

Learning about epilepsy

An easy English guide



Seizures

What is epilepsy?

The messages in your brain get all mixed up for a short time.

This is called a seizure. They used to be called fits.

Your body does strange things or feels strange.

What seizures could I have?

People have different seizures.

For example you might



walk around and talk to yourself



 feel scared, sick or worried in your stomach



• chew or lip-smack



play with your clothes



go stiff



• fall over and shake, this is called a tonic-clonic seizure



• stare.

Some people have seizures when they are

- awake
- asleep.

Some people have seizures every day.

Some people only have a seizure sometimes.

Can I stop my seizure?

No.

Will I know the seizure is coming?

Some people know when a seizure is coming.

For example they might



• have a strange taste



have a strange smell



feel sick



• feel worried.

Why do I feel funny after a seizure?

The messages in your brain get all mixed up for a short time.

You may feel



tired and sleepy



confused



If you can, tell someone you have had a seizure.

After a rest you may feel better.

How do I feel?



Some people with epilepsy can get sad or worried.

This can be part of having epilepsy.

Always talk to your doctor about how you feel.

How can I tell people about my epilepsy?

If you know a seizure is coming, tell people.

Make notes about your seizures. For example use



a diary



• mobile phone and iPad apps



 an Epilepsy Management Plan
You can say how you want help in this Plan.

Visit your doctor about your epilepsy one time every year, or sooner if you have more seizures.



Use the My Epilepsy Medical Review document to get ready for your visit.

The doctor will:

- check your health
- say what medication to take.

Medication

Do I have to take medication?



Yes. Take your medication every day.

Most people take medication in the morning and at night.

Do not forget.



If you forget talk to your chemist or doctor.

You may need emergency medication to stop a seizure.

Your doctor can talk to you about this.

What side effects might I feel from my medication?



stomach ache



tired



• feeling sad



angry



staying awake at night



• put on or lose weight.



If you get a rash on your skin from new medication, you **must** tell your doctor quickly.

Tell your doctor about how your medication makes you feel.

Seizure triggers

A trigger is something that might bring on a seizure.

What might trigger a seizure? If you



• miss your seizure medication



are sick or hot



drink too much alcohol

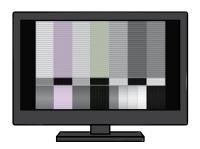
If you



• don't get enough sleep



get angry



• see flashing lights or flickering television screens



• for women it may be before or during your period.

Safety

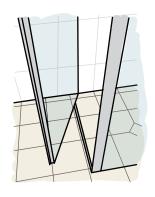
How can I be safe in the bathroom?



have showers not baths



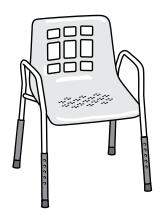
• tell someone before you shower



 have a shower door that opens out, not in



 fit a temperature control for your hot water



• use a shower chair if your seizures make you fall.

How can I be safe at home and in the community?

You can do the things you like. To stay safe you can



 wear a helmet when you ride a bike AND ride with another person



 swim with another person AND tell the lifeguard you have epilepsy



- ask someone to help you with safe cooking ideas
- use a microwave instead of a stovetop and a food processor rather than a knife



 wait for a train or tram behind the yellow line, or wait for a bus away from the road



 keep your personal emergency information on you.

Can I die from epilepsy?

A very small number of people can die from a seizure.

Look after yourself

- visit your doctor regularly
- take your medication
- do not miss medication
- make notes about your seizures.
- give your notes to the doctor
- be safe.

Can I get a job?

Yes.

All people in the workplace need to be safe.

Some jobs may not be safe for you to do.

There are support services that can help you get or keep your job.

Call the Epilepsy Information Line 1300 761 487 for more information.

Epilepsy Management Plan



What is an Epilepsy Management Plan?

It has information about:

- a person's seizures
- how to help the person
- when to call an ambulance.

Your support person can use the booklet *Developing an Epilepsy Management Plan* to help you have your say in your Plan.

Help

Where can I get more help?



your doctor



• your family, carer or support worker



• Epilepsy Information Line 1300 761 487.

Other resources you can get from www.epilepsyfoundation.org.au



• Seizure First Aid poster



 Developing an Epilepsy Management Plan for support workers



 My Epilepsy Medical Review Appointment document



Epilepsy Management Plan and Emergency Medication Plan (midazolam or rectal valium)

Words in this book

Community

A group of people who live in the same area or like doing the same things

Epilepsy

People who have epilepsy have seizures

Home

Where people live, keep things and sleep

Job

Work people do, sometimes for money

Medication

Medicine that a doctor gives to people

Safety

When you are safe and okay. When things can't hurt you

Seizures

The messages in your brain get all mixed up for a short time

Side effects

When medication makes you feel unwell

Trigger

Something that can make a seizure happen

This publication is part of a suite of resources for people living with epilepsy and a cognitive disability, and all those who support them.

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