

Women and Epilepsy

A guide to help women with epilepsy navigate unique challenges across the life course.



A resource informed by real-world needs

Navigating life as a woman involves many stages—from puberty and menstruation to fertility, pregnancy, and menopause. For women with epilepsy, each of these life stages can come with added complexity. Beyond the everyday challenges that epilepsy brings, women often face unique issues related to their health, hormones, and medical care. These challenges are not always well understood or addressed in general healthcare settings.

To better understand these needs, we surveyed nearly 900 women with epilepsy across Europe. Their insights were invaluable in identifying where information and support were lacking—especially for women of childbearing age. Many shared a need for clearer guidance on topics like trying for a baby, pregnancy, and postpartum care, which has directly shaped the content of this resource.

This resource was created in response to what women told us they needed. It covers a wide range of topics, including epilepsy and puberty, sex, menopause, and aging. Our goal is to provide reliable, relevant, and accessible information that supports women with epilepsy throughout every stage of life—empowering them to advocate for their health and make informed decisions with their care providers.

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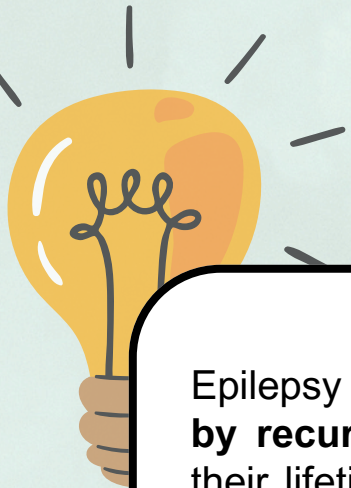
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Understanding Epilepsy



What is epilepsy?

Epilepsy is a condition that affects the brain and is **characterised by recurrent seizures**. About 1 in 10 people have a seizure in their lifetime, but epilepsy is usually diagnosed only after multiple unprovoked seizures or a high risk of more.

What is an epileptic seizure?

Our brain uses **electrical signals** to communicate and control the body. A seizure happens when there is a **sudden surge of abnormal electrical activity**, disrupting normal brain function. This can cause temporary confusion in signals between the brain and body.

There are many types of seizures, and their effects depend on which part of the brain is involved and how far the disruption spreads.

What causes seizures?

Epilepsy can have many causes, including:

- Brain injuries (from head trauma, infections, or strokes)
- Brain development issues before birth
- Brain tumors
- Genetic factors
- Parasitic infections (such as neurocysticercosis in some regions)

For many, the cause remains unknown, but advances in brain imaging (MRI) and genetic research are improving diagnosis and treatment.



Understanding Epilepsy

Epilepsy treatment

Anti-seizure medications (ASMs) can help to control or reduce seizures. Finding the right medication may take time. If ASMs are not effective, other options include:

- Vagal nerve stimulation (VNS)
- Ketogenic diet
- Brain surgery (in some cases)

Despite treatment, about 30% of people with epilepsy still experience seizures.

Side effects of epilepsy

Epilepsy can lead to a variety of side effects, such as:

- Confusion
- Memory problems
- Fatigue
- Mood changes such as anxiety or depression.

Seizures themselves can cause:

- Temporary disorientation
- Muscle stiffness or twitching
- Loss of consciousness.

Long-term effects might include:

- Cognitive challenges
- Sleep disturbances
- In some cases, injury from falls or convulsions during seizures.

It's important to work closely with healthcare providers to manage these side effects and improve your quality of life.



Epilepsy and Birth Control

Some contraceptives can lower the levels of certain ASMs (e.g., lamotrigine). Other **ASMs can reduce the effectiveness** of hormonal birth control.

If your ASM affects hormonal birth control, long-acting contraception may be a good alternative. A doctor can help find the best option to manage both epilepsy and birth control effectively.

Hormonal Birth Control and ASMs:

The most common contraceptive method is the **combination pill**, which contains **estrogen** and **progesterone**. It prevents pregnancy by:

- Stopping ovulation (release of an egg)
- Thickening cervical mucus to block sperm
- Changing the uterine lining to prevent implantation

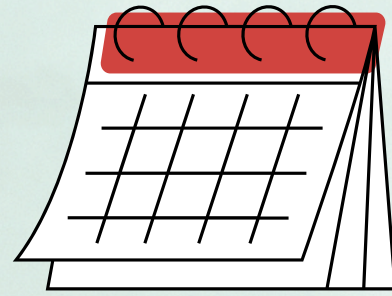


There are also **progesterone-only contraceptives**. However, some ASMs **speed up hormone breakdown** in the liver, which can make birth control pills **less effective** and increase the risk of unintended pregnancy.

