

A woman's guide to epilepsy

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Introduction

This leaflet is for women with epilepsy. It is a general guide and looks at the issues which may affect you throughout your life. Talk to your doctor or epilepsy specialist nurse about your own situation.

Young women

As you grow from a child into an adult you become more independent. You make new friends and begin to find your sexuality. You will find your emotions, behaviour and physical shape change as a young woman. Physical changes can happen quickly. Sometimes this means your dose of epilepsy medication is increased to keep up with the changes in your body. Being able to control your epilepsy can give you confidence to live your life to the full.

Contraception or starting a family may not be important now. However, it may be in the future. Talk about this with your doctor or epilepsy specialist nurse. This helps you plan ahead and use the best treatment as you become an adult.



Epilepsy and hormones

Your hormones can affect your seizures. Hormonal changes happen when your periods first start and during your monthly cycle. Hormone changes also take place during pregnancy and when periods stop (menopause). Some women are more likely to have a seizure around the time of their period. Other women may have more seizures half way through their cycle.

Keep a seizure diary over a number of months to identify any pattern. Speak to your doctor if you think there may be a link between your seizures and your monthly cycle. Some women take another epilepsy drug around the time of their period.

What are the side effects of treatment?

People can experience side effects when they start medication. These often lessen or stop after a few weeks. You will get a patient information leaflet with your medication. This lists all possible side effects but not everyone will have side effects. Some people may only have one or two of those listed. The most common side effects are sleepiness, feeling sick, dizziness and a sore head.



Talk to your GP if you are worried about any side effects. **Tell your doctor straight away if you have a skin rash.** Our Treatment factsheet has more information on epilepsy drugs. Please call our Helpline for a copy.

You can also view this leaflet online at www.epilepsyscotland.org.uk

Sexuality and epilepsy

Having epilepsy should not stop you from being intimate. You may worry you will have 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 can have problems, for example a low sex drive. This can be for different reasons including worrying about sex or having low self-esteem. Accepting yourself and your epilepsy will help give you the confidence to develop a close relationship.

Talk to your doctor if you are worried that your epilepsy or treatment is affecting your sex life.

Contraception

Most women want to plan when they will have children. They can then work this around other goals, like an education or career. Avoid unplanned pregnancies by speaking to your doctor or nurse about contraception before you have sex.

What contraception can I use if I have epilepsy?

There are lots of types of contraception for women. Some can be affected by your epilepsy and medication. Speak to your doctor or epilepsy nurse to find out which is best for you. Your local family planning clinic can tell you more about the different types.

The Pill and hormone implants

Some epilepsy tablets can interfere with the way your oral contraceptives and hormone implants work. This increases the chance of unplanned pregnancy. Speak to your doctor, family planning clinic or epilepsy specialist nurse about the best contraceptive for you.

Table 1**These epilepsy drugs do not affect the Contraceptive Pill:**

- acetazolamide (Diamox)
- benzodiazepines
- gabapentin (Neurontin)
- levetiracetam (Keppra)
- pregabalin (Lyrica)
- tiagabine (Gabitril)
- sodium valproate (Epilim)
- vigabatrin (Sabril)
- zonisamide (Zonegran)

Table 2**These epilepsy drugs can affect the Contraceptive Pill and hormone implants:**

- carbamazepine (Tegretol)
- oxcarbazepine (Trileptal)
- phenobarbital
- phenytoin (Epanutin)
- primidone (Mysoline)
- topiramate (Topamax)

lamotrigine (Lamictal)

If you take lamotrigine and are on the Pill ask your doctor for more information. As with epilepsy drugs from Table 2, it can make the Pill and hormone implants less effective. In addition, taking the Pill may lower the level of lamotrigine in your body. This may cause a seizure.

Sometimes women who take an epilepsy drug from Table 2 are given an increased dose of the Pill. Even with the increased dose the Pill is not always reliable. Bleeding between periods can suggest the dose is not high enough to work properly.

