

# A woman's guide to epilepsy



Epilepsy Action and NHS Tayside –  
working together to support  
people with epilepsy.

Epilepsy Action aims to improve the quality of life and promote the interests of people living with epilepsy.

## Our work...

- We provide information to anyone with an interest in epilepsy.
- We improve the understanding of epilepsy in schools and raise educational standards.
- We work to give people with epilepsy a fair chance of finding and keeping a job.
- We raise standards of care through contact with doctors, nurses, social workers, government and other organisations.
- We promote equality of access to quality care.

Epilepsy Action has local branches in most parts of the UK. Each branch offers support to local people and raises money to help ensure our work can continue.

## Join us...

You can help us in our vital work by becoming a member. All members receive our magazine *Epilepsy Today*, free cover under our unique personal accident insurance scheme and access to our services and conferences.

“Our vision is to live in a society where everyone understands epilepsy and where attitudes towards the condition are based on fact not fiction”

*Epilepsy Action, vision statement*

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## **Word list:**

**AEDs** – anti-epileptic drug(s)

**HRT** – Hormone replacement therapy

**PCOS** – Polycystic ovary syndrome





## Introduction

Epilepsy affects around 230,000 women in the UK. As a woman with epilepsy, you may have lots of questions. Does epilepsy affect my periods? Which type of contraception can I use? Can I take HRT? The aim of this booklet is to answer these questions and more.

There is a separate booklet available called *Epilepsy and having a baby*. If you would like a copy, please contact Epilepsy Action. Alternatively, you can find the information on our website at [www.epilepsy.org.uk/info/women](http://www.epilepsy.org.uk/info/women)

If you have any further questions about anything to do with epilepsy, you could speak to an adviser on the Epilepsy Helpline, freephone 0808 800 5050. You can also contact your GP, epilepsy specialist, or epilepsy specialist nurse.

Further information on all the topics covered in this booklet is available from Epilepsy Action.



## About epilepsy and seizures

Epilepsy is a condition which affects the brain. If you have epilepsy, it means that you may sometimes have seizures (also called fits).

There are many types of seizure and each person will experience epilepsy in a way that is unique to them. For example, some people lose consciousness during a seizure but other people don't. Some people experience strange sensations, or parts of their body might twitch or jerk. Other people fall to the floor and convulse (when they jerk violently, due to their muscles tightening and relaxing in turn).

Seizures usually last between a few seconds and several minutes. After a seizure, the person's brain and body will usually return to normal.

Some people only ever have seizures when they are awake. Other people only ever have seizures when they are asleep. Some people have a mixture of both.

*More information about seizure types and symptoms is available from Epilepsy Action.*

# Periods (the menstrual cycle)

- Periods and epilepsy
- Polycystic ovary syndrome
- Seizures and your menstrual cycle
- Premenstrual tension

## Periods and epilepsy

Your menstrual cycle starts on the first day of your period and ends on the day before your next period starts. Most women have a menstrual cycle of between 24 and 35 days. The average is 28 days. If you have epilepsy, you might find that your periods happen more often than every 24 days or less often than every 35 days.

Many women have regular periods, so the number of days between the start of one period and the start of the next is the same each time. Some women have irregular periods. The number of days between the start of each period can be different each time. Some women have periods very rarely. If you have irregular periods, it can make it harder for you to get pregnant.

Any woman can have irregular periods. However, they seem to be slightly more common in women with epilepsy, especially women who have frequent seizures. Irregular periods may be caused by epilepsy itself, seizure patterns or anti-epileptic drugs (AEDs).

If you have irregular periods, it would be a good idea to talk to your doctor. They will look into all the possible reasons for this and try to find ways to help you have regular periods.



## Polycystic ovary syndrome

In a small number of women, irregular periods are caused by a medical condition called polycystic ovary syndrome (PCOS). Women with PCOS have lots of tiny cysts on their ovaries and unusual hormone levels. This makes it difficult for them to get pregnant. Other possible symptoms of PCOS include weight gain, acne and excess body and facial hair.

If you have temporal lobe epilepsy, or take the AED sodium valproate, there is slightly more chance that you will develop PCOS than other women. There is even more chance if you have taken sodium valproate from a young age. However, if sodium valproate is the cause of the PCOS, the PCOS goes away when you stop taking sodium valproate.

It is worth talking to your doctor if you notice any of the following.

- Your periods are often less than 21 days apart
- Your periods are often more than 35 days apart
- Your periods last longer than seven days

Your doctor can look into the possible causes, which include PCOS. They can then suggest treatments that may help you to have more regular periods.

