Epilepsy and Seizures

Quality Area 2 | Version 1

NERPSA acknowledges the contribution of The Epilepsy Foundation in review of this policy.

Purpose

This policy will outline the procedures to:

- ensure that educators, staff, volunteers and families are aware of their obligations and required strategies in supporting children with epilepsy and non-epileptic seizures to safely and fully participate in the program and activities of NERPSA
- ensure that all necessary information for the effective management of children with epilepsy
 and non-epileptic seizures enrolled at NERPSA is collected and recorded so that these
 children receive appropriate attention when required.

This policy should be read in conjunction with the Dealing with Medical Conditions Policy

Policy Statement

Values

NERPSA is committed to:

- providing a safe and healthy environment for all children enrolled at the service
- providing an environment in which all children with epilepsy and non-epileptic seizures can participate to their full potential
- involving families in developing the policy and management plan for children with epilepsy or non-epileptic seizures
- providing a clear set of guidelines and procedures to be followed with regard to supporting children with epilepsy and the management of seizures
- educating and raising awareness about epilepsy and non-epileptic seizures, its effects and strategies for appropriate management, among educators, staff, families and others involved in the education and care of children enrolled at the service

Scope

This policy applies to the approved provider, persons with management or control, nominated supervisor, persons in day-to-day charge, early childhood teachers, educators, staff, students, volunteers, families, children, and others attending the programs and activities of NERPSA, including during offsite excursions and activities.

Responsibilities

| | | Approved provider and persons with management or control | Nominated supervisor and persons in day-to-day charge | Early childhood teacher, educators and all other staff | Families | Contractors, volunteers and students |
|---|---|--|---|--|----------|--------------------------------------|
| | R indicates legislation requirement, and should | not be | e delet | ed | | |
| 1 | Providing all staff with a copy of the service's <i>Epilepsy</i> and <i>Seizures Policy</i> and ensuring that they are aware of all enrolled children living with epilepsy or non-epileptic seizures | R | 1 | ✓ | | √ |
| 2 | Providing families of children with epilepsy or non- epileptic seizures with a copy of the service's <i>Epilepsy</i> and Seizures Policy (Regulation 91) and Administration of Medication Policy, upon enrolment/diagnosis of their child | R | √ | | √ | |
| 3 | Facilitating communication between management, educators, staff and families regarding the service's Epilepsy and Seizures Policy | √ | 1 | √ | √ | 1 |
| 4 | Ensuring that all educators' first aid qualifications, including CPR training, are current, meet the requirements of the <i>National Law: Section 169(4)</i> and <i>National Regulations 137</i> , and are approved by ACECQA | R | 1 | √ | | 1 |
| 5 | Informing staff, either on enrolment or on initial diagnosis, that their child has epilepsy or non-epileptic seizures | | | | √ | |
| 6 | Providing a copy of their child's Epilepsy Management Plan (including an Emergency Medication Management Plan where relevant) to the service at the time of enrolment. This plan should be reviewed and updated at least annually | | | | √ | |
| 7 | Ensuring that all children with epilepsy have an Epilepsy Management Plan, seizure record and, where relevant, an Emergency Medical Management Plan, filed with their enrolment record. Records must be no more than 12 months old | 1 | √ | | ✓ | |

