Epilepsy Action – together we can change lives

Together we can help more people gain the knowledge and confidence to live better with epilepsy. We can raise awareness, so that more people understand epilepsy.

Together we can:

• Provide expert information and advice, so everyone affected by epilepsy can get the support they need to live better with epilepsy
• Run local events and support groups, so that fewer people have to face epilepsy alone
• Campaign to help make sure health services and national policies take into account the needs of everyone living with epilepsy

It’s only your support that can make this life-changing work possible.

Please donate today.

You can call the Epilepsy Action fundraising team on 0113 210 8851 or donate online at epilepsy.org.uk/donate
You can also stay up-to-date with all the latest epilepsy news and information by joining Epilepsy Action. Membership starts from just £1 a month - join today by calling 0113 210 8800 or sign up online at epilepsy.org.uk/join

Thank you.
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Introduction

Around 275,000 women in the UK have epilepsy. As a woman with epilepsy, you might have some questions, such as:

- Does epilepsy affect my periods?
- What types of contraception can I use?
- Can I have a baby?
- Can I use hormone replacement therapy (HRT)?

We hope this information will answer these questions and more.

If you have any further questions about anything to do with epilepsy, contact Epilepsy Action.
Will epilepsy affect my periods?

Your menstrual cycle starts on the first day of your period and ends on the day before your next period. Most women have a menstrual cycle of between 24 and 35 days and ovulate (release an egg) around 10-16 days before their next period.

Your menstrual cycle can be affected by many things including your age, your epilepsy, the number of seizures you have, or your epilepsy medicine. Some women with epilepsy find that their periods don’t follow a pattern, or happen very rarely.

If your periods don’t follow a pattern, happen rarely, or are very heavy, it’s a good idea to talk to your GP. If they feel your epilepsy medicine could be affecting your menstrual cycle, they might refer you to an epilepsy specialist, or gynaecologist.
Will my menstrual cycle affect my epilepsy?

Some women with epilepsy find their menstrual cycle has an effect on their seizures.

Catamenial epilepsy

You might have more seizures than usual at certain times in your menstrual cycle. This could be at the start of your period, around the middle of your cycle (when you ovulate) or in the week before your period. When changes in the hormones that control your menstrual cycle cause you to have more seizures, it’s called catamenial or cyclical epilepsy.

If you think you may have catamenial epilepsy, try keeping a diary for three months, to see if there is a clear pattern. If there is, your doctor might prescribe a drug such as clobazam (Frisium). Clobazam is taken as well as your usual epilepsy medicine, but just on the days when you are at risk of having seizures.

Premenstrual tension

Premenstrual tension (PMT) affects many women. It can make you feel moody, bloated, stressed and anxious in the days leading up to your period. If PMT makes you feel stressed or anxious, you might notice that you have more seizures at this time.
**Will I be able to get pregnant?**

Most women with epilepsy can get pregnant. So if you are having sex and don’t want to get pregnant, it’s important to use contraception.
If you decide you would like to have children, you have a very good chance of getting pregnant. Most women will get pregnant in the first year of trying. But if you’ve been trying to get pregnant for a while, and it hasn’t happened, talk to your doctor. They can look into the possible reasons for you and your partner and, if needed, suggest treatment.

If you have reduced fertility, you might be offered hormone based drugs to help you get pregnant.

**Polycystic ovary syndrome**

Polycystic ovary syndrome (PCOS) is a condition that causes cysts on the ovaries, and unusual hormone levels. If you have PCOS, it can stop you from ovulating (releasing an egg) every month, and make it difficult for you to get pregnant. You might also have other symptoms, such as hair loss, weight gain, acne and excess facial hair.

Any woman can be affected by PCOS, but studies suggest it’s more common in women with epilepsy. It also seems to be more common in women taking sodium valproate. If you are concerned that you might have PCOS, talk to your doctor. With treatment, most women with PCOS are able to get pregnant.

You might be worried that your epilepsy medicine is causing PCOS, but it’s important not to stop taking it without speaking with your doctor. If you suddenly stop taking epilepsy medicine, it could cause you to have more seizures, or they might become more severe.
Will having epilepsy affect my sex life?

Most women with epilepsy can have a healthy sex life.

Seizures during sex

Some women say they worry about having a seizure during sex. If you do notice an increase in seizures relating to sex, it’s worth talking to your doctor.
Sexual problems

Any woman can have problems with sex from time to time. These can include problems getting aroused, having an orgasm, or having little interest in sex.

