

Disability Resource Hub Disclaimer

The material on the Disability Resource Hub is for reference only. No claim or representation is made or warranty given, express or implied, in relation to any of the material. You use the material entirely at your own risk.

The material is provided as point-in-time reference documents. FACS does not maintain the material and does not undertake to ensure that it is accurate, current, suitable or complete.

Where conditions and warranties implied by law cannot be excluded, FACS limits its liability where it is entitled to do so. Otherwise, FACS is not liable for any loss or damage (including consequential loss or damage) to any person, however caused (including for negligence), which may arise directly or indirectly from the material or the use of such material.



Epilepsy Procedures

Summary: The Epilepsy Procedures are a guide for the support of the person with epilepsy. They detail good practice in epilepsy management, particularly around medical needs, seizure awareness and response, minimisation of risk to the person, and monitoring and reporting.





Epilepsy Procedures

Document name	Epilepsy Procedures
Policy	Health and Wellbeing Policy
Version number	1.2
Approval date	January 2016
Policy manual	Health and Wellbeing Policy and Practice Manual Volume 2
Approved by	Deputy Secretary, ADHC
Summary	The Epilepsy Procedures are a guide for the support of the person with epilepsy. They detail good practice in epilepsy management, particularly around medical needs, seizure awareness and response, minimisation of risk to the person, suitably skilled support workers, monitoring and reporting.
Replaces document	Epilepsy Policy and Procedures, 2006 v1
Authoring unit	Contemporary Residential Options Directorate
Applies to	People who are being supported in ADHC operated and funded non-government accommodation support services.
Review date	2017

Version control

The first and final version of a document is version 1.0.

The subsequent final version of the first revision of a document becomes version 1.1.

Each subsequent revision of the final document increases by 0.1, for example version 1.2, version 1.3 etc.

Revision history

Version	Amendment date	Amendment notes
V1.0	December 2006	Epilepsy Policy and Procedures
V1.1	September 2010	Amended to incorporate new position titles under the Community Living Award
V1.2	January 2016	Formatted for Health and Wellbeing Policy and Practice Manual, Volume 2

Table of contents

1	Purpose.....	4
2	Minimum practice requirements for the support of people with epilepsy	4
3	Mandatory procedures for ADHC operated accommodation support services.....	6
	3.1 Planning and assessment.....	6
	3.2 Developing an epilepsy management plan.....	7
	3.3 Minimising environmental risks to the person.....	8
	3.4 Water safety and the person.....	10
	3.5 Inducting and training support workers.....	11
	3.6 Monitoring and auditing.....	12
	3.7 Communication and reporting.....	12
4	Explanation of terms.....	13
5	Policy and Practice Unit contact details.....	16

1 Purpose

The ADHC Epilepsy Procedures (the Procedures) embody the principles of legal and human rights found in the New South Wales Disability Service Standards (the Standards), the commitment to deliver culturally responsive services to Aboriginal and Torres Strait Islander people under the Aboriginal Policy Statement (the Statement), and the person centred guiding principles of the ADHC Health and Wellbeing Policy.

The Procedures are a guide for supporting people with disability and a diagnosis of epilepsy, to exercise their rights and entitlements under the Standards and the Statement. The Procedures describe how ADHC supports people to manage and direct their own health needs, under the guidance of their 'usual' General Practitioner (GP)¹ and other health specialists.

Support workers from ADHC operated and funded non-government accommodation support services (see Section 4 Explanation of terms) are required to implement Section 2 of the procedures.

