Epilepsy: Know Me, Support Me

Developing an Epilepsy Management Plan

A resource for support workers and families

Thank you for the contributions and expertise of:

The information contained in this publication provides general information about epilepsy. It does not provide specific advice. Specific health and medical advice should always be obtained from a qualified health professional.

The images in this publication show models who do not necessarily have an epilepsy diagnosis and are for illustrative purposes only.

Epilepsy: Know Me, Support Me

Developing an Epilepsy Management Plan

Name of person with Epilepsy:...

....

Name of support person: ....

....

Date: ....

The information you will need to gather to write an Epilepsy Management Plan (EMP) is summarised by the icons below.

These icons are used in the EMP document and are referenced throughout this booklet.

General information

Doctor

Emergency medication

Behaviour

Risk/safety alerts

Triggers

Seizure

Support during seizure

Support after seizure

Overnight support

C L E A R

Collect the key medical information and clarify the epilepsy record keeping process

Listen to the person

Engage key people in the development of the EMP

Agree on seizure descriptions and recording of seizures

Develop the **Right** plan

Why develop an EMP?

People living with epilepsy usually have seizures at unpredictable times. Because epilepsy varies so much between individuals, it is crucial that everyone understands how to support the person – an EMP documents the person's seizure types, support needs and emergency procedures.

The person with epilepsy is an integral part in the development of the EMP.

Understanding Epilepsy

Support workers, school staff and other community service staff are encouraged to attend epilepsy training through their local state epilepsy organization prior to using this booklet. A list of these organizations can be found at www.epilepsyaustralia.net .

Families and people living with epilepsy can access the toll free

epilepsy can access the toll free Australia wide Epilepsy Helpline on 1300 852 853 to find out about services and support in their state or territory.

Epilepsy: know me, support me

This booklet is part of a suite of free resources that can be accessed via www.epinet.org.au:

1. *Learning about Epilepsy: an easy English resource*

2. *Developing an EMP: a resource for support workers and families*

3. *My Epilepsy Review Appointment: an easy English resource*

4. Epilepsy Management Plan electronic template

5. Emergency Medication Management Plan electronic templates

6. *Epilepsy Management in the Disability Sector: a resource for better practice.*

Using this booklet

This booklet provides you with checklists to support you through the process of developing the EMP using the CLEAR approach.

You can access a video case study to help you use this booklet via www.epinet.org.au

You can view the EMP template at the end of this booklet.

Picture icons are used throughout – these correspond with the final EMP document.

It is recommended that the main support people complete as much of the EMP as possible prior to meeting with the doctor. It is essential that the treating doctor review and sign the completed EMP.

C

Collect the key medical information and clarify the epilepsy record keeping process

- [ ] What type of epilepsy does the person have?

- [ ] What is the medication treatment plan (medication/s) from the doctor?

- [ ] What defines an emergency for the person with epilepsy?

- [ ] What should a support person DO in an emergency?

- [ ] Is emergency medication prescribed? If yes, you will need to obtain a separate signed Emergency Medication Management Plan from the doctor (this can be accessed via www.epinet.org.au)

- [ ] What method of seizure record keeping will you put in place?

- [ ] How will you ensure that seizure record keeping and the medication plan is consistent between service provider/s/home?

- [ ] If you are reviewing an existing EMP, is it less than 12 months old?

All medication treatment plans should have clear instructions that document the person's name; drug name; administration route (nose, mouth etc); dose; time of administration and date of prescription. This document should be signed by the treating doctor and be no older than 12 months.

Listen to the person

This section is only useful for people with epilepsy who can:

- ☑ understand conversational speech

- ☑ can use words, signs or gestures to express 'yes' or 'no'

- ☑ relate to photographs/ pictures to real objects or people (or those with a vision impairment, who can understand the spoken accompanying picture descriptions)

If the answer is 'no' to any of the statements above, then go directly to section 'E' in this booklet (page 13) so that you can find out more about the person's epilepsy.

Instructions for the support person:

a. Make a time and place when the person feels relaxed

b. Explain to the person that the EMP is a document that:

  – Has information about their seizures
  – How to help them
  – When to call an ambulance

c. Explain that with their consent, afterwards you will also speak to other people about their epilepsy so that the EMP is complete

d. Ask the person to use the stickers located in the back of this booklet when they agree with any of the statements.

e. Use the diagrams to guide your questions – remember, the person may have limited capacity to tell you about their seizures due to the nature of the seizures. Reassure them it is okay to say 'I don't know'.

Does the person understand their epilepsy? This easy English booklet is available free via www.epinet.org.au. It can also be accessed in alternative formats.

Epilepsy: know me, support me

Learning about Epilepsy   An easy English booklet
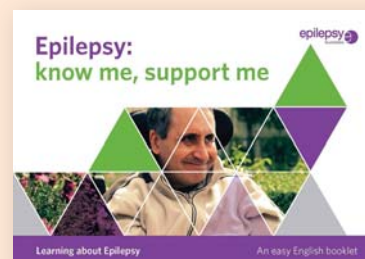
Start your conversation by saying;

- You can tell people about your epilepsy and how you want to be supported

- Using this booklet, we will listen to how you want to be supported

- It's okay to say "I don't know" or "I don't remember"

- Use this page to find out if the person has more than one seizure type
- Write the person's own seizure name/s in the space provided below
- Go through each seizure type separately with the person

Tell me about your seizures (previously called fits)

I call these seizures: **1.** .... **2.** .... **3.** ....

