

Women and epilepsy

Epilepsy can affect anyone at any age, and all genders. However, hormonal changes during puberty, pregnancy, or peri/menopause can sometimes affect seizure control.

This information may also apply to some trans and non-binary people, and those who take gender affirming hormones. There is very little clinical research to date on the impact of gender affirming hormones on seizures, but anecdotal evidence suggests these can sometimes affect seizure control.

Monthly periods

Some women find their seizures are linked to their periods. This is called catamenial epilepsy. Seizures can happen just before your period or around the time of ovulation. This may be due to fluctuations in hormone levels during your cycle. Keeping a seizure diary alongside recording the dates of your periods can help you identify if there is a link.

Your epilepsy specialist may prescribe the contraceptive pill to help control seizures related to your monthly periods. A neurologist or epilepsy specialist nurse may sometimes prescribe 'booster' medication to be taken at a certain point in the monthly cycle to help control seizures.

Contraception

Always seek advice from your GP, family planning clinic and epilepsy specialist nurse on the right contraception for you. This is important because some contraceptive methods may interact with anti-seizure medication and vice versa.

Contraceptive pill and hormone patch

If you take the contraceptive pill or use hormone patches, some anti-seizure medications could make these less effective. This could increase the chance of an unplanned pregnancy.

If you take lamotrigine (Lamictal), seek medical advice from your doctor or epilepsy specialist nurse, as some contraceptive pills and patches can potentially make this anti-seizure medication less effective, increasing the risk of seizures. At the same time, Lamictal can also decrease the effectiveness of your contraceptive methods and increase the risk of an unplanned pregnancy.

Vaginal ring

A vaginal ring is a small soft plastic ring that is placed inside your vagina. It releases the hormones oestrogen and progesterone into your bloodstream to prevent you from getting pregnant. Some anti-seizure medications can reduce the effectiveness of the vaginal ring and increase the chance of an unplanned pregnancy.

Progesterone implant

This is a matchstick-sized rod inserted under the skin that slowly releases progesterone. This implant can also be affected by some anti-seizure medications, making it less reliable.

Depo Provera/contraceptive injection

The contraceptive injection 'Depo Provera' contains the hormone progesterone. It is effective with any anti-seizure medication.

Barrier methods

Barrier methods include condoms, caps and diaphragms, intrauterine devices like the coil, and intrauterine systems like the Mirena coil. These do not interact with your epilepsy medication and are usually safe for women with epilepsy to use.

Emergency contraception/morning after pill

If you need emergency contraception (morning-after-pill), make sure the prescriber/pharmacist knows which anti-seizure medication you take. This is important as you may need a higher dose, depending on your anti-seizure medication, to ensure the emergency contraception is effective.

Planning a family

Women of childbearing age who have epilepsy should get regular reviews by their neurology team discussing possible pregnancy and preparing for it, if this is planned. With the right care and support, most women with epilepsy will have a normal pregnancy and delivery.

These pre-pregnancy reviews provide an opportunity to discuss and plan for improved seizure control and review of anti-seizure medication.

This is important because there are some anti-seizure medications which should not be taken during pregnancy as they can affect the development of a baby. This includes [sodium valproate \(Epilim\)](#) and [topiramate \(Topamax\)](#).

If you find out you are pregnant, and this was not planned, or think you may be pregnant, speak to your doctor or epilepsy specialist nurse as soon as possible.

Do not stop your medication unless your medical team asks you to. Suddenly stopping your medication could put you and your baby at risk of sudden and severe breakthrough seizures.

Genetic counselling

If a parent (mother or father) has epilepsy, there can be a small increased chance of a child also developing epilepsy. This is slightly higher if the mother has epilepsy. This, however, depends on factors, such as the cause of the parent's epilepsy or the type of seizures. If, for example, your epilepsy was caused by an event like a head injury, this cannot be passed on to your children.

To get a clearer understanding of risks, you can ask to be referred to genetic counselling.

Obstetric care

All women with epilepsy who are pregnant will usually be taken care of jointly by their neurology team and an obstetrician. An obstetrician specialises in pregnancy and birth.

Folic acid

Current guidelines say that all women trying to get pregnant should take folic acid. This helps protect the baby from spina bifida, a condition that affects the spine and spinal cord.