These are some common causes of sexual problems that can affect any woman:

• Stress
• Illness
• Tiredness
• Alcohol

If you have epilepsy and are having sexual problems these could also be related to your epilepsy medicine, or the way your seizures affect your hormones.

It’s worth talking to your GP if you have any concerns about your sex life. They can look for physical or other causes for your problems. Depending on what they find, they may be able to refer you for treatment or talking therapies, such as counselling or cognitive behaviour therapy.

More information about sexual problems and counselling and cognitive behaviour therapy is available from the NHS website: nhs.uk
What contraception can I use?

Your choice of contraception will depend on which epilepsy medicine you take, and your own preference. Advice about epilepsy and contraception changes from time to time, as research brings about new information. For up-to-date, comprehensive information go to: epilepsy.org.uk/contraception

Your GP or staff at your sexual health clinic will also be able to help you choose the contraception that’s right for you.
How do I plan to have a baby?

It’s recommended that all women with epilepsy have pre-conception counselling, before they become pregnant. This is because having epilepsy and taking epilepsy medicines can increase your risk of having a baby with a birth problem. Getting specialist support at the right time, particularly if you are at risk of an unplanned pregnancy, may reduce these risks.

If you are having sex and not using contraception you are at risk of unplanned pregnancy. Contraception can help you plan pregnancy by giving you time to get support from your specialist.

Epilepsy Action has more information about planning for a baby, getting pregnant and giving birth at epilepsy.org.uk/babies
Information about sodium valproate and pregnancy

Valproate medicines (brand names: Epilim, Epilim Chrono, Epilim Chronosphere, Episenta, Epival, Depakote, Convulex, Kentlim, Syonell and Valpal) can seriously harm an unborn baby.

You are advised to use effective contraception at all times while taking valproate. You should be seen by an epilepsy specialist at least yearly to go through a risk acknowledgement form. If you are thinking about becoming pregnant, or you become pregnant, talk to your GP or specialist straight away.

If you do get pregnant unexpectedly, don’t stop taking your epilepsy medicine. Instead, talk to your doctor as soon as possible to get the help and advice you need.

Epilepsy Action has more information about sodium valproate risks in pregnancy at epilepsy.org.uk/valproatepregnancy
Will my epilepsy medicines affect my bones?

Some people who take epilepsy medicines are at risk of decreased bone mineral density. This condition is called osteoporosis and osteopenia. It’s a condition that can weaken bones, making them fragile and more likely to break. It can happen over a period of time.

You can improve bone health with exercise, healthy eating and safe exposure to sunlight. Some people may also benefit from vitamin D and calcium supplements. If you are concerned about your epilepsy medicines affecting your bone health, speak to your doctor. Don’t stop taking your medicines, as this could cause you to have more, or more severe, seizures.

Epilepsy Action has more information about bone health and epilepsy at epilepsy.org.uk/bonehealth
About the menopause

The menopause is when you stop having periods. It is sometimes called ‘the change of life.’ As you get near to the menopause your periods may happen less often.

Around the time of the menopause you might have hot flushes, night sweats, and trouble sleeping. Poor quality sleep can cause poor concentration and make you feel irritable.

When does the menopause happen?

In the UK, most women reach the menopause around the age of 51. If you have had frequent seizures with your epilepsy, you could have the menopause a few years earlier than this.

The menopause and seizures

You may notice a change in your seizure pattern around the time of the menopause. It’s often difficult to predict how seizures will change - you might have more seizures, or you might have fewer.

Catamenial (cyclical) epilepsy is when seizures follow a pattern related to the cycle of your periods. Women with this type of epilepsy may have more seizures in the run up to and during their menopause. But after the menopause, they often have less.
Can I take hormone replacement therapy (HRT)?

HRT involves using hormone treatment to control the hot flushes and night sweats that some women experience during the menopause. It is helpful for women who find that the symptoms of the menopause are worsening their quality of life.

HRT comes in many different forms. Oestrogen alone is used in women who have had a hysterectomy (operation to remove their womb). In women who have not had a hysterectomy, a synthetic progestogen hormone, or natural progesterone is added to protect the lining of the womb from overgrowing.

Some women have told us they’ve had more seizures than usual when taking HRT. There have only been a very small number of studies looking at HRT and epilepsy. So, at the moment, there’s not enough evidence to say that HRT can trigger seizures. More research is needed.

