greater access to information, linkages and referrals
- Actively contribute to influencing and shaping your community
- Be able to make informed decisions, choices and protect your rights

To participate in the project, contact Dianne Rogers - 0417 567 824, [drogers@epilepsyqueensland.com.au](mailto:drogers@epilepsyqueensland.com.au)

## Townsville Parent's Support Group First Meetup

My four-year-old son was diagnosed with Absence seizures eight months ago in Townsville. Straight away, I looked for a support group through Epilepsy Queensland and realised there wasn't one in Townsville. I started up a Facebook group for those parents in Townsville and surrounding areas that have a child or children with epilepsy. It was slow to start but with the help of Epilepsy Queensland we now have 25 members in our support group. We met up on Sunday for the first time with a small group of four parents and their children. It was so great to talk to each other and have our children meet. It was a great feeling to know that there are parents out there who understand what you are going through. We are planning to meet up at least once a month. Looking forward to our next get together! - Naomi Dollisson



## Contents

2	..... North Queensland update
3	..... Ask an educator – Safety: Making a splash
4-5	..... My epilepsy story and my year of yes
6-7	..... Advocacy feature - NDIS
8-9	..... Lendlease charity golf day
10	..... Thank you for the sizzle

11	..... A lasting legacy of Sammy Milne
12	..... Thank you Dr Cecile Lander
13	..... My Health Record – a potential life saver
14-15	..... 30 minutes with Peter Jones
16	..... Diary dates , AGM, awards



### 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](http://www.epilepsyqueensland.com.au)*

# SAFETY: MAKING A SPLASH

Many people living with epilepsy will be able to safely enjoy the water. However, it is important to assess each situation individually, taking into consideration the person's epilepsy, their age, abilities, any other disabilities, the location in which they are going to be swimming, and if there are any other supports/people around that may be able to help supervise or provide assistance in the event of an emergency.

## Water Safety

Supervision ensures people with epilepsy can participate safely in water activities. Even those with well controlled epilepsy should never swim alone. Important things to consider about supervision include:

- A dedicated 1:1 spotter or swimming companion if possible.
- People with uncontrolled epilepsy should have two people accompany them. One should remain in the pool and one as a spotter outside the pool.
- Companion/spotter to maintain constant supervision, eye contact and/or stay within an arm's reach of you at all times.
- Companion/spotters should be aware of your seizure types and know what to do in the event of a seizure

## Other key points:

- Always seek advice from your doctor before swimming
- Inform the life guard (if available) of the potential risk of a seizure occurring
- A brightly covered swimming cap or swimming costume can help ensure quick and easy identification
- Avoid resting on the edge of a body of water
- If flickering or reflective light is a potential trigger for your seizures, try wearing tinted goggles or sunglasses
- If you have had brain surgery check with your doctor before diving
- Do not swim or continue to swim if fatigued, feeling unwell, having missed medication or experiencing warning signs of a seizure
- Avoid swimming under water for long periods of time as this can cause hyperventilation, a potential trigger for seizures
- Swimming programs, both private or school based may require a letter from your doctor (approving participation) and an epilepsy management plan

- If a tonic-clonic seizure occurs before/during water activities, the person should not continue swimming or participate in water activities that day, even if they have fully recovered
- People with uncontrolled seizures should consider wearing a safety vest that helps keep their head above water. According to Maritime Safety Queensland lifejackets fall into two broad categories:
  - o Inflatable (can be either self-inflating or automatic)
  - o Non-inflatable

If a lifejacket is worn it is very important to ensure it is correctly fitted for each individual. Maritime Safety Queensland is currently running the Life-jacket wear it campaign which stresses that lifejackets are not an optional safety feature and encourages us to think of lifejackets as the seat belts of the sea.

[www.msq.qld.gov.au/About-us/Maritime-safety-campaigns/Life-jacket-wear-it](http://www.msq.qld.gov.au/About-us/Maritime-safety-campaigns/Life-jacket-wear-it)

If you have any queries about water safety contact the team at Epilepsy Queensland Inc. who will be happy to help you. Call: (07) 3435 5000 or 1300 852 853 (outside Brisbane).

