



Epilepsy  
Action  
Australia  
life changing impact

# EPILEPSY

## 360°

*Keeping you in the loop*

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## Children and Risk:

Adjusting to a diagnosis of epilepsy can take time. When your child is diagnosed, it's important to discuss safety and risks to help you make informed decisions about their well-being. Here are some key topics to consider.

### Seizure related risks with children

#### Seizures

Seizures vary from person to person, but most seizures affect awareness and can lead to falls or injuries. Some seizures pose more risks than others.

#### Seizures during sleep

If your child has seizures at night or during sleep, consider using a monitor to alert you (e.g. seizure alarm device or audio monitor such as a baby monitor). Your child's Doctor may discuss this and advise on available options. If your child is sleeping away from home, make sure the adults present know what to do if a seizure happens.

#### Seizure emergencies – prolonged or cluster seizures

If your child has had or is thought to be at risk of prolonged convulsive or clusters of seizures, their doctor may prescribe an emergency medication as these seizure types are considered a medical emergency and can be life threatening. If this is the case, they will also need a seizure management plan to inform people who take care of your child (e.g. other family members, support staff, their school or childcare) about what to do in case of a seizure.



**SUDEP**

Sudden Unexpected Death in Epilepsy (SUDEP) is when a person with epilepsy dies suddenly and prematurely and no reason for death is found. Sadly, about 1 in 1000 children with epilepsy will die from SUDEP. This means 999 children with epilepsy will not. However, SUDEP is something you should be aware of, and knowing the risks can be the first step in taking action to reduce them.

Epilepsy Action Australia, or your child's doctor can discuss and provide further information about SUDEP and individual levels of risk, which can vary from person to person.

**Preventing accidents**

Unfortunately, accidents can occur, and seizures can elevate the risk of these incidents. Here are some potential seizure-related risks to consider, along with steps you can take to mitigate them. For more suggestions see our Safety Factsheet

**Water Safety**

It is always important to take care around water to avoid risk of submersion or drowning.

**Swimming**

- Swimming should always be supervised by adults, or with young children, always accompany them in the water.
- Floatation devices are recommended for children with active seizures.
- If you have any garden ponds at home, keep it covered with a grill or secure the area with fencing. It is best to still supervise your child around any ponds.

**Bathing**

- Young children should always be supervised in the bath.
- When they are old enough to bathe alone, use a shower instead and leave the bathroom door unlocked in case a seizure occurs.
- Consider fitting an outward opening bathroom door in case they have a seizure behind the door.

**Sport and recreation**

Seizures during exercise are uncommon but occasionally vigorous exercise or activity may increase the chances of a seizure. Be aware of your child's seizure triggers and seek advice from your child's doctor regarding specific activities.

Most sports activities are okay as long as the person with epilepsy avoids anything that may increase their individual seizure risk. These are individual and can include overexertion, overheating, dehydration, and low blood sugar. Things to bear in mind:

- Be careful around heights. Avoid free style climbing unless using proper climbing safety equipment
- Wear the right protection during contact sports or physical activity, such as a protective helmet
- Make sure your child stays well hydrated and has eaten something prior to activities
  - DON'T let them continue the activity if child feels faint, lightheaded or nauseous

Make sure those around your child know what to do to help them during and after a seizure. Having a seizure management plan can help with this.

## Mental health and wellbeing

Epilepsy involves more than just seizures; children with epilepsy may face physical, emotional, behavioural, and social challenges. These challenges can significantly affect their health, wellbeing, and overall quality of life.

The most common challenges associated with childhood epilepsy are:

- physical (excessive fatigue, memory issues, headaches, visual impairments),
- emotional (depression, anxiety),
- behavioural (inattentiveness, distractibility, aggression), and
- social (peer rejection, bullying, stigma) (MacKinnon et al 2016).

If your child has issues socialising, controlling feelings appropriately, learning, or meeting milestones, it can be helpful to talk about your concerns with your GP, child health nurse, school or kindergarten staff.

Good mental health is essential for children's development. Unlike adults, children and young people express emotional distress in various ways, so it's crucial to pay attention to any changes in your child's mental health and emotions. Early identification, referral, and management typically lead to the best possible outcomes.

[Strong Foundations](#) covers issues related to epilepsy and learning.

[Emerging minds](#) will help you understand children's emotions and behaviour.

## Working with your child's healthcare team

The best way to reduce epilepsy risks is to help your child to have as few seizures as possible and encourage them to build healthy habits in managing their condition. Help them with this by:

- Supporting them to take their medication as prescribed
- Keeping regular doctors' appointments
- Keep a record of seizures to identify patterns and changes and report to the doctor
- Identify and avoid seizure triggers when possible
- Ask the doctor about other epilepsy treatments if seizures are resistant to medication

**Different children will require different precautions at different times.**

Not all the above will apply to all children, but it is important to know so you can take positive action to reduce risks.

