

**epilepsy
society**

women

Issues for women





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This symbol means further information is available.

You can find any further updates at
epilepsysociety.org.uk/women

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helpline

01494 601 400

Confidential, national call rate.
Information and emotional support.

issues for women

Some issues around epilepsy and its treatment are specific to women, and do not apply in the same way to men. These include links between epilepsy and hormones, puberty, contraception, pregnancy, and the menopause.

In this leaflet when we talk about women, this also includes girls of childbearing age.

hormonal influences

Epilepsy can be different for everyone, and changing hormone levels in the body may affect some women and not others. Research has shown that, for some women with epilepsy, there may be a close link between hormones and epileptic seizures. Hormone levels change throughout a woman's life and may affect when her epilepsy starts, how often her seizures happen, and if and when she stops having seizures.



See our leaflet *seizures*.

Changes in hormone levels through a woman's life can make managing epilepsy different to how it is managed for men. It may also explain why treatment for epilepsy may need to change throughout a woman's life.

If you have questions about how hormones may affect your epilepsy, you may want to talk to your doctors or you might like to call our confidential helpline.



See opposite for contact details.

Oestrogen and progesterone are hormones naturally produced in a woman's body, which bring about sexual development, menstruation, and pregnancy. They can speed up or slow down brain activity and can affect when a woman has seizures.

Epilepsy and puberty

Puberty is the time in life when hormonal changes in the body cause sexual development to begin. It can also be a common time for epilepsy to start. During puberty, changes might also be happening in other areas of life, such as education and friendships. This can be a time when you don't want to feel different from your friends, and having epilepsy can be an added challenge.

Anti-epileptic drugs (AEDs) are usually taken to try and stop seizures from happening. As with any medication, AEDs can cause side effects in some people. Side effects may differ from one person to another.

Young women may be concerned about some possible side effects in particular. These include weight gain or weight loss, or side effects that can delay the start of periods, or affect the menstrual cycle. Some side effects can affect an unborn baby. This may not seem relevant for a young girl, but see the opposite page about sodium valproate.



See our booklets *medication for epilepsy*, and our booklet for young people, *your epilepsy – now and next*.

Sodium valproate – an important case

Sodium valproate (brand names include Epilim, Episenta and Epival) has greater risks in pregnancy than other AEDs, with 7 women in 100 (7%) having a baby with a major malformation, rising to 1 in 10 women (10%) if they take more than 1000mg (1g) per day.

Also, up to 4 children in 10 (up to 40%) whose mothers took sodium valproate have problems with development and learning.

The Medicines and Healthcare products Regulatory Agency (MHRA) states that sodium valproate should not be prescribed to girls or women who are pregnant, or who may become pregnant in future, **unless** it is the only effective drug for them and they are on a pregnancy prevention programme. They also recommend that treatment with sodium valproate should only be started by a doctor experienced in managing epilepsy.

If you are taking sodium valproate, do not suddenly stop taking it, but talk to your doctor as soon as possible about the best treatment options for you. Sodium valproate is an effective drug for epilepsy and, for some women, it is the best or only drug that controls their seizures.



See our leaflet *pregnancy and parenting*.



For more detail on the pregnancy prevention programme, see next page.

Pregnancy prevention programme (PPP)

Current MHRA regulations state that sodium valproate must no longer be used for any woman or girl able to have children, unless she has a pregnancy prevention programme (PPP), sometimes called PREVENT, in place.

- Your specialist (consultant) will discuss the risks of taking sodium valproate with you, and whether or not you are planning to become pregnant. This will help to decide if the PPP is right for you.
- They will explain the risks to an unborn child if the mother takes sodium valproate during pregnancy. (See previous page for risks of taking sodium valproate during pregnancy).
- Before you start to take sodium valproate, you will need to have pregnancy tests.
- Your specialist will explain the options for highly effective contraception.
- Your specialist will carry out reviews of your treatment at least annually. You and your specialist will complete an annual risk acknowledgement form at each review. This confirms that appropriate advice has been given and understood.



For more information visit gov.uk/guidance/valproate-use-by-women-and-girls

Menstrual cycles and periods

Because of the changes in hormone levels that happen throughout the menstrual cycle, one in three women with epilepsy finds that their seizures are affected by their periods.