| 8 | Providing staff with a new updated Epilepsy Management Plan and medication record when changes to the order have been made (signed by the child's doctor/neurologist) | | | | ✓ | |
|----|--|---|---|----------|----------|---|
| 9 | Communicating regularly with educators/staff in relation to the ongoing general health and wellbeing of their child, and the management of their child's epilepsy or non-epileptic seizures | | | | ✓ | |
| 10 | Developing a risk minimisation plan for every child with epilepsy or non-epileptic seizures, in consultation with families/ their state epilepsy organisation/medical practitioner | R | 1 | √ | ✓ | 1 |
| 11 | Identifying and, where possible, minimising possible seizure triggers <i>(refer to Definitions)</i> as outlined in the child's Epilepsy Management Plan | R | 1 | √ | 1 | √ |
| 12 | Taking all personal Epilepsy Management Plans, seizure records, medication records, Emergency Medication Plans and any prescribed medication on excursions and to other offsite events | R | √ | √ | | √ |
| 13 | Ensuring that all staff have current CPR training and are aware of seizure first aid procedures (refer to Attachment 1) when a child with epilepsy or non-epileptic seizures is enrolled at the service | R | ✓ | √ | | √ |
| 14 | Ensuring that all staff attend training conducted by their state/territory -based epilepsy organisation on the management of epilepsy and, where appropriate, emergency management of seizures using emergency (epileptic) seizure medication, when a child with epilepsy is enrolled at the service. Training must be completed prior to the child starting at the service. | R | ✓ | √ | | √ |
| 15 | Ensuring that only staff who have received child- specific training in the administration of emergency medications are permitted to administer that medication | ✓ | ✓ | | | |
| 16 | Ensuring that medication is administered in accordance with the <i>Administration of Medication Policy</i> and information provided in the EMMP (method of administration, dose, time frame, frequency, maximum doses in a 24-hour period) | R | 1 | √ | | √ |
| 17 | Ensuring a medication record is kept for each child to who medication is to be administered by the service (Regulation 92) | R | √ | √ | | √ |
| 18 | Ensuring that emergency medication is stored correctly, as outlined in the training provided by the state/ | R | √ | √ | √ | 1 |

| | territory- based epilepsy organisation, and that it remains within its expiration date | | | | | |
|----|--|----------|----------|----------|----------|---|
| 19 | Where emergency medication has been prescribed, providing an adequate supply of emergency medication for their child at all times | | | | √ | |
| 20 | Being aware of, and sensitive to, possible side effects and behavioural changes following a seizure or changes to the child's medication regime or following administration of emergency medication following an emergency event. | R | √ | √ | 1 | √ |
| 21 | Compiling a list of children with epilepsy and non- epileptic seizures and placing it in a secure, but readily accessible, location known to all staff. This should include the Epilepsy Management Plan, seizure record and Emergency Medical Management Plan for each child with epilepsy | R | 1 | | | |
| 22 | Ensuring that induction procedures for casual and relief staff include information about children attending the service who have been diagnosed with epilepsy and non-epileptic seizures, and the location of their medication and management plans | R | 1 | | | |
| 23 | Ensuring programmed activities and experiences take into consideration the individual needs of all children, including any children with epilepsy and non-epileptic seizures | R | 1 | ✓ | | 1 |
| 24 | Ensuring that children with epilepsy and non-epileptic seizures are not discriminated against in any way | R | √ | √ | | 1 |
| 25 | Ensuring that children living with epilepsy and non- epileptic seizures can participate in all activities safely and to their full potential | R | 1 | √ | | √ |
| 26 | Encouraging their child to learn about their epilepsy and non-epileptic seizures, and to communicate with service staff if they are unwell or experiencing symptoms of a potential seizure. | | | | ✓ | |
| 27 | Immediately communicating any concerns with families regarding the management of children with epilepsy at the service | R | √ | 1 | | 1 |
| 28 | Communicating any concerns to families if a child's epilepsy is limiting his/her ability to participate fully in all activities | √ | ✓ | √ | √ | √ |
| 29 | Following appropriate reporting procedures set out in the <i>Incident, Injury, Trauma and Illness Policy</i> in the event that a child is ill, or is involved in a medical | R | R | R | | R |

| emergency or an incident at the service that results in | | | |
|---|--|--|--|
| injury or trauma | | | |

Background And Legislation

Background

Epilepsy is a common, serious neurological condition characterised by recurrent seizures due to abnormal electrical activity in the brain. While about 1 in 200 children live with epilepsy, the impact is variable – some children are greatly affected while others are not.

"Epilepsy is unique: There are virtually no generalisations that can be made about how epilepsy may affect a child. There is often no way to accurately predict how a child's abilities, learning and skills will be affected by seizures. Because the child's brain is still developing, the child, their family and doctor will be discovering more about the condition as they develop. The most important thing to do when working with a child with epilepsy is to get to know the individual child and their condition. All children with epilepsy should have an Epilepsy Management Plan" (Children with epilepsy: A Teacher's Guide, Epilepsy Foundation – refer to Sources).

