

Epilepsy in the later years

A guide for people living with epilepsy in their later years



UNDERSTAND ME
SUPPORT ME

Purpose of this resource

No one should go it alone with their epilepsy; this booklet is part of a suite of epilepsy resources that have been developed for people diagnosed with epilepsy in their later years.

As you age, physical changes occur in the brain as a natural part of ageing. However, when these changes are abnormal or there is damage to the brain, for example, when there has been a history of stroke, dementia, head trauma or brain tumours, epilepsy may develop.

The information contained in this booklet is not intended to include everything about epilepsy and should not replace medical advice or training in epilepsy awareness and/or medication administration. We recommend that you also visit our website www.epilepsyfoundation.org.au for further information about living with epilepsy, peer support and training options available from us.

So you have epilepsy

Epilepsy is the most common neurological condition and can be diagnosed at any age. Around 4% of Australians will develop epilepsy at some stage in their life.

People in their later years are fast becoming one of the largest population groups as the population group is generally living longer. However, with increasing age also comes an increasing risk of developing epilepsy.

What this means is that almost a quarter of cases of new onset epilepsy are experienced by people in their later years like you.¹

What is epilepsy?

Epilepsy is a disorder of brain function where there is a tendency to have unprovoked, recurring seizures as a result of abnormal bursts of electrical activity in the brain.

What is a seizure?

A seizure is a temporary sudden change in the electrical and chemical activity in the brain which causes a change in behaviour, thought or sensation.

Your brain usually transmits regular electrical impulses which carry messages between your brain and body. When this pattern is disrupted by a sudden burst of activity a seizure can occur.

Your experience of a seizure will be different from everyone else. Some people experience seizures every day, whilst others may only have a seizure occasionally. You may not be aware that you are having a seizure.



The incidence of any type of seizure increases substantially over the age of 60¹. People **over 65 years of age** have the highest incidence of seizures/epilepsy of any age.

Because of this it is important that you take notice of any behavioural changes that friends, family or carers bring to your attention and a medical investigation should be sought.



If you are over 60 years of age, the risk of recurrence of seizure after a first unprovoked seizure greatly increases after the first seizure **if the seizures go untreated.**¹

Seizure types

The ILAE (International League Against Epilepsy), the peak international medical epilepsy organisation, determines the official names of seizures and epilepsy syndromes. Seizures fall into two categories: focal and generalised seizures.



Most people think there is only one type of seizure that people with epilepsy experience being convulsive. This is not true; **there are many different types of seizures.**

Focal seizures

Focal seizures are the main type of seizure experienced by people in their later years. Focal seizures start in one part of the brain and may or may not spread to other parts of the brain. The impact of a focal seizure will vary depending on what function that part of the brain controls e.g. smell, taste, and sight. These seizures usually last less than two minutes in duration.

Generalised seizures

Tonic-clonic seizures belong to a group known as generalised seizures in which the person falls, loses consciousness, stiffens and the body jerks or convulses. Generalised seizures involve the whole brain and therefore impact the whole body, however they are not always convulsive in nature and can last 1-3 minutes in duration. In older people, seizures where you fall are less common than in other age groups.

Status epilepticus

Status epilepticus is a very long seizure (more than 30 minutes) or a continuous state of seizures where one seizure follows another without a break. This status can occur in almost any seizure type, however convulsive status epilepticus where the person is experiencing ongoing tonic-clonic seizures is considered a medical emergency and an ambulance must be called.

What could a seizure look like?

Seizures are different for each person, it depends in which part of the brain the seizure occurs and what functions that part of the brain controls. Some of the behavioural changes you may experience include:

- loss or disturbance of awareness ('absence', blackout spells), blank stare
- feelings of déjà vu or an unpleasant smell or taste
- confusion
- fall, with no memory of the fall
- involuntary movement - twitching or abnormal sensory disturbance (funny feelings) of a limb, limbs or face without a loss of consciousness
- automatisms - repetitive, automatic trance-like movements, e.g. fiddling with clothes or repeated swallowing
- sleep disturbances
- loss of bladder control.

You might be alert during a seizure and remember what happens. Alternatively, you may only remember certain aspects before or after the seizure.

Following the seizure, you may feel tired and sleepy, confused, angry, sad or worried. Confusion following a seizure can last several hours or days or sometimes even weeks.



It is important to remember that **there is no 'normal'**, everyone experiences seizures differently.