2 Minimum practice requirements for the support of people with epilepsy

Minimum practice requirements for ADHC operated and funded non-government accommodation support services are as follows:

1. At least one person on shift must hold a current first aid certificate.
2. Every person with epilepsy², and epilepsy with ongoing seizures, has a current **Epilepsy Management Plan** (EMP) that is endorsed by the treating doctor. Funded non-government support services may develop their own EMP or adapt and use the ADHC EMP tool (see Tools and templates).
3. A person with epilepsy and ongoing seizures is supervised at all times when bathing, showering or swimming in all accommodation support options where health and wellbeing support is included in the model.
4. Environmental and other risks are identified and managed by conducting six-monthly audits to review the currency and quality of EMPs, the physical environment, and risk mitigation strategies particularly in relation to water-based activities. Funded non-government support services may develop their own audit tool or adapt and use the **Audit of practice and risk**

¹ [Medicare](#) defines the person's 'usual' GP as: 'The GP (or a GP in the same practice) who has provided the majority of services to the patient in the past 12 months, and/or is likely to provide the majority of services in the following 12 months'

² A **person with epilepsy** is defined as a person who has either had a seizure within the past ten years or is on medication for epilepsy. A person who has had a seizure during the previous two years, despite taking medication, is classified as having epilepsy with **ongoing seizures**.

management systems for a person with epilepsy requiring supervision when bathing, showering or swimming (see Tools and templates).

5. All people who support the person with epilepsy and ongoing seizures must know the triggers of seizures for the person they support, and how to prevent them occurring.
6. Support workers are responsible for reading, and ensuring they understand, the first aid information for seizures in the person's EMP.
7. Specific training is required for all support workers (including casuals and agency workers) to respond to seizures that require the administration of buccal Midazolam.
8. Support for Aboriginal and Torres Strait Islander people with epilepsy is provided in a culturally appropriate way that supports and empowers them. In providing this support the following impacts are to be considered:
 - communicate with the person and family in a way that is understood; if the person has a communication profile use it to learn the best way of communicating
 - acknowledge the history of trauma and loss that Aboriginal and Torres Strait Islander people have experienced since settlement
 - understand their experiences and difficult relationships with government services, especially hospitals
 - enquire about the proper contact person for discussing issues about the person's epilepsy, including treatment and support
 - ask who the Aboriginal and Torres Strait Islander person would prefer to have as an advocate or support person
 - determine how the issue of epilepsy is viewed in the person's community
 - confirm whether the person or family would prefer to work through an Aboriginal Liaison Officer
 - ensure that the person and family understand the support options related to epilepsy (such as neurology services, support groups and specialist epilepsy services) and how they can access them.

See 'Other resources' for links to Aboriginal and Torres Strait Islander specific support services.

3 Mandatory procedures for ADHC operated accommodation support services

The following Procedures are mandatory in ADHC operated accommodation support services.

ADHC funded non-government disability support services may develop their own procedures and tools, or adapt and use these Procedures and the accompanying 'Tools and templates'.

3.1 Planning and assessment

1. Planning for the management of epilepsy is based on the person's individual needs and personal history. It is discussed and reviewed at the annual health assessment and, where relevant, during lifestyle planning with the person.
2. The treating doctor is either the person's GP or a medical specialist such as a neurologist.
3. Support workers, the person and person responsible work with the person's treating doctor to jointly manage the person's epilepsy.
4. A support worker, who is familiar with the person's health record and epilepsy, accompanies the person to consultations with the treating doctor. Attendance by the person responsible is recommended.
5. The support worker supports the person to provide results of medical tests, other written health information, a copy of the person's current EMP (including the seizure record), the person's medication or Webster-pak[®] and medication information.
6. The treating doctor should determine the need for, and frequency of blood tests at the time of the initial consultation or at the introduction of the treatment regimen.
7. At specialist medical reviews, the support worker requests copies of all reports that go to the person's GP be also provided to the person or the manager of the unit where the person lives. The information will be filed permanently in the person's **My Health and Wellbeing Plan**³ and be available to other health professionals as needed.

³ Other ADHC operated accommodation support services such as Large Residential Services and Supported Specialist Living can use adapt the My Health and Wellbeing Plan to meet the complex needs of the people they support and any nursing registration requirements.