If you do have PCOS, your doctor may advise you to change your AEDs. Or they may suggest you take the combined oral contraceptive pill, which may help to prevent PCOS.

It is very important that you do not stop taking your AEDs without getting advice from your doctor. This could cause you to have more seizures.

## Seizures and your menstrual cycle

You may notice that you have more seizures than usual at certain times of your menstrual cycle. This could be at the start of your period, around the middle of your menstrual cycle, or in the week before your period. These seizures could be caused by the changing levels of hormones in your body. When there is a link between your menstrual cycle and your tendency to have seizures, it is called catamenial epilepsy.

If you think you may have catamenial epilepsy, it would be a good idea to keep a seizure diary for three months. This would help you and your doctor to see if there is a pattern. If there is, your doctor can discuss possible treatments with you. One possible treatment is the drug clobazam (Frisium). This can be taken as well as your usual AEDs, but just on the days when you are at a higher risk of having seizures.

## Premenstrual tension

It's not unusual for any woman to feel moody, bloated, stressed and anxious in the days leading up to her period. This is known as premenstrual tension (PMT). Some people with epilepsy find that feeling stressed or anxious makes them more likely to have seizures. If this applies to you and your PMT causes you to feel stressed or anxious, you might notice that you have more seizures when you have PMT.



## Sex life

Sex and epilepsy

Seizures during sex

Sexual problems

## Sex and epilepsy

Many people with epilepsy have normal sexual relationships. However, it's not unusual to worry that your epilepsy might affect your sex life. We hope the following information will help.

## Seizures during sex

Some women worry that they will have a seizure when they are having sex. In fact, you are no more likely to have a seizure during sex than at any other time.

## Sexual problems

Any woman may have problems with sex from time to time. These may include problems getting aroused or having little interest in sex.

Here are some common causes of sexual problems that can affect anyone.

- Stress
- Illness
- Tiredness
- Alcohol

Here are some more possible causes of sexual problems if you have epilepsy.

- Your own feelings about your epilepsy might make you lose interest in sex.
- You might be taking certain AEDs which can cause some women to have less interest in sex.
- Your seizures might affect the way that your body releases hormones that affect your sexual responses.

If you have any worries about your sex life, you are not alone. It's really worth talking to your GP. Your GP may suggest treatments which may help. If your GP feels that your epilepsy or AEDs are causing your problems, they may refer you to see an epilepsy specialist. The epilepsy specialist may make changes to your AEDs to see if that can help.

If your GP thinks that your problems are connected to how you are feeling, they may refer you to a relationship therapist or psychologist.



## Contraception

### Contraception and epilepsy

Why natural birth control isn't recommended for women with epilepsy

### Contraception and epilepsy

If you are sexually active and want to avoid getting pregnant, it's important to find a form of contraception that works well for you. If you take AEDs, some types of contraception will not work as well for you as for other women. For example some AEDs reduce how well the Pill works. This could lead to an unplanned pregnancy.

These types of contraception are not affected by epilepsy or AEDs.

- Condoms
- Diaphragms and caps
- Femidoms
- The coil
- The Mirena coil
- Depot injections of progesterone

The advice about epilepsy and contraception changes from time-to-time. This is because research is always being carried out, which brings about new information. To make sure that you get the most up-to-date information about which types of contraception may be suitable for you if you have epilepsy, please contact Epilepsy Action. Alternatively, you can find the information at [www.epilepsy.org.uk/info/women/contraception](http://www.epilepsy.org.uk/info/women/contraception)

Your family doctor or staff at your local family planning clinic will also help you to choose the best contraception for you.



## Why natural birth control isn't recommended for women with epilepsy

Natural birth control methods involve you only having sex at the times of the month when you are least likely to get pregnant. They rely on you having regular periods and normal levels of hormones in your body. If you have epilepsy, natural birth control methods are not recommended for you. This is because epilepsy and AEDs may cause you to have irregular periods or have an effect on your hormone levels.

## Planning a pregnancy

Most women with epilepsy have healthy pregnancies and give birth to healthy babies. However, there is a small risk that having epilepsy or taking AEDs may affect the health of your unborn baby. This is why you are advised to plan your pregnancies, where possible. If you plan your pregnancy carefully, with advice from your epilepsy specialist or epilepsy specialist nurse, these risks may be lowered.

If you would like information about epilepsy and planning a pregnancy, please contact Epilepsy Action. Alternatively, you can find information on our website at [www.epilepsy.org.uk/info/women](http://www.epilepsy.org.uk/info/women)



## Bone health

Osteoporosis is a condition caused by loss of calcium in the bones. Calcium helps to make bones strong. When it is lost, bones become thinner, more brittle and can break more easily. Osteoporosis can happen to anyone, but it is more common in women than men, particularly after the menopause.

