

## Women and epilepsy

Epilepsy can affect women at any age in their lives, from childhood to puberty, during their reproductive years and pregnancy, through to menopause and later life. This factsheet addresses many of those epilepsy related issues experienced by women of all ages.

### Puberty and young women

Puberty sets in when levels of hormones change in our bodies, and most girls will begin to show signs of puberty by the time they are 14. While epilepsy usually does not affect puberty, sometimes taking anti-epileptic drugs (AEDs) or having seizures can affect the production of sex hormones. This may mean that puberty starts a bit later than usual. Always seek medical advice if you feel puberty is delayed.

The change in hormone levels around puberty can also affect seizure control. Hormonal changes can be stressful and affect mood. If stress is a seizure trigger for you, this could make you more likely to have a seizure. Keeping a seizure diary can help you identify any seizure patterns or any changes in your seizure pattern. If you feel your seizures have changed, speak to your doctor, epilepsy specialist nurse or consultant. Some young people may develop epilepsy around the time of puberty. For others, their seizures may stop.

Once you start having monthly periods and become sexually active there are a number of issues to consider, such as contraception and being on the right medication should you become pregnant. This is important as some AEDs could be harmful to an unborn baby. There is more about this in the following chapters. At this stage in your life, your epilepsy specialist may want to review and possibly change your medication.

## Monthly periods

Some women find their seizures are linked to their periods. Seizures can happen just before your period or around the time of ovulation. This may be due to changing levels of different hormones during your cycle. Keeping a seizure diary along with a record of your periods can help you identify if your cycle could be a seizure trigger.

Speak to your doctor if you think there may be a link between your seizures and your periods. Some epilepsy specialists prescribe the contraceptive pill to help control any seizures related to your monthly periods. Occasionally some women are prescribed additional 'booster' medication to take at a certain point in their monthly cycle to help control seizures.

## Epilepsy and relationships

Having epilepsy does not mean you cannot have a happy and intimate relationship. If you are dating, there is no right or wrong time to talk about your epilepsy, just follow your gut instinct. Some people prefer to disclose their epilepsy as soon as possible, others prefer to wait to see where the relationship goes. Having sex is not any more likely to trigger a seizure than at any other time.

Some women with epilepsy may experience a low sex drive. There can be several reasons for this such as:

- \* you may worry about having a seizure during sex
- \* you may have low self-esteem because of your epilepsy
- \* your seizures may be affecting hormone production
- \* it may be a side effect of your medication

Talking to someone you trust can help if you are finding any aspect of your relationship difficult. Speak to your doctor if you feel your epilepsy or treatment may be affecting your sex life. Your GP may also be able to refer you for counselling,

refer you back to your neurologist to review your epilepsy medication, or discuss other treatment options.

## Contraception

If you are sexually active and do not want to become pregnant, speak to your doctor, nurse or local family planning service about contraception. You need to make sure that your contraception is right for you. This is because some contraceptive methods may not be as effective and suitable because of your epilepsy and the medication you take.

### Contraceptive pill and hormone patch

If you take the contraceptive pill or use hormone patches, some AEDs could make these less effective. This could increase the chance of an unplanned pregnancy. Epilepsy drugs that may do this include:

- \* carbamazepine (Tegretol)
- \* oxcarbazepine (Trileptal)
- \* phenobarbital
- \* phenytoin (Epanutin)
- \* primidone (Mysoline)
- \* rufinamide (Inovelon)
- \* topiramate (Topamax)
- \* eslicarbazepine (Zebinix)

If you take lamotrigine (Lamictal), seek medical advice from your doctor or epilepsy specialist nurse as the contraceptive pill and patches can make this anti-epileptic medication less effective. If you become pregnant your dose of lamotrigine (Lamictal) may need to be adjusted after the first three months.

## 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 blood stream to prevent you from getting pregnant. It can be affected by the medications listed above, which may make the vaginal ring less effective and increase the chance of an unplanned pregnancy.

## Progesterone implant

Some women use a progesterone implant as a form of contraception. This is a matchstick size rod inserted under the skin which slowly releases progesterone. This implant can also be affected by the AEDs listed above, making it less reliable.

## Depo provera / contraceptive injection

The contraceptive injection 'Depo provera' contains the hormone progesterone. It can be used by women with epilepsy including those who take one of the AEDs listed above.

