Starting a family

Planning for a pregnancy

This information looks at the issues around pregnancy that may affect some people with epilepsy.

Preconception counselling

If you are thinking of starting a family, it is essential to talk to your neurologist about planning your epilepsy treatment for your pregnancy and for when your baby arrives. It is important that you do this before you become pregnant.

You may have questions about the type of medication you take, the dose, how being pregnant could affect your seizures, and how seizures could affect your unborn baby.

Because women with epilepsy have a slightly higher risk of complications than women who don't have epilepsy, forward planning can help keep these risks to a minimum.

If you have seizures, you are likely to be advised to keep taking your anti-seizure medication (ASM) throughout your pregnancy. Your doctor may suggest adjusting your ASM so you take the lowest possible dose that will still control your seizures. However, some ASMs are used up more quickly in the body during pregnancy, so the dose may need to be increased during your pregnancy to keep your seizures under control (see page 5).

Your doctor might suggest a change to the type of ASM that you take, as some are more risky to unborn babies than others.

Women with epilepsy who take some ASMs during pregnancy have a higher risk of having a baby with a birth abnormality than women with epilepsy who don't take ASM.

Because of the possible effects of ASM on an unborn baby, having your ASM reviewed before you become pregnant can help you and your neurologist make sure that you are taking the most appropriate ASM and at the most suitable dose during your pregnancy. See page 2 for more about the effects of ASMs on an unborn baby.

Some women prefer not to take ASM during their pregnancy and may want to discuss this option with their neurologist. If you have seizures during pregnancy there is a risk of injury to yourself and your baby. This risk could be higher (depending on the type and frequency of seizures you have) than the risk of the ASMs affecting your baby. See page 5 for more about these risks.

If you have been seizure-free for two or three years, your doctor might suggest slowly stopping your ASM before you try for a baby. However, if your ASM is stopped there is a risk that your seizures could start again.

Having seizures could affect your home or work life, and if you are currently driving and have a seizure, you will need to stop driving and tell the DVLA.
Visit epilepsysociety.org.uk/driving

Making decisions about your medication is not always easy and preconception counselling can give you the chance to ask any specific questions, or talk about concerns you have.

Physical birth abnormalities

For any woman there is a small ('background') risk that her baby may be born with a birth abnormality or malformation. Physical birth abnormalities are problems that happen when the development of a baby is affected while it is in the womb. There are different types of birth abnormality, which can affect different organs in the body, and can happen for various reasons. Birth abnormalities can be classed as 'minor' and 'major'.

Having epilepsy does not necessarily mean that starting a family will be any more difficult than for anyone else. However, it may mean that you have a few more things to consider before, during, and after the pregnancy.

Helpline 0300 102 0024
Confidential, freephone number.
Information and emotional support.
Visit epilepsysociety.org.uk/helpline for opening hours.

Minor malformations are those that do not need surgery, for example small fingers and toes, and eyes set wide apart.

Major malformations are those that need surgery to correct them. These include a hole in the heart, problems with the kidneys or genitals, cleft lip, and cleft palate (where the roof of the mouth is not correctly joined). They also include problems with the development of the spine and nervous system (neural tube defects), such as spina bifida (where part of the spinal cord is exposed).

Sometimes the child's arms or legs, or the way their face looks, may also be affected. If you are pregnant, avoiding the following will all help reduce the risk of birth abnormalities: alcohol, smoking, unprescribed medication, and illegal drugs. This is because all these substances can be passed through your bloodstream to your baby and so may affect your baby's development.

Women with epilepsy have a higher chance of having a baby with a birth abnormality than women who don't have epilepsy. This may be due to an underlying genetic condition which also caused the epilepsy. Or risks can be due to injury to your unborn baby if you have seizures during pregnancy, or from taking some types of ASM.

Can ASM affect an unborn baby?

For a woman with epilepsy who takes ASM during pregnancy, her baby will be exposed to ASM in the womb. While she is pregnant, a mother's bloodstream is kept separate from her unborn baby's.

However, some substances can pass from her blood into her baby's blood via the placenta. These substances include nutrients, oxygen, alcohol, and medication including ASM.

Some ASMs can affect how the baby grows and develops inside the womb, particularly in the first 12 weeks of pregnancy when the main organs and skeleton are developing.

ASMs and birth abnormalities

Different ASMs vary in the risk they pose, and the risk of abnormalities rises with higher doses of the drug and if you already have a child with a birth abnormality.

Taking more than one ASM increases the risks, especially if this includes sodium valproate or topiramate.

