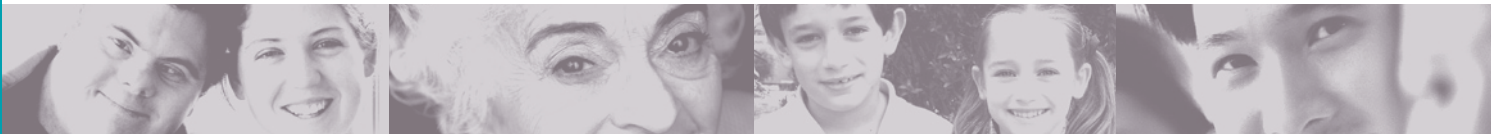


epilepsy

management plan

Epilepsy Management Plan and Support Package



Purpose

The primary purpose of this epilepsy support and management package is to help people involved with the person living with epilepsy to recognise when seizures are occurring and to give clear directions about the appropriate support and first aid to be provided to the person, whether they are a child or an adult.

How to use this package

Section 1 contains management plans and seizure record forms while Section 2 contains guidelines and support materials to help complete Section 1.

We suggest completing the plans on-line at www.epinet.org.au, then downloading and printing a copy for inclusion in this folder. This enables plans to be revised to ensure they remain up-to-date, with all information kept in one location.

Who should use this package?

This package is intended for use by the person with epilepsy, their family and any other person who has a role in supporting the person with epilepsy, either in a paid or unpaid capacity, including:

- Childcare and early childhood staff
- Teachers, integration aides, other school and Out of School Hours Care program staff
- Medical practitioners
- Hospital accident, emergency and nursing staff
- Aged care, Home and Community Care (HACC) and disability support workers
- Sports, Scouts, Girl Guides and other recreation staff
- Employers or any other place where the person with epilepsy or their family believes this would be useful.

Further assistance

Support is available to families and organisations to use this epilepsy support and management package, including training in understanding epilepsy and the emergency management of seizures by contacting your state service provider.

www.epilepsyaustralia.net

Epilepsy Help Line: 1300 852 853

Table of contents

Section 1: Management Plans

1. Epilepsy Management Plan	5
2. Seizure Record	11
3. Emergency Medication Management Plan – Midazolam	13
4. Emergency Medication Management Plan – Rectal Valium	15

Section 2: Guidelines and Support Materials

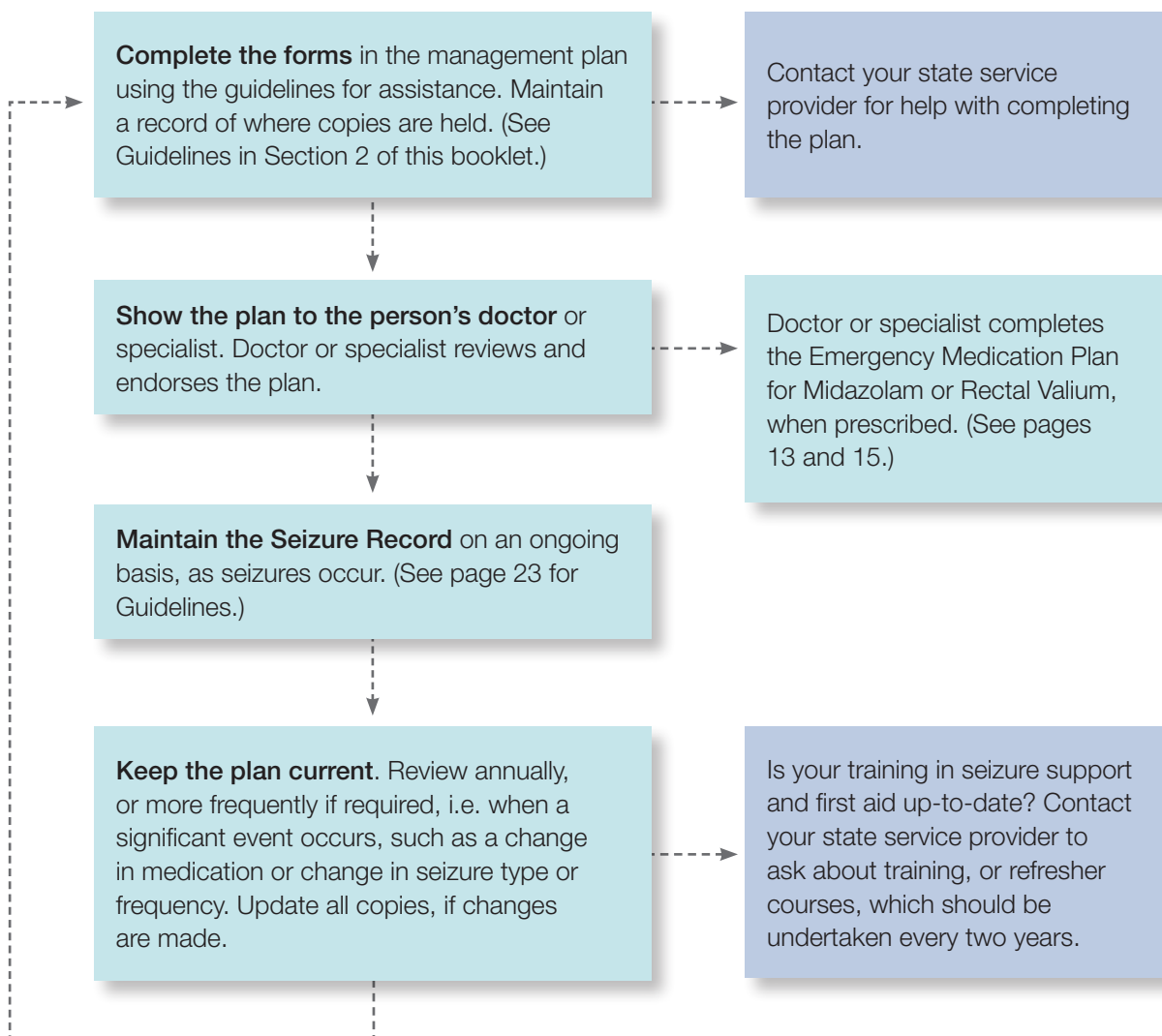
1. Guidelines for Creating an Epilepsy Management Plan	19
2. Guidelines for Recording Seizures	23
3. When an Ambulance is Called in an Emergency for Epilepsy	25
4. Guidelines for Creating an Emergency Medication Management Plan	27
5. Use of Midazolam for the Emergency Management of Seizures	29
6. Use of Rectal Valium for the Emergency Management of Seizures	31
7. Training for Families in the Emergency Management of Seizures	33
8. Training for Organisations in the Emergency Management of Seizures	35
9. Epilepsy Support and Management Training for Organisations	37

Roles and responsibilities

In using this publication, there are some clear roles and responsibilities for the person with epilepsy and people who have the most knowledge and experience of the person's epilepsy and seizures. A team approach is necessary, with the person living with epilepsy at the centre.

