

Q&A - CaRE Brain Series: Epilepsy

Please find the answers to the questions that were left unanswered during the webinar. Kindly note that we have not repeated the answers to questions that were addressed during the session.

- **Researchers:** Where can we find information on the Monash Epilepsy Consumer Advisory Panel (EpiCAP)?

Please contact us via email - stm.care@monash.edu

- **Community member:** How does epilepsy affect you in your day to day life? Even when on medication?

Not driving is a pain at times, but have good public transport. I must remember not to push myself too hard or do too much, especially if I haven't been sleeping well for a few days. And I'm reminded 3 times every day to take my pills But most days are good. The main effect of the medications is tiredness.

Even when seizures are under control there is also anxiety about having a seizure. Medication side effects, and having to adjust lifestyle such as not driving, no alcohol, not being able to swim alone, and feelings of being a burden to others

- **Clinician:** Can people with refractory epilepsy make any changes to their lifestyle (such as reducing stress, improving sleep hygiene, etc.), to improve their quality of life or management of epilepsy?

Reducing stress, improving sleep hygiene, avoiding too much alcohol are good ways to reduce the risk of seizures.

- **Panel:** how can we as a community help to raise awareness and encourage more funding for epilepsy research?

Joining a consumer panel, donate any funds raised from your charity events.

More awareness in the public eye like these events can show that there are many people in need, and there are ideas to help solve but more attention and funding is needed.

It can be hard, but talking more openly about epilepsy and seizures helps make epilepsy less hidden.

- **Clinician & Community member:** Do you have any advice for managing common side effects of medications like feeling 'out of it', difficulty concentrating, or feeling fatigued?

It can be helpful if you can communicate with people around you so that you can get support or to explain your limitations. For example, I will say to my partner I have brain fog today and I'm not able to do something. I find it difficult to pay attention for long periods and sometimes use this technique <https://www.pomodrotechnique.com/>.

For the side effects, the best thing I've found is to get out and enjoy the times you're feeling okay, and rest if you can when you're fatigued. I know that's not always possible. Exercise and a reasonable diet have helped, but not all the time.

- **Community member:** Chris can you speak on how your role as a consumer has been for you and why you engage with researchers?

I've been contributing to some incredible epilepsy studies in my role as a consumer and I've enjoyed every minute. The researchers are easy to engage with, they're interested in my story and I like to find out about what they're working on.

- **Clinician:** Is AI for drug resistant patients available in Australia? If it is, why wouldn't an epileptologist suggest it as an alternative to help patients who are on multiple anti-epileptic drugs?

AI model for drug resistant epilepsy is under development.

- **Clinician:** As a person's seizures continue to evolve whilst already being diagnosed as being drug resistant, and have gone through more than 6+ medications, how can we engage our neurologist to look further abroad outside of Australia and provide recommendation options, so that we can live our best lives?

Discuss with your neurologist actively about these options. It is possible that some are already available in Australia or are being introduced.

- **Community member:** How do your friends and family manage and support you with your condition? And what advice would you have for your younger self?

The best thing that they do is to understand that you're not always feeling 100%, even if you look okay. Tiredness, from side-effects or poor sleep, means you must cancel and get a good rest. I would tell my younger self to slow down, not be so hard on yourself. Take more rest. But that's not always easy to do.

I'm not always very good at being open or telling people when I'm struggling but I have some close friends who I can confide in great detail about how I am, and they try as best as they can to empathise - even if they don't get it. I just show my children my pill case full of medications and remind them why I am sometimes forgetful or tired! My young self didn't know she had epilepsy, but I would tell her that she's not alone and to be kinder and more patient with myself.

- **Clinician:** For those who already have a VNS, is it possible to have other technical/electrical treatment?

Yes. for example, it is possible to have both VNS and DBS.

- **Clinician:** Is brain surgery available for people with catamenial epilepsy?

Not per se, but people have catamenial epilepsy are eligible for surgery, just like those with other forms of epilepsy.

- **Clinician:** I hear a lot about treatment or surgery advancements for focal type seizures but there doesn't seem to be much advancement when it comes to GTCS. Have there been any advancements in this area whether it be in medical treatments or ways of predicting seizures before they happen? and how close are we to a cure?

Great question. People with generalised epilepsy are generally not candidates for 'resective' surgery, i.e. an operation to remove part of the brain. This is because their epilepsy does not originate from a discrete part of the brain but rather more diffusely. However, they may benefit from stimulation therapies.

- **Clinician:** For Patrick & Emma What were the main reasons people weren't attending the clinic?

This is our next research project! We suspect there could be many reasons, e.g. lack of time, inconvenience, decided to seek private healthcare.

- **Clinicians:** as someone who's had epilepsy since 18 months of age, is it dangerous or not really worth it, to think about brain surgery?

Brain surgery can be considered irrespective of how long someone has epilepsy. Sadly it is typical for a person to have had epilepsy for more than 20 years before they have an operation.

- **Clinicians:** had my first seizure (Tonic Clonic) at 35 years old. That's just coming up to be only a year ago. I have only just now tonight heard about the 'First Seizure' Clinic. Why would the doctors & neurologists choose not to send me there?

Thanks so much for your question. First Seizure Clinics were first pioneered in Australia in the '90s, but there are still not a lot of them around. This is likely because they are quite resource intensive, and so generally are found only in major hospitals with an epilepsy unit. We would be keen to hear from people with lived experience if there are networks or strategies we could perhaps use to help spread the word about First Seizure Clinics.

- **Patrick:** How can I have you, Professor Patrick Kwan, as my neurologist?
Not only intellectual, but you also sound incredibly supportive and understanding of people with epilepsy.

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