Most people living with epilepsy have good control of their seizures through medication. It is important that all those working with children living with epilepsy have a good understanding of the effects of seizures, required medication and appropriate first aid for seizures.

Epilepsy smart Australia (ESA) *(refer to Sources)* has a range of resources and can assist with the development of an Epilepsy Management Plan. ESA and its national partners in every state/territory provides training and support to families and educators in the management of epilepsy, and in the emergency administration of midazolam or rectal Valium.

Legislation that governs the operation of approved children's services is based on the health, safety and welfare of children, and requires that children are protected from hazards and harm. *Regulation 136 of the Education and Care Services National Regulations 2011* requires the approved provider to ensure that there is at least one educator on duty at all times who has a current approved first aid qualification. As a demonstration of duty of care and best practice, NERPSA recommends all educators have current approved first aid qualifications. Services who are caring for children living with epilepsy are advised that educators may need to undertake epilepsy emergency medication training and seizure first aid training for educators depending on the child's needs. The *Education and Care Services National Regulations 2011* states that an approved provider must ensure that at least one educator with current approved first aid qualifications is in attendance and immediately available at all times that children are being educated and cared for by the service.

Legislation And Standards

Relevant legislation and standards include but are not limited to:

- Education and Care Services National Law Act 2010
- Education and Care Services National Regulations 2011
- Health Records Act 2001 (Vic)
- National Quality Standard, Quality Area 2: Children's Health and Safety
- Privacy and Data Protection Act 2014 (Vic)
- Privacy Act 1988 (Cth)

- Public Health and Wellbeing Act 2008 (Vic)
- Public Health and Wellbeing Regulations 2009 (Vic).

The most current amendments to listed legislation can be found at:

- Victorian Legislation Victorian Law Today: <u>www.legislation.vic.gov.au</u>
- Commonwealth Legislation Federal Register of Legislation: <u>www.legislation.gov.au</u>

Definitions

The terms defined in this section relate specifically to this policy. For regularly used terms e.g., approved provider, nominated supervisor, notifiable complaints, serious incidents, duty of care, etc. refer to the Definitions file.

Absence seizure: Occurring mostly in children, this consists of brief periods of loss of awareness, most often for less than 10 seconds. Some children can experience these types of seizures multiple times during the day which may compromise learning. Absence seizures can be mistaken for day-dreaming. They are no longer called 'petit mals'.

ASMs: Anti-seizure medications used for the treatment of many epilepsy syndromes. AEDs do not cure epilepsy but most seizures can be prevented by taking medication regularly one or more times a day. For many people, medication makes it possible to live a normal, active life, free of seizures. Others may continue to have seizures, but less frequently.

Emergency epilepsy 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 or nasal midazolam. Rectal Valium has been used in the past but is not often prescribed for use as an emergency epilepsy medication. Medication information is included in a child's Emergency Medication Management Plan, and this must be kept up to date. Only staff who have received child-specific training in the emergency administration of midazolam can administer this medication.

Emergency Medication Management Plan (EMMP): Completed by the prescribing doctor in consultation with the individual and/or their family/carer. This medication plan must be attached to the individual's Epilepsy Management Plan which has been signed by the child's treating doctor. The preferred template to be used by the prescribing doctor can be found at: www.epilepsyfoundation.org.au

Epilepsy: A neurological disorder marked by sudden recurrent (two or more) episodes of sensory disturbance, loss of consciousness, or convulsions associated with abnormal electrical activity in the brain.

Epilepsy Management Plan (EMP): Designed to help people recognise when seizures are occurring, and gives clear directions about appropriate first aid. The plan is developed by the person who has the most knowledge and experience of the individual's epilepsy and seizures, and should be less than 12 months old. The management of epilepsy requires a team approach and the plan should be reviewed and signed by the individual's treating doctor. An Epilepsy Management Plan and Support Package has been designed by The Epilepsy Foundation: www.epilepsyfoundation.org.au

Epileptic seizures: Epileptic seizures are caused by a sudden burst of excess electrical activity in the brain resulting in a temporary disruption in the normal messages passing between brain

cells. Seizures can involve loss of consciousness, a range of unusual movements, odd feelings and sensations or changed behaviour. Most seizures are spontaneous and brief. However, multiple seizures known as seizure clusters can occur over a 24 hour period.