Person with epilepsy or their legal guardian	Epilepsy Plan Coordinator (person with epilepsy, family or support staff)	Doctor/specialists	State service provider
<ul style="list-style-type: none"> • Give consent for the development of an epilepsy management plan • Be involved in the development of the epilepsy management plan and reviews • Have the option to be part of any education and training delivered • Keep all medication current, check expiry date and that storage is appropriate • Ensure any support staff are involved in the process 	<ul style="list-style-type: none"> • Oversee the development and review of the plan • Keep a record of who has copies of the plan • Ensure seizures are recorded • Liaise with your state service provider and take part in training as required 	<ul style="list-style-type: none"> • Prescribe medication and the first aid support to be provided • Complete the emergency medication plan if emergency medication is prescribed • Review and endorse the plan • Consult with emergency services and hospital staff as required 	<ul style="list-style-type: none"> • Support the person with epilepsy and those around them to understand epilepsy and seizure management • Assist with the development and implementation of the plan through individual support and training

How to use this package



Note: All forms contained in this publication can be completed by handwriting on the appropriate form or by downloading electronic versions of the forms at www.epilepsyaustralia.net to create typed copies.

Section 1

Management Plans

Epilepsy Management Plan

This plan should be current, accurate and easy to understand. The plan should be developed by the person or people who have the most knowledge and experience of the person's epilepsy and seizures. It is very important for the person with epilepsy to be part of this planning process. A team approach to developing a plan is often helpful. The plan should be reviewed and signed by the person's doctor.

Attach photo
if required

Epilepsy Management Plan for _____

1. DATE _____ 2. DATE TO REVIEW _____

3. DATE OF BIRTH _____ CURRENT WEIGHT (kg) _____

ADDRESS _____ POSTCODE _____

PHONE _____ MOBILE _____

EMAIL _____

4. FIRST EMERGENCY CONTACT NAME _____

RELATIONSHIP _____ PHONE (HOME) _____

PHONE (WORK) _____ MOBILE _____

EMAIL _____

SECOND EMERGENCY CONTACT NAME _____

RELATIONSHIP _____

PHONE _____ MOBILE _____

EMAIL _____

5. CURRENT EPILEPSY MEDICATION:

NAME (e.g. sodium valproate)	DOSE REGIME (e.g. 8am-200mg / 8pm-400mg)

COMMENTS:

6. HAS AN EMERGENCY EPILEPSY MEDICATION BEEN PRESCRIBED?

(Must attach separate Emergency Medication Management Plan) YES NO

8. SEIZURE TRIGGERS: (if known)

9. OTHER SEIZURE TREATMENTS: Surgery Ketogenic Diet Vagal Nerve Stimulator (VNS)
 Specific instructions/relevant information

10a. OTHER MEDICAL CONDITIONS:

10b. OTHER CURRENT MEDICATION

NAME	DOSE REGIME (e.g. 8am–200mg / 8pm–400mg)

11. SEIZURE FIRST AID PROCEDURE SPECIFIC TO THIS PERSON:

15. ENDORSEMENT BY ONE TREATING DOCTOR / EPILEPSY SPECIALIST: (only ONE endorsement is required)

YOUR DOCTOR / SPECIALIST'S NAME

SIGNATURE

PHONE

MOBILE

DATE

EPILEPSY PLAN COORDINATOR

NAME

PHONE

MOBILE

DATE

16. PEOPLE INVOLVED IN PREPARATION OF THIS PLAN:

PERSON WITH EPILEPSY

YES NO

CONTACT NAME

RELATIONSHIP

PHONE

MOBILE

EMAIL

CONTACT NAME

POSITION

ORGANISATION

PHONE

MOBILE

EMAIL

CONTACT NAME

POSITION

ORGANISATION

PHONE

MOBILE

EMAIL

CONTACT NAME

POSITION

ORGANISATION

PHONE

MOBILE

EMAIL

17. COPIES OF THIS PLAN ARE LOCATED AT:

DOCTOR

ADDRESS

PHONE

EMAIL

SCHOOL

STAFF CONTACT

ADDRESS

PHONE

EMAIL

OTHER

CONTACT

ADDRESS

PHONE

EMAIL

OTHER

CONTACT

ADDRESS

PHONE

EMAIL

For more information [Web www.epilepsyaustralia.net](http://www.epilepsyaustralia.net) [Help Line 1300 852 853](tel:1300852853)

Seizure record

Seizure record for _____

NAME OF PERSON COMPLETING THIS FORM _____

PHONE _____

DATE	TIME OF THE DAY/NIGHT	HOW LONG SEIZURE LASTED

DESCRIPTION OF THE SEIZURE AND OTHER INFORMATION TO BE DISCUSSED WITH THE DOCTOR:

DATE	TIME OF THE DAY/NIGHT	HOW LONG SEIZURE LASTED

DESCRIPTION OF THE SEIZURE AND OTHER INFORMATION TO BE DISCUSSED WITH THE DOCTOR:

DATE	TIME OF THE DAY/NIGHT	HOW LONG SEIZURE LASTED

DESCRIPTION OF THE SEIZURE AND OTHER INFORMATION TO BE DISCUSSED WITH THE DOCTOR:

DATE	TIME OF THE DAY/NIGHT	HOW LONG SEIZURE LASTED

DESCRIPTION OF THE SEIZURE AND OTHER INFORMATION TO BE DISCUSSED WITH THE DOCTOR:

Seizure record for _____

NAME OF PERSON COMPLETING THIS FORM _____

PHONE NUMBER _____

DATE	TIME OF THE DAY/NIGHT	HOW LONG SEIZURE LASTED

DESCRIPTION OF THE SEIZURE AND OTHER INFORMATION TO BE DISCUSSED WITH THE DOCTOR:

DATE	TIME OF THE DAY/NIGHT	HOW LONG SEIZURE LASTED

DESCRIPTION OF THE SEIZURE AND OTHER INFORMATION TO BE DISCUSSED WITH THE DOCTOR:

DATE	TIME OF THE DAY/NIGHT	HOW LONG SEIZURE LASTED

DESCRIPTION OF THE SEIZURE AND OTHER INFORMATION TO BE DISCUSSED WITH THE DOCTOR:

DATE	TIME OF THE DAY/NIGHT	HOW LONG SEIZURE LASTED

DESCRIPTION OF THE SEIZURE AND OTHER INFORMATION TO BE DISCUSSED WITH THE DOCTOR:

Use additional page if more space is required (available for download from www.epilepsyaustralia.net or by contacting your state service provider).