Both the contraceptive injection and some AEDs can cause loss of bone density. This can lead to a condition called osteoporosis where bones become less dense and can break more easily. You can check with your doctor if you are at risk of developing this condition and how best to prevent this.

## Barrier methods

Safe forms of contraception include barrier methods like condoms, caps and diaphragms, intrauterine devices like the coil, and intrauterine systems like the mirena coil. These do not interact with your epilepsy medication.

## Emergency contraception / morning after pill

If you need to take the morning after pill as emergency contraception, make sure you remind the person prescribing it that you take AEDs. Depending on which AED you take, you may need to be prescribed a higher dose to make sure it is effective.

## Planning a family

If you have epilepsy, planning your pregnancy is the best way to keep you and your baby safe. Seeking pre-pregnancy advice well in advance of becoming pregnant, if possible, can help avoid complications.

The first step is to speak to your GP, consultant or epilepsy specialist nurse. They will want to review the medication you are on, and will want to bring your seizures as much as possible under control. This will lower any potential risks to you and your baby during pregnancy and birth.

Some AEDs are best avoided in pregnancy as they could increase the risk of birth abnormalities. If you find out you are pregnant, or think you might be, speak to your doctor or epilepsy specialist nurse as soon as possible. **Do not stop taking your medication without medical advice, as this could put you and your baby at risk.**

## Genetic counselling

Some women may want to know if they could pass their epilepsy onto their child. If your epilepsy is caused by an event like a head injury this cannot be passed on to your children. If there is a different cause for your epilepsy, such as a potential genetic cause, then there is a small chance this could be passed on if you have a child. This risk can vary depending on what type of seizures you have and other factors. You can ask your doctor to refer you for genetic counselling to get a clearer idea of your own situation.

## Epilim / sodium valproate and birth defects

If you are sexually active or planning to get pregnant, you should not be on this drug, as it can cause serious physical and developmental issues to your unborn baby if taken during pregnancy. In fact, guidelines around this medication have been tightened up and this drug should not normally be prescribed to women of child

bearing age, unless they are on a strict pregnancy prevention programme. Your GP or epilepsy specialist will be able to give you more information about this.

**If you are on Epilim / sodium valproate and are pregnant, do not stop your medication unless advised by your medical team. Suddenly stopping your medication can trigger a severe seizure putting you and your unborn baby at serious risk.**

## Folic acid

Current guidelines say that all women trying to get pregnant should take folic acid. This helps protect the baby from spina bifida. If you have epilepsy, the recommendations are to take a high dose of folic acid (5mg per day). Ideally, you should take this for at least three months before trying to get pregnant and continue to take it for at least the first three months of your pregnancy.

This higher dose needs to be prescribed by your doctor, midwife or nurse as you cannot buy this over the counter. Some health professionals suggest that all women who are sexually active should take folic acid daily. This offers protection to the baby if you have an unplanned pregnancy. Ask your doctor about this.

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 drugs less effective, increasing your risk of seizures.

## Epilepsy and fertility

Some women with epilepsy find it can take a bit longer to get pregnant. This could be a sign that you have reduced fertility. Epilepsy can be one of many reasons for this. It could be a side effect of your AEDs or as a result of your seizures. If you are having problems getting pregnant speak to your doctor.

Your doctor may suggest taking medication to improve your fertility. Some women find that this can affect their seizure control, causing them to have more seizures. Your doctor or epilepsy specialist will be able to give you more specialist medical advice.

## Pregnancy

Most women with epilepsy will experience no problems during pregnancy and will have a healthy baby.

**Never stop taking your AEDs during pregnancy. Having uncontrolled seizures during pregnancy could put you and your baby at risk.**

If you are affected by morning sickness, seek urgent medical advice. Feeling queasy or being physically sick can make it difficult for you to take your epilepsy medication increasing the chance of seizures.

Some women find that pregnancy reduces their seizures. Other women may find they have more seizures while pregnant. This may be because being pregnant is affecting the way the AEDs are working. Some women need to have the dose of their AEDs adjusted throughout pregnancy to maintain good seizure control. If your seizure control changes during pregnancy speak to your doctor or epilepsy specialist.