3.2 Developing an epilepsy management plan

1. A person diagnosed with epilepsy, and who accesses an ADHC operated accommodation support service, must have a current and complete EMP in place.
2. The EMP is developed during the annual health planning process. People accessing respite services have an EMP developed with their **Respite Care Profile** (see the Centre-based Respite Policy and Centre-based Respite Procedures).
3. The EMP is a risk management document that tells support workers how to respond to a usual seizure and includes an emergency response plan for an unusual seizure.
4. Joint management of the person's epilepsy includes regular medical reviews and accurate documentation of seizures in the seizure record of the EMP.
5. People accessing an ADHC operated accommodation support service have an EMP developed in consultation with the person, person responsible, the support worker and the person's treating doctor.
6. In other accommodation support options, where health and wellbeing support is included in the model, the person or person responsible agrees to and signs the EMP before it is implemented.
7. In ADHC operated accommodation support services, the line manager or case manager is responsible for ensuring that the EMP is reviewed and dated by the person's treating doctor annually, or more frequently if the person's medical condition changes.
8. In other accommodation support options, where health and wellbeing support is included in the model, and the person asks the support worker to attend medical consultations, the support worker encourages the treating doctor to sign the EMP.
9. The EMP contains information specifically about the person. The sections within the EMP include:
 - information about the person's identity
 - when the plan was approved by the treating doctor and consent provided by the person and person responsible
 - when the plan was developed and by whom
 - when the plan was reviewed
 - a description of the types of seizure(s) experienced by the person
 - how to respond to a usual seizure, a seizure in a wheelchair or in water
 - how to respond to an unusual seizure (Emergency protocol – refer to section 3.2.1 below)

- signatures of support workers who have read and understood the plan
- evidence of copies provided to other providers
- risk and safety factors for the person
- advising others when a seizure occurs
- what time the seizure occurred and observations of the seizure, completed by the support worker who is with the person during the seizure.

3.2.1 Emergency epilepsy medication and administration

1. If the person is prescribed emergency medication this is documented by the treating doctor under the Emergency protocol⁴ in Section 4 of the EMP.
2. The Emergency protocol is authorised by the treating doctor.
3. The Emergency protocol includes information on:
 - how to recognise and respond to an unusual seizure
 - administering emergency medication
 - supporting the person during the seizure
 - observations of the seizure including the time it starts and ends
 - what emergency medication has been prescribed by the treating doctor
 - when and how often to administer the emergency medication
 - when to call an ambulance.

3.3 Minimising environmental risks to the person

1. Any environmental risks to the person must be identified and recorded in the person's My Safety Management Plan.
2. Where activities involve water, each ADHC operated accommodation support service must have the following measures in place (monitored by the line manager) to address safety issues.
 - An automatic system for removing the plug is installed in all bathrooms, or the plug has a chain attached that is secured above the water level. This is to ensure time is not lost searching for the plug in an emergency when the bath has to be drained.
 - If there is risk of the person re-lodging the plug, a risk assessment is completed and documented in the person's **My Safety Management Plan**.

⁴ Refer to the Health Care Procedures Register regarding the requirements for the administration of buccal Midazolam.

