

EPILEPSY:
KNOW ME,
SUPPORT ME



Epilepsy Management in the Disability Sector

A resource for better practice

epilepsy 
foundation

Why is better practice important?

It enables people with a disability to exercise choice and control in living their lives.

It provides people with a disability living with epilepsy a nationally consistent approach in access to and delivery of high quality epilepsy support by disability services.

What do better practices look like?

- The person understands their epilepsy
- The person and their circle of support have been actively involved in decision making
- Staff are educated and trained in epilepsy management
- Staff are confident in supporting the person
- There are clearly established communication pathways between all the relevant services and the person's key supporters

Service providers will:

- have policies and procedures that meet the needs of the person in accordance with this better practice resource
- provide a safe and healthy environment that enables the person to participate to their full potential
- identify opportunities to refer people to relevant services

How can the better practice resource be used?

Individuals and supporters can use the better practice resource to assist them in their decision when choosing a service provider.

Service providers can benchmark themselves against the better practice resource and identify ways to enhance the person's support and epilepsy management.

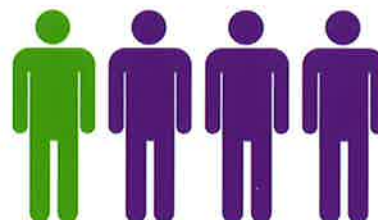
The impact of epilepsy on the person with the disability and their family is often far greater than the seizure itself¹



People with a disability and epilepsy tend to have more severe, difficult to control seizures and an increased risk of preventable deaths¹



1 in 4 people with a disability are likely to live with epilepsy²



Use this table to further develop your better practice in epilepsy management

Epilepsy Knowledge

- The person is supported to understand their epilepsy **1**
- The person with epilepsy and their circle of support is involved in all planning to meet their individual needs **2**
- Support workers have completed epilepsy education and training that includes:
 - consideration of common co-existing conditions, such as mental health, bone health, memory and sleep
 - seizure impact and the person's capacity to be involved in self-management

When an emergency medication is prescribed, person specific training is undertaken. Only those staff who are trained are permitted to administer the medication to that client **3**

- Support workers have current First Aid and CPR training
- Clear communication pathways are documented with all key supporters

Epilepsy Health Management

Documentation is in place for:

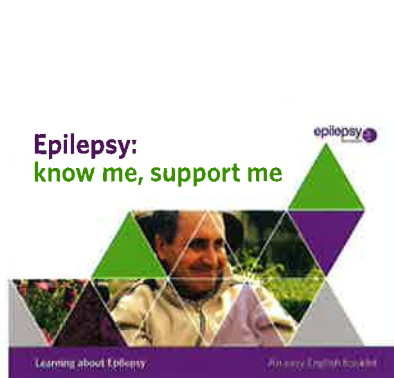
- seizure records and observation charts
- medication records
- PRN administration records
- safe drug storage and handling
- any observations relating to changes in sleeping patterns, steadiness of movement, general alertness, communication and mood or behaviour

Medical management:

- the person is involved in their annual epilepsy medical review with the General Practitioner/ Specialist
- support workers will prepare the person and themselves for a medical review appointment **4 5**
- where identified allied health support and assessments will be facilitated

A person with epilepsy should obtain medical advice before their usual antiepileptic medication is changed to another brand or a generic medication.³

Additional resources available to support better practice via www.epinet.org.au or 1300 852 853



1

Learning about Epilepsy – An easy English booklet

This easy English booklet helps the person understand their epilepsy with the use of pictures. Available in various accessible formats



2

Developing an Epilepsy Management Plan for support workers and families

A resource to involve the person in the development of their epilepsy plan



**Epilepsy Helpline
1300 852 853**

3

Education and Training for Epilepsy and Emergency Medication administration



4

My epilepsy medical review document:

A booklet to assist the support worker of a medical appoi

Risk Management

Everyone, not just those with epilepsy faces risks in the home and in the community.

For people with disability living with epilepsy, risk should be balanced between what's important **TO** and **FOR** the person.

Consultation with the person and their circle of support will occur regarding risk management for everyday, recreational and/or sporting activities.

