Epilepsy in the later years
A practical guide for people in their later years, families, aged care workers and carers

UNDERSTAND ME
SUPPORT ME
This guide summarises the *Living with epilepsy in later years* suite of resources which provides the epilepsy smart approach for supporting a person diagnosed with epilepsy in their later years.

### Epilepsy awareness

To ensure that older people living with epilepsy receive the best care it is important that:

1. The older person who has received a diagnosis of epilepsy and their aged care workers, carers, family and friends understand what epilepsy is.
2. The older person who has received a diagnosis of epilepsy understands what this means for them.
3. Aged care workers and carers understand what a diagnosis in the later years can mean for the older person.
4. A process for documentation of seizure signs, triggers and impacts is in place.
5. Aged care workers, carers and families understand referral pathways for epilepsy assessment and diagnosis.
6. Aged care workers, carers and families understand where they can go for assistance and support.

### Epilepsy Management Plan (EMP)

An up to date Epilepsy Management Plan is vital in caring for an older person living with epilepsy and the following steps should be followed:

1. The Epilepsy Foundation, Epilepsy: *Know me, Support me* – EMP template is used.
2. The plan is current and updated yearly, developed with the older person and endorsed by the doctor.
3. All relevant parties have access to the plan.

### Emergency Medication Management Plan (EMMP)

Emergency Medication Management Plans should be developed taking into account the following points:

1. Some older people with epilepsy are prescribed emergency medication (most commonly midazolam) to stop a seizure or a cluster of seizures (multiple seizures within a short time).
2. The Epilepsy Foundation, Epilepsy: *Know me, Support me* EMMP template is used.
3. The EMMP is current, endorsed by the doctor prescribing the medication and updated annually.
4. The EMMP is attached to the EMP and is readily available to all trained people supporting the older person with epilepsy.
5. The administration of emergency medication is not a substitute for emergency treatment.
6. Only people who have received appropriate person specific training in accordance with the EMMP can administer the emergency medication.

### Risk management

The management of risks for older people with epilepsy must be taken into account by ensuring:

1. Aged care workers, carers and families are trained to support the older person living with epilepsy.
2. Close observation of seizure activity is maintained.
3. For older people with epilepsy, risk is balanced between what’s important to and for the individual.
4. Consultation between the older person, aged care worker and/or carer and where appropriate the family, regarding risk management for day-to-day activities and outings is held.
5. All risk assessments are based on the older person’s individual circumstance.
The following resources can be accessed at www.epilepsysmart.org.au

1. Epilepsy in the later years: A guide for people living with epilepsy in their later years
A practical booklet to assist an older person understand the impact of an epilepsy diagnosis in later years, and a valuable resource for family and friends to better understand the impact of epilepsy on the individual.

2. Epilepsy in the later years: An epilepsy smart aged care approach
A practical booklet to assist the aged care worker or carer understand the impact of epilepsy on the older person.

3. Epilepsy Management Plan (EMP) and Emergency Medication Management Plan (EMMP)
Electronic templates available online to record the person’s seizure types, support needs and emergency procedures.

4. 10 things you should know about epilepsy
An overview of the 10 things you should know when supporting an older person living with epilepsy.

5. Is it epilepsy? Older person reflection and witness statement checklists
Practical tools that provide lists of questions to ask following a possible seizure event.

6. Referral pathways: further investigation of possible epilepsy
A practical resource for identifying referral pathways for an older person presenting with undiagnosed seizures.

7. Living with epilepsy in the later years – Information sheets
A suite of information sheets for the older person living with epilepsy, aged care workers, family and friends; including information on Risk, Medication, Travelling, Self-esteem, Memory, Staying active, Falls and Dementia and epilepsy.

8. Living with epilepsy in the later years – video
Visit the Epilepsy Foundation You Tube channel and hear from Pat about being an older person living with epilepsy. www.epilepsyssmart.org.au

9. First Aid poster
A practical resource for display in the home or aged care setting.

10. Epilepsy Information line 1300 761 487
Why have this guide?
This guide provides an easy-to-read reference for the older person living with epilepsy, their families, aged care workers and carers to better understand what an epilepsy smart aged care approach for those living with epilepsy looks like.

Whether supporting the older person at home or in an aged care environment, this guide provides an overview of the resources available to the aged care worker or carer, family and friends so that they better understand what the potential impacts of epilepsy are on the older person and what resources are available to support the person.

What is an epilepsy smart aged care approach?
An epilepsy smart aged care approach ensures that:

- Through engagement in education and training staff supporting an older person living with epilepsy understand epilepsy and the impact of seizures and epilepsy on the individual.
- Seizure activity is fully documented and investigated, ensuring that assessment and diagnosis is accurate and seizures are managed appropriately.
- Epilepsy management plans for all older people living with epilepsy are in place and current, ensuring that the person’s needs are understood and supported as they relate to their epilepsy diagnosis, treatment and seizure activity.
- All risks relevant to the epilepsy diagnosis are managed in a manner that does not restrict or negatively impact the older person’s enjoyment of and engagement in life.

Glossary

**Aged care worker:** Provides personal, physical and emotional support to older people who require assistance with daily living either within the aged care setting or in the home. Aged care workers are paid to provide daily living assistance and support for outings and activities.

**Carer:** Provides unpaid support to an older person, usually a family member or close friend. The carer provides similar support to the older person as that provided by the aged care worker.

**Emergency medication:** Medication that has been prescribed for the treatment of prolonged seizures or a cluster of seizures (multiple seizures over a defined time). The most common type of emergency medication prescribed is Midazolam.

**Epilepsy:** Characterised by recurrent seizures due to abnormal electrical activity in the brain.

**EMP:** The Epilepsy Management Plan (EMP) documents seizure description and what to do in the event of a seizure, the impact of seizures and the post seizure support required. The EMP also identifies whether emergency medication has been prescribed, records specific support needs and when to call 000.

**EMMP:** Where emergency medication has been prescribed, the Emergency Medication Management Plan (EMMP) is the authority for a trained person to administer the emergency medication in the event of a seizure. The EMMP also provides information on when to call 000.

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