**SUDEP Action Day is Wednesday October 16th** and is devoted to raising awareness around the world about SUDEP. If you want to know more about your individual risk, ask to go through a [SUDEP and Seizure Safety Checklist](#) with an epilepsy nurse or your doctor.

# Drug Resistant Epilepsy

In Australia, approximately 14,000 people are diagnosed with epilepsy each year and around 250,000 people are currently living with epilepsy. What many people don't know is that about **1 in 3 people with epilepsy continue to have seizures** despite treatment. This is called medication or drug-resistant epilepsy (DRE).

## What is drug resistant epilepsy?

DRE is when seizures are not fully controlled after trying two appropriately prescribed anti-seizure medications and used for an amount of time as determined by the specialist. Living with drug-resistant epilepsy can be a significant burden and can greatly impact quality of life.

## The effects of drug resistant epilepsy



Figure 1. Living with medication resistant epilepsy. Tang, F., Hartz, A., & Bauer, B. (2017). Drug-Resistant Epilepsy: Multiple Hypotheses, Few Answers. *Frontiers in neurology*

## It may not be drug resistant

If your seizures are continuing despite taking anti-seizure medication, it does not always mean you have drug resistant epilepsy. Sometimes there are other reasons for poor seizure control.



## Let's talk about medication

When you are diagnosed with epilepsy, medication is the first treatment. The aim of anti-seizure medication is to get the best seizure control with the lowest dose and the least amount of unwanted side effects. The neurologist will choose a medication that is appropriate for your type of epilepsy.

### When seizures don't respond to medication, what's next?

People with drug resistant epilepsy often experience:

- Frequent medication changes,
- Taking two or more medications at the same time,
- Unwanted medication side-effects,
- More frequent visits to the doctor, emergency department or hospital

“*Studies show that adding more medication is not likely to control this kind of epilepsy*”

### Firstly, if you haven't already done so, get a referral to a specialist epilepsy centre

There you will see an epilepsy specialist who may be able to:

- Suggest a more appropriate medication or trial a newer epilepsy medication
- Investigate if epilepsy surgery is a possible option. Some epilepsy types are suitable for surgery to help control or stop seizures
- Find out if vagal nerve therapy is an option. Vagus nerve stimulation (VNS) is a pacemaker-like device implanted in the chest to manage seizures that do not respond to medication or when surgery is not possible
- Consider dietary therapies. Examples of diets currently being used are the ketogenic diet, Modified Atkins Diet, or low glycemic diet.

There is no single treatment that works for everyone. Individuals can respond differently to medications and various treatment strategies.

If you have trouble with seizure control, seeing an epilepsy specialist is a good step to finding out what other treatment options may be suitable for your type of epilepsy.

“*Medication alone isn't the answer for 1 in 3 people with epilepsy.*”

## Epilepsy Surgery

Epilepsy surgery offers a chance to be seizure-free or have fewer seizures. Surgery may also allow antiseizure medications to be reduced – although ongoing medication is often necessary. This will depend on your circumstances. **Only a small number of people are suitable for epilepsy surgery.**

Listen to neurosurgeon Dr Erica Jacobsen answer questions about epilepsy surgery.



“

*Speak with your doctor about surgery as an option for you.*

”

## Vagus Nerve Stimulation (VNS Therapy™)

VNS Therapy™ is used for children and adults with focal and generalised seizures with DRE. It is a form of neuromodulation that offers another way to manage seizures and has been proven to be safe and effective.

The VNS Therapy™ System includes a pulse generator that is implanted under the skin and connected via leads to the left vagus nerve in the neck. The generator sends mild pulses through the vagus nerve to the brain.

VNS Therapy™ can lead to fewer and shorter seizures and better recovery after seizures. It can also lead to improvement in alertness, mood, memory, energy levels and general quality of life.

For more information scan the QR code



## Dietary Therapies

Dietary therapies have long been used to control seizures in people with severe epilepsies and DRE. The dietary therapies used today are all low in carbohydrates and high in fat.

The classic ketogenic diet was the original epilepsy diet developed for children however it is also used in adults. The modified Atkins diet is a less restrictive diet that helps with seizure control in adults and children. Other diets include the Low Glycemic Index Treatment & Medium-Chain Triglyceride diet.

