



**KNOW ME
SUPPORT ME**

Developing an Epilepsy Management Plan

A resource for families, carers and support workers

About this resource

Why develop an EMP?

People living with epilepsy often have seizures at unpredictable times and seizures are different from person to person. Because of this, it is important that everyone understands how to best support a person living with epilepsy when they experience seizures. An Epilepsy Management Plan (EMP) can help with this by documenting the person's seizure types, support needs and emergency procedures.

It is important that the person living with epilepsy plays a part in developing their EMP, and this resource can help you to work with the person to collaboratively develop their plan.

Developing an EMP

When developing an EMP it is very important to listen to the person and, as much as possible, include them in the discussion. When talking with the person make sure they feel comfortable, have the discussion in a private space, and remind them that it is OK to say "I don't know" or "I don't remember" if they are unable to respond to a question.

The person you are supporting may have never completed an EMP before, or may have forgotten completing one in the past. So, it is a good idea to explain what an EMP is, why it is valuable and the importance of the person contributing to its development.

When working with a person to develop their EMP, please ensure they understand that their plan will:

- contain information about their seizures
- describe behavioural signs indicating that they may be about to have a seizure
- outline the support they would like if a seizure occurs
- describe when it might be necessary to call an ambulance.

Also, ensure the person knows that it may be necessary to speak to others to develop a detailed EMP. But assure the person that you won't do so without their consent to talk with others.

Going through this process with the person is a good way of discussing their seizures and their epilepsy diagnosis. It may also lead to learning more information which could indicate that the person needs some additional help or an appointment with relevant specialists (e.g. doctor, neurologist, psychologist, social worker).

Contact the Epilepsy Foundation Information Line on 1300 761 487 for assistance when developing an EMP.

How to use this booklet?

This booklet is aligned against each question in an EMP, explaining the purpose of the question and ways of collecting the information needed.

This booklet is part of a suite of *Know Me, Support Me* epilepsy resources that have been designed for people who care for a person living with epilepsy and a cognitive disability.

You may find the *Learning about epilepsy: An easy English guide* useful when developing the EMP.

Additional resources that may be useful when developing an EMP:

1. *Living with epilepsy and a cognitive disability: a guide for individuals, families, carers and support workers*
2. *Living with epilepsy and a cognitive disability: a practical guide for individuals, families, carers and support workers*
3. Information Sheets
4. *Referral pathways: further investigation of possible epilepsy*
5. *Is it epilepsy? Reflection statement*
6. *Is it epilepsy? Witness statement*
7. *Ten things you should know about epilepsy in people who live with a cognitive disability*
8. Epilepsy Management Plan – electronic template
9. Emergency Medication Management Plan – electronic template

Epilepsy Foundation training

The Epilepsy Foundation recommends that families, support workers, school staff and other carers take part in training as this will assist in gaining a better understanding of epilepsy, gain sector-specific information and learn how to administer individualised emergency medication where needed.

Contact the Epilepsy Foundation Information Line on 1300 761 487 or via email edutra@epilepsyfoundation.org.au for more information about training options.

Guidelines to help in developing an EMP

This section goes through each of the key parts which make up an EMP.

Developing a detailed EMP is important for the person living with epilepsy and anyone who provides support. Ideally the EMP should be a document that can be used and understood by anyone who supports or works with the person. Writing clear and detailed answers to each question is therefore very important.

Information to include about the person

This section of the EMP is where you will write the:

- person's full name
- person's date of birth
- date the EMP was signed by the doctor
- date the EMP is to be reviewed.

It is highly recommended that the plan be updated each year. It is also a good idea to update the plan earlier if any changes take place in the person's life (e.g. seizure activity changes, risks increase, new treatments are being used, changes to living arrangements).