“ I was driving one day with a friend, and we stopped at a red light and I think I got one then, because I stalled the car and I couldn't remember what to do. Very quickly it happened, but it wasn't until somebody behind me honked and the light had changed. I thought, oh. **It was only in hindsight that I realised I had a little absent seizure.** ”

Understanding your epilepsy

Causes

There are many causes of epilepsy and seizures. It is very important that the cause of your seizures is investigated as this will help determine the appropriate management and support you may need.

- Having a stroke is by far the single greatest contributor to an epilepsy diagnosis in later years, this is due to the lack of oxygen to the brain after a stroke, which can cause epilepsy.
- A brain injury, which results in scar tissue can also predispose you to developing epilepsy.
- Epilepsy can also be caused by a brain tumour impacting on the brain's normal electrical and chemical functions,
- Degenerative conditions which affect brain tissue such as dementia can also cause epilepsy.

Other risk factors associated with the development of epilepsy can include lifestyle factors such as alcohol, smoking, sleep deprivation and stress. Other medical conditions affecting brain function can also increase the risk of developing epilepsy.



About half of all diagnosis of epilepsy for people in their later years **has no known cause**.

Triggers

Seizures can be brought on by specific events which are recognised as triggers. You may or may not recognise triggers which bring on your seizures.

Some common seizure triggers identified for people of all ages include:

- missed medication
- feeling unwell or overheated, running a temperature
- dehydration, insufficient intake of water
- low blood sugar from missed meals
- drugs and alcohol, including prescribed medication
- sleep deprivation, not getting enough rest/sleep
- significant stress, including emotional and physical stress
- bright, flashing or flickering lights

These triggers alone, however, do not explain why a seizure has occurred because not everyone who is exposed to one of these triggers will have a seizure.

Diagnosis

It is quite common for people in their later years to experience seizure symptoms that are not always recognised as being epileptic in nature. Misdiagnosis can happen when behavioural changes are assumed to be related to another condition or the ageing process and not a seizure. This makes diagnosing epilepsy in people in their later years complex.



Getting a confirmed diagnosis of epilepsy can sometimes be a **lengthy process**.



Not all seizures lead to a diagnosis of epilepsy.

An acute symptomatic seizure refers to a seizure provoked by an acute illness or injury to the brain, although this is not uncommon in older people and does not necessarily lead to a diagnosis of epilepsy. An unprovoked seizure is a seizure which occurs without any obvious immediate cause, only further investigations by your doctor will identify the cause of the seizure and whether there is a diagnosis of epilepsy.

Your doctor may refer you to a specialist such as a neurologist or epileptologist who specialises in treating people with epilepsy for further investigation if they cannot identify the cause of your behavioural changes or possible seizure activity.

Your medical history, any eyewitness accounts, and medical tests are needed to make a diagnosis of epilepsy by a specialist. Medical tests may include blood tests, an EEG [electroencephalogram], a CT scan [computerized tomography] or an MRI [magnetic resonance imaging].



“ I was diagnosed with epilepsy 10 years ago, when I was 63. The only major seizure I’ve had was one night when I slept through it and wondered why my pillow was on the floor the next morning, and my husband explained **I had had a major seizure**. I was a trained nurse and midwife, and when I was diagnosed with epilepsy at 63, I was gobsmacked, because I thought it was a childhood disease, and I had never heard of anyone of my age being diagnosed with epilepsy. ”

Treatment

Deciding on the correct treatment for your epilepsy is important and requires specialist expertise.

It is common for people in their later years to also have other health conditions which

require medications; your specialist will consider these factors in developing your treatment plan for your epilepsy.

Anti-epileptic drugs (AEDs)	For most people diagnosed with epilepsy, anti-epileptic drugs are prescribed. AEDs will not cure your epilepsy, but they can control your seizure activity, the best outcome from taking the AEDs being that you will become seizure free.
Emergency medication	If you have many seizures, or seizures which last a long time, your specialist may also prescribe emergency medication. If emergency medication is prescribed your specialist will go through with you when the emergency medication is to be administered, how it is to be stored and how it is to be administered. You will also receive a medically endorsed Emergency Medication Management Plan (EMMP) from your specialist (see Managing your epilepsy).
Diet	<p>Your specialist may also discuss diet treatment options such as the ketogenic diet or a modified Atkins diet. It is important for you to understand that these dietary therapies should only be used under the supervision of your doctor.</p> <p>Ketogenic Diet</p> <p>The ketogenic diet is a high fat, low protein and low carbohydrate medically supervised diet used as a treatment for epilepsy that does not respond to anti-epileptic drugs. This is sometimes called “drug resistant epilepsy” or “refractory epilepsy”.</p> <p>Modified Atkins Diet</p> <p>A modified Atkins diet is a special high-fat, medically supervised diet that is also used for difficult to treat seizures. Heavy cream, butter and vegetable oils provide the necessary fat. This diet differs from the ketogenic diet as it allows all protein rich foods such as meat, chicken, eggs and fish.</p>
Surgery	Epilepsy is sometimes caused by an area of abnormal brain tissue. There are many reasons why an abnormality occurs and it may not be important unless it causes seizures. The size and position of the area, referred to as the epilepsy focus, varies between individuals. If surgery can remove the epilepsy focus, seizures can often be prevented. The chance of successful surgery and the risks of complications differ for each patient and your doctor will discuss with you whether this is an appropriate treatment.