Non-epileptic seizures (NES): also known as dissociative seizures. There are 2 types of non-epileptic seizures:

- organic NESs which have a physical cause
- psychogenic NESs which are caused by mental or emotional processes

Focal (previously called simple or complex partial) seizures: Focal seizures (previously called partial seizures) start in one part of the brain and affect the area of the body controlled by that part of the brain. The symptoms experienced will depend on the function that the focal point controls (or is associated with). Focal seizures may or may not cause an alteration of awareness. Symptoms are highly variable and may include lip smacking, wandering behaviour, fiddling with clothes and feeling sick, 'edgy' or strange.

Focal seizures where a person has full awareness were previously called simple partial seizures. Focal seizures where a person has an altered sense of awareness were previously called complex partial seizures. Focal seizures can progress into a generalised seizure.

Generalised seizure: Both sides of the brain are involved, and the person will lose consciousness. A Tonic-Clonic seizure is one type of generalised seizure.

Ketogenic diet: A high fat, low carbohydrate, restricted-calorie diet that may be prescribed as additional therapy. This is an effective therapy for some children, although its mechanisms are not well understood. When introducing this diet, a child is usually hospitalised, as such radical dietary changes have the potential to cause serious problems for the child. Once the child is stabilised on a ketogenic diet, they can return home, with the diet managed by the families or carers.

Midazolam: Also known as Hypnovel, midazolam belongs to a group of pharmaceuticals called benzodiazepines. Its main purpose is as a sedative or hypnotic, and it is used for medical and surgical procedures. In epilepsy, midazolam is used for emergency management of seizures, as it has the ability to stop the seizures quickly. Once absorbed into the blood, midazolam travels to the brain, attaching to brain receptors that control electrical impulses that are firing at an unusually rapid rate. Midazolam also works by relaxing muscles, which is particularly beneficial in many types of seizures. The effect of midazolam should occur rapidly.

Not all individuals living with epilepsy require emergency medication, but for a small group of people whose seizures are difficult to control, or for people who are isolated from emergency care, midazolam is an excellent medication. It is most commonly administered buccally or nasally.

Midazolam is fast-acting and can be easily administered by family and carers in a variety of settings. Only staff specifically trained to the requirements of a child's Emergency Medication Management Plan can administer midazolam.

Midazolam kit: An insulated container with an unused, in-date midazolam ampoule/s, a copy of the child's Emergency Medication Management Plan and Epilepsy Management Plan (which includes a picture of the child), and telephone contact details for the child's families, doctor/medical personnel and the person to be notified in the event of a seizure requiring administration of midazolam if families cannot be contacted. Midazolam must be stored away

from light (cover with aluminium foil) and in temperatures of less than 25°C. EFV Administration flyer – e.g., buccal, gloves, tissues, pen and paper, +/- stopwatch.

Seizure record: An accurate record of seizure activity, which is important for identifying any seizure patterns and changes in response to treatment.

Seizure triggers: Seizures may occur for no apparent reason, but common triggers include: forgetting to take medication, lack of sleep, other illness, heat, stress/boredom, missing meals and dehydration. Flashing or flickering lights can trigger seizures in about 5% of people living with epilepsy.

