



# All about epilepsy

## Booklet 3: Living with epilepsy



Supported by UCB

# Contents

# Page



Telling people you have epilepsy

**1**



Forgetting things

**2**



Keeping yourself safe

**3**



Driving a vehicle

**9**



Getting the bus

**10**



Going to school or college

**11**



Getting out and meeting people

**12**



Having epilepsy at work

**13**

# Contents

# Page



Getting help with money

16



Drinking alcohol

17



Doing exercise

18



Having sex

19



Having a baby

20



Feeling down

22



Groups for people with epilepsy

23



More information about epilepsy

25

# Telling people you have epilepsy



You don't need to tell anyone you have epilepsy, if you don't want to.

You might need to tell the people who support you.



This could be your family, your partner, a friend, a support worker or a teacher.



It is not always easy to talk about having epilepsy. It might make you feel upset.



You should talk to people you know well and trust.

They can support you until you feel better about your epilepsy.

## Forgetting things



Having epilepsy can make you forget things.

This is because seizures stop information from going into your brain.



You may not remember anything that happened before a seizure, while it was happening or after it finished.

For example, you may not remember what you had for breakfast.



If you have lots of seizures, you might find it hard to remember things from when you were young.



Talk to your doctor if you need help with this.

## Keeping yourself safe



When you have a seizure, you could hurt yourself. There are lots of things you can do to stay safe.

### Take your medicine

You should always take your medicine. If you forget it, you could have a seizure.



### When you go swimming

When you go swimming, you should take someone with you. They can help you if you have a seizure.



You should only swim in a swimming pool with lifeguards. They can stop you from drowning if you have a seizure.



If you have a lot of seizures, it might be safer not to swim.



## Riding a bike



To keep yourself safe when you ride a bike, you should:

- always wear a helmet. This will protect your head if you have a seizure and fall off your bike
- take someone with you. They can help you if you have a seizure
- try not to ride on busy roads or near water. This could be dangerous if you have a seizure and fall off your bike





## If you feel unwell

When you feel unwell, you are more likely to have a seizure.



If you feel unwell, you should:

- stay at home if you can
- tell someone so they can look after you



- stop doing things like ironing or cooking until you feel better.



This is in case you have a seizure and burn or cut yourself



## Keeping safe at home

Some things you can do to keep safe when you are at home include:



- use a microwave instead of a cooker. This is safer in case you have a seizure



- use a trolley to carry hot food or a hot drink.

This will stop you from burning yourself if you have a seizure



- use a cup with a plastic lid. The lid will stop the hot drink spilling and burning you



- take a shower, not a bath, especially if you are alone.

If you have a bath, you could drown if you have a seizure

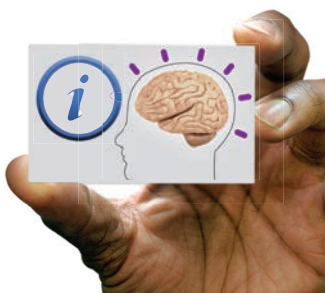


- do not smoke inside your house. If you have a seizure, this could cause a fire



- ask your nurse about an **epilepsy alarm**. If you have a seizure, the alarm can call someone for you.

That person can make sure you are ok and not alone



## Carry information about your epilepsy with you

You can carry information about your epilepsy with you when you go out and about.



This might include what medicine you take and who to contact if you have a seizure.



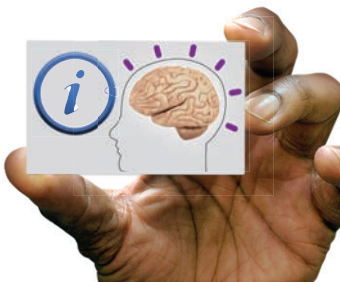
This will help if someone needs to call an ambulance for you.

It gives hospital staff important information about your epilepsy

There are different ways you can carry your information:



- you can wear a necklace or wristband that says you have epilepsy



- you can also take a small card with you when you go out.

This card tells someone you have epilepsy.

 epilepsy scotland



You can get this card from Epilepsy Scotland. It is free.

## Driving a vehicle



A **vehicle** is things like a car, bus, van, or a motorbike.



You **cannot** drive a vehicle if you have seizures. This is because it is not safe.



Some people are allowed to drive again if their seizures have stopped for 1 year.



You might not be allowed to drive if you have other health problems or a learning disability.

Everybody needs to be safe when driving a vehicle.

## Getting the bus



You can get a free bus pass if you have seizures. This means you do not have to pay when you get on the bus.



You may also get a free bus pass if you have other health problems or a learning disability.



If you need help getting a free bus pass, you can phone us on:

**0808 800 2200**



We are open on Monday to Friday from 10am to 4.30pm.

## Going to school or college



Sometimes having epilepsy makes it harder to learn and remember things.



You might need extra support to help you with your learning.



Your school or college should talk to you and find out what extra support you need.

# Getting out and meeting people



Having epilepsy should not stop you from doing things you enjoy and that are important to you.

You can still do lots of fun things like:



- going to the cinema



- meeting up with friends



- going for something to eat



If you have a lot of seizures, you may need to take someone with you.

This could be a friend, family member or support worker.

# Having epilepsy at work



If you have lots of seizures, you might need to be careful what job you do.

This is to stop you from hurting yourself.



For example, you might not be allowed to go up a ladder or use some machines.



The law says you should have the same chances in life as people who do not have epilepsy.



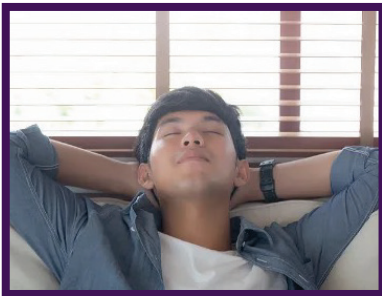
Your boss should talk to you to find out what support you need at work.