Living with epilepsy

A diagnosis of epilepsy can have a significant impact on your life. Having a frank and open conversation with your doctor is the first step in ensuring all potential impacts on your life are considered.



Any side effects you experience should be discussed with your doctor.

➤ Refer [Medication and epilepsy information sheet](#)

“*Being a person who’s always been fiercely independent, one of the things I feared was having my independence curtailed in some way, but it hasn’t. People that I’ve got friendly with through the gym or book group or other things, I don’t know that many of them know I have epilepsy. **I don’t wander around with a big sign on my forehead.***”

Medication side effects

Like any medication AEDs can bring undesirable side effects. Some common side effects that may occur in the first few weeks of taking AEDs include tiredness, stomach upset or discomfort, dizziness or blurred vision.

Taking medication is a personal choice, and you are encouraged to discuss any concerns you may have with your doctor to ensure that you have a good understanding of why the AED is being recommended for you and the potential side effects you need to be aware of.

Seizure diary

You may find it useful to record your seizures in a diary. You may also want a carer, family member or friend to video what happens during a seizure using a mobile phone. Recording how long the symptoms last, how often the seizures are taking place and how the seizures are affecting your behaviour during and after the seizure, can be helpful.

When you see your doctor or specialist they can use the information in your seizure diary and the video when developing your on-going treatment plan.

“*I keep **lists** for everything on a daily basis, and I also keep a **daily diary.***”

Wellbeing mapping

You may consider completing an epilepsy wellbeing map. The map is a tool to help you to prepare for consultation with your doctor or specialist, by completing the mapping document you can provide valuable information to your doctor or specialist about how living with epilepsy impacts you.

The mapping process asks you to review all areas of your life and reflect on how having a diagnosis of epilepsy impacts your overall wellbeing. The mapping process helps you to think about the impact of epilepsy and any concerns you have, highlighting the most important questions to ask at your next consultation.

The map is a tool to support you in communicating effectively with your doctor or specialist. If you receive support from an aged care worker or carer, you may find it helpful to also discuss the the outcome of your wellbeing map with them.

➤ Refer www.epilepsywellbeing.com.au

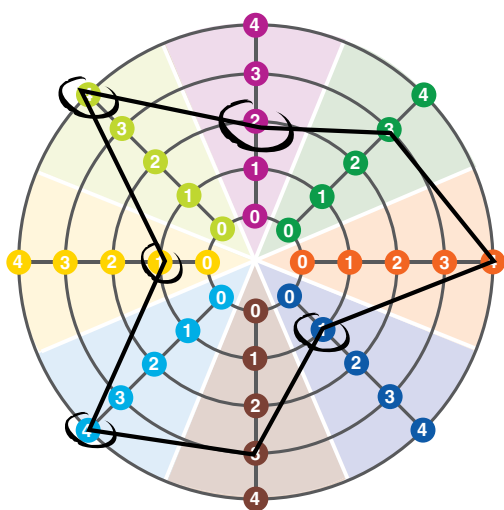


Figure 1: Epilepsy Wellbeing Map™

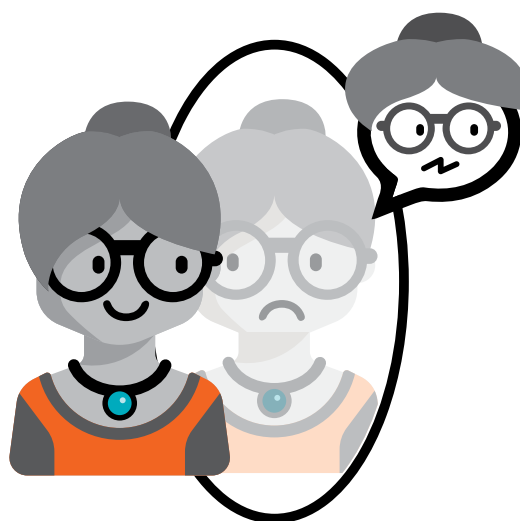
Self-esteem

Developing epilepsy at any age can be difficult to come to terms with. A diagnosis may raise concerns about:

- loss of independence
- being a burden on family members
- confusion as to why it is happening
- fear of how others might react
- fear of the unknown.