Other Birth Control Options

Hormonal contraceptives can also be delivered via **patches**, **injections**, **intrauterine** systems (also known as the coil), or **implants**. These methods may still interact with ASMs, so it's important to discuss the best option with your doctor.

Hormones and Epilepsy



Hormones

Hormones regulate body functions, including seizure activity. **Estrogen** and **progesterone**, the main female reproductive hormones, can influence seizures. Their levels fluctuate throughout life, particularly during **puberty**, **menstrual cycles**, **pregnancy**, and **menopause**, meaning many women experience variations in their seizures at different stages of life.

Hormonal conditions like **polycystic ovary syndrome** or **diabetes** can also affect seizure patterns.

Epilepsy can affect **transgender people** in unique ways; hormone therapy, mental health, and access to supportive healthcare can all influence **seizure control**. For those taking **hormone replacement therapy** (HRT), certain hormones may affect how anti-seizure medications work. **Mental health challenges** like anxiety and depression are also more common and can be worsened by epilepsy. Access to respectful, knowledgeable care is important, especially when planning for pregnancy or choosing contraception.

Puberty

Hormonal changes during puberty can affect **seizure frequency**, and **physical growth** may alter how the body processes anti-seizure medication. Some girls see their seizures stop, while others experience them for the first time.

It's important to **keep taking prescribed medication**, as stopping suddenly can cause **serious complications**. Adolescents are more likely to skip doses, so understanding the risks is crucial.

Understanding Catamenial Epilepsy



Catamenial epilepsy is a type of epilepsy, specific to women and people who menstruate, in which seizures happen **more often** at certain points of the **menstrual cycle**. Neurologists are developing new ways to help those affected.

When does catamenial epilepsy occur?

Catamenial epilepsy can happen at different points in the menstrual cycle. Some women experience more seizures just before or during their period, due to a **drop in progesterone**. Others notice an increase around **ovulation**, likely caused by a **surge in estrogen**. In some cases, seizures happen more often in the **mid-to-late cycle**, especially in women who **do not ovulate regularly**.

Recognising catamenial epilepsy

If you think your periods may be affecting your seizures, **keep a diary** that tracks your seizures and your menstrual cycle for a few cycles. You can then **ask a health care professional to review it**.

If a medical review of your seizure/ menstruation diary **reveals an increase in seizure frequency** during one phase of the menstrual cycle, your doctor may **diagnose catamenial epilepsy**. You will then be able to discuss the best specific treatment plan.

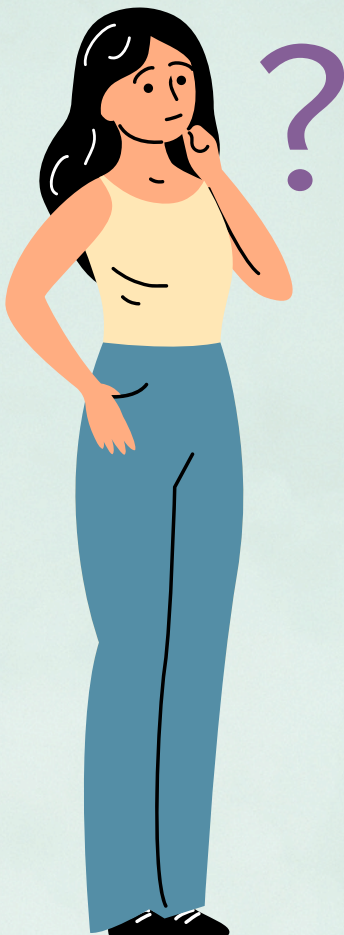
Epilepsy and Sex

Will epilepsy affect my sex life?

Studies have shown that up to a third of women with epilepsy have problems with sex, for example:

- a **low interest** in sex
- **difficulties** in being able to reach **orgasm**
- **painful sex** due to vaginal dryness or vaginal spasms.

We don't fully understand yet what causes sexual problems and how they relate to epilepsy, so consult your doctor if you have concerns.



Will my anti-seizure medication affect my sex life?

ASMs can cause side effects like **acne**, **hair loss**, or **excessive hair growth**, which may **impact self-esteem** and **sexual desire**. It's important to accept yourself and your epilepsy to build intimate relationships.

If you experience sexual difficulties with one ASM, talk to your doctor about trying a different medication.

Epilepsy and Sex

Do I need to worry about seizures during sex?

