Women with epilepsy

epilepsy.org.uk
Epilepsy Action Helpline: 0808 800 5050
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 donations like yours that make this life-changing work possible.

Please donate today.

Text ACT NOW to 70700 to give £5 (message will cost £5 plus your usual cost of sending a text, Epilepsy Action will receive 100% of your donation).

You can also join Epilepsy Action and add your voice to the UK’s biggest epilepsy movement. Together we can campaign for change, support each other and fight for a better future.

Find out more by calling the Epilepsy Action membership team on 0113 210 8800 or visit epilepsy.org.uk/join
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Introduction

Around 275,000 women in the UK have epilepsy. As a woman with epilepsy, you might have some concerns 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)?

The aim of this information is to answer these questions and more.

If you would like more detailed information about planning a pregnancy and having and caring for a baby, please contact Epilepsy Action.

If you have any further questions about anything to do with epilepsy, you can speak to an adviser on the Epilepsy Action Helpline, freephone 0808 800 5050.
Periods (the menstrual cycle)

Does 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. If they have sex, this is the time of the month when they are most likely to get pregnant.

Your menstrual cycle can be affected by your epilepsy, the number of seizures you have, your age or your epilepsy medicine. Some women with epilepsy find that their periods don’t follow a pattern, or happen very rarely. This can make it difficult to work out when you have the best chance of getting pregnant.

If your periods don’t follow a pattern, happen rarely, or are very heavy, it’s a good idea to talk to your GP. They might give you advice about your lifestyle or suggest you have some blood tests. If they feel your epilepsy medicine could be affecting your menstrual cycle, they might refer you to an epilepsy specialist.
Epilepsy and fertility

Fewer women with epilepsy become pregnant than women without epilepsy. This might be because they have chosen not to. Or there might be other reasons, such as:

• They may have less interest in sex
• They may have irregular periods
• They may have polycystic ovary syndrome

Polycystic ovary syndrome

If you have polycystic ovary syndrome (PCOS), you have cysts on your ovaries and unusual hormone levels. This might stop you from ovulating (releasing an egg) every month, and will make it difficult for you to become pregnant. You might also have other symptoms with PCOS 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. There is some evidence to suggest that this is 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 you to have PCOS. However, it’s very important you don’t 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.

**Can having epilepsy affect my fertility?**

Women with epilepsy may have a slightly higher risk of reduced fertility than women who don’t have epilepsy. This means it might take them longer to get pregnant. If you have 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 treatment with hormone based drugs to help you get pregnant. Some women with epilepsy have said they have had more seizures than usual while taking these.
Seizures and your menstrual cycle

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 epilepsy. Some professionals call catamenial epilepsy cyclical epilepsy.

If you think you have catamenial epilepsy, try keeping a diary for three months, to see if there is a clear pattern. If there is, your doctor can look at possible treatments with you, such as a prescription for the drug 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) is something that affects many women. It can make you feel moody, bloated, stressed and anxious in the days leading up to your periods. Some women with epilepsy find that feeling stressed or anxious makes them more likely to have seizures. If PMT makes you feel stressed or anxious, you might notice that you have more seizures at this time.
Sex life

You might be worried that your epilepsy will affect your sex life, and for some people it will, but for many people it won’t.

Seizures during sex

Some women have told us they worry about having a seizure during sex. This is in fact rare. But if you 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 anyone:

• Stress
• Illness
• Tiredness
• Alcohol

If you have epilepsy and are having sexual problems these could also be related to:

• Your epilepsy medicine
• Anxiety about your seizures
• The way your seizures affect your hormones
If you have any concerns about your sex life, it’s worth talking to your family doctor. They can look for physical or other causes for your problems. If they think your problems relate to how you are feeling, they may be able to refer you for talking therapies such as counselling or cognitive behaviour therapy.

More information about counselling and cognitive behaviour therapy is available from the NHS Choices website: nhs.uk
**Contraception**

**Contraception and epilepsy**

At some time in their lives, most women need to think about their needs for contraception. Having epilepsy and taking epilepsy medicines can affect the choices available.

Natural birth control methods rely on accurately tracking your menstrual cycles, and not having sex when you identify that you are fertile. The two main methods are:

- The rhythm method
- The Persona method
The body’s hormone levels are an important part of using natural birth control.

Natural birth control methods are not recommended for any women with epilepsy. This is because some epilepsy medicines, and epilepsy itself, can affect hormone levels.

Some epilepsy medicines reduce how well the contraceptive and morning-after pills work, which could lead to an unplanned pregnancy.

The following forms of contraception are not affected by epilepsy, or epilepsy medicines:

- Intrauterine devices (IUD), also known as the coil
- Intrauterine systems (IUS)
- Contraceptive injections
- Barrier methods, such as diaphragms, caps and condoms

**Choosing a method of contraception**

Your choice of contraception will depend on which epilepsy medicine you take. And the 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 family doctor, or staff at your local family planning clinic will also help you to choose the contraception that’s right for you.
Planning a baby

Most women with epilepsy have healthy pregnancies and give birth to healthy babies. To have the best chance of having a healthy pregnancy, medical professionals advise you have pre-conception counselling before you become pregnant. This is because your epilepsy and epilepsy medicines might slightly increase your risk of having a baby with a birth problem. The risk varies, depending on the type, dose and epilepsy medicine you take. Getting specialist support at the right time, particularly if you are at risk of an unplanned pregnancy, may reduce these risks.
Information about sodium valproate

Research has shown that taking valproate medicine during pregnancy can harm your unborn child. Valproate medicines include sodium valproate (Epilim, Depakote) and valproic acid (Convulex). Taking valproate medicine during pregnancy can cause birth defects and problems with a child’s development and learning.