- A bathroom poster **Bath Safety Rules for Staff** is posted on every bathroom wall in the unit, to remind support workers to stay in the bathroom with the person with epilepsy and ongoing seizures who chooses to have a bath or shower (see Other resources).
3. Additional safety measures to minimise environmental risks to the person with epilepsy may include:
 - Ensure that temperature controls for the hot water supply are set at a temperature below 43°C.
 - Use sliding doors in toilets where practical or a door that can be unlocked from the outside.
 - Install an emergency call button in the bathroom.
 - Remove sharp edges on shower recesses, including removing shower hobs (the slightly elevated part of the shower base) and soap dishes.
 - Ensure fittings are as flush with the wall as possible. Use a flat floor rather than a sloping shower tray, and recessed (i.e. block-proof) shower and bath drains. Ideally the shower recess should contain a shower chair and have curtains around it.
 - Ensure shower screens, doors and panels with glass, are made from safety glass or plastic, or plain glass with a safety film applied over it.
 - Use approved textured hospital grade vinyl flooring in wet areas to minimise harm to the person during a seizure.
 - Use a microwave oven for cooking. If a stove or cook top is in place, use a cooker guard that requires handles of pots and pans to be turned inwards to prevent them being knocked over in the event of a fall.
 - Ensure that furniture has rounded edges, or that sharp or pointed edges are padded with foam rubber.
 - Use wall-mounted heaters or central heating and cooling rather than lightweight or free-standing heaters. If lightweight or free-standing heaters are used, ensure they have safety guards fitted and are tagged as safe for use.
 - Use non-breakable crockery and cordless electrical appliances with automatic switch-off.
 4. A person who has epilepsy and experiences seizures causing falls may be at risk of suffering a head injury. To minimise the risk of injury, a helmet may be recommended by the neurologist or treating doctor.
 5. The decision on the need for use of a helmet is made in consultation with the person, the person responsible or guardian, and the neurologist or treating doctor, after considering all the risks to the person.
 6. The use of a helmet to prevent injury to a person with epilepsy who is likely suffer a head injury during a seizure, does not require consent by a person

responsible, as long as the use of the helmet is reasonable, in the best interests of the person and the person does not object.

7. Where the person objects to wearing a helmet, support workers should help the person to understand the consequences of not wearing a helmet (see Other Resources).
8. The person cannot be forced to wear a helmet.
9. If the person continues to refuse the helmet, support workers must ensure the environment is made as safe as possible to avoid harm to the person during a seizure.
10. The line manager ensures that the need for a helmet and conditions for use are regularly reviewed by a treating doctor, in consultation with the person and the person responsible or guardian.
11. Procedures describing when the person needs the helmet and how support workers are to support the person are to be implemented by all support workers.
12. Where a helmet has been prescribed by a treating doctor, and procedures for wearing a helmet are in place, a Restricted Practices Authorisation is not required.

3.4 Water safety and the person

1. Activities involving water are a high risk for people with epilepsy and ongoing seizures. Constant vigilance must be a primary focus for the support worker and manager when the person with epilepsy and ongoing seizures is involved in water based activities.
2. 'Duty of care' will override 'dignity of risk' in all circumstances involving a person with epilepsy and ongoing seizures who chooses to take a bath or shower, or go swimming.
3. Support workers in all ADHC operated accommodation support services will encourage the person with epilepsy and ongoing seizures to take a shower rather than a bath, as there is less risk involved in showering.
4. Whether a person with epilepsy and ongoing seizures chooses to have a bath or shower, the support worker must be in a position to observe the person at all times.
5. The support worker must not leave the bathroom to answer the telephone or fetch equipment while the person is showering or bathing. Using a cordless telephone will avoid the need to leave the bathroom to answer calls.
6. Except in an emergency, if the support worker observing the person has to leave the bathroom, he or she must remove the plug, soap and wash cloths from the bath and wait until all the water has drained from the bath **before** leaving the bathroom. In this circumstance, the person's dignity and comfort

is maintained by draping a towel over the person. The support worker returns to the bathroom as soon as possible.

7. If there is an emergency, and the support worker observing the person has to leave the bathroom, he or she removes the plug and ensures that soap and wash cloths are removed from the bath. Depending on the nature of the emergency, the support worker may not need to wait until all the water has drained from the bath before leaving the bathroom. The support worker returns to the bathroom as soon as possible.
8. Managers are responsible for ensuring that support workers understand and are able to implement the procedure for responding to seizures that occur while a person is in the bath or shower, as documented under Responding to a seizure that occurs in water in Section 3 of the EMP.
9. In ADHC operated accommodation support services, if a person with epilepsy and ongoing seizures chooses to go swimming, the person must be accompanied by two support workers. One support worker must be in the water, facing the person and remain within arm's length of the person. The other support worker must be out of the water and observing the person at all times.
10. The support workers must be capable of rescuing a person who has a seizure while swimming. Use of a buoyant safety swimming vest that holds the person's head out of the water and a brightly coloured top or swimming cap should be considered. Pool attendants or lifeguards should be notified of potential risk of seizures and be aware when the person is in the pool with the support worker.
11. An assessment of risk to the person while swimming should consider the person's history of seizure activity, the possibility of having other support at the pool, for example, the pool attendant agrees to watch the person from the poolside, or any circumstances that would reduce risk and support the person to exercise choice.