“

*Always speak to your doctor about any treatment changes you are considering & do not start any dietary treatment for epilepsy without advice. These diets are to be closely monitored & you need medical supervision.*

”

DRE poses many challenges and despite the introduction of many new antiseizure medications over the last 30 years, the number of people with DRE has not lessened.

Poor seizure control has been associated with, increased risk of injury and death, difficulties with education and gaining employment, social isolation, anxiety and depression and consequently poor quality of life.

It is important to explore other approaches to treatment if antiseizure medication does not work.

## Epilepsy Clinics

Fortunately for Australians, there are comprehensive epilepsy centres in nearly every state, allowing for people with drug-resistant epilepsy to be referred to optimise their treatment plan.

**Epilepsy centers are best equipped to evaluate people who have DRE and offer a better chance at finding the most appropriate treatment.**

It is recommended that Australians with drug-resistant epilepsy should be referred to a comprehensive epilepsy centre to gain a clearer diagnosis, review of their epilepsy and targeted management as soon as possible to improve their seizure control.

If you continue to have seizures, ask for a referral to a comprehensive epilepsy centre for review of your epilepsy as soon as possible.

To find an epilepsy centre in your state, search your state, or contact us on **1300 37 45 37** or email [epilepsy@epilepsy.org.au](mailto:epilepsy@epilepsy.org.au)

**For more information:**

**Listen to epilepsy experts answer your questions about drug resistant epilepsy**

- **Professor Terry O'Brien**
- **Professor Patrick Kwan**

## **Drug Resistant Epilepsy Factsheet**

*Many thanks to LivaNova Australia for their contribution and assistance with this material.*



**Professor Terry O'Brien**



**Professor Patrick Kwan**



**Drug Resistant Epilepsy  
Factsheet**



# News E360 Sept 2024

The latest on epilepsy



## Mental health in secondary school-aged children with epilepsy and their primary caregivers

In school-aged children, epilepsy is associated with an increased risk for mental health and neurodevelopmental problems compared with both healthy children and children with other chronic conditions. Caregivers of children with epilepsy also had significantly more problems than controls.

## Researchers Use AI-Powered to Identify Genetic Epilepsies Much Earlier than Epilepsy Diagnosis

“Since most clinicians use electronic medical records, we believe this system could be widely adapted and utilized even in patient populations where genetic testing is not immediately available after symptom onset”

## Checklist of non-seizure Dravet features may aid diagnosis

A newly created checklist (DANCE), to be completed by caregivers, may help diagnose additional conditions that often occur alongside Dravet syndrome by identifying non-seizure features – such as language, cognitive, and behavioural problems.

## Study suggests potential heatwave impact on epilepsy

Heatwaves could be associated with an increase in abnormal brain activity among people with epilepsy, suggests a recent clinical study carried out by University College London (UCL).

## 35 Facts About Myoclonic Astatic Epilepsy

Learn more about Myoclonic Astatic Epilepsy (Doose Syndrome).

## Intellectual Disability Health Capability Framework Launched

The Australian Government has created an Intellectual Disability Health Capability Framework.

### What is the Framework for?

The Intellectual Disability Health Capability Framework aims to equip future health professionals with the required core capabilities to provide quality health care to people with intellectual disability, so they are confident and skilled to work with people with intellectual disability.

This will help to give better health care for people with intellectual disability.

- **Read the Framework and the Easy Read documents** to help you speak up for better quality health care.
- **Use the Easy Read Activity** to help you think about the type of care you want from your own health care team.
- **Watch a video** to see why the Framework is important to people with intellectual disability.
- **Spread the word** and tell other people with intellectual disability about the framework.

If you would like more information, please contact the Department of Health and Aged Care via [IntellectualDisability@Health.gov.au](mailto:IntellectualDisability@Health.gov.au)

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**Q3 Can drinking coffee cause seizures? I drink about 6 cups a day.**

A: Some people report that excessive amounts of caffeine triggers their seizures. It's hard to know exactly how much caffeine is a problem, as its effects on the body vary from person to person. The rough guideline for the average person is to drink (or eat) less than 600 mg per day – around four cups of strong coffee, or five or six cups of tea.

High dose caffeine products can pose an increased risk of adverse effects, including seizures, which is attributed to its action as a central nerve stimulant in addition to the known drug-to-drug interaction with some antiseizure medications. Caffeine, as a stimulant, has been shown to increase wakefulness and decrease the perception of fatigue which can act as a seizure trigger.

It would be worthwhile to monitor your caffeine intake and see if it is linked to an increase in seizure activity, if so, it would be best to avoid high dose caffeinated products or switch to decaffeinated beverages. It may be worth reducing your intake of caffeinated coffee to two or three cups a day at most and consume it before lunch time.