Some AEDs can make you more likely to have bone loss. These AEDs are carbamazepine, phenobarbital, phenytoin, primidone and sodium valproate.

If you have uncontrolled epilepsy, it's particularly helpful to be aware of the risks of osteoporosis. This is because if you fall when you have a seizure, there is more risk that thinner, brittle bones will break.

If you are concerned that you may be at risk of developing osteoporosis, it's a good idea to talk to your GP. They may refer you to hospital for a bone density scan. They may also suggest ways to look after your bones, such as taking vitamin supplements and exercising, if this is appropriate. HRT may also offer some protection against osteoporosis.

*More information about epilepsy and bone health is available from Epilepsy Action.*

# The menopause

The menopause affects every woman in different ways. This means that it's not possible to predict exactly how the menopause will affect each woman with epilepsy. There is a real need for more research into the possible effects of the menopause on women with epilepsy to be carried out.

## About the menopause

Every woman goes through the menopause. It's sometimes called 'the change of life'. Around the time of the menopause, your periods become less frequent and eventually stop altogether. Your body stops releasing eggs, which means that you are no longer able to get pregnant naturally. Among other symptoms, you may experience hot flushes and night sweats. You may also have difficulty sleeping. This can lead to poor concentration and general irritability.

## When the menopause happens

In the UK, most women reach the menopause around the age of 51. However it can happen earlier or later than this. If you have epilepsy, there is a possibility that you may go through the menopause about three years earlier than other women. There is more risk of this if you have frequent seizures or have had epilepsy for a long time.

## The menopause and seizures

Many women with epilepsy notice a change in their seizure pattern during or after the menopause. Some women have more seizures and some women may have fewer seizures.

If you have catamenial epilepsy (when your seizures follow a pattern that is connected to your periods), some research suggests that you might have more seizures than usual in the time leading up to the menopause. After the menopause, you might find that your seizures happen less often.



## Hormone replacement therapy

About hormone replacement therapy

Hormone replacement therapy and epilepsy

Hormone replacement therapy and seizures

Hormone replacement therapy and anti-epileptic drugs

### About hormone replacement therapy

Hormone replacement therapy (HRT) is a treatment that involves taking certain hormones. The aim of HRT is to reduce or stop symptoms of the menopause, such as hot flushes and night sweats. Many women do not take HRT, because their menopause symptoms are not severe. However, it can be helpful for women who find that the menopause is having a negative effect on their quality of life.

HRT is available in over 60 different forms, including oestrogen alone and oestrogen combined with a progestogen hormone, with or without the hormone testosterone.

### Hormone replacement therapy and epilepsy

There has been little research carried out into the effects of HRT on women with epilepsy. So at the moment, there is very little information available.

If you decide to try HRT, your doctor will help you decide which would be the best form for you. They will take your epilepsy and AEDs into consideration when making this decision.

### Hormone replacement therapy and seizures

HRT may not have any effect on the number of seizures you have. Or you may have more or fewer seizures than usual. If you have a history of catamenial epilepsy (when your seizures follow a pattern that is connected to your periods), a small amount of research suggests that you may be at a higher risk of more seizures when you take HRT.

### Hormone replacement therapy and anti-epileptic drugs

Before you start taking HRT, make sure that your doctor knows which AEDs you are taking. They will be able to check for any interactions between HRT and your AEDs.

At the moment, it's known that HRT can interact with the AED lamotrigine, lowering the levels of lamotrigine in the blood. This may increase the risk of seizures. If you take lamotrigine and wish to take HRT, your doctor should discuss these risks with you.

## Sources of further advice and information

Here are some organisations that offer advice and information about issues that affect women.

### **NHS Direct**

Tel: 0845 46 47

Website: [www.nhs.uk](http://www.nhs.uk)

### **National Osteoporosis Society,**

Tel: 0845 4500 230

Website: [www.nos.org.uk](http://www.nos.org.uk)

### **Relate**

Tel: 0300 100 1234

Website: [www.relate.org.uk](http://www.relate.org.uk)

### **Menopause matters**

Website: [www.menopausematters.co.uk](http://www.menopausematters.co.uk)

### **Family Planning Association**

Tel: 0845 122 8690

Website: [www.fpa.org.uk](http://www.fpa.org.uk)

## About this publication

This booklet is written by Epilepsy Action's advice and information team, with guidance and input from people living with epilepsy, and medical experts. If you would like to know where our information is from, or there is anything you would like to say about the booklet, please contact us.

Epilepsy Action makes every effort to ensure the accuracy of information in its publications but cannot be held liable for any actions taken based on this information.