1

General information

This section of the EMP is where you will write down the location of the person's medical and health records if available. In this section you may want to note:

- medication records - note where epilepsy-specific medication records are located (these may be with family, a doctor, community organisation)
- seizure records - note where any seizure records (which may include medical documents or a seizure diary) are located
- general support needs documents - note where other general support needs information (which may not be epilepsy-related) is located
- whether an epilepsy diagnosis has been made by the doctor, but if a diagnosis has not been made write "not known".

If any of the above records are attached to the EMP then write "attached" but if not note where they are located (if known).



2

Has emergency epilepsy medication been prescribed?

Sometimes a person with epilepsy is prescribed emergency medication. These medications are only used in specific situations and are not used in place of daily anti-epileptic drugs (AEDs). If a person has been prescribed emergency medication by their treating doctor then a separate Emergency Medication Management Plan (EMMP) should be completed and attached to the EMP. The EMMP must be completed by the doctor and either be attached to the EMP or its location noted. Emergency medication must only be administered by a trained person.

This section of the EMP allows you to note:

- whether emergency medication has been prescribed by ticking 'yes' or 'no'
- where the EMMP is located if emergency medication has been prescribed.



3

My seizures are triggered by?

A trigger is a situation or event that can make a seizure more likely to happen, although not all people living with epilepsy have a known trigger. Examples of some common triggers include stress, drinking too much alcohol, temperature changes, being unwell, flashing lights, and/or lack of sleep.

This section of the EMP allows you to:

- describe the person's seizure triggers (if known)
- write "not known" if the person doesn't have a known seizure trigger.

Discussion

The *Learning about epilepsy: An easy English guide* can be used to discuss the person's triggers (if known). This will assist in completing section 3 of the EMP. Some common triggers are noted in the *Learning about epilepsy: An easy English guide* (Seizure Triggers, Page 10). However, the person may experience different ones.



4

Changes in my behaviour that may indicate a seizure could occur

Some people get a 'sense' that a seizure could happen (e.g. physical, behavioural and/or mood changes). A change in behaviour may happen seconds, minutes, hours, days or weeks prior to a seizure. Some examples include sadness, agitation, irritability, poor appetite and/or being quiet when usually talkative. However, some people living with epilepsy may not experience a change in behaviour prior to having a seizure.

This section of the EMP allows you to note any physical, behavioural or mood changes which can accompany a seizure by:

- describing known pre-seizure behavioural changes
- writing "not known" if the person does not experience changes prior to seizure activity.

Discussion

The *Learning about epilepsy: An easy English guide* can be used to talk about the person's pre-seizure changes (if known). This will help in completing section 4 of the EMP. Some common pre-seizure changes are noted in the *Learning about epilepsy: An easy English guide* (Will I know the seizure is coming? Page 4). However, the person may experience different ones.



My seizure description and seizure support needs

A seizure is a temporary, sudden change in electrical and chemical activity in the brain which causes a change in behaviour, thought, movement or sensations. Every person's experience of seizures are different. Providing descriptions of the person's seizure types and in a language that is common to all people who support and/or work with the person is very important.

Some people have seizures very regularly, but others may only have a seizure occasionally. Some people also experience clusters of seizures. Some people are aware they are having a seizure, whereas others are not aware when they are having one. The individualised nature of epilepsy makes it important to work with the person living with epilepsy to record seizure descriptions and support needs.

This section of the EMP is where you can write down:

- seizure type/s (including what the person looks like before, during and after a seizure and if they occur as a cluster)
- how long a seizure usually lasts (such as seconds or minutes)
- how often seizures occur (such as days, months, years)
- whether emergency medication has been prescribed for a particular seizure type by ticking 'yes' or 'no':
 - when the box is ticked 'yes', people who are specially trained to administer the emergency medication should refer to the Emergency Medication

Management Plan (EMMP) for details. For people who are not trained to administer emergency medication, then write clear and concise instructions as to when an ambulance should be called

- when the box is ticked 'no', write clear and concise instructions for when an ambulance should be called. If no ambulance needs to be called for a certain type of seizure then write "not applicable".