Policy and procedures are documented for:

- bathing and showering
- swimming
- emergency medication administration
- calling an ambulance
- night time support

If helmet usage or other aids are prescribed they are reviewed by a Medical Practitioner.

Epilepsy Management Plan (EMP)

- The Epilepsy Foundation, *Epilepsy: know me, support me* – EMP is used **6**
- Wherever possible, the person with epilepsy is involved with their circle of support in contributing to the development of their EMP **2**
- The plan is current and updated yearly, having been endorsed by the doctor
- Services recognise and accept the principle 'one person, one plan' and use the Epilepsy Foundation EMP and EMMP to minimise duplication and ensure consistent support

Emergency Medication Management Plan (EMMP)

- The Epilepsy Foundation EMMP (Midazolam or Rectal Valium) is used **7**
- The EMMP is completed and endorsed by the doctor prescribing the medication and updated annually
- The EMMP is attached to the EMP

Epilepsy Wellbeing Map™

Are you living with Epilepsy?
Use this map to discuss what's important to you when seeing your neurologist.
Fill in the map and bring it to your consultation with your neurologist.

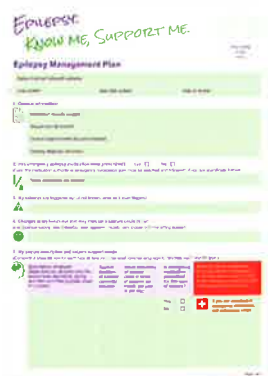


Also available at www.EpilepsyWellbeing.com.au

5

Epilepsy Wellbeing Map™

A communication tool to encourage and assist the doctor-patient conversation by helping the patient express their wellbeing



6

Epilepsy Management Plan™ templates and guidelines

An electronic document to help identify the person's seizure types, support needs and emergency procedures



7

Emergency Medication Management Plans – Midazolam or Rectal Valium

An electronic or hard copy document that identifies a specific emergency medication including dose, route and seizure type for administration

the person and
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EVERYONE'S EPILEPSY
IS DIFFERENT
TO KNOW ME YOU NEED
TO INVOLVE ME



Glossary

Allied health: Areas of health management for example, physiotherapy, speech pathology, dietetics, and occupational therapy.

Emergency medication: Medication that has been prescribed for the treatment of prolonged seizures or a cluster of seizures. The most common type of emergency medication prescribed is buccal (inside the cheek) or nasal Midazolam. Rectal Valium is less commonly prescribed now.

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

Generic medication: is a drug which is produced and distributed without patent protection.³

Medication record: Contains details for each individual to whom medication is to be administered.

Midazolam: Is used for emergency management of seizures as it has the ability to stop the seizures quickly. Not all people with epilepsy require emergency medication. It is most commonly administered buccally (inside the cheek) or nasally.⁴

PRN medication record: A document that records medication that is given only as needed.

Rectal Valium: Rectal Valium (diazepam) is used for emergency management of seizures because it has the ability to stop the seizures.

Seizure record: An accurate documentation of seizure activity which is important for identifying any seizure patterns and changes.

Service Provider: A business or organisation that provides a service.

Specialist: A Medical Practitioner who specialises in the area of neurology, epilepsy and/or paediatrics.

References:

1. Sillanpaa M. et al. (1998). Long-term prognosis of seizures with onset in childhood, *New England Journal of Medicine*, 338:1715-1722.
2. Brown, S.W. (2008). Epidemiology of Epilepsy in People with Intellectual Disabilities, In V.P. Prasher & M.P. Kerr (eds), *Epilepsy and Intellectual Disabilities*, pp. 29-42, London: Springer.
3. *Epilepsy Society of Australia-Position Statement: Generic drug use in epilepsy* (3/10/2008) <http://www.epilepsy-society.org.au/pages/guidelines2.php>
4. *Epilepsy Society of Australia - Guidelines: The use of midazolam for the emergency treatment of seizures out of hospital* http://www.epilepsy-society.org.au/pages/guidelines_other.php

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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 a qualified health professional.

The images in this publication show models who do not necessarily have an epilepsy diagnosis and are for illustrative purposes only.