Sharing your diagnosis with family and friends is your choice however sharing your diagnosis and how you are feeling with people close to you improves their understanding of epilepsy and can help them to provide the support you may need.

Remember epilepsy is **one of the most common neurological conditions** experienced by people today.



It is common to develop depression or anxiety within the first year following a new diagnosis of epilepsy.

This is what others usually see when a person has epilepsy

Seizures

Below are some of the other possible impacts of epilepsy that people may experience because of their seizures and which can often impact a person more than the seizure itself.

Memory

For some people with epilepsy, memory can be a significant challenge

Stigma

A person can experience stigma due to a lack of community awareness and understanding of epilepsy

Tiredness/fatigue

Due to seizure activity (including during sleep) people can be tired and find it difficult to concentrate

Medication

Side effects from medication may cause tiredness, difficulties with concentration or mood/behaviour changes

Self-esteem

The unpredictable nature of seizures can have a negative effect on a person's confidence and self-esteem

Depression and anxiety

Up to 50% of people living with epilepsy experience depression or other mental health illnesses

50% of people living with epilepsy experience depression or other mental health illnesses.

Looking after your own mental health is very important. Talking to your doctor, and your family or friends about what is happening and how you are feeling is the first step in looking after yourself.

➤ Refer [Self-esteem and epilepsy](#) information sheet

Travelling

When travelling it is important that you make sure you carry sufficient medication with you and remember to take the medication at your usual times. If travelling overseas, see www.smartraveller.gov.au/tips/medicine for things to check before you travel.

Being diagnosed with epilepsy can have an impact on your ability to drive. Your diagnosis may result in your licence being limited depending on your type of seizures and time they occur e.g. only during sleep.



➤ Refer to the [Travelling and epilepsy](#) information sheet

Figure 2: Epilepsy is more than just the seizure

Staying active

A diagnosis of epilepsy does not mean you cannot socialise with family or friends or enjoy recreational activities. People with epilepsy can continue to take an active part in leisure activities, sport and recreation.

Staying active is important for your overall health and wellbeing.

It is normal to have a level of concern about the impact of your epilepsy diagnosis on your life. However this concern should be discussed with your doctor so that you can put in place appropriate risk management strategies and supports that will enable you to continue to live the life you want.

- › Refer [Staying active and epilepsy](#) information sheet



“ Try and just go on with life as it was. Not to think, oh, dear... I've got to be careful doing this, that, and something else, because you don't. You just go on with whatever it was. Whatever sort of lifestyle you had. Keep doing it. Keep going. Don't stop. ”



Managing your epilepsy

Managing your epilepsy is about better understanding what is happening and putting in place the supports that you need and want.

Epilepsy Management Plans

The Epilepsy Management Plan (EMP) and the Emergency Medication Management Plan (EMMP) are valuable tools to manage your care. They provide vital information about the types of seizures you experience, your individual support needs, and any procedures required for first aid or emergency medication. You, your doctor and any carers you have should be involved in developing the plans so that your needs are understood and met to best manage your epilepsy.



Epilepsy Management Plans are completed and endorsed by your doctor and updated annually.

- › Plan templates are available online <http://epilepsyfoundation.org.au/epilepsy-management-plans/>

Epilepsy Management Plan (EMP)

The EMP documents your seizure description and what to do in the event of a seizure, the impact of seizures on you and the post seizure support you would like. The EMP also identifies whether emergency medication has been prescribed, specific support needs and when to call **000**.

Emergency Medication Management Plan (EMMP)

Where emergency medication has been prescribed, the EMMP is the authority for a trained person to administer the emergency medication in the event of a seizure requiring an emergency response. The EMMP also provides information on when to call **000**.



Only people who have received person **specific training for the administration of emergency medication** for you should administer emergency medication to you.

- › Refer <http://epilepsyfoundation.org.au/epilepsy-education/>

Risk management

Developing management plans is also about identifying potential risks and putting in place the strategies you need to help you manage your epilepsy. It is important that you consider the safety implications and any risks that may be associated with your epilepsy diagnosis and seizure activity.

Safety

There are a number of devices/assistive technologies available to assist in maintaining your safety:

Medical ID

Your medical information can be recorded on a Medical Bracelet or ID Card to alert medical personnel, emergency services and people in the community on how to provide the most appropriate treatment should you have a seizure.