Caffeine is found in coffee, tea, chocolate, many soft drinks, high energy drinks, some supplements and medications, including some diet pills, antihistamines and decongestants.

**Q4 I'm really finding that my memory is poor and have trouble remembering even the simplest of things. Is this related to my epilepsy?**

A: Yes, some forms of epilepsy are associated with cognitive issues, and this includes memory difficulties. Problems with learning and memory are amongst the most commonly reported problems. Of course, factors such as sleep disruption, stress, anxiety and depression can also add to the difficulties.

First, it is best to try to manage any mood, psychological or fatigue factors that might be playing a role. Have a discussion with your doctor or psychologist for advice and treatment to help to address these issues. If more severe problems persist, then ask for a referral to a Neurologist or Clinical Neuropsychologist for an assessment which can lead to supportive and appropriate advice and management.

If you have mild to moderate problems with everyday memory, there is a new online treatment for adults that involves six sessions with a clinician and three-months of access to educational content and computer-based exercises. It's called MEMOREhab.

**Q5: I'd like to connect with others with epilepsy. Do you have any online support groups?**

A: Yes, we sure do. We offer a few online groups for different audiences and age groups. These online communities provide a safe space to connect with others who also have a lived experience of epilepsy, offering a range of insights and experiences. Many exchange tips, resources, and advice related to their specific challenges and also interests beyond their epilepsy. Have a look at our Online Communities page.

# Research News

## Funding to explore spider venom to treat epilepsy

The University of Queensland has been awarded a \$4.1 million grant for experts in stem cell technology and venom-based drug discovery to making tiny organ replicas – known as organoids – to prove the safety and efficacy of new venom based anti-seizure treatments.

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## Lab-grown spines unlock safer treatment for women with epilepsy

University of Queensland researchers have made a significant step towards enabling women with epilepsy safer access to a common and highly effective anti-seizure medication.

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## Finding epilepsy hotspots before surgery: A faster, non-invasive approach

Neurosurgery for patients with drug-resistant epilepsy requires locating the precise brain areas that are generating the seizures. Typically, patients undergo seven to 10 days of invasive intracranial EEG monitoring, with electrodes surgically implanted inside the brain. Eleonora Tamilia, Ph.D., directs the Epilepsy Monitoring Unit Signal and Data Science Program within the Epilepsy Centre at Boston Children's Hospital has piloted a much briefer, non-invasive method for mapping seizure zones meaning children may access surgery sooner.

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# Interested in Participating in Research?

## Research Survey - Developmental and Epileptic Encephalopathies

Griffith University is partnering with Australian epilepsy researchers on a study to measure the impact of caregiving for a person with a developmental and epileptic encephalopathy (DEE), including Dravet syndrome and Lennox-Gastaut syndrome.

If you are the main caregiver of a person with a DEE, we are seeking your help to complete a 20–25-minute online survey. The results will be used to raise awareness and justify the need for improving care for people with DEEs and their caregivers. This study has received ethics approval, and results will be published in a research journal. We do not collect, store, or publish any personal information in this survey.

Please click on the link to find out more and complete the survey. We also request that you please forward this information to any other caregivers of children with DEE whom you may know through your networks and peers.



Use this QR code to sign up

## Understanding and improving antiseizure medication management

What hinders or helps you in taking your anti-seizure medication?

We are seeking people living in Australia, over the age of 18 years diagnosed with epilepsy taking antiseizure medications to participate in a focus group discussion over Zoom. We will be running three focus group sessions on evenings and weekend between the 7th – 20th October, 2024. Each focus group session will run for approximately 90 minutes. As a small token of appreciation for your time, you will receive an \$80 gift card.

Your input will help us to update existing patient-facing information.

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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.

Use this QR code to sign up



## 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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## Epilepsy & Everyday Memory Study

Royal Brisbane and Women's Hospital and the University of Queensland are seeking adults living with epilepsy, with and without memory problems to participate in this study. Researchers are looking to better understand the experiences of people living with epilepsy regarding their memory in everyday life and to validate the tool that health professionals use to assess memory in people with epilepsy.

You will be asked about your personal history, epilepsy, memory and general well-being. It will take around 45 minutes to complete the survey. At the end, you will be invited to enter a draw to win one of 25 \$50 gift vouchers for your participation.

You will also be asked if you are willing to complete a second shorter survey one month later. This survey should take less than 20 minutes. At the end, you will be invited to enter another draw to win one of 10, \$20 gift vouchers for your participation.

