



Epilepsy
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EPILEPSY

360°

Keeping you in the loop

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Surgery for Epilepsy: When Medication is Not Working

Some people with epilepsy have seizures that are resistant to medication, meaning the person continues to have seizures despite taking antiseizure medication. We call this drug resistant epilepsy.

Epilepsy surgery represents a valuable treatment option for some people with drug-resistant epilepsy. However, surgery for epilepsy remains, arguably, the most underutilised of all acceptable epilepsy treatments, and the reasons for this are unclear. Often people who are ideal surgical candidates are not recognised as such by general neurologists, but if more people with drug resistant epilepsy are referred to an epilepsy centre, then more surgical candidates may be identified as suitable.

What is surgical treatment of epilepsy?

Epilepsy surgery is brain surgery intended to stop or reduce the number of seizures. Not everyone is suitable for epilepsy surgery, but your neurologist should be able to tell you if you may be suitable. Surgery is effective for many people with drug resistant epilepsy, but it is not widely known about and underutilised.

Some surgical approaches to manage seizures include:

- Removing the part of your brain where the seizures start.
- Disconnecting brain nerve cell communication to stop the spread of seizures to other areas of your brain.
- Vagus nerve stimulation. Implanting a pacemaker-like device and electrodes that send electrical signals to block or disrupt seizure activity at its source.
- Deep brain stimulation. Electrodes are placed into deep parts of the brain and connected to a pacemaker-like device. These electrodes stimulate targeted areas to interrupt on abnormal circuitry within the brain.
- Inserting delicate electrode wires to record seizure activity from the depths of your brain. Such as the [Minder® system](#).

Why epilepsy surgery?

Epilepsy surgery offers a chance to be seizure-free or at least to have a lot less seizures. Surgery may also eventually allow your antiseizure medications to be reduced – although ongoing antiseizure medication is often necessary. This will depend on your circumstances. There are emerging treatments, and your epilepsy specialist will be able to tell you if your type of epilepsy is suitable for surgical evaluation.

Surgery may be considered when:

- Seizures are resistant to medication and the person has trialed two or more appropriate anti-seizure medications.
- Seizures (or most seizures) originate from only one small region of the brain.
- Seizures are particularly debilitating or dangerous such as tonic, atonic seizures (drop attacks) and status epilepticus (very long seizures).
- Seizures are happening often, affecting day-to-day life considerably.
- The cause of seizures requires surgery, e.g. a tumour or abnormal brain tissue.

People who have had epilepsy for a shorter length of time are more likely to be seizure-free after seizure surgery, but this does not mean you will not be seizure free if you have had epilepsy for a longer time.

Before surgery

The work up to epilepsy surgery is quite extensive. This is to help to pinpoint the area in the brain where the seizures begin, called the seizure focus, and to determine whether surgery is possible without causing harm or impairment.

The pre-surgical evaluation includes many tests. Some are done as an outpatient and some as an inpatient. This can be a stressful time.

At any stage during the pre-surgical work-up you can decide that you do not want to have surgery. Also be prepared that surgery may not be an option for you.

Surgery - who decides and when?

The decision to operate is only made after all the tests are done and is based on the results of these tests and a joint decision by the team, and of course, you wanting to proceed with surgery. Your chances of successful surgery and risks for complications will be explained to you by the surgeon.

The goal of epilepsy surgery is to improve quality of life by stopping or reducing the number or severity of seizures, without causing neurological impairment.

Dominic's Epilepsy Surgery Story

I can never really accurately recall the day I realised I was having seizures. I know that it was somewhere in my early teens, about 13 or 14 that I started having “smells” and unusual sensations. I know that over some 30 or so years I'd experience the highs and lows of a life journey as an epileptic. The fear of the outcomes, the worry of the brain damage being caused by every seizure- would I lose my memory, get dementia early, etc, the highs and lows of new medications that had initial success before turning into unsuccessful failures.

The search for relief from epileptic seizures can sometimes be a long and frustrating one. The list of medications is lengthy and I'm sure that during my 35 years suffering complex partial seizures (now called focal seizures) I've been on most of them at some point. Unfortunately for me, most of the meds had a “honeymoon period” before their impact diminished. So too, undergoing EEGs, MRIs and other forms of testing can be quite time consuming and sometimes unsuccessful. However, medical science is well advanced, and I was fortunate enough to find an answer to my predicament through surgery.

It's certainly not the most pleasant of ideas having a surgeon remove some of your brain and there are obviously a number of concerns that go with surgery, most of them with a small percentage risk. There are also obviously no guarantees, however, the surgery has an 80% success rate in most circumstances and that is a positive well worth considering. It is important to note here that not all patients are viable for surgery and some forms of epilepsy may simply be inoperable.