Doctors in the UK have been advised not to prescribe valproate to girls, women who could get pregnant, or women who are pregnant. If you fit into one of these groups, your doctor should only prescribe valproate to you if other epilepsy medicines do not suit you.

A valproate medicine may be the only epilepsy medicine that stops your seizures. Don’t stop taking it without advice from your family doctor, epilepsy specialist or nurse.

Epilepsy Action has separate information about everything women with epilepsy need to know about pregnancy, having a baby, and looking after young children.
**Osteoporosis**

Osteoporosis is a condition that affects the bones, causing them to become weak and fragile. Some women who take epilepsy medicines are at risk of osteoporosis, particularly if they have taken the following older epilepsy medicines long-term:

- Carbamazepine
- Phenobarbital
- Phenytoin
- Primidone
- Sodium valproate

Some people take newer epilepsy medicines, such as lamotrigine (Lamictal), oxcarbazepine (Trileptal), levetiracetam (Keppra) and gabapentin (Neurontin). At the moment, there’s not enough information to tell us whether or not the newer epilepsy medicines affect bone health.

If you are concerned about your epilepsy medicines affecting your bone health, speak to your doctor. Don’t stop taking your epilepsy medicines, as this could cause you to have more, or more severe, seizures.

Epilepsy Action has more information about osteoporosis and epilepsy.
The menopause and hormone replacement therapy (HRT)

About the menopause

Every woman goes through the menopause. It is the time of the last ever period and is sometimes called ‘the change of life.’ Leading up to the menopause your periods often happen less often. Around the time of the menopause you may have hot flushes, night sweats, and trouble sleeping. Poor quality sleep can cause poor concentration and make you feel irritable.
When the menopause happens

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

More information about the menopause is available from the NHS Choices website: nhs.uk

The menopause and seizures

You may notice a change in your seizure pattern around the time of the menopause. It is often difficult to predict how seizures will change. Some women have more seizures, and some women have fewer seizures. Catamenial (cyclical) epilepsy is when seizures follow a pattern that is 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.

About HRT

HRT involves taking hormone supplements to control the hot flushes and night sweats of the menopause. Many women don’t have severe menopausal symptoms, so don’t choose to take HRT. HRT 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. Oestrogens sometimes increase seizures. Natural progesterone generally reduces seizures.

**HRT the evidence**

There are not many studies looking at HRT and epilepsy, and all the studies have very small numbers of women. This means there is still not enough information about the risk of seizures when taking HRT. More research is needed.

**HRT and epilepsy medicines**

There may be effects of HRT on your epilepsy medicine. For example, HRT containing oestrogen can lower the levels of lamotrigine in the blood and increase the risk of seizures. If you take lamotrigine and want to take HRT, your doctor should discuss these risks with you.

If you decide to try HRT, your doctor may help you consider the best type for you, 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 Choices  Website: nhs.uk
Northern Ireland: Health and Social Care (HSC) in Northern Ireland  Website: hscni.net
Scotland: NHS Inform  Tel: 0800 22 44 88  Website: nhsinform.scot
Wales: NHS Direct Wales  Tel: 0845 46 47  Website: nhsdirect.wales.nhs.uk

Family Planning Association
Website: fpa.org.uk

Menopause Matters
Website: menopausematters.co.uk

National Osteoporosis Society
Tel: 0808 800 0035  Website: nos.org.uk

Acknowledgement
Epilepsy Action would like to thank Penny Burt, Nurse Specialist (Epilepsy), Dr Yvonne Hart, Consultant Neurologist, Newcastle Upon Tyne Hospitals NHS Foundation Trust, and Michael Marsh, Consultant Obstetrician and Gynaecologist, King’s College Hospital, for their contributions to this booklet.
Conflict of interest

The following interests have been declared:

Penny Burt has received sponsorship to attend epilepsy conferences from UCB Pharma, GlaxoSmithKline, Desitin and Eisai.

Yvonne Hart has received payments for lectures given, advisory work and/or sponsorship to attend epilepsy conferences from UCB Pharma, GlaxoSmithKline, Bial, Desitin and Eisai.

Epilepsy Action does not believe these interests have influenced the content of this booklet in any way.

Michael Marsh has declared no conflict of interest.

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.

Booklet number: B017.06
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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<td>I have talked to my employer/colleague/teacher/family/other (cross out those that don’t apply) and they have improved how well they support me</td>
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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.
Ways to contact the Epilepsy Action Helpline

**Telephone: freephone 0808 800 5050**
We are usually open 8.30am to 5.30pm, Monday to Friday. 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.

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

**Text: 0753 741 0044**
Text us and we aim to send a text reply back to your phone within 24 hours (on work days)

**Twitter: @epilepsyadvice**
Tweet us with your question and we will tweet back (on work days)

**Post: New Anstey House, Gateway Drive, 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.
Epilepsy Action Helpline:
freephone 0808 800 5050
epilepsy.org.uk

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A company limited by guarantee (registered in England No. 797997)
Registered charity in England (No. 234343)

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low-chlorine bleached paper. All paper used to make this booklet is
from well-managed forests.