For more information contact Dr Kate Thompson on **0477 627 827** or email [kate.thompson1@uqconnect.edu.au](mailto:kate.thompson1@uqconnect.edu.au)

This research has been approved by the Metro North B Human Research Ethics Committee  
Use the QR code



## 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](http://www.ecentreclinic.org)

Email: [contact@ecentreclinic.org](mailto:contact@ecentreclinic.org)

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## Australian Pregnancy Register for Women taking Antiseizure Medications: Currently recruiting

Epilepsy Action Australia is a major supporter and partner of the [Australian Pregnancy Register \(APR\)](#).

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.

Call **1800 069 722** or email Janet Graham at [janet.graham@mh.org.au](mailto:janet.graham@mh.org.au)



## 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] & Wendy 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 are interested in participating, please please contact the Study Team on Free Call **1800 257 179**, or email [epilepsy@qimrberghofer.edu.au](mailto:epilepsy@qimrberghofer.edu.au)



# Epilepsy Minimising the Risk

Seizures come with certain risks, but understanding these risks allows for actions to minimize them. This course covers the potential risks in different environments and offers ways to reduce those risks and support someone during a seizure in public.

Note: This course does not include first aid. For an overview of epilepsy, seizure safety, and first aid, please refer to our Epilepsy Essentials course.

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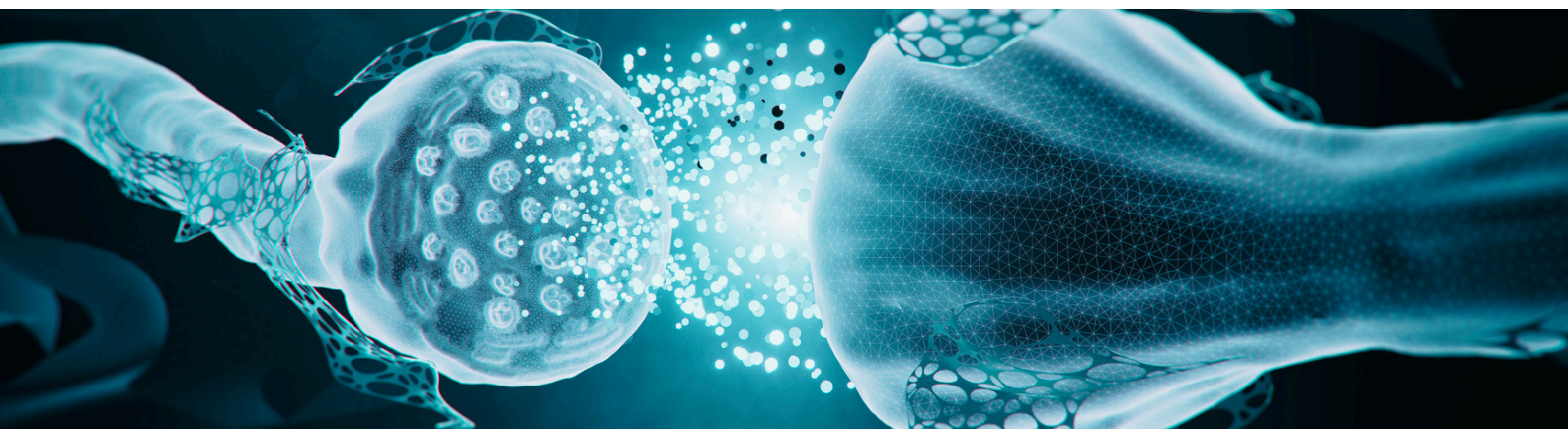
## Training Offer: Living with Epilepsy & Disability

**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*

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group



## Resources to Transition to Adult Health Care Services

We've introduced new resources to help young people with epilepsy transition smoothly to adult healthcare. These include a downloadable Transition Checklist, an online Interactive Quiz that creates a personalized action plan, and videos offering support for parents and sharing tips from young people's experiences.

These resources aim to make the transition easier and more positive, funded by the Australian and NSW Government Disaster Funding Arrangements 2018.

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## Need for Memory Rehabilitation

Memory rehabilitation is essential for individuals with certain forms of epilepsy, as cognitive issues can hinder everyday functioning, particularly in learning and memory. Factors like sleep disruption, stress, anxiety, and depression can exacerbate these challenges. Memory is vital for self-identity, learning, social interactions, decision-making, and future planning. When memory issues arise, it can lead to missed appointments and difficulties in independent living.

Although there are no simple solutions, strategies can enhance memory retention. Dr. Laurie Miller, a Clinical Neuropsychologist, offers advice and insights. One effective option is MEMOREhab, an online memory training program featuring weekly small-group telehealth sessions with a clinician, informational videos, practical application exercises, and reminders.

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MEMOREhab