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# First aid for tonic-clonic seizures

The person goes stiff, loses consciousness and falls to the floor

## Do...

- Protect the person from injury (remove harmful objects from nearby)
- Cushion their head
- Aid breathing by gently placing the person in the recovery position when the seizure has finished (see the pictures)
- Stay with them until recovery is complete
- Be calmly reassuring



## Don't...

- Restrain the person's movements
- Put anything in their mouth
- Try to move them unless they are in danger
- Give them anything to eat or drink until they are fully recovered
- Attempt to bring them round

## Call 999 for an ambulance if...

- You know it is the person's first seizure
- The seizure continues for more than five minutes
- One seizure follows another without the person regaining consciousness between seizures
- The person is injured
- You believe the person needs urgent medical attention

# First aid for focal seizures

The person is not aware of their surroundings or of what they are doing

## Some common symptoms

- Plucking at their clothes
- Smacking their lips
- Swallowing repeatedly
- Wandering around

## Do...

- Guide the person away from danger
- Stay with the person until recovery is complete
- Be calmly reassuring
- Explain anything that they may have missed

## Don't...

- Restrain the person
- Act in a way that could frighten them, such as making abrupt movements or shouting at them
- Assume the person is aware of what is happening, or what has happened
- Give the person anything to eat or drink until they are fully recovered
- Attempt to bring them round

## Call 999 for an ambulance if...

- You know it is the person's first seizure
- The seizure continues for more than five minutes
- The person is injured during the seizure
- You believe the person needs urgent medical attention

## Further information

If you have any questions about epilepsy, please contact the Epilepsy Helpline.

Epilepsy Action has a wide range of publications about many different aspects of epilepsy. Information is available in the following formats: booklets, fact sheets, posters, books, videos and DVDs.

Information is also available in large text.

Please contact Epilepsy Action to request your free information catalogue.

## Epilepsy Action's support services

**Local meetings:** a number of local branches offer support across England, Northern Ireland and Wales.

**forum4e:** our online community is for people with epilepsy and carers of people with epilepsy. For people aged 16 years or over. Join at [www.forum4e.com](http://www.forum4e.com)

**Epilepsy awareness:** Epilepsy Action has a number of trained volunteers who deliver epilepsy awareness sessions to any organisation that would like to learn more about the condition. The volunteers are able to offer a comprehensive introduction to epilepsy to a range of audiences.

If you would like more information about any of these services, please contact Epilepsy Action. Contact details are at the back of this booklet.

## A woman's guide to epilepsy

Please complete this form to tell us what you think of this publication.

How useful have you found this publication?

- Very useful     Useful     Quite useful     Not at all useful

Is the language clear and easy to understand?

- Very clear and easy to understand  
 Clear and easy to understand  
 Quite clear and easy to understand  
 Not at all clear or easy to understand

Does this publication cover all you want to know about the topic?

- Completely     Mostly     Not quite     Not at all

What do you think of the design and general layout of this publication?

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**epilepsy** *action*

**Epilepsy Action**  
**FREEPOST LS0995**  
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**LS19 7YY**

Registered charity in England (No. 234343)

## How to contact the Epilepsy Helpline

Telephone the Epilepsy Helpline freephone **0808 800 5050**

Monday to Thursday 9.00 am to 4.30 pm Friday 9.00 am to 4.00 pm

Our helpline staff are Typetalk trained

Write to us free of charge at **FREEPOST LS0995, Leeds, LS19 7YY**

Email us at **helpline@epilepsy.org.uk** or visit our website:

**www.epilepsy.org.uk**

Text your enquiry to **07797 805 390**

Send a Tweet to **@epilepsyadvice**

## About the Epilepsy Helpline

The helpline is able to offer advice and information in 150 languages.

We provide confidential advice and information to anyone living with epilepsy but we will not tell them what to do. We can give general medical information but cannot offer a medical diagnosis or suggest treatment. We can give general information on legal and welfare benefit issues specifically related to epilepsy. We cannot, however, take up people's cases on their behalf.

Our staff are trained advisers with an extensive knowledge of epilepsy related issues. Where we cannot help directly, we will do our best to provide contact details of another service or organisation better able to help with the query. In doing this, Epilepsy Action is not making a recommendation.

We welcome comments, both positive and negative, about our services.

To ensure the quality of our services we may monitor calls to the helpline.

**Epilepsy Helpline: freephone 0808 800 5050**

[www.epilepsy.org.uk](http://www.epilepsy.org.uk)



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### **Environmental statement**

All Epilepsy Action booklets are printed on environmentally friendly, low-chlorine bleached paper. All paper used to make this booklet is from sustainable forests.