		1	2	3
	I shake in a seizure	1	2	3
	I feel strange in a seizure	1	2	3
	I have seizures during the day	1	2	3
	I have seizures during the night	1	2	3
	I don't know	1	2	3
	I don't remember seizures	1	2	3

Tell me more about your seizures ...

....

....

Before a seizure ...

I call these seizures: **1.** .... **2.** .... **3.** ....

I feel sick

1　2　3

I feel scared

1　2　3

I stare

1　2　3

I feel angry

1　2　3

I don't know when
my seizures are
about to happen

1　2　3

Tell me more about how you feel before a seizure ...

....

....

....

....

After a seizure ...

I call these seizures: **1.** .... **2.** .... **3.** ....

	I feel confused	1	2	3
I feel scared	1	2	3
I feel angry	1	2	3
I feel sick	1	2	3
I feel sleepy	1	2	3
I don't know	1	2	3

Tell me more about how you feel after a seizure ...

....

How do you want someone to help you after a seizure?

Tell me what happened during the seizure

Talk to me and reassure me

Give me some space, I don't like to have people around me
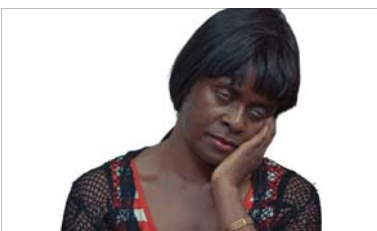
I don't know

Tell me more about how you would like someone to support you after a seizure ...

....

....

....

....

Don't assume that every person wants to have interaction following a seizure – some people can be agitated, confused, embarrassed or scared and need time to become more aware of their surroundings. In these instances, stay close by and keep them safe until they have returned to their usual self.

A seizure trigger is something that can bring on a seizure. Triggers vary from person to person and not everyone can identify if they have a trigger.

Is there anything that brings on your seizures?

Missed medication

Getting hot or feeling ill
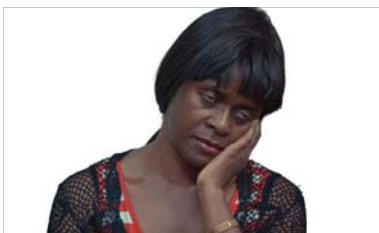
Not enough sleep
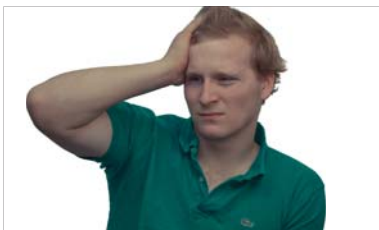
Stress
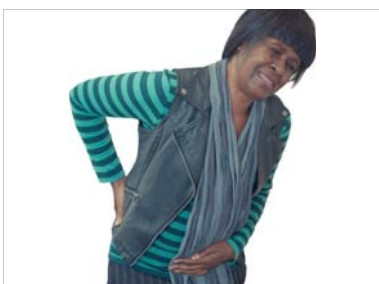
Around your period (for females)

Women can experience increased seizure activity either before or during their period – it is individual to the woman.

TV or flashing or flickering lights

Other …

....

How can we help keep you safe?

Bathing

I like to have showers

I use a shower chair

I like to have a bath

☐ I like the support person to be in the bathroom when I'm showering or bathing

☐ I like the support person to be close-by

Other things I do to keep safe in the bathroom …

....

....

....

....

> Sometimes it's noted that a person is more likely to have seizures during a certain time of day. For example, if a person has more seizures in the afternoon, then taking morning showers is a good idea.

Swimming

I like to go swimming

I use a flotation device
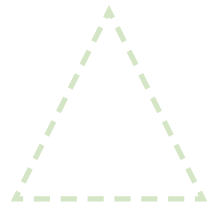
Other things I do to keep safe when I swim …

....

....

....

Community/home

I wear a medical alert

I wear a helmet

If yes, when do you wear the helmet …

....

....

Is there anything that you'd like to do that epilepsy stops you doing?

....

....

....

....

Other things I do to keep safe in the community/home:

....

....

....

....

Do you need help during the night?   Yes ☐   No ☐

If 'yes' how do you like to be supported?

....

....

....

....

Who can I talk to learn more about your epilepsy?

....

....

> If a person does need monitoring during the night, how can this be done in the safest and most sensitive way?

Engage key people in the development of the EMP

☐ Identify appropriate people to talk to – eg. parents; siblings; accommodation or day program providers:

....

☐ How would you know when the person has a seizure?

....

☐ How does the person like to be supported during and after a seizure? (You can access a first aid poster via www.epinet.org.au)

....

....

☐ Does the person have any seizure triggers?

....

☐ Does the person's mood or behaviour change in the hours/days/weeks leading up to a seizure change? Describe.

....

....