Women with epilepsy should take a higher dose of folic acid (5mg per day). Ideally, you should take this for at least three months before conception and continue to take it for at least the first three months of your pregnancy.

This higher dose will need to be prescribed by your doctor, midwife or nurse as you cannot buy this over the counter.

If you take phenytoin, phenobarbital or primidone, you should speak to your doctor or epilepsy specialist before you start taking folic acid. This is because folic acid can make these anti-seizure medications less effective, increasing your risk of seizures.

Pregnancy

With the right support, most women with epilepsy will have a healthy pregnancy and a healthy baby. The majority of women with epilepsy will not experience an increase in seizure activity during pregnancy, some may even experience an improvement in their seizures. The

more controlled your seizures were before pregnancy, the more likely you are to have good seizure control during pregnancy.

Your neurologist may need to adjust the dosage of your anti-seizure medication during pregnancy and, once again, after giving birth.

Never stop taking your anti-seizure medication during pregnancy. Having uncontrolled seizures during pregnancy could put you and your baby at risk.

Feeling queasy and physically throwing up (morning sickness) is common in the early stages of pregnancy. This may make it difficult for you to take your epilepsy medication, increasing the likelihood of seizures. Always seek medical advice if you are affected by morning sickness.

Pregnancy can often affect sleep, especially as the baby gets bigger. If you are struggling to sleep, speak to your midwife or your epilepsy specialist nurse, as tiredness and lack of sleep may potentially be a seizure trigger for some people. Try and rest as much as possible during the day to catch up on your sleep.

Women with epilepsy may be offered further scans in addition to the usual two routine scans that are currently offered to all women by NHS Scotland.

Labour

The majority of women will remain seizure free during labour. It can, however, be an exhausting time making seizures possible for some women. Provide details of your known seizure triggers in advance to your birthing team so that they can give you the best possible support and keep you safe.

Your midwife will usually draw up a birth plan with you (and your partner). Apart from the preferences and wishes you have for your labour and birth, this should also contain information about your type of seizures, frequency and duration, potential triggers and information about your medication. It should also contain information on appropriate pain relief, bearing in mind that not all available pain relief methods are suitable for those with epilepsy.

Should you have a seizure during labour, you may be given medication to stop the seizure.

Labour is unpredictable, so make sure you take enough of your epilepsy medication with you in case you need to stay in longer than anticipated.

You must continue as normal with your medication during and after birth, even though this can be a challenging time. Your birthing partner or someone from your medical team can help prompt you to take your anti-seizure medication at the right time.

Giving birth

Epilepsy in itself does not automatically require a Caesarean section, and in fact, many women with epilepsy will safely deliver their baby vaginally.

If your seizures are not controlled, your obstetric team may discuss the possibility of an elective caesarian section with you. You are likely to be advised to have your baby in a consultant-led maternity unit and will usually be offered one-to-one care from a midwife throughout labour.

A water birth may not always be suitable. Whether this is safe will depend on several factors including seizure control and type of seizures. Having a seizure while in a birthing pool carries a risk of drowning.

New mothers

Being a new mum with epilepsy can be challenging. Be mindful of potential seizure triggers that go hand in hand with looking after a newborn.

Spend some time and plan for what steps you may need to take after birth, to help you stay seizure free.

Lack of sleep

Your midwife, health visitor and your family and friends can help you put some measures in place to help you get more sleep. Your partner, or a family member, may, for example, be able to bottle feed your baby during the night to allow you to get some sleep.

Changing hormone levels

Your hormone levels will begin to change again, potentially triggering seizures. Keep a seizure diary to help you track any increased seizures after birth and seek advice from your epilepsy specialist nurse if you notice an increase, a change in pattern or seizure type.

Some women may need a review of their anti-seizure medication with possible dose adjustments, particularly if the dose was increased during pregnancy.

Lack of routine

Sleep deprivation and lack of your usual routines may make it more difficult for you to remember to take your medication at the right time. This can make you more vulnerable to seizures. Set an alarm reminder on your mobile phone or smart speaker, or ask your partner, family or friends to prompt you.

Anxiety and stress

Many new mothers can feel anxious or overwhelmed when looking after a baby. If you are not sleeping well, all of this will be intensified. If you are noticing a considerable increase in your stress or anxiety levels, talk to someone. This could be family and friends, your epilepsy specialist nurse, health visitor or GP.