Some people with epilepsy fear **having a seizure during sex**, especially if excitement or physical activity triggers their seizures. However, for most people, **the risk is no higher than normal**. Talk to your partner about your concerns and what to do if a seizure happens; **open communication** helps manage the fear.

Can I resolve the sexual issues my epilepsy is causing?

Epilepsy can affect sex, and sex can affect epilepsy. Many people with epilepsy have a satisfying sex life, as it can **reduce stress** and **lower seizure frequency**. When seizures are under control, sexual desire and arousal often improve.

If you're having problems, don't hesitate to talk to your doctor for help. Also, **depression, anxiety, tiredness**, and **stress** can affect sex, so consider seeking support for **mental health** if needed.

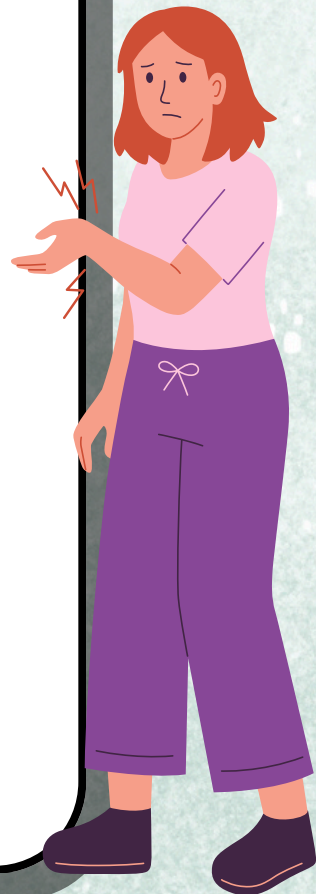


Epilepsy, Menopause and Osteoporosis

Epilepsy and menopause can affect each other, influencing seizures and overall health. Here's what to know:

- **Hormonal changes:** A decline in estrogen and progesterone during menopause can alter seizure patterns, causing an increase or decrease in frequency.
- **Medication adjustments:** Changes in metabolism means your anti-seizure medications may need adjusting to maintain control.
- **Bone health:** Both epilepsy and menopause raise the risk of osteoporosis. Women with epilepsy should monitor bone density, as some medications can increase this risk.
- **Mood and cognitive changes:** Menopause can worsen mood swings, depression, and cognitive issues.
- **Sleep disturbances:** Both epilepsy and menopause can cause sleep problems, which may trigger seizures. Improving sleep quality is important for overall health.

Close collaboration with healthcare providers during menopause is crucial for women with epilepsy to adjust treatment and maintain a good quality of life.



Pregnancy and Epilepsy

If you think you might be pregnant:

- Contact your doctor or epilepsy nurse immediately
- Take your ASM as prescribed—don't adjust without medical advice
- Track seizures, avoid stress, eat well, rest, and avoid alcohol/smoking.

Seizures and pregnancy

Most women have no change or fewer seizures, but some may have more due to:

- **Hormonal changes** affecting ASM effectiveness
- **Morning sickness** reducing medication absorption
- **Weight gain** requiring dosage adjustments
- **Stress** and lack of sleep.



Reducing risks for your baby

Seizures can lead to **premature labour, miscarriage**, or a **drop in the baby's heart rate**. Some ASMs increase the **risk of birth defects**, especially if taking multiple medications. However, **uncontrolled seizures pose a greater risk than ASM use**.

To reduce risks for your baby, **take folic acid** before and during pregnancy to help prevent birth defects. **Taking vitamin K** at birth helps prevent clotting issues. Always consult your doctor before making any medication changes.

Seizure control is the priority—work with your doctor to find the safest plan for you and your baby.

Pregnancy and Epilepsy

If you are thinking of having a baby

More women with epilepsy are now having healthy pregnancies, thanks to better seizure control and a stronger understanding of the condition. However, women with epilepsy often have fewer children and a **slightly lower fertility rate** than the general population. This may be due to a mix of **hormonal changes**, the effects of **seizures** or **certain ASMs**, and **psychosocial factors**.

Planning for Pregnancy

Most women with epilepsy can have healthy pregnancies, but **careful planning** is essential.

Doctors recommend starting preparations **6 to 12 months** in advance. Both **seizures** and **ASMs** can affect a developing baby, especially in the very early stages—even before you know you're pregnant. That's why early planning and professional guidance are key.

