

**epilepsy  
society**

# women

Issues for women



# epilepsy society

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Words set in **black bold** within the text are explained on pages 18–19.



When you see this symbol, it means further information is available.

## Call us for a large print version

Epilepsy Society is grateful to the UK Epilepsy and Pregnancy Register for their guidance on this leaflet.

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## helpline

**01494 601 400**

Monday to Friday 10am to 4pm  
(national call rate)

## issues for women

There are some issues around epilepsy and its treatment that 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

Research has shown that for some women with epilepsy there may be a close link between **hormones** and epileptic seizures. Hormone levels can 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 hormones 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.**

Epilepsy can be different for everyone, and changing hormones may affect some women and not others. **Oestrogen** and **progesterone** are two hormones that are naturally produced in a woman's body. These hormones 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 can include unwanted changes in appearance, 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 now for a young girl, but the **paediatrician** or **neurologist** may take this into account if a girl is likely to be taking AEDs for some time.

If you have any concerns about taking AEDs, then talking to your paediatrician or neurologist may be helpful.

 **See our leaflets *medication for children or medication for adults*, for children aged 13 and over.**

 **See our guide for young people *your epilepsy – now and next*.**

## **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 at a particular time during their menstrual cycle. This might be just before or during their period, or at another time, such as **ovulation**. 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 can help to keep track of seizures, to see if there are any patterns to when they happen.

 **Contact us for a *seizure diary*.**

Women with catamenial epilepsy may be prescribed an extra AED, in addition to their regular AEDs, 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 also causes higher levels of **testosterone** than normal, as well as irregular periods, weight gain and increased hair growth. It can also make becoming pregnant more difficult.

PCOS may be more common in women with epilepsy than women without epilepsy. It may also be more common in women 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 [www.verity-pcos.org.uk](http://www.verity-pcos.org.uk)

## contraception

There are many different methods of **contraception**. Some 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

Enzyme-inducing AEDs may make some methods of contraception less effective.

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

Enzyme-inducing AEDs may affect methods of contraception that contain hormones, such as the Pill, or contraceptive implants. This is 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 doctors 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.

<b>Drug (generic name)</b>	<b>Available as (brand name)</b>
acetazolamide	Diamox
clobazam	Frisium
clonazepam	Rivotril
ethosuximide	Zarontin, Emeside
gabapentin	Neurontin
lacosamide	Vimpat
levetiracetam	Keppra
piracetam	Nootropil
pregabalin	Lyrica
retigabine	Trobalt
sodium valproate	Epilim, Episenta
stiripentol	Diacomit
tiagabine	Gabitril
vigabatrin	Sabril
zonisamide	Zonegran

 **For lamotrigine see page 11.**

 **See our leaflets *medication for children or medication for adults*, for children aged 13 and over.**

## 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.



**Contact the Family Planning Association on 0845 122 8690 or visit [www.fpa.org.uk](http://www.fpa.org.uk)**

## The combined oral contraceptive pill – 'the Pill'

The combined oral pill contains the hormones oestrogen and **progestogen**. 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.

Some AEDs can affect how well the Pill works:

- non-enzyme-inducing AEDs do not affect the Pill so it can be a good type of contraception to use; while
- 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. It is often best to use other methods of contraception as well, such as a barrier method (see page 13).

If you bleed between your periods, it may mean that the dose of oestrogen is not high enough to prevent pregnancy. If bleeding happens, your doctor can advise you.

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 contains just the hormone progestogen. This 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.



## 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 doctors before starting any contraception that contains the hormones progestogen and oestrogen.

## The 'morning-after' pill

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

If you take enzyme-inducing AEDs, you will need a bigger dose of the morning-after pill than other women. The morning-after pill is a single tablet dose and you will need to take double the dose (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.

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

### **Contraceptive implants**

Contraceptive implants, such as Implanon, 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 as a form of contraception if you take enzyme-inducing 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.

The following methods of contraception do not affect, and 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 women, 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 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 may want to 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 AEDs or the effects of epilepsy on you and your baby.

If you are thinking about becoming pregnant, you can ask to have preconception counselling with your GP, epilepsy specialist nurse or neurologist. This is an opportunity to talk through any issues you may have before becoming pregnant: to plan the pregnancy and to review your epilepsy and its treatment.



**See our leaflet *pregnancy and parenting*.**

## the menopause

The **menopause** is the time in a woman's life when her 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. However the amount of oestrogen in HRT is small and usually not enough to cause seizures to happen.

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**.

Osteoporosis can happen to anyone but it is more common in women than men, especially after the menopause. Epilepsy and taking AEDs may contribute to the risk of developing osteoporosis, but how much they contribute to this risk is not clear, and will vary from person to person.

For women taking enzyme-inducing AEDs, having calcium and vitamin D levels checked every 2–5 years can help to see if there are any problems with calcium levels. In some cases, having a bone density scan can be helpful. Calcium and vitamin D can be taken to help replace the natural loss of calcium. If you have concerns about osteoporosis, talking to your neurologist about the possibility of calcium level checks or bone density scans 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.



**Contact the National Osteoporosis Society on 0845 450 0230 or visit [www.nos.org.uk](http://www.nos.org.uk)**

Information and support can help you make informed choices about your life, and the treatment and management of your epilepsy.



## further information

### Epilepsy Society information

Medication for adults

Medication for children

Pregnancy and parenting

Seizure diary

Seizures

Your epilepsy – now and next

## other organisations

### FPA (Family Planning Association)

Helpline: 0845 122 8690

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

Information about sexual health and contraception.

### National Osteoporosis Society

Helpline: 0845 450 0230

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

Information about osteoporosis.

### Verity

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

UK charity for women with Polycystic Ovary Syndrome.



## summary of terms

**Catamenial epilepsy** – when seizures only happen at a particular time in a woman's menstrual cycle.

**Contraception** (birth control) – a variety of methods used to prevent pregnancy.

**Cysts** – eggs in the ovary that are not properly developed. Cysts are not usually removed.

**Enzyme-inducing** – drugs that increase the amount of enzymes in the liver.

**Enzymes** – Natural proteins that help with normal chemical reactions in the body.

**Hormones** – natural chemicals made in the body that cause reactions in different parts of the body.

**Menopause** – when a woman's body stops releasing eggs and she can no longer become pregnant.

**Menstrual cycle** – the events in a woman's body where an egg is released into the ovary and is either fertilised (and she becomes pregnant) or is lost during a period. Stages of this cycle include ovulation, and menstruation (where the lining of the womb is shed in a period). The different stages of the cycle are caused by different hormones.

**Neurologist** – a doctor who specialises in conditions that affect the brain and nervous system.

**Non-enzyme-inducing** – drugs that do not increase the amount of enzymes in the liver.

**Oestrogen** and **progesterone** – two hormones that bring about sexual development, menstruation and pregnancy.

**Osteoporosis** – a condition where bones lose calcium, become more brittle and can break more easily.

**Ovulation** – part of the menstrual cycle (mid cycle) when an egg is released from the ovary.

**Paediatrician** – a doctor who specialises in treating children, usually until they are around 16 years old.

**Period** – the shedding of the lining of the womb which comes out with monthly bleeding (see menstrual cycle).

**Progestogen** – a man-made hormone similar to the natural hormone progesterone.

**Puberty** – when a boy or girl starts to become sexually mature, due to the activity of sex hormones. At puberty a girl's periods start and she can become pregnant.

**Testosterone** – male hormone that is also produced in a women's ovaries.

Every effort is made to ensure that all information is correct. Please note that information may change after printing. 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.

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

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