

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 Epilepsy Foundation of Victoria recommends this plan 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

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

Guidelines for Creating an Epilepsy Foundation of Victoria **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.

The Epilepsy Foundation of Victoria 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.

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. The Epilepsy Foundation 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 the Epilepsy Foundation's First Aid Fact Sheet and First Aid poster for more detailed first aid information.

Epilepsy Support and Management Package

Feedback Form

We encourage you to provide feedback about the Epilepsy Support and Management Package or the individual documents from that package that you have received. This will enable us to ensure it meets the needs of people with epilepsy and their family/carers, as well as other support workers. All comments are appreciated and will be treated with confidentiality.

1. **Name:** **Contact No:** (Optional)

2. **Are you a:**

- | | | |
|--|---|---|
| <input type="checkbox"/> Person with epilepsy | <input type="checkbox"/> Aged care worker | <input type="checkbox"/> Secondary school teacher |
| <input type="checkbox"/> Family member | <input type="checkbox"/> Disability support worker | <input type="checkbox"/> Integration aide |
| <input type="checkbox"/> Doctor | <input type="checkbox"/> Early childhood worker/teacher | <input type="checkbox"/> School Nurse |
| <input type="checkbox"/> Neurologist/paediatrician | <input type="checkbox"/> Primary school teacher | <input type="checkbox"/> Other:..... |

3. **Name of Organisation:**

If you have the Epilepsy Support and Management booklet please complete Section 1 & 2
If you have received single document/s please complete section 2

Section 1

1. **Would you recommend the package to someone else?** **Yes / No**

Why/ Why not?.....

2. **Please circle your response to the following statements (with 1 being strongly disagree and 5 being strongly agree)**

Package Introduction & Instructions	Strongly Disagree		Agree		Strongly Agree
There is adequate information provided on how to use the package	1	2	3	4	5
The table of contents is clear	1	2	3	4	5
I understand my role, and the role others play in managing the person's epilepsy	1	2	3	4	5

Comments:

Please add any comments or suggestions you would like to make

.....

Section 2

1. Please tick the box corresponding to the document/s you have used and then circle your response to the following questions (with 1 being strongly disagree and 5 being strongly agree)

Individual Document/s	Strongly Disagree		Agree		Strongly Agree
<input type="checkbox"/> Epilepsy Management Plan is easy to complete	1	2	3	4	5
<input type="checkbox"/> The Emergency Medication Plan (midazolam or rectal valium) is easy to complete	1	2	3	4	5
<input type="checkbox"/> The seizure record page is useful	1	2	3	4	5

Guidelines and Support Materials

<input type="checkbox"/> The Guidelines for Creating a Management Plan are helpful	1	2	3	4	5
<input type="checkbox"/> Guidelines for Creating an Emergency Medication Plan are helpful	1	2	3	4	5
<input type="checkbox"/> The Guidelines for Recording Seizures are helpful	1	2	3	4	5
<input type="checkbox"/> When to Call an Ambulance is helpful	1	2	3	4	5
<input type="checkbox"/> The Use of Midazolam for Emergency Management of Seizures is informative	1	2	3	4	5
<input type="checkbox"/> The use of Rectal Valium for Emergency Management of Seizures is informative	1	2	3	4	5
<input type="checkbox"/> Information about Training for Families is useful	1	2	3	4	5
<input type="checkbox"/> Information about Training for Organisations in the use of emergency medications is useful	1	2	3	4	5
<input type="checkbox"/> Epilepsy Support and Management for Organisations is useful	1	2	3	4	5
<input type="checkbox"/> Top Ten Tips for living with epilepsy is useful	1	2	3	4	5
<input type="checkbox"/> Seizure first aid is useful	1	2	3	4	5

Comments:

Please add any comments or suggestions you would like to make

.....

.....

.....

.....

.....

.....

Thank you for taking the time to provide feedback which is appreciated.

Please return in the prepaid envelope provided, or alternatively scan and email to: epilepsy@epilepsy.asn.au or fax to: 9882 7159