

Living with epilepsy and a cognitive disability

A practical guide for families, carers and support workers

KNOW ME
SUPPORT ME



This practical guide summarises the *Know Me, Support Me* suite of resources, which have been developed to support people living with epilepsy and a cognitive disability.

Epilepsy awareness

To ensure that people living with epilepsy and a cognitive disability receive the best care, it is important that:

- The person and their family, carers and support workers understand what epilepsy is. 1 2 5
- Family, carers and support workers understand what a diagnosis of epilepsy can mean for a person living with a cognitive disability. 1 5 8 9
- A process for documenting potential seizure activity and referral pathways for investigation is in place. 6 7
- The person and their families, carers and support workers understand where they can go for assistance and support. 11

Risk management

The management of risks for people living with epilepsy and a cognitive disability is taken into account by ensuring that:

- Families, carers and support workers feel empowered to support the person. 1
- Consultation is held between the person, carer and support workers (and where appropriate the family) regarding risk management for day-to-day activities and outings. 1 2 4 8
- Potential seizure activity is documented. 6
- Risk is understood and balanced with what interests and is important to the individual. 1 3 4 8

Epilepsy Management Plan (EMP)

An up-to-date Epilepsy Management Plan (EMP) is a vital resource for supporting a person living with epilepsy and a cognitive disability. In order to achieve this, the following steps are recommended:

- Work with the person to develop their EMP. 3 4
- Ensure the EMP is updated annually (or earlier if required).
- Ensure that all relevant parties have access to the person's EMP.

Emergency Medication Management Plan (EMMP)

Some people living with epilepsy are prescribed emergency medication by their treating doctor for specific seizure events. If a person is prescribed this:

- Their doctor should work in collaboration to complete an EMMP. 4
- Ensure the EMMP is updated annually (or earlier if required).
- Ensure the EMMP is attached to an EMP.
- Ensure that all relevant parties have access to the person's EMP and EMMP.
- Understand that only people who have received person-specific training should administer the emergency medication in accordance with the EMMP. Consider contacting the Epilepsy Foundation to receive person-centred training. 11

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The following resources can be accessed at www.epilepsyfoundation.org.au



1

Living with epilepsy and a cognitive disability: A guide for families, carers and support workers

A practical booklet to assist individuals, families, carers and support workers to understand the impact of a diagnosis of epilepsy.



2

Learning about epilepsy: An easy English guide

A guide with questions and images to assist in discussing epilepsy with a person who also lives with a cognitive disability.



3

Developing an Epilepsy Management Plan

A guide to assist individuals, families, carers and support workers prepare an Epilepsy Management Plan (EMP).



4

Epilepsy Management Plan (EMP) and Emergency Medication Management Plan (EMMP)

Electronic templates available online to record a person's seizure types, support needs and emergency procedures.



5

Ten things you should know about epilepsy in people who live with a cognitive disability

An overview of the 10 things you should know when supporting a person living with epilepsy and a cognitive disability.



6

Is it epilepsy? Individual and witness reflection statements and checklists

Practical tools that provide lists of questions to ask following a possible seizure event.



7

Referral pathways: further investigation of possible epilepsy

A practical resource for identifying referral pathways for a person with a cognitive disability presenting with potential undiagnosed seizures.



8

Living with epilepsy and a cognitive disability - Information sheets

A suite of information sheets including: Cognitive disability and epilepsy; Risk; Medication; Education and employment; Travel and transport.



9

Living with epilepsy and a cognitive disability videos

Visit the Epilepsy Foundation YouTube channel and hear from a number of people who live with epilepsy and cognitive disability.



10

First Aid Poster

A practical resource for display in the home, community or disability support setting.

11

Epilepsy Information line 1300 761 487

Why have this guide?

An *Epilepsy: Know Me Support Me* approach means that people living with epilepsy and a cognitive disability are best understood and supported. It enables people to exercise choice and control over their life.

This guide provides an easy-to-read reference for a person living with epilepsy and a cognitive disability, their families, carers and support workers to better understand what an 'epilepsy smart' approach looks like. Whether supporting the person at home or in a supported care environment, this guide takes a person-centred approach so that everyone involved in the person's life has an enhanced understanding of epilepsy, its impacts and ways of providing assistance.

What is an epilepsy smart approach?

An *Epilepsy: Know Me Support Me* approach helps to ensure that:

- ✓ through engagement in education and training families, carers and support workers supporting a person living with epilepsy and a cognitive disability understand epilepsy and the impact on the individual
- ✓ seizure activity is documented and investigated, ensuring that assessment and diagnosis is managed appropriately
- ✓ Epilepsy Management Plans for people living with epilepsy are in place and current, and the person's diagnosis, seizure activity, treatment, needs, and safety considerations are noted
- ✓ all risks relevant to the epilepsy diagnosis are managed in a manner that does not restrict or negatively impact the person's enjoyment and engagement in life.

Glossary

Carer. Provides unpaid care and support to a person living with epilepsy and a cognitive disability. This assistance is usually provided by a family member or close friend, and their caring may include the provision of personal, physical and emotional support.

Cognitive disability. The term cognitive disability encompasses various intellectual or cognitive deficits, including intellectual disability, developmental delay, developmental disability, learning disabilities, and conditions causing cognitive impairment such as acquired brain injuries or neurodegenerative diseases.

EMP. The Epilepsy Management Plan (EMP) documents a person's seizure types 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, emergency procedures and when to call for an ambulance.

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. A neurological condition characterised by recurrent seizures due to abnormal electrical activity in the brain.

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.

Support worker. Provides paid assistance to people living with epilepsy and a cognitive disability living in home, community or supported accommodation facility settings. This role may include the provision of personal, physical, social assistance and support.

This publication is part of a suite of resources that are targeted at family members, carers and support workers, to assist in caring for people living with epilepsy and a cognitive disability

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