Some women regularly have their seizures just before or during their period, or at ovulation (mid menstrual cycle). Women who have their seizures only at these specific times during their menstrual cycle (and at no other time), may have catamenial epilepsy.

Keeping a seizure diary and noting down periods can help to see if there are any patterns to when they happen.



Contact us for a free *seizure diary*.

Women with catamenial epilepsy may be prescribed the contraceptive injection Depo Provera (see page 15). This may reduce seizures for some women as it stops their regular cycle. An extra AED, in addition to their regular AEDs, may be prescribed for the week before and during the first few days of their period.

If you have catamenial epilepsy, you can discuss options for treatment with your specialist.

Polycystic Ovary Syndrome

Polycystic Ovary Syndrome (PCOS) is a common hormonal condition where eggs from the ovary do not develop properly. Eggs are usually released each month during a period. For women with PCOS, eggs are not released and stay in the ovary forming non-harmful cysts.

PCOS causes higher levels of the male hormone, testosterone, than normal, as well as irregular periods, weight gain, and increased hair growth. It can also make it harder to become pregnant.

PCOS may be more common in women with epilepsy. It may also be more common in women who take certain AEDs such as sodium valproate, or who gain weight, which can be a side effect of some AEDs.

If you are concerned about PCOS, talking to your specialist might help, as changing your AEDs can sometimes stop or reverse these effects. As for everyone with epilepsy, it is recommended that you talk to your specialist before making any changes to your AEDs.



Visit verity-pcos.org.uk

contraception

Some methods of contraception may be less effective in preventing pregnancy for women taking certain AEDs. This is because some AEDs affect how well methods of contraception work.

AEDs are either enzyme-inducing or non-enzyme-inducing.

Table 1. Enzyme-inducing AEDs

Drug (generic name)	Available as (brands include)
carbamazepine	Tegretol
eslicarbazepine acetate	Zebinix
oxcarbazepine	Trileptal
phenobarbital	<i>no brand name</i>
phenytoin	Epanutin
primidone	<i>no brand name</i>
rufinamide	Inovelon
topiramate	Topamax
perampanel	Fycompa

Enzyme-inducing AEDs may affect methods of contraception that contain hormones, such as the Pill, or contraceptive implants, because they increase the amount of enzymes that break down hormones in the body.

This means the hormones in contraceptives are broken down more quickly than usual, so they stay in the body for less time and are less effective in preventing pregnancy.

If you take an enzyme-inducing AED, you may be advised by your doctor to use a method of contraception that is not affected by your AED, such as a barrier method, or to use more than one method to help prevent pregnancy.

Table 2. Non-enzyme-inducing AEDs

Non-enzyme-inducing AEDs are unlikely to affect any form of contraception.

Drug (generic name)	Available as (brands include)
acetazolamide	Diamox
brivaracetam	Briviact
clobazam	Frisium, Tapclob
clonazepam	<i>no brand name</i>
ethosuximide	<i>no brand name</i>
gabapentin	Neurontin
lacosamide	Vimpat
levetiracetam	Desitrend, Keppra
piracetam	Nootropil
pregabalin	Alzain, Lyrica
sodium valproate	Epilim, Episenta
stiripentol	Diacomit
tiagabine	Gabitril
vigabatrin	Sabril
zonisamide	Zonegran



See page 13 for details on lamotrigine.

What is best for me?

You may want to talk to your neurologist or a family planning advisor about the combination of AEDs and contraception that is best for you.



The next few pages cover different methods of contraception and how well they work alongside AEDs. When we refer to types of contraception as 'being effective' or not, this means effective in preventing pregnancy.



For more information visit
nhs.uk/conditions/contraception-guide

The combined oral contraceptive pill – 'the Pill'

The combined oral pill contains the hormones oestrogen and progesterone. For any woman there are risk factors such as age, weight, high blood pressure, and smoking that can cause side effects with taking the Pill.

Enzyme-inducing AEDs cause the hormones in the Pill to be broken down more quickly, so the Pill may not be effective. If you are taking an enzyme-inducing AED, your doctor may advise you to take a double dose of the Pill with 30µg (micrograms) of oestrogen (so that you take 60µg micrograms of oestrogen in total), especially if the Pill is your only method of contraception.