- 2 – 3 women in every 100 (2 – 3%) in the general population will have a baby with a major malformation (the 'background risk').
- 3 women in every 100 (3%) who have epilepsy and don't take ASM will have a baby with a major malformation.
- 4 – 10 women in every 100 (4 – 10%) who have epilepsy and who take an ASM will have a baby with a major malformation.
- In 2021 the Commission on Human Medicines (CHM) reviewed safety data for epilepsy medications taken during pregnancy. This showed that lamotrigine (Lamictal), and levetiracetam (Keppra) are safer to use during pregnancy than other ASMs. They have low rates of physical birth abnormalities, in line with the background risk (2 – 3%).

The Medicines and Healthcare products Regulatory Agency (MHRA) has produced more guidance on the risks for ASMs in pregnancy.

A further study into pregabalin was published in April 2022, which showed a slightly higher risk of birth abnormalities with pregabalin, although the overall risk is low.

Visit gov.uk/government/publications/epilepsy-medicines-and-pregnancy
gov.uk/government/publications/pregabalin-and-risks-in-pregnancy

Fetal anti-convulsant syndrome

Some ASMs are thought to affect a child's development after they are born – this is called Fetal anti-convulsant syndrome (FACS). The risk of this happening is higher with sodium valproate than with other ASMs.

Problems with the child's development and learning can include: delayed walking and talking, poor speech and language, and problems with memory, attention, lower intelligence, and behaviour. Often these effects are not seen until the child gets older, for example when they start nursery or school.

Children exposed to sodium valproate in the womb may also be more likely to be on the autism spectrum.

The following organisations provide information and support to families affected by FACS.
Visit infactuk.com and oacscharity.org

Sodium valproate – Important information
Sodium valproate (brand names include Epilim, Depakote, Convulex, Episenta, Epival, Kentlim, Orlept, Sodium Valproate, Syonell, Valpal, Belvo and Dyzantil) has greater risks in pregnancy than other ASMs, with 7 women in 100 (7%) having a baby with a major abnormality, rising to 1 in 10 women (10%) if they take more than 1000mg (1g) per day.

Also, up to 4 children in 10 (up to 40%) whose mothers took sodium valproate have problems with development and learning. In addition, the MHRA have also issued information about an increased risk of lower birth weight for babies exposed to sodium valproate.

There is also evolving information about potential risks in men.

The (MHRA) states that sodium valproate should not be prescribed to anyone under the age of 55, unless it is the only effective drug for them. Women should be on a pregnancy prevention programme (PPP - see opposite).

They also recommend that treatment with sodium valproate should only be started by a doctor experienced in managing epilepsy.

Sodium valproate is an effective drug for epilepsy and, for some people, it is the best or only drug that controls their seizures.

Whichever ASM you are taking, **do not** suddenly stop taking it, but talk to your doctor or ESN about any specific risks, and the best options, for you individually.
Visit epilepsysociety.org.uk/sodium-valproate

Topiramate - specific risks in pregnancy
New safety measures were introduced in June 2024 for the epilepsy medication, topiramate, also known by the brand name Topamax.

The safety measures follow a major safety review triggered by a European study which showed that children born to mothers who take topiramate during pregnancy face a two to three times higher risk of intellectual disabilities, autism spectrum disorders, and attention deficit hyperactivity disorder.

The Medicines and Healthcare products Regulatory Agency (MHRA) is advising that topiramate should no longer be prescribed for epilepsy during pregnancy unless there is no suitable alternative treatment.

If you are a woman or girl of childbearing age taking topiramate medication, you will need to be on a pregnancy prevention programme (PPP) - see below.

If you are pregnant, or planning to become pregnant, and you currently take topiramate for epilepsy, you should **not** stop taking the medication but should seek the advice of a specialist. Stopping medication without supervision may cause your seizures to start again, happen more often, or last longer. Anyone planning to start a family should make an appointment with their GP to discuss their treatment options.

If you suspect you have had a bad drug reaction with topiramate, you can report this through the Yellow Card scheme.
Visit epilepsysociety.org.uk/yellow-card-scheme

Pregnancy prevention programme (PPP)
Current MHRA advice states that sodium valproate must not be prescribed for any woman or girl under the age of 55, unless she has a pregnancy prevention programme (PPP sometimes called PREVENT) in place. Topiramate should not be prescribed to any woman or girl of child bearing age unless they have a PPP:

- Your specialist will discuss the risks of taking sodium valproate or topiramate with you, and whether or not you are planning to become pregnant. This will help to decide if the PPP is right for you.
- They will explain the risks to an unborn child if you take sodium valproate or topiramate during pregnancy (see page 4 and above).
- Before you start to take sodium valproate or topiramate, you will need to have pregnancy tests.
- Your specialist will explain the options for highly effective contraception.
- Your specialist will carry out reviews of your treatment at least annually. You and your specialist will complete an annual risk acknowledgement form at each review. This confirms that you have been given appropriate advice, which you have understood.