They may need to make some changes to your job. Things like:



- letting you start work at a later time. This might be if your epilepsy makes you feel tired in the mornings



- quiet places to rest after a seizure



- making sure there are other people around when you are at work.

This means there is always someone there to help you if you have a seizure



These changes are called **reasonable adjustments**. They will help you stay in your job.



If you feel you are not being treated fairly at work, you should talk to someone. You can:



- phone us on:  
**0808 800 2200**



We are open on Monday to Friday from 10am to 4.30pm.



- go to your local **Citizens Advice Bureau**



- phone an organisation called **ACAS**. They give advice to people who have problems at work.

You can phone ACAS on:  
**0300 123 1100**

# Getting help with money



If you have epilepsy, you might be able to get **benefits**. This is money from the government.

It can help to pay your bills.



You can often get benefits if you cannot work or you have a disability.

If you need help with getting benefits, you can:



- speak to your local Citizens Advice Bureau

or

- we can tell you what benefits you can get. You can phone us on: **0141 427 4911**



We can also help you to fill in any forms.

## Drinking alcohol



Your doctor will tell you if it is safe to drink alcohol.

This is because some medicines for epilepsy might make you sick if you drink alcohol.



Drinking alcohol can also stop your medicine from working properly. This means you might have more seizures.



If your doctor says it is ok to drink alcohol, you should only drink a small amount.



If you drink a lot of alcohol, you might have a seizure.



You might also have a **hangover**. This is when you feel ill after drinking alcohol.



If you have a hangover, you might forget to take your medicine. This could give you a seizure.

## Doing exercise



Exercise is good for you. It keeps you healthy and makes you feel good.



If you have a lot of seizures, you might need to take someone with you.

This should be someone who knows what to do if you have a seizure.

## Having sex



You can still have sex if you have epilepsy.



Some people may worry about having a seizure while they are having sex.



But this might only happen if you are feeling stressed about having sex.



Your doctor will also talk to you about **contraception**.

**Contraception** is things you can use so you can have sex and not get pregnant. Things like condoms or a tablet.

## Having a baby



If you want to have a baby, you should speak to your doctor.



There are some medicines you should not take while you are pregnant.

This is because they can make your baby poorly.



Your doctor might change your medicine before you become pregnant.

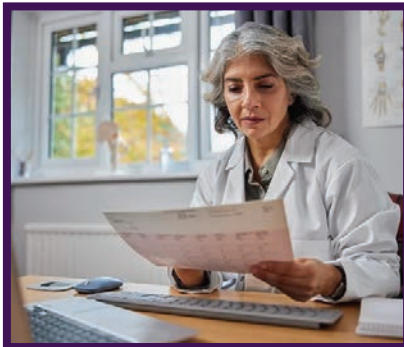


You can have a healthy pregnancy and baby even though you have epilepsy.



Your doctor or **epilepsy specialist nurse** will keep an eye on you and your baby while you are pregnant.

This is to make sure you and your baby are well.

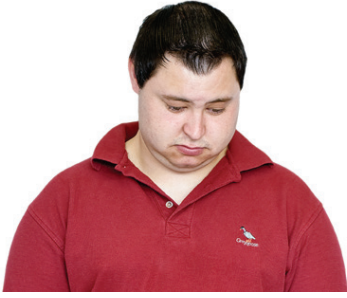


**Epilepsy specialist nurse**

An **epilepsy specialist nurse** is someone who has lots of training and supports people with epilepsy.



## Feeling down



Some people feel down or stressed because they have epilepsy.



If you feel like this, you should talk to someone about how you feel. This can often make you feel better.



You can speak to your doctor or epilepsy specialist nurse.

**Or**



Phone us on:  
**0808 800 2200**

We are open on Monday to Friday from 10am to 4.30pm.



We will listen to you. We can also answer any questions you have about epilepsy.

## Groups for people with epilepsy



There are some groups where you can meet other people with epilepsy.

You can share your experiences about epilepsy and support each other.



Some groups are online, or on Facebook. This means you can join in wherever you live.



At Epilepsy Scotland, we have a support group for people with epilepsy.

They meet once a month on Zoom.



We also have a **private** Facebook group. This is where people with epilepsy can talk about their epilepsy and ask questions.



**Private** means only the people who join the group can see what you post.



Phone us to find out if there is a group near you:

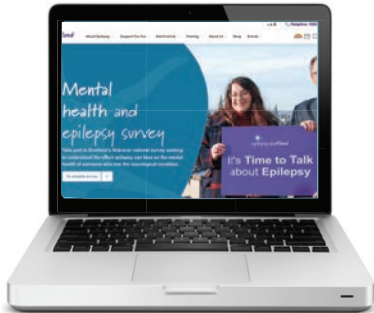
**0808 800 2200**



You can also email us at:

**[contact@epilepsyscotland.org.uk](mailto:contact@epilepsyscotland.org.uk)**

## More information about epilepsy



We have lots of information about epilepsy on our website:

**[www.epilepsyscotland.org.uk](http://www.epilepsyscotland.org.uk)**



We also have more easy read leaflets about epilepsy. We can send you copies of the leaflets in the post.



You can phone us to ask for a leaflet on:

**0808 800 2200**



Or email us at:

**[contact@epilepsyscotland.org.uk](mailto:contact@epilepsyscotland.org.uk)**

Copyright 2023

Charity Number: SC000067

We worked on this easy read with [easyreaduk.co.uk](http://easyreaduk.co.uk)