Reference:

Maritime Safety Queensland

## Seizure First Aid in Water

1. Time the Seizure
2. Protect from injury
3. Remove from water & gently roll the person onto one side
4. Call for an ambulance - 000
5. If no signs of life, commence CPR immediately
6. Reassure & re-orientate
7. Stay with the person

**ALWAYS CALL AN AMBULANCE** for seizures occurring in the water.

**DO NOT** restrain

**DO NOT** put anything in the person's mouth

**DO NOT** give food or drink





## Linda McClelland

Linda McClelland is a role model for many people in the Hinchinbrook community, but she would also like to be a role model for people living with epilepsy. Her epilepsy is mostly invisible to those that meet her, but the impacts are still very real and it took a number of years for her to come to terms with the 'new normal' of epilepsy and start a year of yes.

Like many people, it wasn't obvious to Linda or her GP that she was living with epilepsy and for this reason, she is unsure how long she has actually had epilepsy. It started with injuries in her sleep. She went to her GP for a shoulder injury that just wasn't healing. She wasn't even sure how she had hurt herself.

Initially epilepsy was not something that was even considered. People just don't talk about epilepsy and when they do, it is generally thought of as being the tonic-clonic seizures where you go stiff, fall to the ground and convulse. That wasn't happening for Linda.

When they discovered Linda was living with nocturnal epilepsy, there was a sense of shock and then there were many hurdles for her and her family to overcome.

As CEO of the Hinchinbrook Community Support Centre, she is a leader for 20 staff and numerous volunteers. Their aim is to support people in the community who are struggling with domestic violence, housing, transport, youth issues or just trying to make ends meet. Suddenly Linda had seizures that were not controlled and she was no longer able to drive. So she went from being the one that everyone relies on at the school, local


# MY EPILEPSY STORY AND MY YEAR OF YES

Epilepsy is different for each person, but by sharing our stories, we feel less alone and also help educate people in the community about living with epilepsy. To share your epilepsy story contact Karen on 07 3435 5000 or 1300 852 853.





sports clubs and the Community Centre, to having to rely on various people for support.

This included her 17-year-old daughter, who was going through the madness of year twelve and older women from her community as for the first seven months Linda didn't have a license. As an independent woman, Linda found this inconceivable that  life could change overnight. The first seven months Linda didn't have a license. She was coming to terms with epilepsy and trying different medications.

"People don't understand epilepsy, they are fearful, so they treat you with kid gloves. You don't want epilepsy to run your life, but it can, so you end up just not telling people."

Linda considers herself lucky that her seizures are now managed with medication. She sees a neurologist in Townsville once a year and has made changes to her very busy life.

"I try to keep anxiety and stress under control and getting enough sleep is also important for me. Your life has to be holistic to maintain your health."

"I also had to make some decisions about work hours and everything I was involved with in the community. Work was life prior to epilepsy, but I had a reality check and now do things in moderation. It just meant

that I couldn't work 20 hour days anymore and I had to step back from the P&C and sports clubs."

It has taken time but Linda has learned to cut herself some slack.

"For me something important is that I don't blame everything on epilepsy. I don't have to be superwoman anymore."

"I also know when I am not having my best day. Epilepsy and the medications affect my mood. I always feel chronically tired but it's the memory loss and the cloudy feeling that are the hardest. I call it the spectrum of confusion and I know some days it is better and some worse. Some days I just need to decide that it's not the best to be social or have that work meeting. I could know more on a subject than anyone else in the room, but if I'm having a cloudy day I just can't recall it."

For Linda, epilepsy didn't just bring difficult changes, but positive ones as well.

"About two years ago I realised that I had given away a lot of my power to epilepsy. Fear that my epilepsy might get worse again was stopping me living life. I joined a gym, started walking regularly, developed better sleeping habits and looked at my diet. From there, I haven't looked back. I decided this was my year of saying 'yes' and I have done things I had never done, even prior to epilepsy. I went on my first trip overseas to Europe (by myself), did a

high ropes course and I decided to share my story of living with epilepsy. I wasn't seeing life for all of the colours it had. It took time, but epilepsy is one thing that has opened me up to that."