Sources And Related Policies

Sources

- The National Epilepsy Support Service phone 1300 761 487 Monday Saturday, 9.00am to 7.00pm (AEST) provides support and information across Australia.
- Epilepsy Foundation: <u>www.epilepsyfoundation.org.au</u> or phone (03) 9805 9111 or 1300 852 853
- Australian Children's Education and Care Quality Authority (ACECQA): www.acecqa.qov.au
- Guide to the Education and Care Services National Law and the Education and Care Services National Regulations 2011, ACECQA
- Epilepsy Smart Schools initiative and resources: www.epilepsysmartschools.org.au

Related Policies

- Administration of First Aid
- Administration of Medication
- Dealing with Medical Conditions
- Emergency and Evacuation
- Excursions and Service Events
- Incident, Injury, Trauma and Illness
- Inclusion and Equity
- Privacy and Confidentiality
- Staffing

Evaluation

In order to assess whether the values and purposes of the policy have been achieved, the approved provider will:

- regularly seek feedback from everyone affected by the policy regarding its effectiveness
- monitor the implementation, compliance, complaints and incidents in relation to this policy
- keep the policy up to date with current legislation, research, policy and best practice
- revise the policy and procedures as part of the service's policy review cycle, or as required
- notifying all stakeholders affected by this policy at least 14 days before making any significant changes to this policy or its procedures, unless a lesser period is necessary due to risk (Regulation 172 (2)).

Attachments

- Attachment 1: Seizure first aid
- Attachment 2: Enrolment checklist for children prescribed midazolam
- Attachment 3: Sample risk minimisation plan for children prescribed midazolam

Authorisation

This policy was adopted by the approved provider of NERPSA on [Date].

Review Date: [DAY]/[MONTH]/[YEAR]

Attachment 1. Seizure First Aid

TONIC-CLONIC SEIZURE

A convulsive seizure with loss of consciousness, muscle stiffening, falling, followed by jerking movements.

- Note the time the seizure started and time until it ends.
- Protect the head use a pillow or cushion, if available.
- Remove any hard objects that could cause injury.
- **Do not** attempt to restrain the person, stop the jerking or put anything in their mouth.
- As soon as possible, roll the person onto their side you may need to wait until the seizure movements have ceased.
- Talk to the person to make sure they have regained full consciousness.
- Stay with and reassure the person until they have recovered.

ABSENCE SEIZURE

Occurring mostly in children, this consists of brief periods of loss of awareness. Can be mistaken for day-dreaming.

- Timing can be difficult count how many happen daily.
- Reassure the person and repeat any information that may have been missed during the seizure.

FOCAL SEIZURE

A non-convulsive seizure with outward signs of confusion, unresponsiveness or inappropriate behaviour. Can be mistaken for alcohol or drug intoxication.

- Note the time the seizure started and time until it ends.
- Avoid restraining the person and guide safely around objects.
- Talk to the person to make sure they have regained full consciousness.
- Stay with and reassure the person until they have recovered.

Call an ambulance:

- for any seizure if you don't know the person or if there is no Epilepsy Management Plan,
- if the seizure continues for more than five minutes,
- if the seizure stops but the person does not regain consciousness within five minutes, or another seizure begins,
- when a serious injury has occurred, if a seizure occurs in water, or if you believe a woman who is having a seizure is pregnant.

EMERGENCY SERVICES: 000

National Epilepsy Support Service

- The National Epilepsy Support Service is available Mon Sat, 9:00am 7:00pm (AEST) to provide support and information across Australia. Phone: 1300 761 487. Email: support@epilepsysmart.org.au
- The National Epilepsy Support Service is not a medical emergency line. If you are experiencing a medical emergency, call 000.

Epilepsy Smart Australia

- A <u>national partnership</u> working together to bring you the best knowledge and resources about the management of epilepsy. There's help for people with epilepsy, those who support them, and for broader community organisations and companies.
- Please contact the National Epilepsy Support Service for details of your state/territory epilepsy organisation.