If you decide to try HRT, your doctor should help you consider the best type, or they may refer you to a specialist for advice.

For more information about HRT and the menopause, see the British Menopause Society’s website: thebms.org
## Sources of further advice and information

### NHS and HSC

**England:** NHS website  
Website: nhs.uk

**Northern Ireland:** Health and Social Care (HSC) Online  
Website: online.hscni.net

**Scotland:** NHS Inform  
Tel: 0800 22 44 88  
Website: nhsinform.scot

**Wales:** NHS Direct Wales Tel: 0845 46 47 or 111  
Website: nhsdirect.wales.nhs.uk

### Sexual Health Helpline

Tel: 0300 123 7123

### Menopause Matters

Website: menopausematters.co.uk

### Royal Osteoporosis Society

Website: theros.org.uk  
Osteoporosis Helpline: 0808 800 0035
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 else you would like to say about this booklet, please contact us.

To find out why you can trust Epilepsy Action’s information, please contact us or visit epilepsy.org.uk/trust

Date: July 2020
Due for review: July 2023
Code: B017.07

Our thanks

Epilepsy Action would like to thank Dr Janine Winterbottom, advanced nurse specialist in epilepsy at the Walton Centre NHS Foundation Trust, for her contribution to this information.

Dr Janine Winterbottom has declared no conflict of interest.

Disclaimer

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.
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 on their side (in the recovery position) when the seizure has finished (see picture)
• 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 or
• The seizure continues for more than five minutes or
• One seizure follows another without the person regaining consciousness between seizures or
• The person is injured or
• You believe the person needs urgent medical attention
First aid for focal (partial) seizures

The person is not aware of their surroundings or of what they are doing. They may pluck at their clothes, smack their lips, swallow repeatedly or wander 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 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 or
• The seizure continues for more than five minutes or
• The person is injured or
• You believe the person needs urgent medical attention

Epilepsy Action has information on what to do if someone has a seizure in a wheelchair.
Further information

If you have any questions about epilepsy, please contact the Epilepsy Action 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 and DVDs.

Information is also available in large text.

Please contact Epilepsy Action to request your free information catalogue. Or download a copy at epilepsy.org.uk/catalogue

Epilepsy Action’s support services

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

Coffee and chat groups: these give people living with epilepsy the chance to meet new people, share experiences and learn more about life with epilepsy.

forum4e: our online community is for people with epilepsy and carers of people with epilepsy. You have to be aged 16 or over to join. Go to forum.epilepsy.org.uk

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 epilepsy. 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.
Women with epilepsy

We would like to know if you have found this booklet helpful.

As a result of reading the information, please let us know if you agree (tick yes) or disagree (tick no) with any of the following statements.

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Please tell us how you think we can improve this information

____________________________________________________________________________________________________
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Please return the completed form to:
FREEPOST RTGS-LEYK-XGCK, Epilepsy Services, Epilepsy Action, New Anstey House, Gate Way Drive, Yeadon, Leeds LS19 7XY

You can also give us feedback online. Visit epilepsy.org.uk/feedback

Thank you.
FREEPOST RTGS-LEYK-XGCK,
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Registered charity in England and Wales (No. 234343)
Ways to contact the Epilepsy Action Helpline

📞 freephone 0808 800 5050
We are usually open 8.30am to 8pm, Monday to Thursday, 8.30am to 4.30pm on Friday and 10am to 4pm on Saturday. Our helpline staff are Text Relay trained and we are able to offer advice and information in 150 languages. To ensure the quality of our service, we may monitor calls.

📧 helpline@epilepsy.org.uk
Email us your question about epilepsy. We aim to reply within 48 hours (on work days)

☎ 0747 963 8071
Text us and we aim to send a text reply back to your phone within 24 hours (on work days)

📍 New Anstey House, Gate Way Drive, Yeadon, Leeds, LS19 7XY
Write to us and we aim to reply within seven working days

About the Epilepsy Action Helpline

We do:
• Provide confidential advice and information about epilepsy to anyone
• Give general medical information
• Give general information on legal and welfare benefit issues related to epilepsy

We do not:
• Tell people what to do
• Offer a medical diagnosis or suggest treatment
• Take up people’s legal cases on their behalf

If we cannot help you directly with a query, we will do our best to provide details of other organisations that may be able to help. In doing this, Epilepsy Action is not making a recommendation.

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