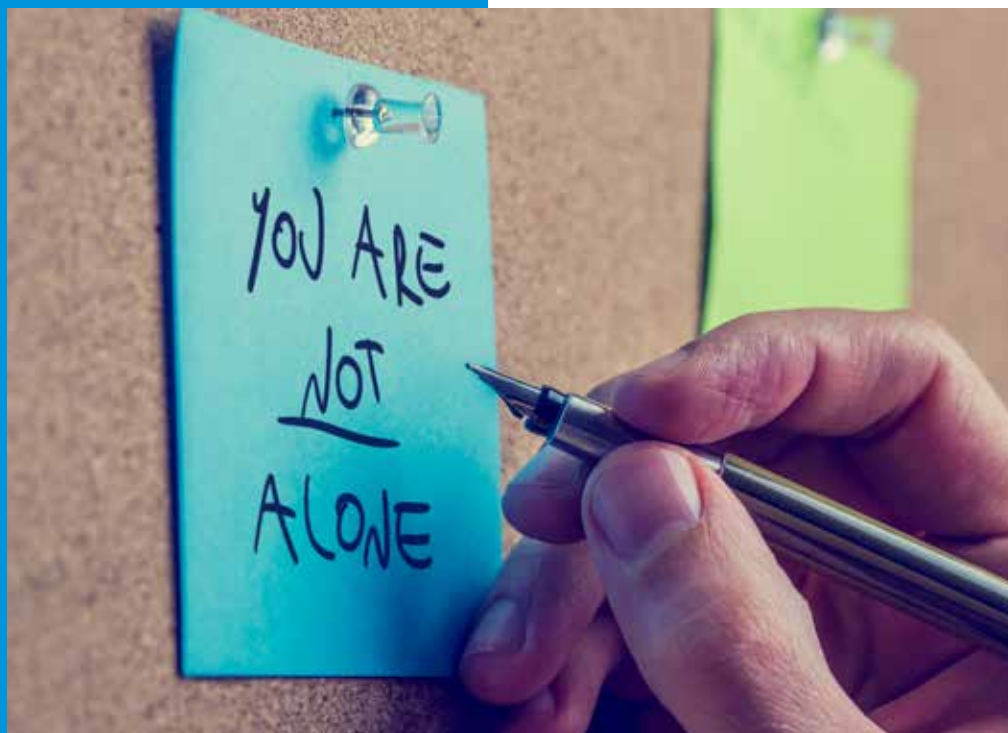
Living with epilepsy in regional Queensland can be very isolating. People don't often talk about epilepsy, so most people won't know someone with epilepsy to connect. There are extra challenges that Linda wanted to highlight.

"For people living in regional Queensland the impact of not having a license can be devastating. I live 35km from the closest town Ingham where I work and there is no public transport. For people living in regional areas having access to information about epilepsy and connections to local services would be really helpful."

"Also ways to save on medications and transport and apps that could help with medication reminders and track sleep would help. A Facebook group to connect for support and as a place to ask questions and find information would also be helpful."

Linda's message for anyone struggling with epilepsy is: "Take control of your own health and don't let it disempower you. Don't lose life waiting for the worst to happen. Seize every opportunity and don't let epilepsy control you."





# ADVOCACY FEATURE – NDIS

**Q: I've heard many people with epilepsy have been rejected for support for the NDIS. Can you tell us more about this and how EQI can help?**

EQI have had a number of contacts from people who have been deemed ineligible for the NDIS. Some of the reasons given are - that there was insufficient information provided, or the evidence did not state that the condition was life long, or the information provided mostly focused on confirming a diagnosis, rather than focusing on the functional impact of the condition.

The Access Request Form needs to be completed to access the scheme if you have not been receiving supports previously funded by the State or Commonwealth service. Epilepsy is already considered a grey area under the NDIS, as the NDIA has clearly stated that the responsibilities of the mainstream services, such as health, education etc. need to remain the responsibility of these sectors, and that the NDIS cannot pick up any short falls, as this will risk the sustainability of the scheme.

Health practitioners must complete the form aligned to the functional impact that epilepsy (and any other disabilities) have on the person's life, and not purely a confirmation of medical diagnosis. As per the Access Request Form, this is in the areas of mobility, self care, self management, learning, social interaction and communication.

To assist health practitioners to complete this form, Epilepsy Queensland have developed a document that is based on the Access Request Form, which includes prompts under each of these core areas. If you would like a copy of this, please do not hesitate to contact us. Another option is to spend time writing out the functional impact in each of these areas and having a health professional to review and sign off.

**Q: Are people with epilepsy eligible for the NDIS.**

Epilepsy is a very complex condition. With over 40 seizure types and 100 syndromes associated with it, the impact of the seizures and other effects can be varied and highly individualised. Epilepsy on its own is not an automatic condition under the NDIS. Therefore, the Access Request Form and other evidence submitted, needs to provide as much information and evidence as possible about the functional impact of epilepsy on the person's life. This may be from a range of sources, such as Neurologists,



Leonie Hogarth



Paediatricians, Occupational Therapists, Speech Therapists, other allied health services, teachers etc.

Another consideration is if the person seeking access has another disability/condition that may be eligible under the scheme. There is a list of eligible conditions on the NDIS website. If this is the case, we suggest using this as the primary disability on the access request forms, with epilepsy as the secondary disability.