Do not stop taking your medication or change the dose without medical advice. If you stop your medication suddenly you are more likely to have a seizure.

Women who are on these listed drugs often use barrier methods of contraception as well.

Barrier methods

Barrier methods of contraception are male and female condoms, caps and diaphragms. These are suitable for women with epilepsy. Condoms also protect against sexually transmitted infections.

Intrauterine systems (IUS)

Intrauterine systems are fitted into the womb. They contain the hormone progesterone. They are not affected by epilepsy medication. This is because the progesterone goes straight into the womb rather than around the body.

Intrauterine devices (IUD)

Intrauterine devices are also called 'the Coil'. They are fitted into the womb. They are suitable for women with epilepsy.

Tell the person fitting the IUD you have epilepsy. It is unlikely you will have a seizure when it is being put in.

Contraceptive injection

The contraceptive injection 'Depo provera' contains the hormone progesterone. It can be used by women with epilepsy including those who take an epilepsy drug from Table 2. If you have been getting your contraceptive injections every 10 weeks, you may find that your doctor will want to switch you to injections every 12 weeks. This is because most recent evidence has shown that you do not need more frequent injections if you take an epilepsy drug from Table 2.

Contraceptive patch

The contraceptive patch releases hormones similar to the natural hormones produced by your ovaries. Not much is known about the effectiveness of this method of contraception for women with epilepsy. Speak to your family planning clinic, doctor or epilepsy specialist nurse about this.

Rhythm methods

Rhythm methods are a form of natural birth control. These will help you find out when you are most likely to become pregnant. If you don't want to become pregnant you should avoid having sex during this time. Persona, for example, is one of these methods. It monitors hormone levels in your urine.

Both epilepsy itself and the drugs you take for epilepsy can affect hormone levels in your urine. This is why this particular method is not suitable for women with epilepsy.

Will I be able to use emergency contraception (the 'morning-after pill')?

Yes, but if you are taking certain epilepsy drugs you may need a higher dose. Tell the doctor which epilepsy medication you take.

For further information about all methods of contraception, visit www.fpa.org.uk.

Planning a family

Many women want to have a baby. Women with epilepsy are no different. It is important to know the effects epilepsy and treatment may have on you and your baby if you are starting a family.



Will epilepsy stop me from being able to have a baby?

One in six people have fertility problems. Both women and men with epilepsy have a slightly higher chance of experiencing problems. This could be for different reasons like worries about your seizures. In women, fertility can be lowered by a condition called polycystic ovarian syndrome (PCOS). PCOS is more common in women with epilepsy. Talk to your doctor if you are worried about this.

Don't stop your medication without medical advice. If you stop your medication you may have a seizure.

It's also worth bearing in mind that the Driving Vehicle Licensing Authority (DVLA) recommend that anyone that stops or reduces their medication should stop driving during this time and for six months after.

If you have problems conceiving then both you and your partner should get advice. If you need fertility treatment your epilepsy should not affect this. Be aware some women may have more seizures during the treatment because fertility treatment can affect your hormones.

Should I plan my pregnancy beforehand?



Yes, if you can. Plan your pregnancy with your GP, consultant, obstetrician and epilepsy specialist nurse. You can then talk about treatment choices and get advice before you are pregnant. This 'pre-conception counselling' gives you the time to improve seizure control before pregnancy and labour.

Together you can decide on the best way to lower any risks to you and your baby. Ideally you will take a low dose of one drug to stop your seizures. Your doctor may suggest you slowly come off your medication before trying for a baby. **Do not do this without your doctor's advice.**

What are the risks to my baby?

Most women with epilepsy have healthy babies. With any pregnancy there is a small risk of complications. This risk is slightly higher if you take epilepsy medication. However, many of the complications are small. These could be the baby having small nails or a broad bridge over the nose.

Rarely, more serious problems like heart defects and spina bifida (a condition which affects the development of the central nervous system) can happen. The risk of your unborn child being affected is small if you take only one drug.