Attachment 2. Enrolment Checklist for Children Prescribed Midazolam

| A risk minimisation plan is completed in consultation with families prior to the attendance of the child at the service, and is implemented, including following procedures to address the particular needs of each child prescribed midazolam. |
|---|
| Families of a child prescribed midazolam have been provided with a copy of the service's Epilepsy Policy and Dealing with Medical Conditions Policy. |
| The Emergency Medication Management Plan (EMMP) and Epilepsy Management Plan (EMP) of the child is completed by the child's registered medical practitioner and is accessible to all staff (sample documents can be accessed at: https://www.epilepsyfoundation.org.au/epilepsy-management-plans/). |
| A copy of the child's EMMP is included in the child's midazolam kit <i>(refer to Definitions)</i> . |
| The midazolam kit (within a visible expiry date) is available for use at all times the child is being educated and cared for by the service, and includes a picture of the child. |
| Midazolam is stored in an insulated container (midazolam kit), in a location easily accessible to adults but inaccessible to children, and away from light (cover with aluminium foil) and direct sources of heat. |
| All staff who are trained in the administration of midazolam for a particular child, are aware of the location of each midazolam kit and the location of each child's EMMP. |
| Staff have undertaken epilepsy training through their state/territory epilepsy organisation, which includes strategies for epilepsy management, risk minimisation, recognition of seizures and emergency first aid treatment. Details regarding attendance at this training are to be recorded on the staff record <i>(refer to Definitions)</i> . |
| Staff have undertaken practise with a mock midazolam ampoule at some time in the last 12 months. Details regarding participation in practice sessions are to be recorded on the staff record <i>(refer to Definitions)</i> . |
| A procedure for first aid treatment for seizures is in place and all staff understand requirements <i>(refer to Attachment 1)</i> . |
| Contact details of all families and authorised nominees are current and accessible. |

Attachment 3. Sample Risk Minimisation Plan for Children Prescribed Midazolam

The following information is not a comprehensive list but contains some suggestions to consider when developing/reviewing your service's risk minimisation plan template in consultation with families.

| How well has the service planned for meeting the needs of children with epilepsy, and those children who are prescribed emergency midazolam? | | | | |
|--|---|--|--|--|
| Who are the children? | List the name and room location of each child diagnosed with epilepsy and ensure appropriate privacy is maintained in identifying these names to non-staff. | | | |
| What are their seizure triggers? | What are the seizure triggers for the children? List strategies that will minimise these triggers occurring (e.g., avoiding flickering lights, blowing into wind chimes (hyperventilating), sudden noise, becoming over-excited etc.). | | | |
| Do staff know what the child's seizures look like and how to support the child? | List the strategies for ensuring that all staff, including casual and relief staff, recognise what the child's seizures look like and what support the child may need. | | | |
| | If the child is prescribed midazolam for emergency use, ensure that trained staff know where the midazolam kit is located. | | | |
| Do staff know what constitutes an emergency and do they know what to do? | All staff have read and understood the child's Epilepsy Management Plan (EMP), and know: what constitutes an emergency and when to call an ambulance? how to provide support to the child during and after a seizure. | | | |
| If midazolam is prescribed, how does the service ensure its safe administration and | Record the date on which each family of a child with epilepsy (and who is prescribed midazolam) is provided a copy of the service's <i>Epilepsy Policy</i> . | | | |
| storage? | Record the date that families provide an unused, in-date and complete midazolam kit. | | | |
| | Record the date and name of staff who have attended child-specific training in the administration of midazolam. | | | |
| | Test that all trained staff know the location of the midazolam kit and Emergency Medication Management Plan (EMMP) for each child. | | | |
| | Ensure that there is a procedure in place to regularly check the expiry date of each midazolam ampoule. | | | |

| | Ensure the midazolam kit is maintained according to the instructions in this <i>Epilepsy Policy (refer to Definitions: midazolam kit)</i> . | | | |
|---|--|--|--|--|
| | Display the Epilepsy First Aid poster in staff areas. | | | |
| | The midazolam kit, including a copy of the EMMP, is carried by an educator/staff member when a child prescribed midazolam is taken outside the service premises e.g., for excursions. | | | |
| | | | | |
| | ribed it? | | | |
| | Know the contents of each child's EMMP and EMP and implement the procedures. | | | |
| | Know: | | | |
| | who will administer the midazolam and stay with the child? who will telephone the ambulance and the families of the child? who will ensure the supervision of other children at the service? who will let the ambulance officers into the service and take them to the child? | | | |
| Ensure that all staff have undertaken training through your Epilepsy Smart Australia state/territory epilepsy organisation. | | | | |