What to do

Talk to your doctor so they can help you find the safest and most effective ASM for your type of epilepsy. They may check your medication levels before pregnancy to guide adjustments later. Also, **consult a gynaecologist**, follow a healthy lifestyle and **keep a seizure diary**. If possible, bring a family member or friend to your appointments for support. Avoid making changes without medical advice.

Epilepsy and Valproate

Valproate is a **highly effective ASM** for epilepsy and bipolar disorder, but it **carries serious risks during pregnancy**. It can cause **developmental disorders** in up to 40% of exposed children and **birth defects** in about 11% of cases.

Because of these risks, valproate is generally **not recommended for women of childbearing age** who could become pregnant. However, it may be the only effective option.

Contraception and Safety Measures:

Women taking valproate are strongly advised to **use contraception**, even if they're not currently sexually active, unless their doctor confirms there is no risk of pregnancy.

If you become pregnant while taking valproate, **do not stop your medication without consulting your doctor**, as this could worsen your condition.



Epilepsy and Valproate

Risks of taking valproate when pregnant:

If a woman taking valproate chooses to become pregnant, she must understand and accept the **high risk of serious birth defects**.

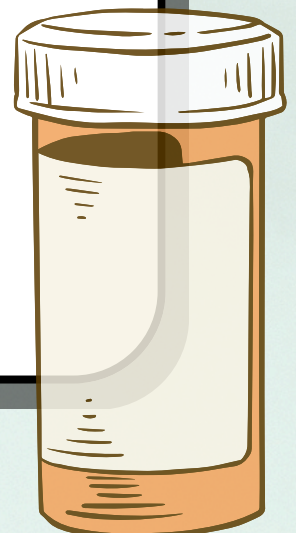
About 11 in 100 babies will be affected, compared to 2–3 in 100 for the general population.

Potential birth defects include:

- Spina bifida, where the bones of the spine do not develop properly
- Face and skull malformations – including cleft lip and cleft palate, when the upper lip or bones in the face are split
- Malformations of the limbs, heart, kidney, urinary tract, sexual organs, and of the eyes - which may affect vision, hearing problems or deafness.

At pre-school age, between 30 and 40 children in every 100 will have serious developmental disorders, such as:

- Being late learning to walk and talk
- Lower intelligence levels than other children of the same age
- Reduced speech and language skills
- Memory problems
- An increased risk of autism and ADHD.



Epilepsy and Valproate

What if I find out I'm pregnant while taking valproate?

If you think you're pregnant, it is very important to **speak with your doctor as soon as possible**. They may continue to prescribe valproate, but only if there's no other suitable treatment for your epilepsy.

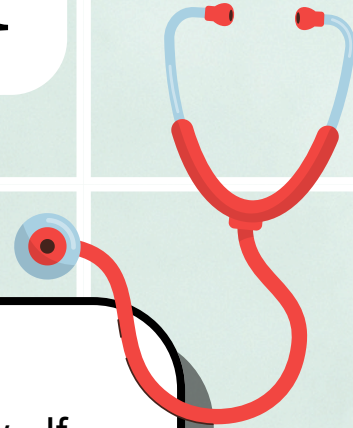
Safety regulations and research

In 2018, the European Medicines Agency (EMA) introduced **rules to reduce foetal exposure** to valproate. Most EU countries and the UK have **safety programmes**. If you take valproate, ask your doctor or pharmacist about the **prevention programme** in your country.

Research is ongoing into the safety of other ASMs for women of childbearing age, and some studies are also exploring the impact of ASMs on **men with epilepsy**. Medicine regulators in many countries are introducing **new guidelines** around prescribing certain ASMs to people who could become pregnant, to help reduce risks and improve care.



Labour and Delivery



The risk of having a seizure during labour is low. If needed, doctors **may recommend a caesarean section**. You can take steps to lower your risk, such as:

- **Early preparation:** Talk with your doctor and obstetrician about seizure management while in labour, so the decisions you make with them are included in your hospital notes.
- **Take your ASM to the hospital** with you and take it at your usual time; you could ask the medical team or your partner to help you remember to take it.
- **If you are scheduled to have a C-section**, make sure your medical team knows about your medication. You might take it in advance of surgery or have it administered intravenously if necessary.
- **Have an epidural early in labour** to control your pain if pain is a seizure trigger.
- **Make sure your medical team is aware** of your usual triggers, especially if they include emotional stress and sleep deprivation, and how best you can avoid them.
- **If you feel nauseous**, ask your care team for something to help with this so that you don't vomit up your ASM before your body has absorbed it. It is vital that you continue your ASM as normal during this time.