For more information [Web www.epilepsyaustralia.net](http://www.epilepsyaustralia.net) [Help Line 1300 852 853](tel:1300852853)

Emergency Medication Management Plan Midazolam

Attach this document to your Epilepsy Management Plan if midazolam is prescribed

This Emergency Plan should be completed by the prescribing doctor in consultation with the person and/or their family or carer. It must be attached to their epilepsy management plan which has been signed by their doctor.

1. DATE _____ 2. DATE TO REVIEW _____

3. NAME _____ DATE OF BIRTH _____

4. DRUG NAME _____

Method of administration Intranasal Buccal

5. First dose

First dose = _____ mg _____ ml **Special instructions:** _____

For single seizures: _____

As soon as a _____ (seizure type) seizure begins

If the _____ (seizure type) continues longer than _____ minutes

For clusters of seizures:

When _____ (number and type of) seizures have occurred in _____ mins/hrs

Other (please specify) _____

6. Second dose

Second dose = _____ mg _____ ml **Special instructions:** _____

Not prescribed _____

OR

If the _____ seizure continues for another _____ minutes following the first dose

If another _____ seizure occurs within _____ mins/hrs following the first dose

Other (please specify, including when to administer in relation to the first dose)

7. Total number of midazolam administrations authorised to be given in a 24-hour period = _____

8. Describe what to do after midazolam has been administered:

9. DIAL 000 to call the ambulance if:

- It is the first time the person is administered midazolam
- If the seizure has not stopped after _____ minutes after giving the midazolam
- Other (please specify) _____

10. Prescribing doctor or specialist

NAME OF DOCTOR

SIGNATURE

DATE

PHONE

11. Family/carers to complete

Any special instructions e.g. storage of medication, when on outings etc. or people to contact if emergency medication is given.

NAME

RELATIONSHIP

SIGNATURE

DATE

PHONE

EMAIL

Emergency Medication Management Plan Rectal Valium

Attach this document to your Epilepsy Management Plan if rectal valium is prescribed

This Emergency Plan should be completed by the prescribing doctor in consultation with the person and/or their family or carer. It must be attached to their epilepsy management plan which has been signed by their doctor.

1. DATE _____ 2. DATE TO REVIEW _____

3. NAME _____ DATE OF BIRTH _____

4. DRUG NAME _____

Method of administration Rectal

5. First dose

First dose = _____ mg _____ ml Special instructions: _____

For single seizures: _____

- As soon as a _____ (seizure type) seizure begins
- If the _____ (seizure type) continues longer than _____ minutes

For clusters of seizures:

- When _____ (number and type of) seizures have occurred in _____ mins/hrs
- Other (please specify) _____

6. Second dose

Second dose = _____ mg _____ ml Special instructions: _____

Not prescribed _____

OR

- If the _____ seizure continues for another _____ minutes following the first dose
- If another _____ seizure occurs within _____ mins/hrs following the first dose
- Other (please specify, including when to administer in relation to the first dose) _____

7. Total number of rectal valium administrations authorised to be given in a 24-hour period = _____

8. Describe what to do after rectal valium has been administered:

9. DIAL 000 to call the ambulance if:

- It is the first time the person is administered rectal valium
- If the seizure has not stopped after _____ minutes after giving the rectal valium
- Other (please specify) _____

10. Prescribing doctor or specialist

NAME OF DOCTOR

SIGNATURE

DATE

PHONE

11. Family/carers to complete

Any special instructions e.g. storage of medication, when on outings etc. or people to contact if emergency medication is given?

NAME

RELATIONSHIP

SIGNATURE

DATE

PHONE

EMAIL

Section 2

Guidelines and Support Materials

Guidelines for Creating an Epilepsy Management Plan

People living with epilepsy have seizures at unpredictable times. Because epilepsy varies so much between individuals, it is crucial that everyone who supports the person understands the essential information relevant to that person's unique epilepsy circumstances.

This information can be usefully contained in an Epilepsy Management Plan that is current, accurate and easy to understand, and developed by the person or people who have the most knowledge and experience of that person's epilepsy and seizures. Encouraging the person with epilepsy to be part of this process is very important. A team approach to developing a plan is essential.

1. Date of plan

Use the date the doctor reviewed and endorsed the person's plan, otherwise use the date the plan was completed.

2. Date to review the plan

The plan should be reviewed and revised annually or more frequently if there is a change of circumstances or information that should be recorded in the plan, such as a change in the dose of medication.

3. Personal details and current weight

Ensure the person's correct full name, date of birth, address, telephone number and current weight are recorded, as this is crucial if the person is transferred to hospital with existing medical records. If they require emergency medication the dose is calculated based on their current weight.

4. Emergency contacts

It is advisable to have more than one emergency contact as people are not always available in emergency situations.

5. Current epilepsy medication

A list of the current antiepileptic medication/s and doses is helpful if an ambulance is called and the person is taken to hospital. If the person is allergic to any antiepileptic medications, include these in the comments section. This section of the plan *must* be kept up-to-date.

6. Emergency epilepsy medication

If emergency medication has been prescribed for prolonged seizures or clusters, an Emergency Medication Management Plan should be completed and must be attached to the Epilepsy Management Plan¹.

Your state service provider has Management Plans¹ available upon request and can provide training for people required to administer emergency medication.

7. Epilepsy diagnosis and seizure description

Not everyone has a specific type of epilepsy or syndrome diagnosed. If you are aware of the type of epilepsy or syndrome, include this information here.

A management plan is designed to help people recognise when seizures are occurring and to give clear directions about appropriate first aid.

If possible, name the type of seizure/s the person experiences e.g. tonic clonic, complex partial, and only include the name if absolutely certain this information is correct.

Include a description of all seizure types if the person experiences multiple seizures, with a detailed description of what happens before, during and after each seizure.

Consider the sequence of events that occur during the seizure and describe all aspects from start to end, e.g.:

- what is the earliest predictable sign that the seizure has begun?
- when do the seizures usually occur, how long do they last and how frequently do they occur?
- do they occur during the day or night, or occur at any time?
- is the person unconscious, unaware, dazed or confused?
- do they fall at the start of the seizure, wander about or freeze and stare?
- is there a history of prolonged or clusters of seizures or multiple admissions to hospital?
- how can you tell the seizure has stopped?
- how does the person normally recover after a seizure?