#### **Q: Is epilepsy a disability?**

EQI have engaged with many of our members on this topic, and understand that this is a very personal consideration. One of the features of whether a person considers epilepsy as a disability is the impact that the seizures have on the person's life – this may also include the frequency, duration and severity. Some people with epilepsy consider it be a medical condition that requires treatment, and not disability at all.

From an NDIS perspective, it is acknowledged that epilepsy is a health condition, as people usually see the Neurologist and other health practitioners, have medications etc. These are the health sector responsibilities and will not be funded under the NDIS. However, depending on the functional impact of the epilepsy, as well as a need to meet the other NDIS Access criteria, epilepsy is also a Neurological disorder. This terminology is used in various NDIS access documents.

#### **Q: What do I need to do/provide to give me the best chance of getting NDIS support?**

If you or your loved one was previously receiving State based or Commonwealth funded supports, it is likely that your information will be transferred from this department to the NDIA. Although the NDIA have been working to ensure this information is correct, in our experiences some of the information transferred is out of date. You may wish to phone the NDIA to clarify what information they have to ensure this is correct.

If you are seeking to access the NDIS and have not had funded supports in the past, the focus is on ensuring that you meet the eligibility criteria and that you seek comprehensive reports that refer to the functional impact of epilepsy (and any other disabilities). As noted above, EQI have comprehensive and easy to use documents that can help with this process.

#### **Q: What NDIS supports do EQI provide?**

EQI are committed to supporting people through all stages of their NDIS process. This includes resources and information in relation to the access and eligibility process; reviewing and providing comments on any documents prior to submission; pre-planning support, particularly in relation to wording of goals and considering what supports are needed; as well as epilepsy assessments – that is, identifying and recommending various epilepsy related assistive technologies designed to keep the person safe and enhance independence, such as monitoring equipment, anti-suffocation pillows etc.; staff training on Understanding Epilepsy and Administration of Midazolam and developing/updating epilepsy management plans.

#### **Q: What sort of support should someone with epilepsy be seeking?**

At a minimum we recommend that people with epilepsy should be seeking three types of support, these are all covered under Improved Daily Living (within the NDIS plan),

- Epilepsy assessment to identify various assistive technologies to promote safety and independence, such as monitoring equipment, anti-suffocation pillows, adaptive equipment etc.
- Training for families/carers on Understanding Epilepsy and the

Administration of Midazolam, and

- Updating/developing an epilepsy management plan.

However, the NDIS also enables greater opportunities for supports and services aligned to the persons identified goals, than has been the case in previous years. We encourage people to start to think big – what are the supports that you/your loved ones need to have a good life? This may include, assistance to meet new people, assistance to get out of the home, social activities/camps, help around the home, going back to study, finding a job etc.

#### **Q: I've heard that the NDIS does not provide supports for carers, is this true?**

The focus of the NDIS is on the person with the disability. However, a key focus of the NDIS is to maintain and strengthen informal (carers) support. The thinking is that if the person requiring support is now receiving support to meet their needs, there will be less of a demand on the carer, which may allow the carer to return to the workforce, enhance their social and wellbeing needs etc.

Supports which may provide (indirect) support for carers, include:

- In-home or community support for the person requiring it
- Training for the carer on how to provide safe and effective supports aligned to disability
- Access to short term accommodation (previously 'respite') for the person requiring support. This can be delivered flexibly, such as support in the home, support outside the home, camps etc. The focus of this is to develop life skills, including being away from home, engage in social and recreational activities etc.

#### **Q: I've been rejected by the NDIS, what do I need to do now, and how can EQI help?**

If you have been rejected by the NDIS, please contact us, so we can talk you through your options. To consider the best next step, it is important to understand on what grounds the application was rejected, for example, not enough information, not stating that the condition is permanent etc. This information will be on the letter you received from the NDIA, or you may need to contact them for further clarity. From here, a more targeted response can be developed. EQI have assisted many people through the appeals process.

#### **Q: What else is EQI doing to educate the NDIS assessor and advocate for people with epilepsy?**

Not only is EQI working hard to support people applying for the NDIS, EQI have and continue to proactively engage with the NDIA. This has been in relation to providing training to various NDIS staff on Understanding Epilepsy; liaising with NDIA about specific people and circumstances; providing the NDIA with comprehensive information about epilepsy and the NDIS. EQI are also heavily involved in various networks and meetings to promote and advocate for people with epilepsy.