Discussion

The *Learning about epilepsy: An easy English guide* can be used to discuss the person's seizure types. This will help in completing section 5 of the EMP. Some common types are noted in the *Learning about epilepsy: An easy English guide*, and remember the person may have more than one seizure type. If the person has more than one seizure type, discuss and record each type separately.

Refer to the *Learning about epilepsy: An easy English guide* to assist with completing this section:

- What seizures could I have? Page 2
- Will I know the seizure is coming? Page 4
- Why do I feel funny after a seizure? Page 5.



6

How do I want to be supported during a seizure?

Just as epilepsy differs between people, so does the type of support (help) that people need or want during a seizure.

This section of the EMP allows you to note:

- the specific support needed during each seizure type (e.g. follow first aid instructions)
- whether an emergency response is required (e.g. ambulance).

Discussion

Information already completed in Section 5 will assist you to complete this part of the EMP.

7

My specific post-seizure support

Everyone recovers from seizures differently. Some people may want post-seizure support and contact after a seizure (e.g. be told what happened, be assured they are safe). Whereas other people may not want to talk about their seizure as they may be agitated, embarrassed, scared or need time to become more aware of where they are and what happened.

This section of the EMP is where you will write:

- what the person's post-seizure behaviour may look like
- what should be done to help the person after a seizure
- how long it usually takes for the person to recover from a seizure
- how long the person should be supervised after a seizure.

Discussion

Questions and discussion points already completed in Section 7 may assist you to complete this part of the EMP. Some common post-seizure feelings are noted in the *Learning about epilepsy: An easy English guide* (Why do I feel funny after a seizure? Page 5). However, the person may experience different ones.



8

My risk/safety alerts

Understanding epilepsy-related risks is important as this helps to support the person in a safe manner. With this information in mind, the right risk management strategies can be put in place.

Section 8 of the EMP is where you can discuss risks that are common to many people living with epilepsy, learn about ways that risks can be reduced for the person and develop appropriate safety strategies and plans.

Discussion

The *Learning about epilepsy: An easy English guide* can be used to discuss the person's risk and safety issues. This will help in completing section 8 of the EMP. Some common risks and safety strategies are noted in the *Learning about epilepsy: An easy English guide* (Safety, Page 12-14). However, the person may have additional risks that need to be considered.

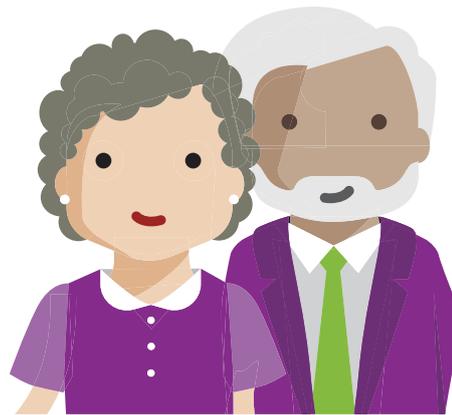


9

Do I need additional overnight support?

Understanding whether the person living with epilepsy needs overnight support is important. Knowing this will help you to discover whether the person feels scared when alone and/or whether any overnight risk management strategies and plans can be put in place.

Section 9 of the EMP allows you to document the need for overnight support and what assistance should be provided (e.g. use of a low bed, anti-suffocation pillows, alarms or staff monitoring).



Plan co-ordination

In this section of the EMP, note who assisted the person to develop the EMP (e.g. family member, support worker, carer), and sign if the person is under 18 years of age or under guardianship.

Endorsement by treating doctor

The person's treating doctor should sign the EMP (e.g. Neurologist, GP). It is also recommended that the treating doctor play a part in developing the EMP, along with the person living with epilepsy and anyone who provides support.

This publication is part of a suite of resources that are targeted to family members, carers and support workers, to assist with caring for people living with epilepsy and a cognitive disability.

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