Having information about the person's normal recovery after a seizure helps to provide appropriate support for the person and also helps to identify abnormal circumstances that might require an emergency intervention.

8. Seizure triggers

It is useful to know if there are any recognised triggers that may provoke seizures for this person (do not include information about this if you are uncertain).

9. Other seizure treatments

Has the person had surgery, had a Vagal Nerve Stimulator² implanted or are they on the Ketogenic Diet³?

10a. Other medical conditions

The person may have other significant medical conditions such as diabetes or asthma, which must be included, especially if family or carers are unavailable when an ambulance attends or the person is taken to hospital.

10b. Other medication

A list of the current medication/s and doses is helpful if an ambulance is called and the person is taken to hospital. If the person is allergic to any medications, include these in the comments section. This section of the plan *must* be kept up-to-date.

11. Seizure first aid procedure specific to the person

Give clear, step-by-step instructions about what to do to assist the person when they are having a seizure. If the person has more than one type of seizure you need to give clear instructions for each seizure type.⁴

Delegate roles in advance e.g. who will time the seizure and stay with the person and who will ring an ambulance if necessary.

12. When to call an ambulance

Clearly document when an ambulance is to be called. If uncertain, consult with the person's doctor before completing this section of the plan.

An ambulance may be required e.g. if the seizure lasts a certain time (often 5 minutes), if the person has not regained consciousness after a specified period of time, the seizure occurred in water, or there are injuries as a consequence of seizures.

13. Post-seizure monitoring

As recovery from seizures varies greatly, state clearly what needs to be done to assist the person during the recovery phase and how long they should be supervised after the seizure.

Some people may need to sleep; others may have a headache or be incontinent and need an opportunity to shower and change clothes. Some may be very confused for quite a long time after their seizure has ended.

It is advisable to monitor someone until they have fully recovered from the seizure; this means ensuring they know who they are, where they are and understand what has happened.

14. Other specific instructions

This is where you can include important information about how to provide support in various circumstances, such as instructions for the workplace or recreational activities including sports, excursions or camps, or specific risk management strategies.

15. Epilepsy specialist or other doctor

Name and telephone number of the person's treating doctor is to be included in the plan to allow emergency services and hospital staff to consult when necessary. The doctor should review the plan and endorse it with their signature.

16. People involved in developing a confidential plan

Document all contributors to enable input when the plan is due for review. Nominate a plan coordinator who can take responsibility for the maintenance and review of the plan.

17. Plan location

Maintaining privacy and confidentiality by protecting the information in the plan is important. Ensure the plan is kept in a secure location. A record of where copies of the plan are located should be maintained and kept current. A copy of the current plan should be with the person, if hospitalisation occurs.

Seizure record

Keeping an accurate record of seizure activity is important. This helps to identify any seizure patterns and changes in response to treatment. Your state service provider has guidelines for recording seizures, which include a seizure record form.

Disclaimer

The Epilepsy Management Plan is available in print and electronic format, and under no circumstances should the format be modified in any way.

Important information

1 Medication substitution: People with epilepsy are strongly advised to avoid brand or generic substitution of their medication if they have excellent seizure control and experience no side-effects on their current medication. Pharmacists will often ask if a person wants a cheaper, generic version of existing medication. There are subtle differences in the composition of these medications, which might cause break-through seizures or an exacerbation of side-effects in some people.

There is no way of predicting who might be at risk, so avoiding substitution is the best way to prevent this problem in people with well-controlled epilepsy. Notify your pharmacist if you don't want to change and always check the medication each time it is dispensed.

2 The Vagal Nerve Stimulator (VNS) is an implanted device that provides electrical stimulation of the vagus nerve, which may help control or decrease seizures in some cases. About the size of a pocket watch, it is programmed to automatically generate 30 seconds of stimulation every five minutes. It can also be activated with a magnet, as required, and is powered by a lithium battery. It sends electrical impulses to the left vagus nerve in the neck via a lead wire that is implanted under the skin.

3 The Ketogenic Diet is a low carbohydrate, limited protein and high fat diet that has been found to help control seizures in some people with difficult to control epilepsy, especially children, and must be provided under strict medical supervision due to potential complications with the diet. Food must be carefully weighed and measured with a prescribed ratio of fat to proteins and carbohydrates. The body goes into a state of ketosis, which burns fat for energy instead of glucose. This is a treatment that may be considered, if medication fails to control seizures.

4 First aid: There are some general first aid rules for people experiencing seizures regardless of the type of seizure the person is having, and some specific rules depending on the type of seizure. Always time the seizure from the start to the end and stay with the person until they have fully recovered. Protect the person from injury but don't attempt to remove or restrain the person unless they are in immediate danger.

If the person is unconscious during their seizure, protecting their airway is of paramount importance. The easiest way to achieve this is to put the person on their side and to extend their chin upwards. If the person is in a wheelchair, ensure their head is raised and their airway is clear, during and after a seizure. Always follow a person's Epilepsy Management Plan (if one exists). Refer to your state service provider's First Aid Fact Sheet and First Aid poster for more detailed first aid information.

Guidelines for Recording Seizures

Keeping a record of seizures is important because few doctors ever see their patient having a seizure and rely heavily on an accurate account from an observer when diagnosing epilepsy. There are many different types of seizure, and other conditions that can be misdiagnosed as epilepsy. A precise diagnosis is easier to make if a clear description of the person's seizures is available.

In addition, after diagnosis, the doctor will welcome an ongoing record of seizures, which details their frequency and any changes that may occur in the pattern or type of seizures. This information may guide the doctor's choice of antiepileptic medication and will also help assess the response to treatment.

Important information to consider

Phases

There may be several phases in a seizure that should be carefully observed and recorded. Remember to time the seizure from the beginning to the end and note the frequency if the seizures are very brief.

Build-up and onset

This may last for minutes, several hours or, rarely, days, in the form of a build-up of tension or irritability. A clear change in behaviour prior to the onset of a seizure only occurs in some people with epilepsy. In some instances, an 'aura' or warning (called a simple partial seizure), consisting of odd sensations, such as an unpleasant smell, tingling feeling, déjà vu, or 'butterflies' in the stomach, may precede a complex partial or tonic clonic seizure.

The seizure

This may be one of many different types and each person's seizure experience is unique to them.

The period after the seizure

Recovery may be immediate or may take a few hours or, rarely, a few days. There is often confusion and drowsiness immediately after some seizures such as tonic clonic or complex partial seizures.