We would love to hear about your experiences, whether they are positive or negative, as this is invaluable learning and no doubt will assist other people through their NDIS journey.

#### **Q: What if I am not eligible for the NDIS, how can I get help?**

If you are not eligible for the NDIS, but still require support, there are various other support services that may be accessed, such as the Aged Care Service, taxi subsidy cards, companion cards, Home and Community Services, just to name a few.

**Please feel free to contact us on 1300 852 853 or [ndis@epilepsyqueensland.com.au](mailto:ndis@epilepsyqueensland.com.au) if you would like information on anything you have read here, or would like to chat about your NDIS journey - we are here to help.**

# LENDLEASE CHARITY GOLF DAY — A VITAL SUPPORT FOR QUEENSLANDERS LIVING WITH EPILEPSY

On a beautiful spring morning, 136 keen golfers came together at Brookwater Golf and Country Club, in support of Epilepsy Queensland and Legacy for the annual Lendlease Charity Golf Day.

After a fun round of golf featuring a few novelty competitions for golfers of varying skill, the very generous participants dug deep for some fantastic prizes spurred on by MC Darren Curtis from Channel Nine. Our board member Katrina Tune spoke from the heart about being a parent of a child living with epilepsy.

Epilepsy Queensland have been the beneficiary of this fantastic event since its outset in 2010. We are pleased to report that the event raised \$66,116 shared equally between the two charities. Now in its ninth year, the event has raised an amazing \$318,111 towards Epilepsy Queensland's services for children and adults living with epilepsy.

Epilepsy Queensland's CEO, Helen Whitehead, is thrilled with the result. "The Lendlease Charity Golf Day provides vital funding and we are so grateful for this long standing commitment to assisting Queenslanders living with epilepsy. It is not just a fun day, but also a wonderful way to get our message out to the construction industry about epilepsy. One in 50 people will develop epilepsy at some stage in their life, so this is something that will affect a person or their family member in most workplaces."

Lendlease are Australia's largest building business. They not only care about the communities that they live and work in but also value the relationships they have with their subcontractors. Special thanks to Lendlease and the event sponsors, Maria Bran and the Golf Day Committee.

If you would like to raise funds by hosting or supporting an event for Epilepsy Queensland please contact Leigh Gilbert on 07 3435 5000 or email [fundraising@epilepsyqueensland.com.au](mailto:fundraising@epilepsyqueensland.com.au). Together we can make a very real difference for Queensland children and adults living with epilepsy.

## Platinum Sponsor:

- RPS

## Silver Sponsors:

- Beavis & Bartels
- Master Floor Preparers

## Bronze Sponsors:

- Arcadis Australia Pacific
- BSA
- Fredon
- Shamrock Civil
- Allroads
- Pensar











# SIZZLING IN SEPTEMBER

Thank you to everyone who hosted or supported a September Sizzle to raise funds and awareness of seizure first aid. We appreciate the passion of all of our sizzlers who have firsthand experience of the need for seizure first aid through a loved one living with epilepsy. One in 10 people will have a seizure in their lifetime. Together we are helping more people to become familiar with seizure first aid, so that other families don't have to go it alone.

It's not too late to download or order your seizure first aid resources. We have a posters, wallet cards and fridge magnets available for your home, work or school. Visit: [www.epilepsyqueensland.com.au/first-aid](http://www.epilepsyqueensland.com.au/first-aid)

Do you know what to do if someone has a seizure? Take the Epilepsy Queensland seizure first aid quiz and test your knowledge. <https://apps.facebook.com/fb-quizzes/seizure-first-aid-quiz>





# A lasting legacy of Sammy Milne

In 2016, tragedy came to the Milne family with the death of their beloved son and brother Sammy. He was only 19 and he had been struggling with epilepsy since he was 15.

From this terrible tragedy, the Milne family, their friends and colleagues have spent the last two years creating a lasting legacy, working with Epilepsy Queensland to raise funds and awareness of epilepsy. They want to help ensure that anyone living with epilepsy in Queensland, doesn't have to go it alone, but they also want to start a conversation about epilepsy to help end the stigma. To help build understanding of how much it can affect a person's life and encourage people living with epilepsy to speak up and ask for help.

We wanted to share with you part of a speech from Shaye, Sam's sister, at a recent ladies golf day fundraiser held at St Lucia Golf Links.

"My vision with the help of Epilepsy Queensland is for people who live with epilepsy to have courage to be vulnerable. It means be seen. To ask for what they need. To talk about how they are feeling. To have hard conversations. Most people think vulnerability is weakness, but I think it is the cornerstone of confidence. You have to allow yourself to take the risk to be open."