Pregnancy can often affect sleep, especially as the baby gets bigger. If you are affected by this, speak to your midwife and your epilepsy specialist nurse, as tiredness and lack of sleep can sometimes be a seizure trigger. It can help to rest during the day, if possible.

Women with epilepsy will usually be offered a detailed ultrasound scan between 18 and 21 weeks to check your baby is healthy.

## UK Epilepsy and Pregnancy register

This is a register which monitors the safety of different AEDs in pregnancy. You may want to join the register to help with their ongoing research. Findings from this register help to ensure that doctors can give the best advice to women with epilepsy who are thinking of becoming pregnant. To register call 0800 0398 1248, or visit their website [www.epilepsyandpregnancy.co.uk](http://www.epilepsyandpregnancy.co.uk). This is a voluntary register, and you can withdraw from the register at any time without giving a reason.

## Labour

Most women with epilepsy will be able to have a normal pregnancy and natural birth.

During labour you may experience some common seizure triggers like lack of sleep, stress, dehydration, over-breathing and pain. Being aware of potential seizure triggers can help your birthing team give you the best care during labour and minimise the chance of a seizure where possible. For example, if you are getting tired, pain relief can allow you some rest. If you have a seizure during labour, you may be given medication to make sure the seizure stops quickly. A written birth plan should detail all this relevant information.

If your seizures are not controlled during pregnancy, and if there is any concern over your or your baby's health, you may be offered a caesarean section.

You will be advised to have your baby in a consultant-led maternity unit and offered one to one care from a midwife throughout labour.

**Do not stop taking your AEDS during labour, and after giving birth.** It is important that you continue as normal with your medication, even though this is a challenging time. You could ask your birthing partner to help you take your AEDs correctly. If you are unable to swallow your medication during labour you may be given your AED in a different way. If you find you are feeling sick, anti-nausea medication can help ensure you keep your medication down. Some women may be

prescribed extra AEDs during labour to help maintain seizure control. Ask your epilepsy specialist about this.

Make sure you pack enough of your epilepsy medication in the bag you are taking to hospital. You may be in labour for longer than anticipated.

You can discuss pain relief with your midwife early in your pregnancy. Women with epilepsy can use a range of pain relief during labour, for example:

- \* learning relaxation and breathing techniques can help you manage the pain and stay in control. This can also help avoid over-breathing which could be a seizure trigger
- \* gas and air can be an effective pain relief. Your midwife will explain how to use it correctly
- \* TENS machines can help with the pain and these are suitable for women with epilepsy
- \* epidurals are suitable for women with epilepsy
- \* pethidine has been shown to cause seizures in some women so it may not be suitable during labour. As an alternative, you may be offered diamorphine

A water birth may not always be suitable, depending on the type of seizures you have. There could be a risk to your safety if you had a seizure while in the birthing pool.

It is important to make sure that the whole team who will be involved in your care during labour have details about your epilepsy. This should include the type of seizures you have, their frequency and duration, possible triggers and details of your medication. Your midwife can help with this.

## Vitamin K

If you take AEDs during pregnancy, there may be an increased chance your baby will be born with low levels of Vitamin K. Vitamin K is important to help with blood

clotting. Some babies are born without enough Vitamin K which means if they start to bleed in the first few weeks of life the blood flow may not stop or will take a long time to clot. All babies are offered Vitamin K at birth, normally by injection. It can also be given orally.

## New mothers

Being a new mum can be challenging and exhausting. If you have epilepsy, it is even more important to look after yourself and be mindful of potential seizure triggers. Eat a healthy well-balanced diet, drink plenty of fluids and get as much sleep as you can to help you keep safe in these early months after giving birth.

Lack of sleep and disrupted sleep can be a seizure trigger for some women. If you are affected by this, seek medical advice. Your midwife, health visitor and your family and friends can help you put some measures in place to increase your sleep. This could, for example, be asking your partner, or a family member to bottle feed your baby during the night to allow you to sleep.

Once your baby is born, your hormone levels will begin to change. This may alter how well your AEDs are controlling your seizures. Keeping a seizure diary can help you track if your seizures have changed. Your epilepsy specialist may want to review your medication. If your medication was altered during pregnancy your epilepsy specialist may ask you to slowly return to the dose of medication you were taking before you became pregnant.