The following questions should help you to gather useful information for the doctor.

- Date of the seizure
- Exact time of day or night
- What was the person doing at the time?
- Had the person just fallen asleep or woken up?
- What called your attention to the seizure (a cry, fall, stare or head-turn)?
- What parts of the body were affected?
- Was one side affected more than the other?
- Did their body become stiff?
- Did it jerk, twitch or go into convulsions?
- Was the person unconscious?
- If not, was there any alteration in awareness?
- Did their skin show changes (flushed, clammy, signs of blueness)?
- Did their breathing change?
- Did the person talk or perform any actions during the seizure?
- Was the person incontinent?
- Did the person vomit during or after the seizure?
- Did they bite their tongue or inside their cheek?
- Did any injuries result from the seizure?
- How did the person behave after the seizure (alert, drowsy, confused, irritable etc.)?
- After recovery did the person remember any unusual sensations before or at the onset of the seizure?
- How long did the person take to recover completely?
- Was there a known trigger?

For more information [Web www.epilepsyaustralia.net](http://www.epilepsyaustralia.net) [Help Line 1300 852 853](tel:1300852853)

When an Ambulance is Called in an Emergency for Epilepsy

Parents, carers, educators and the community are all advised to be prepared for an epilepsy emergency.

If there is a history of prolonged seizures, clusters of seizures or status epilepticus, consultation should occur with the treating doctor about the need for emergency medication.

If an emergency medication has been prescribed, an Emergency Medication Management Plan should be completed and signed by the prescribing doctor and attached to the Epilepsy Management Plan. These forms are available from your state service provider.

Training in the administration of an emergency medication is strongly recommended and can be provided by your state service provider.

All ambulance officers have been trained to administer midazolam. If ambulance officers attend, the following procedures apply before midazolam can be administered.

1. Paramedics will utilise the doctor's written and signed instructions if they are readily available
2. If there is no prescription or doctor's instructions, the ambulance officers will administer midazolam as per ambulance protocol, calculating dose according to age/weight. In most cases, midazolam will be administered by intramuscular injection (IM)
3. Rectal diazepam (valium) is never used and is always substituted with midazolam.
4. Transport to hospital: if a person has received midazolam, transport would depend upon:
 - Clinical presentation including vital signs and patient response to midazolam
 - Whether this event has been typical or would benefit from further investigation
 - The decision to transport should be a joint one.

Additional information

- Ambulance Victoria membership should be considered to avoid significant costs for individual episodes of service provision
- Participation in an emergency first aid course may be beneficial.

Continued...

DIAL 000 TO CALL AN AMBULANCE

General questions will be asked when you dial 000

- What is the exact location of the emergency?
- What is your contact phone number?
- What is the problem?
- What exactly happened?
- How many people are hurt?
- Are you with the patient now?
- What is the age of the person needing the ambulance?
- Is the person conscious?
- Is the person breathing?
 - No to the last two questions results in the immediate dispatch of the ambulance.
 - Yes, leads to more specific questions.

Questions asked in an epilepsy emergency

- Has the person had more than one seizure?
- If female, is she pregnant? (age 12–50)
- Did the person hit their head before the seizure?
- Does the person have diabetes?
- Does the person have a history of heart problems?
- Is the person known to have epilepsy or has the person had a seizure before?
- Has the jerking (twitching) stopped yet? (You go and check, I'll stay on the line.)
- Is the person breathing now?
 - No, operator will give CPR instructions.

To assist the ambulance service

- Stay calm and answer each question accurately
- If you can, avoid third party calls
- Provide accurate location details – the nearest intersection is useful
- Have someone wait outside
- Ring 000 if the person's condition changes or they have another seizure.

When emergency medication is prescribed

- Inform the operator that the person has a history of prolonged or clustering of seizures
- Inform the operator that emergency medication is available and can be administered.

Guidelines for Creating an Emergency Medication Management Plan

When someone is prescribed an emergency medication by the treating doctor for their epilepsy this information can be usefully contained in an Emergency Medication Management Plan. The plan should be completed by the doctor who provides the epilepsy medical management or prescribes the medication. The following information will help the prescribing doctor and family or carer to create a plan that is clear and accurate. Your state service provider has plans available for use. Training in the administration of an emergency medication for epilepsy is recommended by your state service provider.

1. Date of plan

Use the date the doctor completed the person's plan.

2. Date to review the plan

The plan should be reviewed and revised annually or more frequently if there is a change of circumstances or information that should be recorded in the plan, such as a change in the dose of medication or when it can be administered.

3. Personal details

Ensure the person's full name and date of birth are correct.

4. Drug name

Write the emergency medication name in full. State the route of administration e.g. buccal¹ or intranasal for midazolam. Some doctors tick both boxes to give flexibility and choice. As a general guide, young children usually receive midazolam intranasally and older children and adults by the buccal route. Extra information may be added here, e.g. if the midazolam is in a pre-drawn syringe or rectal valium is in an enema vial.

5. Give first dose

You must write out the first dose of the emergency medication in full e.g. *5mg in 1ml*.

For single seizures: select the preferred option by ticking the appropriate box. It is vital to state for which seizure the medication is to be given e.g. tonic clonic, and when it should be given e.g. if the seizure continues for 5 minutes or longer.

For clusters of seizures: must specify how many seizures are to have occurred before the first dose is administered or write other specific instructions.

Special instructions: this section allows you to stipulate if there are any special instructions e.g. if midazolam comes in a pre-drawn syringe or, if a paediatric dose is required, whether you may need to drip out and discard excess liquid, if not giving the full ampoule.

6. Give second dose

If a second dose is authorised write out the second dose of emergency medication in full e.g. *5mg in 1ml*.

Be specific about for which seizure type and at what time the dose is to be given in relation to the first dose.

Special instructions: this section allows you to stipulate if there are any special instructions e.g. if midazolam comes in a pre-drawn syringe or, if a paediatric dose is required, whether you may need to drip out and discard excess liquid, if not giving the full ampoule.

7. Specify number of emergency medication doses in a 24-hour period

Specify how many doses can be given in a 24-hour period. This section is often overlooked but is very important. Maintaining seizure and medication records is vital, especially when people on emergency medication orders move from home to school or day placement and back again or when staff change shifts.

8. Describe what to do after emergency medication has been administered

This information will be very specific to the person with epilepsy and the way they usually recover from their seizures. It is helpful if the doctor can specify how long it is necessary to supervise someone after they have been given an emergency medication for epilepsy.

9. Call an ambulance if ...

Clearly indicate when to call an ambulance by selecting the appropriate option. If the person with epilepsy has not had the emergency medication before, or the person administering it hasn't given emergency medication before, we strongly recommend an ambulance be called prior to administration.