“
I know I delayed it for a lot longer than I probably should have done.”

I can't recall how long I was considered eligible for surgery, but I know I delayed it for a lot longer than I probably should have done. The decision to have surgery is not an easy one. If your Neurology team says that surgery is a viable option, my advice would be to become educated not only on the procedure itself, but also on the benefits of such surgery. I watched hours of YouTube and other clips of the surgery – which may not be for the fainthearted, read widely including medical journals like the Lancet and generally became somewhat over educated about the operation. I went into the surgery with a good understanding of what was to happen. I was probably a little over educated on it.



So too, ask plenty of questions – not just of your Neurology team, but also of those who have had or are contemplating the surgery. Confront your fears about the surgery with those who have experienced the procedure. I know that the one thing I didn't initially get enough of was dialogue with patients – people who had actually gone through the surgery. Their reassurance was what I probably needed the most.

“*Knowledge from a patient who already had the surgery was the final nudge I needed*”

There were so many questions I needed answered that could only come from a patient. What was the pain like afterwards? Did you have scars? Did you have any more seizures? How long did it take to recover? The list of questions was pretty extensive and whilst my Neurology team was awesome, unless they had been a patient, they could only answer these on a second-hand basis. Of all the material I found, having this knowledge from a patient probably was the final nudge I needed.

So, after letting my consultant know I intended to go forward, I underwent quite a bit of pre-operation testing as part of the preparation. Spending a number of hours under an MRI machine for functional testing to ensure my brain was well mapped was the first step. Obviously, this is quite critical to ensure that surgeons are aware of the active areas of your brain. So too, a series of psychological tests were done pre and post-surgery to be able to identify any anomalies.

After Surgery

I recall waking up later in the evening. My expectations for my regaining consciousness was to discover I had tubes everywhere, connected to monitors, etc. The reality was that there were very few tubes in me aside from a drip canular and a catheter. I could feel the staples down the side of my face where my skin had been stuck back together. Obviously there was pain, but the medication that I was on pretty much nullified that issue.

In the end it comes down to deciding upon how badly you want to be rid of epilepsy. There are no guarantees and I'm not qualified to provide any medical advice – that's best sought from your Neurology team. However, I encourage you to at least investigate the operation thoroughly before making a final decision. Don't cheat yourself out of the potential to be free of seizures.

Whilst I have no medical qualifications, I do write from the point of view of someone who has a wealth of experience as epileptic for 35 years and is now the survivor of successful surgery to free me from the grips of epilepsy.

NOTE: Dominic is happy to communicate with people contemplating epilepsy surgery and discuss his experience. Please contact us on 1300 37 45 37 or email epilepsy@epilepsy.org.au to connect.

News E360 June 2024

The latest on epilepsy

Interview with Professor Jaqueline French

Read an interview with Professor Jaqueline French, Founder and Director of The Epilepsy Study Consortium (TESC), about disease-modifying therapies for epilepsy, both for rare and common epilepsies.

Focal seizures often undiagnosed in emergency departments

Among adolescents with focal epilepsy, non-convulsive seizures are more often missed or misdiagnosed compared with convulsive seizures, according to research presented in Neurology.

Gene linked to epilepsy and autism decoded in new study

A genetic change or variant in a gene called SCN2A is a known cause of infantile seizures, autism spectrum disorder, and intellectual disability, as well as a wide range of other impairments. A new Northwestern Medicine study helps explain how changes in the SCN2A gene affect whether or not a child will develop autism or epilepsy, the age at which seizures start for those with epilepsy, and the severity of the child's other impairments.

Which anti-seizure medications are safest to take while pregnant?

Some common anti-seizure medications are much safer to take while pregnant, according to Australian and international research.

'Epilepsy is so much more than seizures'?

An interview with Chelsea Leyland, diagnosed in her teens, about epilepsy, medicinal cannabis and her mission to raise awareness.

New brain target key to easing tough-to-treat epilepsy

Some people with drug resistant epilepsy might benefit if treatment targets a brain region newly linked to seizures, a new study suggests.

AI uncovers distinct brain differences between male and female brains

Stanford Medicine researchers have developed a powerful new artificial intelligence model that can distinguish brain organisation patterns between women and men's female brains.



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Q3 Is ADHD more common in children with epilepsy?