You should also be given safety and education materials to help explain and support the implementation of these measures.

Your pharmacist will also give you a patient card with information about sodium valproate or topiramate.
For more information visit
gov.uk/government/news/update-on-mhra-review-into-safe-use-of-valproate
gov.uk/drug-safety-update/topiramate-topamax-introduction-of-new-safety-measures-including-a-pregnancy-prevention-programme

What do these risks mean for me?
Most women with epilepsy have over a 90% chance of having a healthy baby. Any individual risks for you will depend on many factors, including your type of epilepsy, the ASM and dose you take, and any other medical conditions.

If you stop taking your ASM, your seizures may increase, or become more severe. Seizures may cause more harm for you and your baby than any risks associated with the ASMs themselves. You and your specialist can discuss any specific risks, and the best options, for you individually.

Getting pregnant

Having epilepsy doesn't usually make it harder for a woman to get pregnant. However, anxieties around having epilepsy, taking medication, and the possibility of seizures can all affect how you may feel about starting a family.

Certain ASMs may reduce the production of sperm for some men, which could lower a man's fertility.

Reduced sperm production and Polycystic Ovary Syndrome (PCOS) can make becoming pregnant more difficult, but they are treatable.
Visit epilepsysociety.org.uk/women-and-girls

Although you may be concerned that ASM might affect your chances of becoming pregnant, it is important not to stop taking ASM suddenly and without the medical guidance of your neurologist or GP.

Some people with epilepsy have a low sex drive. Some men say they struggle to get an erection. Low sex drive and problems with arousal can happen for a number of different reasons including anxiety, depression, or side effects of some ASM.

Both of these problems can be common for people who have focal impaired awareness seizures in the temporal lobe, as this area of the brain is related to sex drive.

These problems can make it difficult for a woman to become pregnant. If you are concerned about your sex drive or sexual response you can ask your doctor for advice.
Visit epilepsysociety.org.uk/relationships-and-sex

What is pre-natal screening?
Pre-natal screening is the name for a number of different checks that all women have during pregnancy, to see how their baby is developing in the womb. They include ultrasound scans which are done at certain intervals throughout pregnancy, commonly at 12 weeks (known as the 'dating scan') and at 18 – 20 weeks (known as the 'anomaly scan').

Women are also offered blood tests that measure a number of things including alpha fetoprotein (AFP) levels. AFP is a type of protein which is passed from an unborn baby to its mother. The levels of AFP in a mother's blood can indicate the risk of their baby being born with certain disorders including spina bifida.

Screening does not show for certain if a baby will be born with or without birth abnormalities. However, it can help to determine the risk of a baby being born with birth abnormalities.

Why is taking folic acid recommended?
Folic acid (vitamin B9) helps a developing baby's spine to form, and reduces the risk of neural tube defects, for example spina bifida.

The Department of Health (DoH) recommends that all women planning to have a baby take 0.4 µg (400 micrograms) of folic acid daily, and throughout the first 12 weeks of pregnancy.

It is strongly recommended that women with epilepsy on ASM take a higher dose of 5000 micrograms (5 milligrams) of folic acid daily, as soon as they start trying for a baby and for at least the first 16 weeks of their pregnancy, or for the whole pregnancy if their doctor feels this is appropriate. This strength of folic acid is only available on prescription but will be free of charge.

Pregnancy

Most women with epilepsy have no change in their seizure frequency during pregnancy. However, you might find that your seizures are better controlled during pregnancy, or that you have more seizures than is usual for you. This could be because of the common side effects of pregnancy such as tiredness, or the effects of morning sickness on your ASM.

If you are having more seizures while pregnant than you normally do, you can talk to your neurologist about how to manage the situation safely for you and your baby.

Could pregnancy affect my ASM?

During pregnancy your body may use up more of your ASM than usual. This means that the amount of ASM you normally take may not be enough to stop your seizures from happening. This is especially true for the ASM lamotrigine (Lamictal) and phenytoin.

Routine monitoring of ASM levels in pregnancy is not generally necessary. However, your neurologist might ask you to have blood tests to make sure that the amount of ASM you take is at the right level for you and your baby throughout your pregnancy, especially if your seizures increase or are likely to increase.

Testing the levels of the ASM in your blood helps your neurologist decide if the dose needs to be changed. If your dose does need to be changed, it will usually be slowly reduced back to its original level after you give birth. However, if the higher dose has led to better seizure control after the birth, and there is no evidence that this dose is causing you problems, then you and your neurologist may decide to leave your ASM at this new dose.