"With the help of Epilepsy Queensland, we can educate with information, training and counseling to schools, health and disability services, so that people like Sam can feel, 'Whatever is in me is stronger than what is out there to defeat me.'"

Golf was one of Sam's great loves and the weekend before he passed away, he won a golf competition at Sandgate. To raise funds and awareness the family have held charity golf days in Sam's memory, generously supported by the electrical industry, with special mention of Schneider Electric and Clipsal.

Sam was also a huge fan of island shirts, so family and friends take on the Bridge to Brisbane each year, wearing the most offensive island shirts they can find, to raise funds for Epilepsy Queensland. The team has received support from Sam's former employer Hayman's Electrical, who have generously contributed \$10,000 for the past three years in support of their fundraising.

We thank the Milne family and their friends, for their dedication to creating a lasting legacy of Sammy and for sharing their beautiful memories with us.

To make a contribution visit:  
[www.epilepsyqueensland.com.au/donate](http://www.epilepsyqueensland.com.au/donate) and mention Sam Milne in the comments.





# THANK YOU... DR CECILIE LANDER

My name is Jane Rae and while waterskiing in 1995 and trying to impress my fiancé David, I, instead of impressing him, gave him an added challenge to live with for choosing me to become his wife. I had a bad waterskiing buster and developed epilepsy. He had chosen my already existing challenges, but it was now also me with my epilepsy.

My epilepsy brought with it many challenges that I found simply so horribly confronting. I know without the support and love from David and our two children, Sophie and Harry and without the care and the relationship Dr Cecilie Lander has developed with me for many years, I humbly know I would not be here writing this today.

I have now had my form of epilepsy for around 24 years and before I started being one of Cecilie's very lucky patients, I simply looked at myself as being just another number with epilepsy. Then I became a patient of Cecilie.

Since becoming a patient of Cecilie in 2002, so much has happened regarding my health. Sometimes I think maybe it is a patient like me that might be the reason she is going to 'sit back' and hopefully do lots of relaxing and retire!

One of the most important things since having her as my neurologist is that I no longer feel like just a number with epilepsy and I don't just feel like a patient. Cecilie has made me feel like I am a friend of hers and a special one. The unique relationship Cecilie has created with me, I am sure every single one of her patients receives. By being not just a neurologist with lots of patients, but by Cecilie being that friend (and a very intelligent one at that!), I have been given the courage and mental strength to cope positively now with my form of epilepsy.

Due to my form of epilepsy I have what I call a 'black' memory. I had to give up my career as a teacher. I have nocturnal seizures and the occasional convulsion. I suffer severe post-seizure depression on top of general depression caused during childhood. It is not possible to attempt brain surgery which Cecilie, David and I spent time looking into. Describing this simply is to say that I am also a very privileged sufferer of epilepsy. Yes I have the conditional love and support from my husband and children, but I have also had the most amazing support from Cecilie.

To describe Cecilie's patience is impossible. Cecilie has allowed me to always be able to move forward. Under the guidance of Cecilie, I have trialed many different medications and possible ways to control my epilepsy so that my quality of life and the quality of life is as high as possible. Cecilie has dedicated so much of her life to learning more about epilepsy, I believe she gives her 'absolute everything' to helping me live the life I aim for.

I just want to thank Dr Cecilie Lander and I could go on and thank her for more but I shall just say thank you Cecilie for absolutely everything you have done for me while being my neurologist. For so many years you have, more than you realise, supported me, David, Sophie and Harry. With the knowledge, guidance, patience and friendship you have given me I am now able to continually keep working on the courage I now have to cope with my epilepsy. I accept myself and I also accept that taking medication is 'part of me'.

With many thanks to you all at Epilepsy Queensland for what you all continually do, but also with the most sincere and huge thankyou to wonderful Dr Cecilie Lander,

*Jane Rae*



# MY HEALTH RECORD A POTENTIAL LIFE SAVER



Access to your medical records in an emergency situation could be a lifesaver for people with epilepsy. There has been a lot of debate in the media about the benefits and concerns associated with the roll out of My Health Record. Their team has provided us with some information that may help you make the decision about whether to keep or opt out of your record.

For people with epilepsy, My Health Record can provide an important safeguard, with key health information including allergies, chronic conditions, medications and test results available securely online for treating health professionals to access, which is particularly important in an emergency situation.

By the end of this year, all Australians will have a My Health Record created for them, unless they choose to opt out by 15 November 2018.