Even with a higher dose, the Pill on its own may not be completely effective in preventing pregnancy. You may need to use another method of contraception as well, such as a barrier method (see page 14).

If you bleed between your periods, it may mean that the dose of oestrogen is not high enough to prevent pregnancy. Your doctor can advise you on what to do if this happens.

Oestrogen can have a pro-convulsant (seizure causing) effect in some women. So when a woman's levels of oestrogen are high, there may be a higher risk of seizures happening. Taking the Pill can further increase your levels of oestrogen but your body gets rid of the oestrogen from the Pill quickly so this doesn't make you more likely to have seizures.

The progestogen-only pill – the 'mini pill'

The mini pill is less effective against pregnancy than the combined pill, particularly if you take enzyme-inducing AEDs. Therefore the mini pill is not recommended as a form of contraception if you take enzyme-inducing AEDs.

Emergency contraception

The 'morning-after' pill

The morning-after pill is a type of emergency contraception that may be taken after unprotected sex. It can be prescribed by GPs, pharmacists, and family planning clinics.

If you take enzyme-inducing AEDs, this may reduce the effectiveness of the morning-after pill in preventing pregnancy. So you will need double the dose of the morning-after pill than other women (two pills rather than one).

As a pharmacist or clinic may not know your medical history, telling them that you take AEDs will help them to give you the right dose.

Emergency intrauterine device or coil

A different type of emergency contraception is the emergency intrauterine device (IUD). The IUD is not affected by AEDs.

The IUD is placed inside the womb to prevent pregnancy and needs to be fitted by a trained doctor or nurse.

Lamotrigine – a special case

Lamotrigine (Lamictal) is a non-enzyme-inducing AED. But unlike other non-enzyme-inducing AEDs, it needs special consideration.

There is no evidence that the Pill affects epilepsy directly, but there is evidence that **the Pill lowers lamotrigine levels in the blood**, and this could reduce seizure control and lead to seizures happening.

Research suggests that lamotrigine can lower the amount of progestogen from the combined oral contraceptive pill in the blood, but not the oestrogen. However, there is currently no conclusive evidence that lamotrigine reduces the effectiveness of the Pill.

If you take lamotrigine, it is important to talk to your doctor before starting any contraception that contains the hormones progestogen and oestrogen.

Contraceptive implants

Contraceptive implants contain progestogen and are implanted under the skin in the upper arm. Implants can be affected by enzyme-inducing AEDs, so they are not recommended if you take these AEDs.

The contraceptive patch

The contraceptive patch contains oestrogen and progestogen and so works in a similar way to the combined pill. Like the combined pill, it may not be an effective form of contraception if you take enzyme-inducing AEDs.

The vaginal ring

The vaginal ring is a flexible plastic ring that is inserted into the vagina. It works by releasing oestrogen and progestogen over 21 days. The vaginal ring may not be an effective form of contraception on its own if you take enzyme-inducing AEDs.

Contraceptives that are not affected by AEDs

Barrier methods

Barrier methods of contraception create a physical barrier against becoming pregnant. They include condoms, femidoms, caps and diaphragms, and are not affected by AEDs.

However, for any woman, barrier methods on their own may not be effective in preventing pregnancy, and you may be advised to use them along with another contraceptive method.

Intrauterine devices (IUDs)

IUDs are devices that are fitted into the womb. IUDs are not affected by AEDs because they do not contain hormones.

Intrauterine systems (IUSs)

IUSs are devices fitted into the womb. Unlike IUDs, IUSs contain the hormone progestogen. An example of an IUS is the Mirena coil, which contains a slow-release progestogen called levonorgestrel.

Although IUSs contain progestogen, they are not affected by AEDs because the hormone is released straight into the womb, rather than travelling around the body where an enzyme-inducing AED can cause it to break down more quickly.

There is a risk that a woman could have a seizure while the IUS is being inserted. This is rare, and the risk is low. If you are concerned about having an IUS fitted, you can discuss this with your doctor.