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 or to take it at all. This can make you more vulnerable to seizures. Set an alarm reminder on your mobile phone, or ask your partner, family or friends for help. They could, for example, message or phone you to remind you of your medication.

As a new mum you may find it difficult to switch off and fully relax. It is completely normal to feel stressed, anxious, or overwhelmed by having to look after a baby. If

you are not sleeping well, all of this will be compounded. If you have epilepsy you need to be mindful that stress and anxiety can also be a seizure trigger. It is not always easy to talk about this. Some women may be worried about being judged. If stress and anxiety are making your seizures worse, speak to your midwife, health visitor, doctor or epilepsy specialist nurse. It can also help to open up and to talk to family and friends about how you feel. They may be able to offer you some extra support and reassurance.

## Breastfeeding

Having epilepsy will not usually stop you from breastfeeding your baby, if this is what you want to do. You should discuss this with your midwife, epilepsy specialist nurse or consultant before your baby is born.

When you breastfeed, your baby will 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 when in the womb. Breastfeeding, in fact, can help wean your baby off your epilepsy medication. However, if you notice your baby has a rash, seems excessively sleepy or anything else which concerns you, contact your doctor or epilepsy specialist and ask for advice. They may suggest that you stop breastfeeding.

Breastfeeding will disrupt your sleep. This improves over time as the baby starts to feed less frequently at night, but as mentioned above, lack of sleep can be a seizure trigger. If lack of sleep is triggering seizures, you could consider asking someone else to 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

If you have epilepsy you need to think more carefully about how to keep your baby safe. Think about the types of seizure you have, how often they occur, if you get a

warning and what the risks might be. There are many precautions you can take to help reduce the risk to yourself and the baby if you have a seizure:

- \* change your baby's nappy on the floor
- \* move your baby around the house in a buggy rather than in your arms
- \* install an epilepsy alarm
- \* get a buggy with brakes that automatically go on when you let go
- \* feed your baby sitting on the floor
- \* keep your medication away from children

There is more like this in 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. If you have any concerns around keeping your baby safe, speak to us or contact your epilepsy specialist nurse.

## Menopause

Levels of hormones in our bodies change as we get older, and eventually your monthly cycles stop. Hormones can affect the excitability of the brain and some women find that their seizures change around the time of menopause. If your seizures are linked to your monthly cycle, you may find that you have fewer seizures after the menopause.

Some women may experience seizures for the first time. Other women experience a change in the type, frequency or length of their seizures.

## Hormone Replacement Therapy (HRT)

HRT can be prescribed by a doctor or nurse to help with symptoms like mood changes, sweats and hot flushes leading up to and around the time of the menopause. There is little research on the effect of HRT for women with epilepsy, although some studies suggest that taking AEDs can make HRT less effective.

HRT can either contain only oestrogen, or a mixture of oestrogen and progesterone. High levels of oestrogen can make seizures more likely to happen. Oestrogen-only HRT will usually not cause a problem, however for some women with epilepsy the combined oestrogen / progesterone HRT is the preferred prescription.

Although HRT may be beneficial it can also have side effects, so a discussion with your doctor or appropriate health professional is advised.

## Bone density and osteoporosis

Osteoporosis (thinning of the bone or loss of bone density) is more common in women after the menopause. While HRT can offer some protection against osteoporosis, some of the AEDs have the opposite effect and can increase the likelihood of developing this condition. Depending on which AED you are taking, your doctor may monitor your bone density, prescribe Calcium and Vitamin D supplements or suggest other lifestyle changes. For more information on this speak to your doctor.

## Complementary therapies

Some women turn to complementary therapies for relief from menopausal symptoms. These can often help with reducing symptoms. Always consult a professionally trained therapist, such as a medical herbalist, rather than buying remedies over the counter. Natural remedies can have side effects too, if incorrectly used, and may interfere with your anti-epileptic medication, making your seizures worse. Your doctor or epilepsy specialist nurse may also be able to suggest further safe ways to help you cope with menopausal symptoms.

## Here for you

If you want to talk or have further questions, please contact our helpline on 0808 800 2200. Our helpline officers will deal with any issues raised by you in a confidential and sensitive way. If you prefer to speak to a female member of staff, please say so, and we will try and accommodate this as much as possible. We are here to help.