10. Epilepsy specialist or other doctor who prescribed the emergency medication

Please ensure this section is signed and dated by the treating or prescribing doctor. It is also useful to include a contact telephone number to be used if any of the doctor's instructions need clarifying.

11. Family/carers to complete

Include other specific instructions in this section e.g. information about storage and safe transporting of medication outside the home (use an insulation pack in hot weather), for outings, school camps or people to contact if the emergency medication has been administered. It is also helpful if the family member or carer who has the greatest involvement with the person's epilepsy completes this section with their name, signature, date and relationship to the person with epilepsy.

Other considerations about emergency medication

- Are there any workplace, school or health care agency policies in relation to administering an emergency medication for epilepsy?
- Who is responsible for ensuring the plan is completed and regularly reviewed?
- Who checks the expiry date of the medication?
- Who is responsible for ensuring the person has a current script for the emergency medication and an ongoing supply?
- Who has a copy of the plan and where is it located?
- Where is the emergency medication stored? List all locations.
- Remember to record the date/time/dose of all emergency medication administered.

Disclaimer

The Emergency Medication Management Plan is available in print and electronic format, and under no circumstances should the format be modified in any way.

1 Buccal: inside the cheek cavity, between the gum and the teeth.

The Use of Midazolam for the Emergency Management of Seizures

What is midazolam?

Midazolam, also known as hypnovel, is a short acting benzodiazepine. It is a sedative or hypnotic drug mainly used for medical and surgical procedures.

Why is midazolam used for some people with epilepsy?

Most seizures are spontaneous, brief and self-limiting but some people with epilepsy can have seizures that continue unless there is emergency intervention. These seizures may be referred to as clusters, prolonged seizures or status epilepticus. Midazolam is used for the emergency management of seizures because it has the ability to stop the seizures very quickly. It may be prescribed for someone with epilepsy when:

1. A person has seizures that last longer than 5 minutes
2. A person has a pattern of cluster seizures – seizures that recur close together
3. A person has a history of status epilepticus
4. A person lives in a rural area and emergency services are unable to respond quickly.

How is midazolam given for seizure management?

Non-medical people can be trained to administer midazolam in the following ways:

1. Buccal – slowly trickled into the side of the mouth, between the gums and cheek
2. Intranasal – dripped slowly into the nasal passage from the ampoule or via a nasal atomiser device, which can attach to a syringe.

The blood vessels in the cheek and nose absorb the midazolam and the drug usually works quickly to stop the seizure. Ambulance officers and medical practitioners are able to give midazolam intramuscularly (into the muscle) or intravenously (into the vein).

How is midazolam packaged?

Midazolam is a clear, colourless liquid and is available in both plastic and glass ampoules (**only use the plastic ampoules**)¹. Traditionally, this medication has been designed for hospital use and will be labelled for 'slow IV' (intravenous), or 'IM' (intramuscular) use, but can also be administered via the buccal or intranasal route.

The drug can be dispensed in two ways for administration by non-medical people:

1. A 5mg: 1ml plastic ampoule (**remember, don't use the glass ampoule**) or
2. Your pharmacist can prepare the midazolam in a plastic syringe. The correct dose is pre-drawn in each syringe and the drug is dispensed from the syringe without needing to attach a needle. The drug has a much shorter shelf life if prepared by the pharmacist in a syringe compared to the plastic ampoules.

Possible side-effects of midazolam

- Drowsiness, tiredness, weakness, nausea
- Rare side-effects: agitation and mood alteration. Shallow and slow breathing where mouth to mouth resuscitation may be required.

A test dose under medical supervision may be recommended or the ambulance can be called prior to the administration of the first dose. This issue should be discussed with the prescribing doctor before the medication is used for the first time.

Storage

- Keep out of reach of children
- Protect from light and store at room temperature (below 25° C)
- Regularly check the expiry date.

What information do you need from the doctor if midazolam is prescribed?

Your state service provider has an Emergency Medication Management Plan for the prescribing doctor to complete. This should be signed and dated and include the following essential information:

1. How much to give – dose will be written as ____ mg ____ ml, and which route (buccal or intranasal)
2. When to give the first dose and for which seizure type
3. If a second dose can be given, the dose and when it is to be given must be specified
4. How many doses can be given in a 24-hour period
5. When to call an ambulance.

If you are required to give midazolam, consider the following:

For families, carers and support workers:

1. Training should be person or client specific
2. It is important you understand and follow the Emergency Medication Management Plan. You must know the dose and for which seizure type and at what time you are instructed to give the medication
3. You know when to call the ambulance
4. You know how to do CPR.

Additional considerations for workers:

1. Your CPR first aid certificate is current
2. You understand and follow your workplace policies in relation to managing epilepsy and administering medication
3. Your workplace should arrange training for you prior to administering midazolam for the first time.

Training and support

Your state service provider offers training in the administration of midazolam and the development of Emergency Medication Management Plans for family or staff supporting a person with epilepsy. Contact your state service provider for further information about training and any costs involved.

-
- 1 Glass ampoules cannot be put into a person's mouth directly for buccal administration. Glass ampoules increase the risk of injury due to possible breakage and the need to use a needle and syringe to draw up the medication.

The Use of Rectal Valium for the Emergency Management of Seizures

What is valium (diazepam)?

Valium is also known as diazepam and belongs to the benzodiazepine group of medications. Its main use is as a sedative, muscle relaxant and as an antiepileptic medication. Valium (diazepam) is available in several forms: as a tablet, in liquid for intravenous or intramuscular administration and in a preparation suitable to administer rectally. Rectal administration can be an effective way to deliver the valium (diazepam) during a seizure, however, another drug called midazolam has become the preferred prescribed emergency medication due to its ease of administration and rapid action.

Why is rectal valium (diazepam) used for some people with epilepsy?

Most seizures are spontaneous, brief and self-limiting but some people with epilepsy can have seizures that continue unless there is emergency intervention. These seizures may be referred to as clusters, prolonged seizures or status epilepticus. Rectal valium (diazepam) is used for emergency management of seizures because it has the ability to stop the seizures reasonably quickly. It may be prescribed for someone with epilepsy when:

1. A person has seizures that last longer than 5 minutes
2. A person has a pattern of cluster seizures – seizures that recur close together
3. A person has a history of status epilepticus
4. A person lives in a rural area and emergency services are unable to respond quickly.

How is rectal valium (diazepam) given for seizure management?