Dr Steve Hambleton, Deputy Chairman of the My Health Record Steering Committee and former AMA President, said having a record will provide important health information which could be potentially life-saving.

“Australia’s doctors are currently hampered by a lack of patient information, especially at the time when they need it most. That’s where having a My Health Record can make such a difference.”

More than six million Australians already have a My Health Record which places Australians in control of their own healthcare and, where permitted by the individual, gives healthcare providers secure digital access to key health information at the point of care.

Benefits include reduced hospital admissions, reduced duplication of tests, better coordination of care for people with chronic and complex conditions, and more informed treatment decisions.

**Some key things to remember about My Health Record**

Your record can contain a summary of information such as medications, medical conditions, pathology and medical imaging results, immunisations, hospital, specialist, GP and allied health visits.

Because healthcare providers have better access to your clinical information, they have a more detailed picture to make decisions, diagnose and provide treatment.

In emergency situations, treating doctors have been able to use My Health Record to provide the appropriate treatment quickly.

Your health information can be viewed securely online, from anywhere, at any time, even if you move or travel interstate.

You don’t need to remember the dates of medical visits, tests, medicine names or dosages.

It’s your record and you can determine what information it contains and set controls on who can view it. You can also ask your doctor that some information not be uploaded to your record.

Only health professionals involved in your care are authorised to access your record. Heavy penalties apply for inappropriate use.

Security is a key design element of the My Health Record system, which adheres to high level Australian Government security requirements.

*For more information or instructions on how to opt out visit: [myhealthrecord.gov.au](http://myhealthrecord.gov.au) or call the help line on 1800 723 471.*

# 30 minutes with...

## Peter Jones

Peter Jones and Marella Jenkins  
at our Annual Celebration



### *What is the exact title of your role?*

My job title is Nurse Practitioner Epilepsy.

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

I currently work at 2 facilities—the Princess Alexandra Hospital in the department of Neurology, and the Mater Hospital Brisbane, in the Mater Advanced Epilepsy Monitoring Unit.

### *I am sure you have seen a great deal of change in epilepsy care and treatments. What do you think is the most exciting change & why?*

Change seems to occur in bursts—recently, we have seen the introduction of high level diagnostics to our state with stereotactic EEG. This is a fascinating example of using state of the art equipment, procedures and clinical expertise to accurately map the network of epilepsy, with the goal of offering the most tailored surgery possible. This in itself is an enormous gain with regard to the rehabilitation requirement and potential after surgery.

Importantly though, I am now seeing a general political interest in epilepsy when perhaps it was lacking or did not seem to be prioritized in the past. Funding is there, albeit small pockets of money, but it's a start. Working across healthcare regions is now happening and is also a step forward I think. It allows us to deliver metro services to all of state—I would love to think that no one now feels that they can't get to the service they deserve.

### *Where else have you worked in your life?*

Wow....lots of places....

I am English (I've been in Australia for 20 years now but I'm still English when the Football is on!). I trained initially in science in the south west of England, but ended up working overseas .....As a watersports instructor in Barbados.

When I had got that out of my system, I went on to study Nursing in the south of England (Southampton) before coming to Australia to live. I worked at the RBWH for over 10 years, first on the wards, then in ICU before moving to management. I

ended up as Nurse Unit Manager of Neurology, overseeing the epilepsy monitoring which I loved. When the Mater opened the Centre for Neurosciences, I jumped at the opportunity to be a part of it as it was designed as an advanced monitoring service—my dream job. I was also going to get the chance again to work with the most inspiring of individuals in Dr Sasha Dionisio—simply the most dedicated, kind and caring specialist you could ever meet, and a great teacher too! It was from this position that I was able to study to become a Nurse Practitioner, which then led to another fantastic opportunity for me at the PA Hospital.

### *What do you love about your job?*

Absolutely everything! Simply, I have always felt, that as a nurse I have the best job in the building—more so now as a nurse practitioner.

My role allows me to see, diagnose and treat individuals with seizures. I have clinics at both the Mater and PA each week where I do just that, in close collaboration with the medical specialists. I am able to order relevant tests (medical imaging, EEGS) and prescribe appropriate medications.

I truly love the scope that the job affords me. It is so refreshing to have a position that allows you to use your understanding of the condition to its fullest—essentially, that's the rewarding part for me. Being a nurse, you also have the opportunity to use your nursing perspective on healthcare, and are able to focus on all that is important—the global picture for the individual.