Medical alert

If you enjoy walking but have seizures which can affect your balance or are convulsive, you may benefit from having a fall detector pendant. These pendants automatically raise an alert if you should lose your balance and fall or if your seizure involves loss of consciousness. Medical alerts can also be activated manually when assistance is required should you recognise behavioural changes signalling the impending onset of a seizure.

Depending on your seizure type there may be additional safety issues which you need to consider. They could include always swimming with a companion, bathing support, having on-call or in-house support overnight and support with commuting. Your doctor or specialist will discuss this with you when developing your EMP.

- › Refer [Risk and epilepsy](#) information sheet

Training

It is important that you and your family or carers understand epilepsy and understand your emergency medication and how to administer it should they need to. Seizure first aid training and administration of emergency medication training is an important step in reducing the risk to you.

- › Refer <http://epilepsyfoundation.org.au/epilepsy-education/>

Seizure First Aid



Seizures are not all the same so it is important for your family, carers, friends, neighbours or anyone looking out for you to know what to do to keep you safe during a seizure.

If you have an Epilepsy Management Plan and/or an Emergency Medication Management Plan then your support network should:

- know where these plans are kept
- be trained in providing a seizure response according to these plans and your wishes.

Only people who have received person specific training for the administration of emergency medication for you should administer emergency medication to you.

- › A comprehensive seizure first aid poster and short video is available online <http://epilepsyfoundation.org.au/seizure-first-aid/>

Where to go for further information

Epilepsy Foundation www.epilepsyfoundation.org.au

Epilepsy Learning www.learning.epilepsyfoundation.org.au

Epilepsy YouTube www.youtube.com/user/EpilepsyVictoria

Epilepsy Australia www.epilepsyaustralia.net

Glossary

EEG (electroencephalogram) An electroencephalogram is a test which shows electrical activity in the brain using small, flat discs attached to the scalp.

CT scan (computerized tomography) A computerised tomography scan uses computer-processed combinations of a number of X-ray measurements taken from different angles to produce cross-sectional images that create visual slices of the brain allowing the doctor to see inside the brain without surgery.

MRI (magnetic resonance imaging) Magnetic resonance imaging is a medical imaging test which uses strong magnetic fields, radio waves, and field gradients to generate images of your the brain.

TIA (a transient ischemic attack) A transient ischemic attack is like a stroke, producing similar symptoms, but usually lasting only a few minutes and causing no permanent damage.

Acknowledgements

This resource was developed in partnership with the Epilepsy Foundation, Council on the Ageing (COTA), the National Ageing Research Institute (NARI) and the Brotherhood of St Lawrence and is part of a suite of resources that are targeted to aged care workers and carers of older people, to assist with caring for older people living with epilepsy.

We also wish to acknowledge Epilepsy Scotland for their publication *Epilepsy and later life guide* (2008), Epilepsy Australia for their publication *Diagnosing Epilepsy ... Answering your questions* (2016) and NARI for their publication *Tackling Epilepsy in the Later Years - Literature Review and Background Report* (2013) for informing the development of this resource.

Funding for this project was generously provided by the JO & JR Wicking Trust, Helen Macpherson Smith Trust and the Aged Persons Welfare Foundation.

Reference

1. Williams, S., Dow, B., Vrantsidis, F., Haralambous, B. and Hill, K. *Tackling Epilepsy in the Later Years - Literature Review and Background Report*, 2013.

The contents of this publication including all text, graphics, logos and images are protected by Australian copyright laws. Copyright of the Epilepsy Foundation's materials belongs to the Epilepsy Foundation. Other than for the purposes of and subject to the conditions prescribed under the *Copyright Act 1968*, no part of this publication may, in any form or by any means, be reproduced, stored in a retrieved system or transmitted without the prior written permission of the Epilepsy Foundation. The images in this publication show models who do not necessarily have an epilepsy diagnosis and are for illustrative purposes only.

The information contained in this publication provides general information about epilepsy. It does not provide specific advice. Specific health and medical advice should always be obtained from an appropriately qualified health professional. Readers should not act on the basis of any material in the book without obtaining advice relevant to their own particular situations. The authors, editor and publisher expressly disclaim any liability to any person in respect of any action taken or not taken in reliance on the contents of this publication.

Epilepsy Foundation, 587 Canterbury Road, Surrey Hills, VIC 3127, Australia, Telephone: (03) 8809 0600.
www.epilepsyfoundation.org.au