This risk is higher if you are taking more than one drug. Talk to your doctor and epilepsy nurse about possible risks before you are pregnant.

The **UK Epilepsy and Pregnancy Register** has information on the risks of epilepsy medication in pregnancy.

Remember, don't stop taking your medication or change the dose without your doctor's advice. If you stop your medication suddenly you are more likely to have a seizure.

Results show some drugs are safer than others. Call **0800 389 1248** to register your pregnancy. You can also tell them if you plan to become pregnant.

What if I'm already pregnant?

Don't panic. See your doctor as soon as possible.

Should I take folic acid?

Yes. All women trying for a baby are told to take folic acid. Folic acid is a vitamin. Women with epilepsy should take a higher level (5mg), ideally for at least three months before trying for a baby. This dose is only available from your GP or maternity clinic. It should also be taken throughout the pregnancy, usually for the first trimester (three months) of pregnancy. Some doctors think all sexually active women with epilepsy should take 5mg of folic acid a day. This is in case they become pregnant by accident. Ask your GP or epilepsy specialist nurse about this.

Pregnancy



Most women with epilepsy have no problems during pregnancy. They also have healthy babies.

Will I have more seizures when I'm pregnant?

Some women have no seizures when they are pregnant. Others have more. This may be because pregnancy affects their medication. Or it may be because they stop their epilepsy drugs as they are worried these will affect their developing baby.

You may need to have your medication increased as your pregnancy goes on. This is because medication is not always absorbed so well as your body changes through pregnancy. If your medication is increased during pregnancy it should be gradually reduced after your baby is born. Your doctor or epilepsy specialist nurse will tell you about this.

Remember, don't stop taking your medication or change the dose without your doctor's advice. If you stop your medication suddenly you are more likely to have a seizure.

Your doctor will give you accurate information on any risks of epilepsy medication. Ultrasound scans and other tests can help look for any development problems

before birth. You will usually get a detailed ultrasound scan at 18-20 weeks. Uncontrolled and prolonged seizures need to be managed as well as possible. This lowers any risks to you and your baby.

Labour



If you and your baby are healthy your epilepsy should not stop you having a normal labour and delivery. It is unlikely you will have a seizure during labour. This rarely happens. If it does, it may be caused by lack of sleep, stress, dehydration and over-breathing linked with labour.

Women with epilepsy are advised to have their baby in hospital. Consultant doctors and midwives are then close by for you and your baby. Tell hospital staff you have epilepsy and mention any seizure triggers that affect you.

Should I take my medication during labour?

Yes. It is important to take your medication even during labour. Missed tablets can lead to seizures. Don't forget to pack your tablets before you go into hospital. Ask your partner, companion or nurse to remind you to take your tablets.

Will I be able to have pain relief during labour?

Women with epilepsy can use a range of pain relief methods during labour. Talk to your midwife about pain relief options early on in your pregnancy. If you want an epidural (spinal anaesthetic) you will need to tell your midwife beforehand. You should also tell the anaesthetist that you have epilepsy and that you take medication. Your midwife will explain breathing techniques and how to use gas and air. It is safe for women with epilepsy to use TENS (Transcutaneous Electrical Nerve Stimulator) machines.

Is there anything else I should know?

Some women who take epilepsy drugs but have a seizure during labour may need extra medication. Women who have a lot of seizures or prolonged seizures near the end of their pregnancy may need to have a caesarean section to deliver the baby. This is very rare though.

Remember, most women with epilepsy will have a normal pregnancy and natural birth.

If you take epilepsy medication your newborn baby should be given a vitamin K injection soon after being born. This is to stop internal bleeding.

New mothers

After labour your hormone levels change. This can affect your epilepsy medication which can lead to side effects. If your medication was increased during pregnancy this may now need adjusted. You can talk about contraception and future pregnancies with your doctor or epilepsy specialist nurse at your postnatal check up.