3.5 Inducting and training support workers

1. All support workers in ADHC operated accommodation support services must hold a current first aid certificate.
2. Managers are responsible for ensuring that all support workers (including regular casual and agency workers) have read and understood the person's EMP, particularly the first aid information about seizures in Sections 3 and 4 of the EMP, and signed the EMP.
3. All support workers supporting a person who has epilepsy must be able to recognise the triggers for seizures for that person, minimise the risk of triggers occurring, and respond to convulsive seizures.
4. All support workers supporting a person with epilepsy are formally inducted by their line manager to these Procedures.

5. When the person accesses other regular services outside of the person's accommodation, such as day programs and work placements, the line manager is responsible for ensuring that the person's EMP is provided to that service with the consent of the person, family or guardian.

3.6 Monitoring and auditing

1. The EMP must be reviewed at least annually by support workers, or more frequently if there are any changes in the person's health and wellbeing.
2. Reviews and discussions of the person's EMP are recorded in the team meeting minutes.
3. All support workers are responsible for observing changes in the person's health and wellbeing, and for notifying the treating doctor when they occur.
4. The line manager is responsible for monitoring support worker practices on all shifts for full compliance with risk and safety procedures.
5. Monitoring includes at least six monthly random checks of support worker practices at shower and bath time using the **Audit of practice and risk management systems for persons with epilepsy requiring supervision when bathing, showering or swimming** (see Tools and templates).

3.7 Communication and reporting

1. In accordance with the person's wishes, the line manager should ensure that support workers know who to contact should the person responsible or guardian wish to be advised when the person with epilepsy has a seizure.
2. Support workers in ADHC operated group home accommodation, respite, large residential centres and specialist support living centres (LRC SSL) will:
 - Immediately advise the line manager of all seizures requiring transportation to hospital. Outside of business hours contact the on-call manager.
 - Support workers should advise the line manager of all seizures resulting in an injury and requiring transport by the NSW Ambulance Service.
 - Advise the family or guardian of all seizures in accordance with the person's or their wishes.
 - Advise the family or guardian of all seizures resulting in hospitalisation of the person.
 - Advise other support workers in the unit of the incident through the **Unit Diary, Communication Book** and **Individual Shift Report Urgent Matter Alert**.
 - Notify the person's treating doctor and/or GP of any unusual seizures.

4 Explanation of terms

Term	Definition
Accommodation support services	Those services provided in community based dwellings in which a person with disability lives independently, with the family or carer, or with other people with disability and includes group homes and family or private homes. People utilising these services may receive minimal daily support from service providers, through to 24-hour support. Large Residential Centres and Specialist Supported Living (LRC SSL) are included as accommodation support options until their closure in 2018.
Consent	Consent is the permission given by a person, person responsible or guardian, for the person to receive specific interventions, or certain treatments.
Dignity of Risk	The belief that each person with disability is entitled to experience and learn from life situations even if these, on occasion, pose a risk to the person's wellbeing.
Duty of Care	The obligation to take reasonable care to avoid injury to a person whom it can reasonably be foreseen might be injured by an act or omission.
Epilepsy	Epilepsy is a sudden discharge of abnormal electrochemical activity that results in seizures of various types and with characteristic effects. With regular medication and other strategies, many people with epilepsy achieve control of their seizures. However, others may continue to experience seizures despite taking regular medication.
Guardian	A guardian is a person who can legally make lifestyle decisions on behalf of another person and provide substitute consent to medical and dental treatment when appointed to do so. Guardians can be appointed by the NSW Civil and Administrative Tribunal (NCAT) Guardianship Division under limited guardianship orders that specify the length of the order and the guardian's decision making authority.
Line manager	In ADHC this term refers to the person who receives a report or request who is in the next line of management from the person making the request.
Ongoing seizures	For the purpose of this policy, epileptic seizures are defined as ongoing if the person has had a seizure during