Labour and Delivery



Coping with pain in labour

You have a lot of options available to you in dealing with labour. It's a good idea to have a **birth plan in place** well before your due date. Consider the following points as you prepare your birth plan:

- **Having an epidural early in labour** can offer strong pain relief so you can relax a little and rest.
- Pethidine is used a lot in early labour and it can help with pain, but a **high dose of pethidine can also be a seizure trigger**.
- **TENS (transcutaneous electrical nerve stimulation)** machines prevent pain being passed into nerve fibres and by stimulating the production of endorphins, the body's natural painkillers. TENS machines work well during the early stages of labour.
- **Many women find breathing exercises**, taught at prenatal classes, are helpful in managing labour pains. As you have epilepsy, you should **avoid over-breathing**, however, as it can also be a seizure trigger.
- **Don't have an unsupervised water birth** as you risk drowning if you have a seizure.



After Giving Birth

Seizures as a parent

After having a baby, your seizures may change, but it's hard to predict how. **Stress, excitement, anxiety, and lack of sleep** can make seizures **more frequent or severe**. **Hormonal shifts** may also mean your medication needs adjusting.

To lower your risk, take your medication as prescribed and have your doctor monitor your levels. If your dose increased during pregnancy, **watch for signs of high drug levels** and contact your doctor if needed. Get support from family and friends so you can rest. Don't stress about housework—focus on relaxing when you can.



Keeping your baby safe

Safety is crucial when caring for your baby. **Change your baby on the floor**, not on a changing table, and **use sponge baths** when you're alone. Always **use straps on baby chairs** or rockers, and **sit on the floor with cushions** when feeding.

If you use a baby carrier sling, **be mindful of the risk of falls** during seizures. For added safety, avoid carrying your baby while handling hot items or electrical appliances. When outdoors, **a pram with reliable brakes** is a safer option.

After Giving Birth

Breastfeeding your baby

If you have epilepsy, you can **breastfeed** your baby **without any harmful effects** to them from your breast milk; your baby will already have been exposed to low levels of ASMs throughout the pregnancy, and their exposure from breast milk will be even lower.

How can I reduce the risks from breastfeeding?

- If sleep deprivation could trigger your seizures, consider **pumping breast milk ahead of time** or using formula, so your partner or a **family member can do some night feeds**.
- If you take your ASM once a day, try taking it at the start of your baby's longest sleep period, usually after the bedtime feed. If you take it more than once a day, wait until after breastfeeding, then take it immediately, so your medication levels are lowest while breastfeeding.



Lactation registries

Joining **pregnancy and lactation registries** helps improve the health and safety of mothers and babies. They **collect information on how medications affect pregnancy and breastfeeding**, helping doctors give safer advice.

- **Increases safety:** Data from registries helps identify risks and benefits, leading to safer care.
- **Supports future mothers:** Registry information helps improve healthcare practices and outcomes.
- **Make informed choices:** Access to updated info empowers you to make better decisions about your health.



Questions For Your Doctor

1. Will my anti-seizure medication affect my sex life?
2. Will my ASM interact with my contraceptive?
3. Do I need to worry about seizures during sex?
4. I am taking or considering hormone replacement therapy (HRT), how will this interact with my anti-seizure medication ?

Planning a pregnancy

1. What should I know before becoming pregnant?
2. Will my epilepsy make it more difficult for me to conceive?
3. What are my options for fertility treatment?
4. What are the benefits of pre-pregnancy seizure control?
5. Are there alternative treatment options to ASMs that could work for me?
6. What are the chances that my child will have epilepsy?
7. I am taking valproate and want to get pregnant – what should I do?
8. Will my seizures change when I am pregnant?
9. What happens if I have a seizure when I'm pregnant?

Questions For Your Doctor

For women who are pregnant

1. I'm pregnant and am taking valproate - what should I do?
2. Will my medicines affect my baby?
3. Can I have a normal delivery and how can I reduce my risk of a seizure during labour?
4. Will I be able to breastfeed my baby?
5. Will my seizures change after having a baby?
6. What is the most suitable contraception use after giving birth?
7. Should I visit the emergency department after a seizure?
8. How do I know when vaginal bleeding could be a sign of something serious?
9. Are there foods I can eat to help my body better absorb folic acid?
10. Will I have to have a caesarean section?
11. How often should I visit a doctor during pregnancy?
12. Are you taking part in the EURAP Register (a long-term international study of antiepileptic drugs in pregnancy)?

This resource was sponsored by a grant from the following companies:

