Caring for epilepsy in the later years

UNDERSTAND ME SUPPORT ME





Purpose of this resource

No one should go it alone with their epilepsy; this booklet has been developed for aged care workers and carers.

An epilepsy smart aged care approach means that people in their later years are better understood and better supported.

This booklet can be used as a tool to build the capacity of aged care workers and carers to better understand epilepsy and seizures and its impact on the older person, to improve service practice and person-centred outcomes. This booklet is part of a suite of resources that

have been written for aged care workers and carers, to assist with caring for older people living with epilepsy.

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 http://epilepsy.org.nz/ for further information about supporting a person living with epilepsy and epilepsy training for the aged care sector.

Understanding epilepsy

Epilepsy is the most common neurological condition and can be diagnosed at any age. Around 2% of New Zealanders will develop epilepsy at some stage in their life.



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.

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.

People in their later years living in nursing homes have been reported to have the highest occurrence of epilepsy compared to the wider community.

What is epilepsy?

Epilepsy is described as a neurological condition in which a person experiences seizures on a recurring basis. In people in their later years, the risk of having further seizures after a first unprovoked seizure is high, ranging from 40–90%, with a worse outcome if untreated.



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.

The brain transmits regular electrical impulses which carry messages between the brain and the body. When this pattern is disrupted by a sudden burst of activity a seizure can occur. Every person's experience of a seizure is different. Some people can have seizures every day, whilst others may only have a seizure occasionally.

Seizures can be provoked, known as reactive or active symptomatic, where there is a particular external or internal factor which brings them on, such as an infection, acute illness or stroke. They can also be unprovoked which means there is no known cause of the seizure.

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.



70% of seizures in older people are focal 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, sight. These seizures usually last less than two minutes in duration.

A person experiencing a focal seizure with impaired awareness may be mistaken as being drug/alcohol-affected or as having a mental health disturbance as the person may appear unresponsive and confused.

Generalized Seizures

Tonic-clonic seizures belong to a group known as generalized 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 and can last 1–3 minutes in duration. In older people, seizures where they fall are less common than in other age groups.

Other generalised seizures, which are not as common in older people, are **absence** seizures. These seizures cause a short period of "blanking out" or staring into space which may be mistaken for daydreaming.



Status epilepticus

Status epilepticus is a very long seizure, more than 30 minutes in duraction, or continuous 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 on-going tonic-clonic seizures is considered a medical emergency and an ambulance must be called.

Status epilepticus is commonly experienced by people in their later years due to a number of factors including medication use, in particularly high dose intravenous antibiotics or coadministration of anti-epileptic drugs, low serum albumin and the ageing process in general.

Approximately 30% of acute seizures in older people will present as status epilepticus with a mortality rate as high as 40%.

What could a seizure look like?

In older people seizure activity and behavioural changes, which may be caused by a seizure, can be subtle. It is important that aged care workers and carers take note of any types of behaviours which are not considered normal for the person they are caring for, as these behaviours may be associated with seizure activity.



30% of people in their later years will not be aware they are having a seizure and it can therefore go unreported.

It is important that aged care workers and carers know what to look for, can recognise the signs of seizure activity and can document it. 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 as to what impact the seizure has.

Some of the behavioural changes that could occur include:

- loss or disturbance of awareness ('absence', blackout spells), blank stare
- feelings of déjà vu or an unpleasant smell or taste
- confusion, disorientation
- 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 trancelike movements, e.g. fiddling with clothes or repeated swallowing
- sleep disturbances, restlessness, inability to maintain a regular REM sleeping pattern
- incontinence, loss of bladder control



For the older person, memory of what happened before the seizure, during or even after the seizure may not be clear. The person's level of alertness can vary greatly depending on the seizure focus and impact. After a seizure (postictal) confusion may be more prolonged in an older person, with the confusion lasting from hours to days and in some cases weeks. Additionally when post ictal the older person may feel tired and sleepy, angry, sad or worried. The person may require additional support and reassurance postictal.

Causes

There are many causes of epilepsy and seizures. It is very important that the cause of seizures is investigated as this assists with diagnosis and will help determine the appropriate management and support required.

Epilepsy in people in their later years is distinct from other age groups for a couple of reasons.

- 1. Underlying causes for developing epilepsy are different epilepsy usually occurs as a result of secondary factors or a build up over time of injuries to the brain. Seizures are usually a result of acquired physical causes rather than genetic ones for example from a stroke, dementia, trauma from falls, or tumours.
- 2. Epilepsy is harder to diagnose people in their later years may have other health conditions, which makes it particularly challenging to recognise seizure activity and reach an epilepsy diagnosis.

Approximately 30% of acute seizures in older people will present as status epilepticus with a mortality rate as high as 40%.

About half of all diagnoses of epilepsy for people in their later years have no known cause.

Having a stroke is the single greatest known contributor to an epilepsy diagnosis in later years (30–50%), this is due to the lack of oxygen to the brain after a stroke, which can cause epilepsy. Following a stroke, the risk of developing epilepsy, known as post-stroke epilepsy, increases 20-fold in the first year and there is a 3-fold risk of subsequent strokes.

People who have had a stroke or who have dementia are more likely to develop epilepsy than people without these conditions.

Alzheimer's disease has a 10-fold increased risk of epilepsy. The most common type of seizures associated with Alzheimer's disease are generalised seizures which is different from older people without dementia who generally experience focal seizures.

A brain injury from trauma (10-20%), which results in scar tissue can also predispose an older person to developing epilepsy. Epilepsy can also be caused by a brain tumour (10-30%) impacting on normal brain electrical and chemical functions, or from degenerative conditions which affect brain tissue such as dementia (10-20%).

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.

Post-stroke epilepsy, increases 20-fold in the first year and there is a 3-fold risk of subsequent stroke.

Triggers

Seizures can be brought on by specific events which are recognised as triggers. There is no data to support seizure triggers specific to older people

An older person may or may not have triggers which bring on a seizure. 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. Observations made by aged care workers or carers are important to identify trends in possible seizure activity and triggers.

Alzheimer's disease has a 10-fold increased risk of epilepsy.

Diagnosis

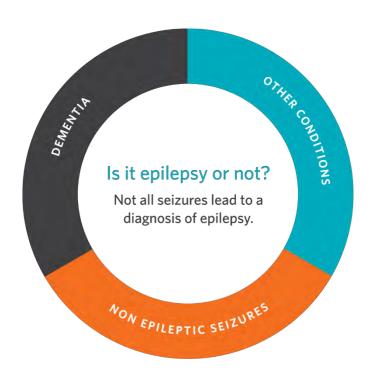
"It can be very difficult to diagnose. Most people have the concept that in a seizure, the person will just collapse and have a full-body convulsion, froth around their mouth and so on. *In fact, there are many other* different types of seizures. In the elderly, their seizures are often more subtle. Just some blankness, loss of awareness, very subtle signs that often mean that they go undiagnosed and there needs to be a high level of suspicion from both the elderly themselves and also the carers and family and even the general practitioners."

Professor Patrick Kwan, Head of Epilepsy, Department of Neurology, Royal Melbourne Hospital and Chair of Neurology, Department of Medicine, the University of Melbourne

A diagnosis of epilepsy is often challenging in older people and can take a long time. Research indicates that about 30% of older people with an epilepsy diagnosis did not have the diagnosis considered at their first evaluation.



A brain injury from trauma (10-20%), which results in scar tissue can also predispose an older person to developing epilepsy.



Dementia:

Older people with dementia can show similar symptoms as those seen in people with epilepsy such as cognitive impairment causing confusion, making it difficult to get a clear diagnosis.

A diagnosis of epilepsy is more likely if these symptoms occur whilst the person is in a variety of postures or if they always occur during sleep, or if the length of time associated with confusion following an episode is longer than one hour.

Non epileptic seizures:

Seizures provoked by an acute illness or injury to the brain, although not uncommon in older people, do not necessarily lead to a diagnosis of epilepsy. Similarly, unprovoked seizures which occur without any obvious immediate cause may or may not be epilepsy.

Other conditions:

Existing health conditions can make a diagnosis of epilepsy more complex. There are many other medical conditions/events which may resemble seizures or epilepsy including: temporary loss of consciousness, transient ischaemic attacks (TIAs) or weakness in limbs, migraines, dizziness, panic attacks, non-specific confusion or amnesia related to dementia, vertigo followed by a fall, infections, metabolic disturbances, sleep disorders and transient global amnesia.

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

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 have other health conditions which require medications; your specialist will consider these factors in developing your treatment plan for your epilepsy. "While they (older people) are at high risk of developing epilepsy, in fact, they're often very responsive to treatment once the right treatment is selected."

Professor Patrick Kwan, Head of Epilepsy,
Department of Neurology,
Royal Melbourne Hospital and Chair of Neurology,
Department of Medicine, the University of Melbourne

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	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. Ketogenic Diet 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".
	Modified Atkins Diet 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.
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.

Referral for investigation

It is common for older people to show symptoms which are thought to be epilepsy related and sometimes found to be other conditions, this is called having a false positive investigation.

Detailed and accurate notes about any possible seizure events that are not easily explained or are suspicious will assist the referral doctor to carry out a thorough investigation.

It may be difficult to know when it is appropriate and necessary to recommend or refer the person to have a clinical diagnosis.

It will often depend on:

- how often the possible seizures are taking place
- how much the possible seizures are impacting on the person's function or quality of life
- the person's preference for seeking expert help.

Investigations may not initially result in an epilepsy diagnosis, this however does not necessarily mean there is nothing wrong.

In some cases, on-going observations of symptoms or further tests may be required to make a clear diagnosis.

> Refer Epilepsy in the later years: Referral pathways resource

Impact of epilepsy on the older person

Risk

Epilepsy can have a significant impact on the life of an older person, including permanent or temporary disability or co-presenting health-related conditions or illnesses. There is an increased risk of having a stroke (3 fold), experiencing a fall which results in traumatic brain injury or fractures (2–6 fold), or developing status epilepticus. The consequence of experiencing any of these impacts can be death with status epilepticus having a mortality rate as high as 40%. People in their later years have a 2-3-fold increased incidence of death from epilepsy in comparison to the general population. Preventive strategies are crucial to ensure negative outcomes are minimised or avoided.

Refer Risk and epilepsy information sheet

Seizure diary

Some older people living with epilepsy may find it valuable to record their seizures in a diary. An aged care worker or carer may be in a position to video a seizure event with a mobile phone to support the diary entries if the person gives consent to do so.

Recording how long the symptoms last, how often the seizures are taking place and how the seizures are affecting behaviour during and after the seizure as well as collecting video evidence of seizure activity for the video evidence of seizure activity for the doctor, is a valuable diagnostic tool and can be used to aid management of the person's epilepsy.

Wellbeing mapping

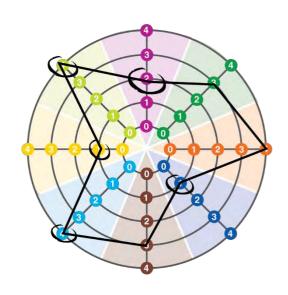
Older people living with epilepsy may consider completing an epilepsy wellbeing map, a tool to help them prepare for consultation with their doctor.

By completing the wellbeing map the person can provide valuable information about how living with epilepsy impacts them.

The map can also be used by aged care workers and carers to facilitate discussion and clear communication on the impact of epilepsy on the life of the older person.

Refer www.epilepsywellbeing.com.au

Figure 1: Epilepsy Wellbeing Map™



Lifestyle

Independence

For an older person the loss of or reduction in independence can be a very confronting challenge to face. Loss of independence for an older person living with epilepsy can come about for a number of reasons.

The following risks can potentially impact a person's independence:

- People with epilepsy are at a high risk of developing memory difficulties.
- Falls associated with seizures in people in their later years can lead to death, injuries including fractures, and a fear of falling in the future.
- The ability of a person with epilepsy to hold a driver licence depends on the likelihood of them having a seizure while driving and the impact of a seizure on their ability to drive.
- Poor sleep, decreased mental status and a higher prevalence of depression and anxiety can exist in older people with epilepsy.
- Level of confidence to travel away from the familiarity of home and medical supports. Loss of Independence correlates closely to risk management

Refer Memory and epilepsy, Falls and epilepsy, Travelling and epilepsy information sheets

Staying active

Being active and mentally alert can help with the management of epilepsy. Activities such as yoga, Tai Chi, playing cards or bowls, walking and socialising with friends and family will help the person stay active and connected. A healthy lifestyle also helps with the medical management of epilepsy. It is important for the older person to get adequate sleep, have a good diet, reduce stress, limit alcohol, and undertake plenty of exercise and stimulating activities.

Refer <u>Staying active and epilepsy</u> information sheet

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

Mental health and well-being

Epilepsy in later life is different from other age groups as people may have other existing health conditions (co-morbidities), may be coming to terms with the loss of their role in their family and society, may be going through retirement and/or may be experiencing the death of loved ones. It is therefore important to understand how epilepsy is experienced by people in their later years and how it impacts on their wellbeing, to better support them in the community.

Some evidence has revealed that older people with epilepsy often experience poorer sleep, decreased mental status and can have a higher prevalence of depression and anxiety. These should be monitored and documented over time for discussion with the person's doctor. It can be upsetting for an older person to learn they have developed epilepsy which can impact their self-perception and esteem. Researchers in the UK carried out a study to look at how people living with epilepsy in their later years feel about and experience their condition. Interviews were undertaken with 10 people over the age of 65, who had an average of 23 years since their diagnosis (ranging from 2–48 years). An analysis of the interviews showed:

- 'The power of epilepsy' was the key theme that dominated the findings, epilepsy was described by people as an 'it' (e.g. separate to themselves) and a chronic, threatening, unpredictable and incurable condition
- This view of the negative consequences of epilepsy (e.g. loss of control, dependence on others, impact of society's attitudes/ stigma) act as a barrier to attempts to adjust and cope with the condition.

These results signify that routine assessments in people in their later years with epilepsy should be performed. Psychological interventions, e.g. psychotherapy, support groups and educational programs should be made available to help people who experience distressing and threatening issues as a result of having epilepsy. The aged care worker or carer can play a large part in supporting these interventions.

Refer_Self-esteem and epilepsy information sheet



Epilepsy Management

The management of epilepsy in people in their later years is not always straight forward. A person centred approach is key to achieving positive outcomes in caring for an older person with epilepsy. Older people may have other medical conditions requiring medication, have cognitive impairment, physical or psychosocial issues which can impact on their epilepsy management. All medical conditions and issues should be considered when developing an Epilepsy Management Plan (EMP), ensuring that a whole of person approach is being applied, this may require consultation with other specialist medical professionals e.g. cardiologist, gerontologist.

Management plans

Seizure Management Plan (SMP)

A Seizure Management Plan (SMP) documents the person's seizure description, triggers, behavioural changes and impacts, what to do in the event of a seizure, and what post seizure support that they require. Importantly the SMP documents the person's needs as they relate to support during or after a seizure. The SMP also identifies whether emergency medication has been prescribed and when to call **111**.

A SMP is developed in conjunction with the doctor and/or epilepsy support worker, the person and their support people e.g. family, carers or aged care worker. The SMP is endorsed by the doctor and reviewed annually.

Emergency Medication Plan (EMP)

When emergency medication is prescribed by the doctor this information is recorded in an Emergency Medication Plan (EMP). The EMP is completed and reviewed annually by the doctor who provides the epilepsy medical management or prescribes the medication and should be attached to the person's SMP.

The EMP is the authority for a trained person to administer the emergency medication in the event of a seizure requiring an emergency medication response. The EMP also provides information on when to call **111**.



Only people who have received **person**specific training for the administration

of emergency medication should

administer emergency medication.

Plan templates are available online epilepsy.org.nz/understanding-epilepsy/epilepsy-and-seizure-management-tools/epilepsy-plans/

Please contact Epilepsy New Zealand for further information regarding training options.

Risk Management

Risk management is an integral part of good management and governance practice.

Developing management plans is part of a risk management cycle — ensuring that older people with epilepsy have been supported in identifying potential risks and putting in place the strategies they need to help them manage their epilepsy in a safe and appropriate manner.

It is important when supporting an older person living with epilepsy to consider the safety implications and any risks that may be associated with that person's epilepsy diagnosis and seizure activity.

Safety

There are a number of devices and assistive technologies available to maintain safety for a person with epilepsy.

Medical ID: Person specific 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 support should a seizure occur.

Medical alert: If the older person has seizures which affect balance or are convulsive in nature, the person may benefit from having a fall detector pendant. These pendants automatically raise an alert if loss of balance is detected or if the seizure involves loss of consciousness. Medical alerts can also be activated manually when the person recognises behavioural changes signalling the impending onset of a seizure and assistance is required.

Depending on the seizure type there may be additional safety issues which need to be considered. They could include always swimming with a companion, having on-call or in-house support overnight and support with commuting.

When looking at strategies to reduce risk and improve safety for a person living with epilepsy, consider:

Bathing strategies: a shower is safer than a bath, a shower chair increases safety, alternatively attaching a hand held shower head to the tap in the bath and taking a shower within the bath, unplugged, could be an option

Falls and tripping strategies: consider personal alerts to trigger alarms should the person fall, personal protective wear options, soft wool carpeting or cushioned linoleum is a safer option than hard flooring, items cleared from floors to reduce trip hazards and potentially dangerous objects should the person fall.

Refer Falls and epilepsy information sheet

Night seizure strategies: night time carer support, personal alerts to trigger alarms should a seizure occur, choice of bed linen and pillows e.g. firm pillows are recognised as better than soft to reduce the risk of suffocation should a seizure occur during the night/whilst the person is sleeping or resting.

Swimming strategies: swimming alone carries a high risk, a seizure event while swimming can be fatal. An observer or swimming companion trained in seizure first aid should always be present.

A home or aged care facility safety assessment can be performed by a registered occupational therapist. Occupational therapists can make recommendations to ensure the person's safety and reduce risk.

Refer Risk and epilepsy information sheet

Seizure First Aid

Seizures are not all the same, so it is important that aged care workers and carers know what to do to keep an older person safe during a seizure.

Seizure first aid involves assisting the person, providing an immediate emergency response and seeking medical attention as required.

A comprehensive seizure first aid posters and short video is available online https://epilepsy.org.nz/understanding-epilepsy/seizure-first-aid/tonic-clonic-seizures



Training

Aged care workers and carers play a key role in supporting the older person living with epilepsy. Providing appropriate person centred support enables the person to live a fulfilling life. Epilepsy education and training ensures that support is provided by an aged care worker or carer with the necessary skills and knowledge to meet the specific needs of the person.

It is recommended that aged care workers and carers supporting an older person living with epilepsy receive training in:

- understanding and managing epilepsy
- seizure first aid
- administration of emergency medication, where prescribed.

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

Where there is no trained person and emergency medication is prescribed, call **111** immediately, let the person taking the call know that emergency medication has been prescribed and follow instructions provided until paramedics arrive to provide the appropriate emergency response.

A SMP and/or EMP provide details on the emergency response required in the event of a seizure.

Please contact Epilepsy New Zealand for further information regarding training options.

Where to go for further information

Epilepsy New Zealand www.epilepsy.org.nz

Epilepsy Videos on YouTube www.youtube.com/user/EpilepsyVictoria

Glossary	
EEG (electroencephalogram) An electroencephalogram is a test which shows electrical activity in the brain using small, flat discs attached to the scalp.	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.
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 so see inside the brain without surgery.	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. slices of the brain allowing the doctor to see inside the brain without surgery.

Acknowledgements

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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 Laurence 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.

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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.*



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