A: There is a higher prevalence of ADHD in people with epilepsy. In fact, ADHD is one of the most common co-existing disorders in children with epilepsy. Among people with epilepsy, it is estimated as many as half of children and 20 percent of adults have been diagnosed with ADHD.

Various studies reported the prevalence rate of ADHD as being 2.7–4 times higher in people diagnosed with epilepsy in comparison to the general population.

There are some antiseizure medications that help with both epilepsy and ADHD symptoms, and contrary to past beliefs, recent studies suggest that stimulant medications can help people safely and effectively manage ADHD symptoms without increasing the risk of seizures.

If you feel you or your child has ADHD speak to your doctor for referral.

Q4 The side effects of my child's antiseizure medication are causing great difficulties with sleep. We have just been given a script for Melatonin from the paediatrician. Can you tell me a bit about it?

A: Melatonin is a hormone that is produced in the brain. Melatonin levels vary in 24-hour cycles and are controlled by our body clock. Melatonin appears to be important in helping regulate the internal body clock's cycle of sleep and wakefulness and is used to treat sleep difficulties in children.

Melatonin use in children appears to be safe and works well in the short term. Long term use is only appropriate if there is a specific sleep disorder.

Side effects in children are very rare. When people report them, it is not yet certain if they are caused by melatonin or by something else. You should talk about this with your child's doctor.



Q5: What can make seizures worse?

A: Seizure frequency and severity can be increased or influenced by many things. Some are reported frequently, whilst others are more individual. Physical and emotional stress, sleep deprivation, illness, drugs and alcohol, and hormonal influences in women can all affect seizures.

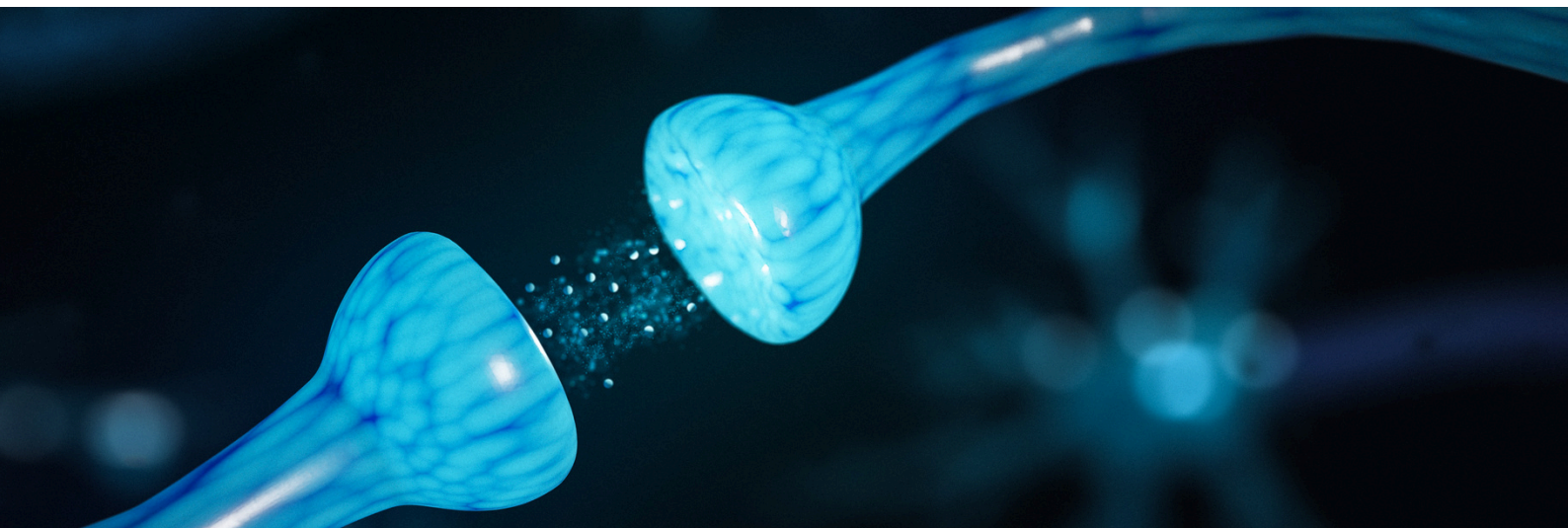
Sometimes you may become aware that specific events or circumstances can set off or “trigger” your seizures. These are usually called seizure triggers. Triggers differ from person to person and identifying your seizure triggers can help you to reduce or even avoid seizures.

