Women and epilepsy

Introduction

Epilepsy can affect women at any age in their lives, from childhood to puberty, during the reproductive years and pregnancy, through to menopause and later life. This guide gives information on things to consider at different points in your life if you are a woman with epilepsy.

Puberty and young women

As we grow from children into adults our bodies change and mature. This is called puberty and happens as the levels of hormones change. Hormones are chemical messengers in our bodies. Epilepsy does not usually affect puberty, although 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. Most girls will begin to show signs of puberty by the time they are 14. If you feel puberty may be delayed, speak to your doctor or epilepsy specialist nurse.

The change in hormone levels around puberty can also affect seizure control. Hormonal changes can be stressful and affect your 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 is a chance you could become pregnant. It is important to check with your GP or epilepsy specialist to make sure you are on the right medication, as some AEDs could harm babies while in the womb. Your epilepsy specialist may want to change your medication or give you more information about the risks.
Monthly cycle

Some women find their seizures are linked to their monthly cycle. The medical term for this is ‘catamenial epilepsy’. 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 monthly cycle. Some epilepsy specialists prescribe the contraceptive pill to help control any seizures related to your monthly cycle. Occasionally some women are prescribed a different medication to take at a certain point in their monthly cycle to help control seizures.

Epilepsy and Relationships

People with epilepsy are able to have happy intimate relationships with others, just like anyone else. Some people may worry about disclosing their epilepsy to a new partner. Part of being in a relationship is accepting the other person for who they are. A loving partner will accept your epilepsy and offer you the support you need. Choose the right time for you to talk about your epilepsy. This is different for everyone. Some people decide to talk about having epilepsy straight away, while others choose to wait a while.

You may be concerned about having a seizure during sex. You are no more likely to have a seizure when you have sex than at any other time.

Some women with epilepsy may find they have a low sex drive. There can be a number of different reasons for this including worrying about sex, having low self-esteem, your seizures affecting hormone production or it may be a side effect of your medication. Talking things over can help if you are finding any aspect of your relationship difficult. Speak to your doctor if you are worried that your epilepsy or treatment is affecting your sex life.
Sometimes your GP will be able to refer you for counselling. They may also refer you back to your neurologist to review your epilepsy medication or offer other treatment.

**Contraception**

If you have epilepsy then planning your pregnancy is the best way to keep you and your baby safe. You can avoid unplanned pregnancies by speaking to your doctor, nurse or local family planning service about contraception before you have sex. There are lots of different types of contraception and some of these can be affected by your epilepsy and medication, so it is important to get good advice.

**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)

Lamotrigine (Lamictal) may be affected by contraceptive pills and patches. To find out more about this speak to your doctor or epilepsy specialist nurse. 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 you place 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 work less well.

Progesterone implant

Some women use a progesterone implant as a form of contraception. This is 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 treat 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.

Morning after pill/emergency contraception

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.
Anti-epileptic medication and menstrual disorders

One AED, sodium valproate/Epilim has been associated with changes in hormone levels and linked to menstrual disorders like polycystic ovary syndrome (PCOS). This could affect your monthly cycle and make it more difficult to get pregnant. Your GP or epilepsy specialist will be able to give you more information about this.

Planning a family

It is important to get pre-pregnancy advice well in advance of becoming pregnant if you can. This is the best way to avoid complications. The first step is to speak to your GP, consultant or epilepsy specialist nurse. They will look at the best way to lower any risks to you and your baby. For example, your neurologist or epilepsy specialist nurse may want to change or reduce your medication, or try a different AED to improve your seizure control. Some AEDs are best avoided in pregnancy as they could increase the risk of birth abnormalities. Your epilepsy specialist will be able to give you advice on the risks of seizures and the effects your AEDs may have on your unborn baby. 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.

Some women may want to know if they could pass their epilepsy onto their child. If your epilepsy is caused by a life event like a head injury this cannot be passed on to your children. If there is a different cause for your epilepsy 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.

The ‘Epilepsy and Pregnancy’ register can give you confidential information and advice on how best to keep you and your baby safe during pregnancy. Call them on: 0800 389 1248 or visit their website: www.epilepsyandpregnancy.co.uk
**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 has 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. It can affect your AED and there is a very small chance it could make you more likely to have a seizure.

**Epilepsy and fertility**

Some women with epilepsy find it can take a bit longer to get pregnant than others. 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 information on how the medication may affect you.

**Pregnancy**

Most women with epilepsy will have no problems during pregnancy and have healthy babies. **It is important you do not stop taking your AEDs during pregnancy** and that you listen to the advice of your epilepsy specialist. Having uncontrolled seizures could put you...
and your baby at risk. Your doctor or epilepsy specialist will be able to explain this in more detail.

Some women get morning sickness when they become pregnant. You may feel queasy or be physically sick and have difficulty taking your epilepsy medication. If this is the case speak to your doctor or epilepsy specialist for advice.

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.

Some women find they have difficulty sleeping while pregnant, especially as the baby gets bigger. For some women tiredness and lack of sleep can be a seizure trigger. Try to get as much rest as you can and speak to your midwife if you are having difficulty sleeping.