Contraceptive injections

Contraceptive injections, such as Depo Provera, contain progestogen and are given at regular intervals. Although they contain progestogen, they are not affected by AEDs because they are broken down in the blood, rather than in the liver where they could be affected by enzyme-inducing AEDs.

starting a family

Having epilepsy does not necessarily mean that starting a family will be any more difficult for you than for anyone else. However, it may mean that you have a few more things to consider, such as the effects of your epilepsy, or your AEDs, on you and your baby.

Preconception counselling

If you are thinking of starting a family it is essential to talk to your neurologist about planning your epilepsy treatment for your pregnancy and for when your baby arrives. It is important to do this *before* you become pregnant. You may have questions about the type of medication you take, the dose, how being pregnant could affect your seizures, and how seizures could affect your unborn baby. Because women with epilepsy have a slightly higher risk of complications than women who don't have epilepsy, forward planning can help keep these risks to a minimum.



See our leaflet *pregnancy and parenting*.

the menopause

The menopause is when a woman's periods stop and she can no longer become pregnant. During the menopause, a woman's body stops making natural hormones and this can cause symptoms such as hot flushes and mood swings. Hormone replacement therapy (HRT) is sometimes used to treat these symptoms.

HRT contains either oestrogen or a combination of oestrogen and progestogen. Oestrogen is known to have a pro-convulsant (seizure causing) effect for some women, but the amount of oestrogen in HRT is small and usually not enough to cause seizures to happen. However, if you take HRT and you do have more seizures than usual, this could be related to the oestrogen in HRT. If this happens it might be helpful to discuss the HRT with your neurologist to consider any possible alternatives or different combinations of oestrogen and progestogen.

Having information and regular medical reviews with your neurologist or GP can be important during the menopause. This is an opportunity to discuss any concerns you may have.

osteoporosis

The mineral calcium is important for our bones. Vitamin D helps calcium to get into the bones, and the calcium helps to make the bones strong. When calcium is lost, bones become thinner, more brittle, and break more easily. This is called osteoporosis. Anyone can develop osteoporosis, but it is more common in women, especially after the menopause when levels of oestrogen start to decrease.

Having epilepsy and taking anti-epileptic drugs may contribute to the risks of developing osteoporosis, but how much they contribute to this risk is not clear, and will vary from person to person.

Anti-epileptic drugs and bone health

Taking high doses of several different AEDs for many years may contribute to the risk of developing osteoporosis. Studies have shown that some enzyme-inducing AEDs may increase levels of chemicals in the liver that destroy vitamin D, reducing the amount of vitamin D in the body.

The NICE (National Institute for Health and Care Excellence) guideline (2012) called 'Epilepsies: diagnosis and management', recommends checking vitamin D levels, and undertaking any other investigations that may be appropriate to assess bone health every 2 – 5 years for all adults who take enzyme inducing AEDs.

A bone density scan can check bone strength and provide information on whether treatment for osteoporosis may be helpful.

Calcium and vitamin D supplements can help replace the natural loss of calcium. If you have concerns about osteoporosis, talking to your neurologist about the possibility of vitamin D level checks or having a bone density scan might help.

If osteoporosis happens when a woman goes through the menopause, HRT containing oestrogen, or a combination of oestrogen and progestogen, may be prescribed. HRT is generally used to relieve the symptoms of the menopause, but it might also help to protect against osteoporosis at this time.



Call the Royal Osteoporosis Society helpline on 0808 800 0035 or visit theros.org.uk

further information

Epilepsy Society information

Medication for epilepsy

Pregnancy and parenting

Seizure diary

Seizures

Your epilepsy – now and next

other organisations

Royal Osteoporosis Society

Helpline: 0808 800 0035

[theros.org.uk](https://www.theros.org.uk)

UK charity dedicated to improving the diagnosis, prevention and treatment of osteoporosis.

Verity

[verity-pcos.org.uk](https://www.verity-pcos.org.uk)

UK charity for women with Polycystic Ovary Syndrome (PCOS).

Every effort is made to ensure that all information is correct at the time of printing. Please note that information is intended for a UK audience. This information is not a substitute for advice from your own doctors. Epilepsy Society is not responsible for any actions taken as a result of using this information.



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