### *Where would you most like to travel?*

I'm lucky that I got to travel a lot during my 20's. It was important to me at the time, and something that I am so glad that I did. Essentially, it's how I ended up in Australia.

If I could choose one place to visit for the first time....Japan. Never been and I love the idea of being exposed and immersed in a totally different culture. I would love to see firsthand what I am sure is a devastatingly beautiful landscape.

If I could go back to a place....the Canadian rocky mountains. I hiked through, and was just overwhelmed with the glory of the mountain ranges and the wildlife (I saw bears in the wild!).







### ***What is your favourite food?***

I'm a lifelong vegetarian, so a big favorite for me are curries with heaps of flavour. But I must say that I will often, during the day substitute food for ...coffee. A really bad habit and definitely not a food, but I do love it!

### ***Describe your most embarrassing moment?***

I made the paper overseas, a long time ago, for some really really bad dancing...say no more.

### ***What is your favourite book/author?***

Now I don't read anywhere near as much as I should for recreation....

Recently as a present I got the Bear Grills book that teaches you how to survive many different dangerous situations. I am now an expert emergency shelter maker, and I like to think I would be able to defend myself against a pack of Wolves. Useful stuff...!

### ***Who is the most famous person you have ever met? Or who would you like to meet?***

When I was really little I met the Queen.

I've met some really iconic individuals through blind luck—I fondly remember meeting Sir David Attenborough who was always a bit of a hero of mine.

If I could choose to meet anyone...any or all of the Arsenal football team. I have no shame in saying that when it comes to football, I am truly shallow.

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

I have what I would consider quite a broad interest in music, but do love music from my youth—Paul Weller, The Stone Roses, The Smiths...Recently I've also fallen into listening to London Grammar.

But I also love pure 80's music! Grew up on it, so I have no shame in acknowledging my love for Duran Duran and Wham!

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

I don't know...I have an 11 year old son so my main hobby is keeping up with him!

### ***What do you feel would greatly improve epilepsy care currently in Queensland?***

We have the skills in this state, and we have the dedication from those that can provide specialist care. What we need is the capacity to do more and this links directly to funding. More government funding would afford us an ability to undertake more clinic reviews, which would flow onto more monitoring and more surgical outcomes.

I also think that we need to keep on working on reducing the stigma of epilepsy. I would love to be able to do more with employers for example, to get the word out there that while there may be some limitation that epilepsy presents for some types of employment, it's not a definition of that person and not a reason to disregard their ability and skills. This is where I see the great work of organisations like Epilepsy Queensland, who I know champion this cause.

2018

## DIARY DATES

15 November	<b>Understanding Epilepsy Workshops (Woolloongabba)</b> For Disability Support Workers, Child Care Workers, Nurses, Allied Health Professionals, Volunteers, People with Epilepsy and their Families
14 November	<b>Understanding Epilepsy Workshops (Gold Coast)</b> For Families, People with Epilepsy, Carers, Child Care Workers, Teachers, Nurses and Allied Health Professionals
Informally First Saturday of the Month Formally –3 November	<b>Brisbane Adult Support Group Meeting</b>
28 November, 19 December	<b>Adult Social Group Ipswich</b>
3 December	<b>Annual Celebration, Awards night and AGM</b> Join us for our annual celebration. The night is an opportunity to recognise the advances we have made in our mission. It is also a chance to recognise and thank those who have provided significant support to people with epilepsy through the awards ceremony. The festivities will include our brief Annual General Meeting.

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

## QUALITY AUDIT

Epilepsy Queensland would like to thank those clients and families who assisted with our recent quality audit. It is your feedback and input during this time that ultimately assists Epilepsy Queensland to continue to provide quality services to its clients and the broader community.

At the conclusion of the audit, Epilepsy Queensland was found to continue to meet the intent of the Human Services Quality Standards and so continues to be certified to those Standards.

# AGM SAVE THE DATE

*You are invited to:*

## **Epilepsy Queensland's Annual Celebration**

Including: • Annual Awards Ceremony • Annual General Meeting • Light refreshments

**When:** Monday 3 December - 6:00pm

**Where:** Queensland Cricketers' Club, 411 Vulture St, Woolloongabba

**RSVP:** <https://eqiannualcelebration2018.eventbrite.com.au> 1300 852 853



## AWARDS

Do you have someone in your life that has been an inspiration or who has made a contribution to people living with epilepsy? They could be an educator, health professional, carer or a person living with epilepsy. Why not nominate them for an Epilepsy Queensland Award? Read more and download a nomination form: <http://bit.ly/AwardsNom>