Breastfeeding

If you want to breastfeed your baby, discuss this with your midwife, epilepsy specialist nurse or consultant before your baby is born.

When you breastfeed, your baby can pick up some of your epilepsy medication which is present in your breast milk. This will, however, be a lot less than the amount of medication your baby was exposed to in

the womb. Breastfeeding, in fact, can benefit the baby by weaning them off this higher level of epilepsy medication while in the womb.

Watch out for your baby developing a rash, or if they seem excessively sleepy, and contact your medical team for advice. They may suggest that you stop breastfeeding if they consider this the cause of your baby's reactions.

Breastfeeding will inevitably disrupt your sleep. This improves over time as the baby starts to feed less frequently at night, but as mentioned before, lack of sleep can be a seizure trigger. To help you stay seizure free, consider asking someone else to bottle feed the baby at night to allow you to get more sleep. This could be with expressed breast milk or formula milk. Speak to your midwife or health visitor for advice on feeding your baby and what is best for both of you.

Caring for your baby safely

There are many precautions you can take to help keep your baby safe should you have a seizure. Here are some examples:

- change your baby's nappy or feed your baby sitting on the floor
- do not bathe your baby alone. Always ensure someone else is there with you. If you are alone, 'top and tail' instead while sitting on the floor
- move your baby around the house in a buggy rather than in your arms
- get a buggy with brakes that automatically engage when you accidentally let go of it during a seizure
- Keep any medication locked away and out of sight from children

Check out our [Staying safe with epilepsy guide](#), which has a specific section for parents with epilepsy. Call our helpline on 0808 800 2200 for a free copy.

Older women

Seizure control can change as we get older. This particularly affects women as their bodies and hormone levels change during the perimenopause or menopause.

Peri/Menopause

Some women find that their seizures change as they are approaching the perimenopause or menopause.

This could mean a reduction in seizures or complete seizure control, an increase in seizures, or a return of seizures after a seizure free period.

Some women may have their first seizure as they are heading towards the menopause leading to an epilepsy diagnosis.

Hormone Replacement Therapy (HRT)

Many women look at HRT to help with symptoms of the peri/menopause. There is, however, little research and conflicting data on the effect of HRT for women with epilepsy to date.

HRT may improve seizures for those women who previously had their seizures around their monthly periods (catamenial epilepsy). However, some women may experience an increase in their seizures when taking HRT.

Some anti-seizure medications can also make HRT less effective and vice versa.

Seek medical advice from your epilepsy specialist nurse or neurologist if you are considering taking HRT.

Bone density and osteoporosis

Osteoporosis (thinning of the bone or loss of bone density) is more common in women after the menopause. Some anti-seizure medications can also increase the likelihood of developing osteoporosis.

Depending on which medication you take, your doctor may monitor your bone density, prescribe supplements or suggest other lifestyle changes. For more information on this, speak to your neurology team.

Here for you

Our helpline 0808 800 2200 is here for you if you have any questions or would like to discuss something mentioned in this factsheet. While we cannot provide medical advice, our experienced helpline officers are always happy to listen and speak with you.

We understand that some of the issues you may want to discuss may be of a very personal nature, so if you prefer to speak with a female member of staff, please let us know, and we will do our best to accommodate this as much as possible.

Further reading

Healthcare Improvement Scotland,
[SIGN 134, diagnosis and management of epilepsy in adults](https://www.sign.ac.uk/media/1079/sign143_2018.pdf),
https://www.sign.ac.uk/media/1079/sign143_2018.pdf
May 2015, Revised 2018

NHS Scotland, National Maternity Network: **[Standards of Care for Women with Epilepsy of Childbearing Age](https://www.perinatalnetwork.nhs.scot/wp-content/uploads/2023/02/2023-02-21-Pregnancy-Standards-of-Care-for-Women-with-Epilepsy.pdf)**,
<https://www.perinatalnetwork.nhs.scot/wp-content/uploads/2023/02/2023-02-21-Pregnancy-Standards-of-Care-for-Women-with-Epilepsy.pdf>, 21-2-2023

Our resources are always free. If you would like to support our work, please text FACTS to 70085 to donate £3. Texts cost £3 plus one standard rate message.



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