Term	Definition
	the past two years, despite taking medication for seizures (see definition of 'seizure' below).
Person responsible ⁵	<p>A person responsible is not necessarily the patient's next of kin.</p> <p>There is a hierarchy of people who can be the person responsible.</p> <p>They are:</p> <ol style="list-style-type: none"> 1. A guardian (including an enduring guardian) who has the function of consenting to medical and dental treatments. <p>If no-one as specified in item 1:</p> <ol style="list-style-type: none"> 2. A spouse or de facto spouse or partner where there is a close, continuing relationship. <p>If no-one as specified in item 1 and 2:</p> <ol style="list-style-type: none"> 3. A carer who provides or arranges for domestic support on a regular basis and is unpaid. (If the person is in residential care, then the carer before the person went into residential care.) <p>If no-one as specified in item 1, 2 and 3:</p> <ol style="list-style-type: none"> 4. A close personal friend or close relative where there is both a close personal relationship, frequent personal contact and a personal interest in the patient's welfare, on an unpaid basis. <p>The person next in the hierarchy may become the <i>person responsible</i> if:</p> <ul style="list-style-type: none"> • a person responsible declines in writing to exercise the function, or • a medical practitioner or other qualified person certifies in writing that the person responsible is not capable of carrying out their functions.
Person with epilepsy	<p>A person with epilepsy is defined as a person who has either had a seizure within the past ten years or is on medication for epilepsy. A person who has had a seizure during the previous two years, despite taking medication, is classified as having epilepsy with ongoing seizures.</p> <p>Many people with epilepsy experience only one type of seizure, but a significant number of people with disability</p>

⁵ NCAT Person responsible factsheet: http://www.ncat.nsw.gov.au/Documents/gd_factsheet_person_responsible.pdf

Term	Definition
	<p>experience a variety of seizure types. Those experiencing the more severe (generalised) types of seizures, especially tonic-clonic (convulsive) seizures where consciousness is lost, require assistance during and after a seizure. Sometimes this includes the administration of emergency medicine to ensure the person's safety, wellbeing and dignity.</p>
Seizures (or convulsions) ⁶	<p>A seizure is a disruption in the normal pattern of electrical impulses in the brain, caused by the brain cells firing simultaneously at a much faster rate.</p> <p>Depending on where a seizure starts and spreads in the brain, they can result in changes in:</p> <ul style="list-style-type: none"> • sensation • awareness or consciousness • behaviour or movement. <p>Under certain circumstances anyone can have a seizure. It is only when there is a tendency to have recurrent seizures (more than one) that epilepsy is diagnosed.</p>
Senior manager	<p>In ADHC this term refers to a manager who is senior to the line manager who is referring a matter up for review or other consideration.</p>
Triggers	<p>Seizures can be provoked by events such as illness, infection, fever, brain tumour or injury, stroke, visual disturbances (patterns of light), alcohol, some drugs, fatigue, hormonal cycles (in some women), missed medication or chemical imbalance. These are triggers.</p>
Unit	<p>A group home, Large Residential Centre, Specialist Supported Living or respite service.</p>

⁶ [Epilepsy Action Australia](#)

5 Policy and Practice Unit contact details

You can get advice and support about this Policy from the Policy and Practice Unit, Contemporary Residential Options Directorate.

Policy and Practice, Service Improvement
Contemporary Residential Options Directorate
ADHC
policyandpracticefeedback@facs.nsw.gov.au

If you are reviewing a printed version of this document, please refer to the Intranet to confirm that you are reviewing the most recent version. Following any subsequent reviews and approval this document will be uploaded to the internet and/or intranet and all previous versions removed.