Non-medical people can be trained to administer rectal valium (diazepam). The medication is squirted in the bowel through the anus. The blood vessels in the bowel absorb the valium (diazepam) and the medication should stop the seizure within 5 to 10 minutes. If ambulance officers attend they will inject midazolam intramuscularly (into the muscle) if the seizure hasn't ceased.

How is rectal valium (diazepam) packaged?

Rectal valium (diazepam) is a clear, colourless liquid and is available in two options for administration by non-medical people:

1. A pharmaceutically prepared enema vial containing 5mg of valium (diazepam) in 5ml of gel-like solution or
2. A rectal valium (diazepam) kit supplied by a hospital pharmacy containing:
 - A 25ml bottle of valium (diazepam) with a stabilising solution, containing 1mg of valium (diazepam) in each 1ml
 - A 10ml syringe
 - A reusable soft plastic tube to attach to the syringe for drawing up and injecting
 - A sachet of lubricant.

Possible side-effects of rectal valium (diazepam)

- Breathing difficulties such as shallow and slow breathing
- Drowsiness, tiredness and weakness
- Puncturing the wall of the rectum (very rare)

- Loss of dignity and embarrassment on recovery
- On rare occasions it may provoke status epilepticus in children with Lennox–Gastaut syndrome.

A test dose under medical supervision may be recommended or the ambulance can be called prior to the administration of the first dose. This issue should be discussed with the prescribing doctor before the medication is used for the first time.

Storage

- Keep out of reach of children
- Protect from light and store at normal room temperature (below 25° C)
- Regularly check the expiry date.

What information do you need from the doctor if rectal valium (diazepam) is prescribed?

Your state service provider has an Emergency Medication Management Plan for the prescribing doctor to complete. It should be signed, dated and include the following essential information:

1. What dose to give: dose will be written as _____ mg _____ ml
2. When to give the first dose and for which seizure type
3. If a second dose can be given, the dose and when it is to be given must be specified
4. How many doses can be given in a 24-hour period
5. When to call an ambulance.

If you are required to give rectal valium (diazepam), consider the following:

For families, carers and support workers:

1. Training should be person or client specific
2. It is important you understand and follow the Emergency Medication Management Plan. You must know the dose and for which seizure type and at what time you are instructed to give the medication
3. You know when to call the ambulance
4. You know how to do CPR.

Additional considerations for workers:

1. Your CPR first aid certificate is current
2. You understand and follow your workplace policies in relation to managing epilepsy and administering medication
3. Your workplace should arrange training for you prior to administering rectal valium (diazepam) for the first time.

Training and support

Your state service provider offers training in the administration of rectal valium and the development of Emergency Medication Management Plans for family or staff supporting a person with epilepsy. Contact your state service provider for further information about training and any costs involved.

Training for Families in the Emergency Management of Seizures Using Midazolam or Rectal Valium

Purpose

Your state service provider offers training in how to administer midazolam or rectal valium for the emergency management of seizures. This document outlines both the scope and the requirements of the training for family members or nominated informal carers.

Background

Your state service provider offers training where the need for emergency management of seizures in the community is required. There are situations where it is unrealistic and dangerous to wait for an ambulance to attend for someone having a seizure and prompt administration of a medication such as midazolam or rectal valium is vital. Midazolam and rectal valium are not formally approved for use in this setting and training is only provided if there are clear, documented and signed instructions from the prescribing doctor.

The training is person-specific and tailored to each individual's needs and is conducted by a registered nurse who has a background in epilepsy and has a Certificate IV in Assessment and Workplace Training qualification.

Training for family members

Your state service provider can provide training if the following criteria are met:

1. A person has been prescribed midazolam (for buccal or intranasal use) or rectal valium for seizures
2. A copy of both the Epilepsy Management Plan and Emergency Medication Management Plan, or a copy of the treating doctor's instructions and/or prescription, are provided with the person's permission prior to the appointment
3. The family will be advised to undertake CPR training with an appropriate training provider and to have an Ambulance Victoria membership for the person with epilepsy.

If you undertake the training, the following will be covered

1. What is midazolam or rectal valium?
 - Why are they prescribed for epilepsy
 - How they work and the potential side-effects
 - How to monitor the person after you have given the medication.
2. How to give the medication following your doctor's instructions:
 - Recognising seizure types and general first aid
 - Demonstration and practice of the administration in a simulated scenario
 - When to call an ambulance
 - Tips on creating an Epilepsy Management Plan and Emergency Medication Management Plan.

Handouts provided

1. Epilepsy Management Plan pro forma
2. Emergency Medication Management Plan pro forma to attach to the Epilepsy Management Plan
3. Guidelines for creating an Epilepsy Management Plan
4. Guidelines for creating an Emergency Medication Management Plan
5. Midazolam (buccal/intranasal) OR rectal valium instructional poster
6. Midazolam or rectal valium information sheet
7. What happens when an ambulance is called for a seizure?
8. Information about types of seizures
9. Seizure record chart
10. First aid poster.

Post-training follow-up

1. An epilepsy counsellor will contact the family 1–3 months after the session to discuss any concerns
2. Epilepsy Management Plans can be checked and feedback provided by the trainer
3. Families should contact their state service provider at any stage, if further information or support is required.

Other options

Training can be provided for organisations that provide services to support the person with epilepsy.

Costs

Contact your state service provider for further information about training and any costs involved.

Training for Organisations in the Emergency Management of Seizures Using Midazolam or Rectal Valium

Purpose

Your state service provider offers training in how to administer midazolam or rectal valium for the emergency management of seizures. This document outlines both the scope and the requirements of the training.

Background

Your state service provider offers training where the need for emergency management of seizures is required in the community. There are situations where it is unrealistic and dangerous to wait for an ambulance to attend for someone having a seizure and prompt administration of a medication such as midazolam or rectal valium is vital. Midazolam and rectal valium are not formally approved for use in this setting and training is only provided if there are clear, documented and signed instructions from the prescribing doctor.

The training is client-specific and tailored to each individual's needs and is conducted by a registered nurse who has a background in epilepsy and has a Certificate IV in Assessment and Workplace Training qualification.

Training for agency workers

Training will be provided when the following criteria are met:

1. The client has been prescribed midazolam (for buccal or intranasal use) or rectal valium for seizures
2. A copy of both the Epilepsy Management Plan and Emergency Medication Management Plan, or a copy of the treating doctor's instructions and/or prescription, are provided with the client's permission. This information is treated in a confidential manner and is required one week prior to the training
3. The workers have a current CPR certificate
4. We strongly recommend that organisations complete the appropriate training offered by their state service provider to be able to support people with epilepsy.