Some commonly reported seizure triggers include:

- Missed medication
- Lack of sleep
- Physical fatigue and exhaustion
- Stress, excitement, emotional upset
- Menstruation/hormonal changes
- Illness or fever
- Poor diet or low blood sugar
- Flickering lights or geometric patterns
- Other medications
- Drug and alcohol use

Triggers for seizures are not the same as the cause for your epilepsy. Causes of epilepsy include things such as structural damage to the brain from events like a stroke or head injury, genetics, brain infections or tumours. A lot of the time, a cause of epilepsy cannot be determined.

The best way to identify triggers and patterns is to keep a diary of not only your seizures, but the circumstances around your seizures. Note things like if you were unwell, feeling stressed, drinking alcohol, had just woken up, not slept well, or having your period.



Research News

CURE Epilepsy Discovery: FCD Genes in Epilepsy, One Piece of the Mosaic

Dr. Jack Parent and his team designed a novel system using human neurons grown in a dish to discover the genes behind focal cortical dysplasia (FCD), a common cause of intractable epilepsy. The researchers systematically turned off genes in these neurons, which for some, revealed telltale molecular signs of FCD. These genes included some known FCD genes, as well as six new genes that could also contribute to FCD

Read more



Glial hyper-drive for triggering epileptic seizures

When epileptic patients suffer seizures, their brain is undergoing repetitive and excessive neuronal firing. But what triggers this has stumped scientists for years. Now, researchers have used fluorescence calcium sensors to track astrocytes' role in epileptic seizures, finding that that astrocyte activity starts approximately 20 seconds before the onset of epileptic neuronal hyperactivity.

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New research has highlighted the profound link between dietary choices and brain health

Research showed that a healthy, balanced diet was linked to superior brain health, cognitive function and mental wellbeing. The study, involving researchers at the University of Warwick, sheds light on how our food preferences not only influence physical health but also significantly impact brain health.

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Interested in Participating in Research?

Epilepsy & Everyday Memory Study

Royal Brisbane and Women's Hospital and the University of Queensland are seeking adults with epilepsy, with and without memory problems, for a study. The goal is to understand their experiences with memory in everyday life and validate a memory assessment tool for people with epilepsy. Participants will complete a 45-minute survey about their history, epilepsy, memory, and well-being, with a chance to win one of 25 \$50 gift vouchers. A follow-up 20-minute survey one month later offers a chance to win one of 10 \$20 gift vouchers.

For more information, contact Dr. Kate Thompson at 0477 627 827 or kate.thompson1@uqconnect.edu.au.

This research is approved by the Metro North B Human Research Ethics Committee.

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The Wellbeing Neuro Course – for adults with Epilepsy

Macquarie University's eCentreClinic is now testing free online courses to help Australians with epilepsy learn to manage their **mental health and wellbeing** including skills for managing:

- Stress, anxiety, frustration, and worry.
- Low mood, sadness, grief, and depression.
- Day-to-day cognitive activities.

To find out more about a current clinical research trial to test the acceptability and efficacy of the Wellbeing Neuro Course.

Visit Website: www.ecentreclinic.org

Email: contact@ecentreclinic.org

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Women with Epilepsy: Beyond the Childbearing Years – Survey

We are seeking the thoughts of women with epilepsy who are approaching the menopausal years, or currently in perimenopause, menopause, or post-menopausal phases of life.

By completing this anonymous, 2-minute survey you will be contributing to the scarce knowledge base about the lived experience of women living with epilepsy and how you can be better supported through this period.

Epilepsy Action Australia is assisting A/Professor Lata Vadlamudi from Queensland University with this survey. The insights from this survey will form the basis of a collaborative research funding application with the University of Queensland and Monash University.

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Sodium Selenate Treatment for Medication Resistant Temporal Lobe Epilepsy: Currently recruiting

This trial is a world first to investigate the effect of 6 months of treatment with sodium selenate in people with medication-resistant temporal lobe epilepsy – to see whether, as in the pre-clinical animal studies, there is a sustained beneficial effect to reduce seizure frequency and neuropsychiatric comorbidities, even after the medication is ceased.

124 patients will be enrolled across at least 9 sites nationwide over 2.5 years.

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Australian Pregnancy Register for Women taking Antiseizure Medications: Currently recruiting

APR is seeking women with epilepsy, or other women taking antiseizure medications, who are pregnant or have recently given birth (infants up to 12 months of age), to help us understand the effects of these medications on the mother and developing baby during pregnancy.

This is a voluntary, ongoing nationwide study supported by Epilepsy Action Australia. Please enquire if you:

- took an antiseizure medication during pregnancy for any reason, or
- have epilepsy and did not take medications during pregnancy, or
- took antiseizure medications during pregnancy and experienced an alternative pregnancy outcome, or
- have epilepsy and did not take medications during pregnancy and experienced an alternative pregnancy outcome.

