Women with epilepsy

Introduction

Around 275,000 women in the UK have epilepsy.¹ 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.² 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

¹Calculated from: Joint Epilepsy Council 2011 Epilepsy prevalence, incidence and other statistics; p2
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
- Because of their epilepsy they don’t feel they could care for a child
- 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.³ There is some evidence to suggest that this is more common in women taking sodium valproate.⁴ If you are concerned that you might have PCOS, talk to your doctor. With treatment, most women with PCOS are able to get pregnant.⁵

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
- The way your seizures affect your hormones

Some people have told us that they are anxious about having seizures during sex.

---

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**

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.

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

- Intrauterine devices (IUD), also known as the coil

---


• Intrauterine systems (IUS) [Mirena is a brand name]
• Depot injections of progesterone
• Barrier methods, such as diaphragms, caps and condoms

**Further information about methods 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 a healthy baby.\(^{15}\) To have the best chance of having a healthy pregnancy, medical professionals advise you have pre-conception counselling before you become pregnant.\(^{16}\) 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.\(^{17}\)

**Information about sodium valproate**

The Medicines and Healthcare Products Regulation Agency (MHRA) have published detailed information about sodium valproate. If you are taking sodium valproate, or your doctor is considering prescribing sodium valproate for you, the MHRA advise you to read the Valproate patient guide along with the patient information leaflet. This is because they are advising that, if you are a woman capable of becoming pregnant, your doctor should only prescribe sodium valproate if nothing else works for you. See MHRA website: mhra.gov.uk

---


Sodium valproate 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 these older epilepsy medicines long-term:

- Carbamazepine
- Phenytoin
- Primidone
- Sodium valproate
- Phenobarbital

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 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.’ Before 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. 23

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

The menopause and seizures
You may notice a change in your seizures 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. 24 But after the menopause, they often have less. 25

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.\textsuperscript{26} Natural progesterone generally reduces seizures.\textsuperscript{27}

**HRT the evidence**

There are not many studies looking at HRT and epilepsy, and all of 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**

In some women, some types of HRT can cause them to have more seizures than usual.\textsuperscript{28} 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.\textsuperscript{29} 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 your, 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


About this information
This information was 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 information, please contact us at epilepsy.org.uk/feedback.

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

Date: February 2017 Due for review: February 2020 Code: B017.05

Our thanks
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.

Your support
We hope you have found this information helpful. As a charity, we rely on donations to provide our advice and information. If you would like to make a donation, here are some ways you can do this.

- Visit www.epilepsy.org.uk/donate
- Text ACT NOW to 70700 (This will cost you £5 plus your usual cost of sending a text. Epilepsy Action will receive £5.)
- Send a cheque payable to Epilepsy Action to the address below.
Did you know you can also become a member of Epilepsy Action from as little as £1 a month? To find out more, visit epilepsy.org.uk/join or call 0113 210 8800.

**Epilepsy Helpline**
Freephone 0808 800 5050, text 0753 741 0044, email helpline@epilepsy.org.uk, tweet @epilepsyadvice

**Contact details**
Epilepsy Action, Gate Way Drive, Yeadon, Leeds LS19 7XY, UK, +44 (0)113 210 8800. A registered charity (No. 234343) and company limited by guarantee (No. 797997) in England.
© Copyright Epilepsy Action 2017