Will I be able to breastfeed my baby?



Breastfeeding is the best way to feed a baby. Small amounts of the epilepsy drug you take will pass to the baby when you are breastfeeding. However, it's a lower amount than the baby had in the womb. Breast milk helps to wean the baby off epilepsy medication slowly. Some medication, including phenobarbital, may make your baby sleepier. If so, or if you have any concerns about your baby, talk to your doctor or midwife.

What's the best way to care for my baby?

Your health visitor will speak to you about caring for your baby. Our Safety factsheet has information on caring for your baby safely if you have regular seizures. For example, it's safer to change your baby's nappy on the floor.

Call our Helpline on **0808 800 2200** for a copy or check our website at **www.epilepsyscotland.org.uk**.

Could my child inherit epilepsy?

Research shows that certain types of epilepsy are genetic where others are not. If you have epilepsy the chance of your child developing the condition is generally low. Speak to your own doctor about your situation. You can ask to be referred to genetic counselling to get a clearer idea.

Menopause



The menopause causes changes in hormones. This can affect your epilepsy and treatment. In the years before the menopause your oestrogen (hormone) levels begin to fall. As hormones can affect the excitability of the brain, some women may see a change in their seizure frequency at this time. Women who had seizures at the time of their monthly period may find they have less seizures after the menopause.

Some women develop epilepsy for the first time during the menopause. Others with epilepsy will stop having seizures when they reach this stage.

What are the effects of Hormone Replacement Therapy (HRT) in women with epilepsy?

Some women experience symptoms like mood changes, sweats and hot flushes leading up to the menopause. Some women may find HRT helps these symptoms.

HRT can also offer some protection against osteoporosis (brittle bone disease). This is more common in women who take certain anti-epileptic drugs. If you take one of the epilepsy drugs listed in Table 2 on page 6 you should have your calcium and vitamin D levels checked. These drugs can reduce your calcium and vitamin D levels. Your doctor may give you extra calcium and vitamin D to take.

HRT can contain only oestrogen or both oestrogen and progesterone. High levels of oestrogen can make seizures more likely to happen.

Usually, the oestrogen level in oestrogen-only HRT is not high enough to be a problem. However, some women with epilepsy may benefit from taking a combined oestrogen and progesterone HRT pill. Little research has been done on the effect of HRT on epilepsy. Some studies suggest that taking anti-epileptic drugs can make HRT less effective. Speak to your doctor about HRT if you think it could help you.

They can also tell you about other ways to treat your symptoms if you are worried about how HRT may affect your epilepsy. Some women have found relief from menopausal symptoms with complementary therapies such as herbal remedies, acupuncture or homeopathy. Contact relevant professional bodies or 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. Our Treatment factsheet has more information on complementary therapies.

Finally



We hope this leaflet gives you information to help you manage your epilepsy. You may need different treatment as your body and lifestyle change. With the right treatment and advice you can do almost anything. Having fewer seizures will help you live a full and active life.

Call our Helpline on **0808 800 2200** with any questions and speak to our trained staff in confidence.

Further information

Epilepsy Scotland can give you further information on:

Factsheets:

- Diagnosis
- Driving
- Employment
- First aid for seizures
- Leisure
- Memory
- Safety
- Seizures
- Treatment
- Triggers (including information on alcohol and photosensitive epilepsy)

Guides:

- A guide to epilepsy - what you need to know
- A parent's guide to epilepsy
- An employer's guide to epilepsy
- Caring for people with epilepsy and learning difficulties
- Epilepsy and later life
- Guidelines for teachers
- Men and epilepsy

We also have information leaflets designed for people with learning difficulties. These include:

- All about epilepsy
- Safety and epilepsy
- Living with epilepsy



If you have questions after reading this leaflet, please contact our Helpline. Our trained staff are available during office hours and until 6pm on Thursdays.

If you would like this leaflet in a different format or language, please call 0808 800 2200.