Some AEDs may be better avoided in pregnancy as they may carry a higher risk to the unborn baby. By planning your pregnancy you can make sure you are on the best medication. If you are already pregnant speak to your epilepsy specialist as soon as possible, but do not stop taking your AEDs. You will be offered a detailed ultrasound scan between 18 and 21 weeks to check your baby is healthy.

The UK Epilepsy and Pregnancy register have been monitoring the safety of different AEDs in pregnancy for a number of years to find out the safest options for women with epilepsy. By joining the register you will help with this research to ensure doctors are able to give the best advice to you and other women who are thinking of becoming pregnant. Call 0800 0398 1248 to register your pregnancy and access free confidential information and advice, or visit their website: www.epilepsyandpregnancy.co.uk.

**Labour**

Most women with epilepsy have a normal pregnancy and natural birth. The chances of having a seizure during labour are low. For every 100 women with epilepsy, only 1 or 2 will
have a seizure during labour. 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. Writing a birth plan and detailing this information can help.

If you do have seizures during pregnancy you may still be able to have a natural birth. However, if there is any concern over the health of you or your baby you may be offered a caesarean section. If you have a seizure during labour you may be given medication to make sure the seizure stops quickly.

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. You should continue to take your AEDs as normal during labour and after giving birth. You could ask your birthing partner to help you take your AEDs correctly. Some women may find they are unable to swallow medication during labour. If this is the case your AEDs may be given in a different way. If you find you are feeling sick, you can be given anti-nausea medication to help ensure you keep your medication down.

Make sure you pack your epilepsy medication in the bag you are taking to hospital. Some women may be prescribed extra AEDs during labour to help maintain seizure control. Ask your epilepsy specialist about this.

You can discuss pain relief with your midwife early in your pregnancy. Women with epilepsy are able to 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 for you during labour. If this is the case you may be offered diamorphine instead.

Depending on the type of seizures you have, you may not be able to have a water birth. 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.

Remember most women with epilepsy will have a normal labour and delivery.

**Vitamin K**

Vitamin K is important to help blood clot. 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. To help ensure babies blood clots naturally all babies are offered Vitamin K at birth, normally by injection. It can also be given orally. If you take AEDs during pregnancy there may be an increased chance your baby will be born with low levels of Vitamin K. Your doctor will advise that your baby is given vitamin K at birth to help keep them safe.

**New mothers**

It is important to look after yourself as well as your baby. Try to avoid potential seizure triggers by eating a healthy well balanced diet, drinking plenty of fluids and getting as much sleep as you can.
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.

For some women not getting enough sleep can be a seizure trigger. You could record your sleep pattern in a seizure diary to help identify if this is affecting your seizures. You could discuss ways to get more rest with your midwife, health visitor or with your family and friends.

If your sleep pattern is disturbed you may find it difficult to take your medication at the right time. Forgetting to take AEDs is the most common seizure trigger. You could set an alarm to remind you to take your medication at the correct time, or ask your friends and family for help. For more information on how to take your medication correctly see the ‘Treatment’ section of our website.

Being a new mum can be stressful and you may find it difficult to switch off and fully relax. Lack of sleep can also increase your level of stress and anxiety and you may feel overwhelmed about looking after your baby. This is a normal experience for any new mother. If you have epilepsy you need to be mindful that stress and anxiety can also be seizure triggers. We have a separate factsheet on ‘Epilepsy and stress/anxiety’ that may give you some tips on how to identify the signs of stress. It also gives some ideas on different ways to reduce stress and anxiety.

**Breastfeeding**

Most women with epilepsy should be able to breast feed their babies if they choose to. You should discuss this with your midwife, epilepsy specialist nurse or consultant before your baby is born.
Some of your epilepsy medication will be passed to the baby in your breast milk. Your baby will be used to the epilepsy medication from being in the womb. Typically the amount in your breast milk will be lower than they were getting while you were pregnant. Breastfeeding can help wean your baby off your epilepsy medication. However, if you notice your baby has a rash, seems excessively sleepy or shows a different side effect, contact your doctor or epilepsy specialist and ask for advice. They may suggest that you stop breastfeeding.

If you choose to breastfeed your sleep will be broken. 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 about the best way 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 a number of things you can do 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.

Call our helpline on 0808 800 2200 if you have a specific concern or for more information on safety.
Menopause

The menopause is where a woman’s monthly cycle stops and happens as the levels of hormones in our bodies change as we get older. 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 have found relief from menopausal symptoms with complementary therapies including herbal medicine, acupuncture and homeopathy. Although naturally based remedies can be effective they are not always safe. For example some herbal remedies could make your seizures worse. It is safest to always consult a fully trained professional before using herbal medicine or other complementary therapy, rather than buying stuff over the counter. Contact the relevant professional bodies to find a suitably qualified practitioner in your area. Also speak to your doctor or epilepsy specialist nurse if you want to find out a bit more about other ways to help you cope with your menopausal symptoms.

**And finally**

We hope this guide gives you the information you need to help you better manage your epilepsy. Your epilepsy treatment may need to be adjusted as you go through life. With the right treatment and advice you can live your life to its fullest potential. For more information call our helpline on 0808 800 2200 and speak to our trained staff in confidence.