Use this QR code to sign up



The Genetics of Pharmacoresistant Epilepsy (GenPhEp) Study: Currently recruiting

The Genetics of Pharmacoresistant Epilepsy (GenPhEp) Study aims to identify the genetic basis of why medications work for some people but not others, and why some medications cause side effects and others do not.

Research Professors Dale Nyholt [QUT], Nick Martin [QIMR] & Wendyl D'Souza [University of Melbourne] were awarded an Australian government NHMRC ideas grant to undertake this study.

Researchers are seeking adults who have a diagnosis of epilepsy or recurrent seizures to participate in our study. We are looking for participants with any type of epilepsy, including from a brain tumour, injury, or whether the diagnosis is related to another condition, to help us find out how to predict the right (and wrong) medications for a person with epilepsy from the beginning. Participants are asked to complete an online questionnaire about their experiences with epilepsy and medications and donate a saliva sample [researchers cover all materials and costs].

If you have any questions about this research, please contact the Study Team on Free Call 1800 257 179, or email epilepsy@qimrberghofer.edu.au



Transition to Adult Healthcare Services

Transition is the planned move from health services for children under 18 years, to health services for adults. Transition takes time and you need to start preparing well before age 18.

When you are a teenager, your doctor might start talking to you and your parents about helping you prepare for moving to adult health services. Don't worry; they usually do this over time so you can start being a little more independent before this happens.

As you get older you will become more involved in discussions and decisions about your epilepsy and its management. It can be difficult to remember everything the doctor says, or even understand some of the information, so it is important that you ask questions when you are not sure.

Adult services will treat you as an adult and will expect that you have some independence and knowledge. With independence comes the need to learn about your condition, how to make medical appointments, get yourself there, get your medication, use your Medicare card and lots of other things.

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Training Offer: Living with Epilepsy & Disability

Enhance your knowledge to gain a deeper understanding of epilepsy in with intellectual disabilities.

This self-paced course sheds light on the unique challenges faced by those with epilepsy and intellectual disabilities. Learn to identify seizure activity, support individuals effectively, and improve their quality of life. Perfect for support workers and families seeking deeper insight. Dive into understanding and make a difference today.



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Healthy Pregnancy with Epilepsy Online Support Group

Healthy Pregnancy with Epilepsy is a private group and a dedicated online space for women with epilepsy to share and discuss their experiences of pregnancy, family planning, parenting a new-born, infant, toddler and beyond.

This project is supported by the Victorian Women's Benevolent Trust

Scan to join the
group



Mind the Treatment Gap

A new campaign focused on helping Australians living with drug-resistant epilepsy to better understand available treatment options and access them sooner has been launched.

The campaign, Mind the treatment gap, asks healthcare professionals and people living with drug-resistant epilepsy to prioritise conversations about treatment pathways alternative to anti-seizure medications to achieve seizure control and improve quality of life. It is supported by leading health experts and consumer advocacy groups as they recognise the stark reality of referral and treatment gaps for people with drug-resistant epilepsy.

Read more about this
campaign



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Making a Difference in Epilepsy

The Australian Epilepsy Project (AEP) continues to grow, adding New South Wales and Queensland sites to its AEP Hub distribution network. The team is celebrating the recent opening of its first regional scanning site at the John Hunter Hospital, Newcastle, as well as AEP Hub: The Mater, Brisbane.

Both hubs are now recruiting participants, providing greater access to advanced testing (neuropsychology, MRI, and genetics) for people experiencing seizures.

By providing access to advanced diagnostics and treatment pathways usually only available within a research setting, the AEP aims to provide benefits to Australians living with epilepsy from day one.

[Join the Study](#)





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SPARK

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IN SUPPORT OF
 national science week

Spark a Conversation About Epilepsy During National Science Week!

Join Epilepsy Action Australia's Spark4Epilepsy campaign this National Science Week (10th – 18th August 2024)! This initiative aims to raise funds and awareness for epilepsy while inspiring students' curiosity about science. Engage your students with hands-on static electricity experiments to illustrate how neurons function and how seizures occur.

With epilepsy affecting over 250,000 Australians, understanding the brain's electrical activity is crucial, especially for those who experience their first seizures in childhood or adolescence.

From lesson plans to resources, including printable materials and videos, there is something for everyone. Schools can host fundraising events to support epilepsy services. Every contribution supports vital services. Join us in sparking a conversation about Epilepsy this National Science Week!