Overview of workshop content

- Overview of working with a client with epilepsy
- What is midazolam or rectal valium?
 - Rationale for use in relation to epilepsy
 - Drug action and potential side-effects
 - Post-administration monitoring issues
- How to administer emergency medication for your client, following the client's specific Emergency Medication Management Plan or the doctor's written instructions and prescription
- Tips on how to create and review the Epilepsy Management Plan and Emergency Medication Management Plan
- Demonstration and practice of the administration in a simulated scenario

- When to call an ambulance
- Understanding your workplace policies in relation to administering emergency medication.

The workshop can include topics that cover the skills required to support someone with epilepsy if general epilepsy training hasn't been provided in the past.

Optional post-training follow-up

1. Epilepsy Management and Emergency Medication Management Plans can be checked and feedback provided by the trainer
2. We recommend that organisations complete a two-yearly update, as a minimum, provided there has been no change in the medication or support staff
3. Any concerns or questions can be discussed with the trainer.

Learner outcomes specifically related to administering emergency medication

1. List what equipment is used when administering midazolam or rectal valium
2. Document when the emergency medication should be given for each client and for which seizure types
3. For each client, correctly write how much medication should be given: ___ mg ___ ml
4. List three situations when an ambulance should be called if midazolam or rectal valium has been given
5. Be able to identify three signs that indicate the client is experiencing side-effects
6. Identify two steps that are required if the worker doesn't understand what is documented on the Emergency Medication Management Plan.

Support materials provided

1. Epilepsy Management Plan pro forma, if an organisation does not have its own
2. Emergency Medication Management Plan to attach to the Epilepsy Management Plan
3. Guidelines for Creating an Epilepsy Management Plan and an Emergency Medication Management Plan
4. Midazolam or rectal valium instructional poster
5. Midazolam or rectal valium information sheet
6. When an Ambulance is Called in an Emergency for Epilepsy

Cost

Contact your state service provider for information on training and any costs that may apply.

Epilepsy Support and Management Training for Organisations

Purpose

Your state service provider offers targeted training to organisations that support people with epilepsy to ensure they have the essential knowledge and skills to appropriately support the person with epilepsy.

Background

Your state service provider delivers education and training to a range of organisations including but not limited to aged care, Home & Community Care and disability service providers, Department of Human Services, early childhood and childcare facilities, schools, hospitals and workplaces.

All education and training programs are informed by current research and delivered by qualified, experienced professionals who have all completed a Certificate IV in Assessment and Workplace Training in addition to qualifications in their specific areas of expertise.

Program content

Education and training programs are tailored to the organisation's needs but typical topics include:

- Overview of epilepsy
- Seizure classification
- Seizure triggers
- Seizure management/treatments
- First aid
- Self-management and lifestyle issues
- Development and/or review of Epilepsy Management Plans.

An Epilepsy Support and Management Package, along with other practical supporting materials tailored to the person's needs, is provided.

Post-training follow-up

Participants consistently rate our education and training sessions as highly relevant and comprehensive. In addition, your state service provider offers ongoing support and advice to organisations and participants post-training.

In instances where more specialised training in emergency medication administration is required, training by a registered nurse can be arranged. Contact your state service provider for further details.

Cost

Contact your state service provider for further information about training and any costs involved.

Top ten tips for living with epilepsy

- 1. Take your medication as prescribed** as this controls seizures in most people. Forgetting a dose, changing the time you take medication or using a different brand can trigger a seizure.
- 2. Learn more about your condition** from reliable sources such as your doctor, pharmacist, state service provider, or other health care professionals. Gather as much information as you can to understand the type of seizures you have, to enable you to manage your epilepsy better and educate those around you about your condition.
- 3. Know your triggers and try to manage them** – for example missed medication, illness and fever, stress, lack of sleep, menstruation, extremes or changes in temperature (especially hot weather) or flickering light can be triggers for some people.
- 4. Keep a seizure diary** – as you may not be aware when you are having a seizure or remember that one occurred, ask someone to write a detailed description each time you have a seizure and keep the date, time and what happened before, during and after the seizure. Take it to each doctor's appointment to help your doctor assess the effectiveness of your treatment.
- 5. Have a healthy, balanced lifestyle** – people living with epilepsy can do a lot to help themselves with good self-management, so avoid getting overtired or stressed, having too much alcohol, taking illegal drugs, exercising excessively or becoming dehydrated. Moderate exercise, yoga, meditation, music or time relaxing with friends can be helpful.
- 6. Have a 'Seizure Management Plan'** so that your family, friends, work or school know what to do if you have a seizure. This will help others understand what is happening so they can help you appropriately.
- 7. See a specialist** to get the best treatment for your condition. Your doctor may refer you to a pediatrician, neurologist or epileptologist who will look at your symptoms, order tests, prescribe the best medication for your type of seizure and provide reviews.
- 8. Manage your risks** – take special care around fire, water, heights, operating machinery and driving. There are strict rules about the length of time you need to be seizure-free before being allowed to drive and your doctor must complete a medical report. See www.austroads.com.au/aftd/index.html for the current edition of Assessing Fitness to Drive.
- 9. If travelling overseas** check that any medications are legal in the countries you are visiting. Take a letter from your doctor detailing your diagnosis, the name of the medication, how much you will be taking and that it is for your own personal use, along with a copy of the prescriptions. Keep the medication in its original packaging. Make sure you have enough prescriptions to cover the time you are away from home. For further information, download a copy of the brochure *Travelling Well* from smartraveller.gov.au/tips/travelwell.
- 10. Get some support if you need it.** Most people with epilepsy lead full and happy lives but sometimes you or your family might need support, information or just someone to talk to. Each State and Territory in Australia has an epilepsy support agency. Contact 1300 852 853 or visit www.epilepsyaustralia.net

For further information contact

- Epilepsy Help Line on **1300 852 853** for the cost of a local call or
- visit www.epilepsyaustralia.net

SEIZURE FIRST AID – Giving help to a person who is having a seizure

Tonic Clonic Seizure

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 – if available use a pillow or cushion
- 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

Mostly in children, consists of brief periods of loss of awareness. Can be mistaken for day-dreaming and complex partial seizures.

- Timing can be difficult, count how many happen daily

- Reassure the person and repeat any information that may have been missed during the seizure

Complex Partial Seizure

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 if another seizure begins
- When a serious injury has occurred, if it occurs in water, or if you believe a woman is pregnant

More information

For further information about services, costs, membership or joining the Research Participant Register, please contact your state service provider.

www.epilepsyaustralia.net

National Helpline: 1800 852 853