☐ Does the person require any additional night support? If yes, describe.

....

....

Is emergency medication prescribed?   Yes ☐   No ☐
If yes, you will need to obtain a separate signed Emergency Medication Management Plan from the doctor (this can be accessed via www.epinet.org.au).

> Going back to the 'Listen' section in this booklet is a useful way to prompt the key people and provides an opportunity to share the person's perspective of their epilepsy.

Agree on seizure descriptions/recording of seizures

☐ Develop a system so that everyone is recording seizures in the same way.

☐ Develop a way for easy communication between service providers/family.

It's important that the same description of seizures is used between all support people. It is better to use a description of the seizure rather than just naming the seizure.

There are helpful apps that can record seizure activity for both iphone/ ipads and android phones/tablets.

Develop the **Right** plan

- [ ] Collate the information that you have gathered throughout this booklet by matching the icons from this document to the EMP.

- [ ] Decide how many different seizure types the person has (this will determine which EMP template you need to download).

- [ ] Choose the electronic EMP that has the correct number of seizure types that you need (from 1 to 5) from www.epinet.org.au and enter brief and accurate notes.

- [ ] Use the guidelines over the page to help complete the EMP.

- [ ] Save the EMP template so that you can make future changes when needed.

- [ ] Take the EMP to the doctor for endorsement.

- [ ] Have the person with epilepsy sign the EMP, or if they are under 18, their parent or guardian.

Guidelines to help you write the EMP

1. General Information

- If these records are attached to the Epilepsy Management Plan (EMP) then write "attached"
- If these records are not attached, then clearly state where they are located
- If the EMP is to be used by multiple organisations, leave blank so that each organization can write in where their organization will store the documents
- An epilepsy diagnosis is made by the doctor. For example Dravet Syndrome, Lennox Gastaut Syndrome. Write 'not known' if this is applicable

2. Has emergency medication been prescribed?

- Emergency medication (eg. buccal/ intranasal midazolam or rectal valium) can be prescribed for prolonged seizures or clusters
- The Emergency Medication Management Plan describes when and how these medications are administered. It must be completed by the doctor and either be attached or its location noted in the EMP
- You can access these electronic templates via www.epinet.org.au
- Only people who are specifically trained to administer the emergency medication to the person can do so
- You can locate your local Epilepsy organization to arrange training by telephoning 1300 852 853

3. My seizures are triggered by:

- A trigger is a situation or event that can make a seizure more likely to occur
- Not everyone will have known triggers
- Examples of common triggers include drinking too much alcohol, being hot or not well, lack of sleep
- Write 'not known' if this is applicable

4. Behaviours

- Some people get a 'sense' that they are leading up to seizure activity.
- For other people, their behaviour or mood may change. Many people have no such indication
- A change in behaviour may occur for hours, days or weeks prior to a seizure
- Examples of changed behaviour may include feeling sad, irritability or poor appetite
- Write 'not known' if this is applicable

5. Seizures

- Determine how many different types of seizures the person has
- Select the EMP that has the corresponding number of rows so that each seizure type can be contained in a separate row
- Go to www.epinet.org.au and download the appropriate EMP – there are between 1 and 5 rows to choose from
- In the description column describe what the seizure looks like before, during and afterwards
- Don't just name the seizure, for example 'absence' as this type of language is not necessarily understood by everyone who reads the EMP

- Always discuss with the support team and agree on common descriptions
- State the typical duration of the seizure in the next column
- The frequency should be expressed in terms of days, months or years. When the last seizure has occurred over 12 months ago, write the approximate date when the last seizure did occur
- If Emergency Medication is prescribed for a particular seizure type, click the box 'yes', otherwise click 'no'
- When the above box is ticked 'yes', people who are trained specifically to administer this medication for that seizure type should refer to the Emergency Medication Management Plan. For staff who are not trained to administer this medication, write clear concise instructions as to when an ambulance should be called
- When the above box is ticked 'no', write clear concise instructions for when an ambulance should be called. If no ambulance needs to be called for a certain type of seizure, for example absence seizures, then state 'Not applicable'

6. Support during a seizure
- Give clear, step-by-step instructions about any specific support requirements

7. Post seizure support
- As recovery from seizures varies greatly, state clearly what needs to be done to assist the person
- State how long they should be supervised after a seizure
- Describe how the support person would know when the person has regained their usual awareness and how long this typically takes

8. Risk
- Everyone, not just those with epilepsy face risks in the home and in the community
- Identify risks that the person may face, for example bathing, swimming, use of a helmet, mobility or eating after a seizure

- After identifying the risk, state what the support person needs to do to reduce the likelihood of the danger

9. Overnight support
- For some people, additional overnight support may include use of a low bed, firmer pillow, or staff monitoring to mention a few strategies
- A thorough assessment should be completed in consultation with the treating doctor to evaluate what, if any additional overnight supports may be needed

Doctor
- The treating doctor should sign the EMP
- The EMP should be updated yearly

Plan co-ordination

Nominate a plan co-ordinator who can take responsibility for the maintenance and review of the plan.

Individuals and families can contact their local Epilepsy organization on 1300 852 853 for help in developing the EMP.