Can morning sickness affect my ASM?

Despite the name, morning sickness can happen at any time of the day and affects some women during the first 12 weeks of pregnancy, although it can last longer.

If you are sick after taking your ASM, the medication may not have a chance to work properly. Changing the time of day you take your ASM, for example taking them when you've stopped feeling sick, may be helpful.

However, it is important (as far as possible) to keep the length of time between doses the same.

Your doctor should be able to advise you on how best to manage your ASM.

Visit epilepsysociety.org.uk/about-epilepsy/treatment/anti-seizure-medication

Can seizures affect an unborn baby?

Tonic clonic seizures could potentially cause miscarriage or serious harm to you and your baby. In rare cases, women with epilepsy have died during pregnancy, mostly due to poor seizure control.

Other seizures are probably less harmful, but may be associated with premature birth and lower birth weight.

However, if you injure yourself during any type of seizure, this can carry risks.

To reduce any risks to you and your baby, the aim is for you to be as seizure-free as possible during your pregnancy. Taking your ASM as prescribed, and telling your doctors or midwife about any seizures you have, can be helpful.

What if I'm already pregnant?

If you become pregnant without having the chance to have preconception counselling, it is recommended that you:

- keep taking your ASM as normal;
- ask your doctor to prescribe daily folic acid supplements of 5 milligrams (see page 4); and
- make an appointment to see your neurologist as soon as possible.

The UK Epilepsy and Pregnancy Register

If you have epilepsy and want to try for a baby, or you are already pregnant, you might like to contact the register.

This is a long-term study looking into the outcomes of children born to women with epilepsy, including the possible effects of ASMs on unborn babies.

If you join the register, you will be asked about your epilepsy and any ASMs that you take, and the register research team will contact you after your baby is born at set time points to find out how you and your baby are doing.

Participating in the register includes follow up of your baby's development and it is hoped that the findings from the study will provide some answers and guidance for other women in the future. It is free of charge to be part of the study.

Visit epilepsyandpregnancy.co.uk

Will epilepsy affect the birth?

Most women with epilepsy have normal deliveries and healthy babies. Your doctors may advise you to give birth in hospital so that you and your baby can have extra care if needed. If a seizure happens during labour, your baby's oxygen supply may be reduced. Drugs may be given to stop the seizure.

You can discuss your individual risk of having a seizure during labour with your neurologist or epilepsy specialist nurse (ESN).

It can be useful for the midwife and medical team who will be at the birth to know about your epilepsy, including what type of seizures you have, which ASMs you take, and when you take them. Ideally, ASMs are taken as normal during labour.

If you want to have a home birth, you need to carefully consider the possibility of having a seizure during labour, which could lead to complications.

If you would like to have a water birth, you may also need to consider the possible risks if you become confused or lose awareness during your seizures.

Generally, a caesarean section (C-section) is only necessary if it is in the best interests of you and your baby.

What pain relief can I have?

Women with epilepsy can use most types of pain relief during labour. These include:

- an epidural (an anaesthetic into the spine);
- breathing techniques; and
- gas and air (called Entonox).

Another way to relieve pain is to use a TENS (transcutaneous electrical nerve stimulation) machine, which uses electrical impulses to stop pain signals getting to the brain.

The NHS recommend that TENS machines are not used by people with epilepsy, and many manufacturers include a warning in their instructions and advise women with epilepsy to speak to their doctor before using a TENS machine.

Visit nhs.uk/conditions/transcutaneous-electrical-nerve-stimulation-tens/

Pethidine, a strong painkiller, has been thought to trigger seizures in some women with epilepsy and, if possible, should be avoided.

It is helpful to tell the midwife and the medical team if your seizures have particular triggers. For example, if over-breathing, tiredness, or pain have triggered seizures in the past.

After your baby is born

Why is vitamin K prescribed?

Vitamin K plays an important part in making our blood thicken (clot). A very small number of newborn babies are born without enough vitamin K. This can cause nose bleeds, mouth bleeds, and in some cases internal bleeding. Some ASMs can reduce a mother's vitamin K levels, and this can increase the risk of their baby having low vitamin K levels.

The Department of Health (DoH) recommends that all newborn babies are given extra vitamin K at birth, or within the first month of being born.

Can I breastfeed my baby?

The DoH recommends that every woman is encouraged to breastfeed her baby if at all possible. Breastmilk usually provides all the nutrients a baby needs for the first six months of their life.

If you take ASMs, your baby will have become used to the drugs while in your womb. If you breastfeed, then a small amount will be passed to your baby in your breastmilk. Breastfeeding can be a useful way of weaning your baby off the medication that they have become used to.

However, you may want to check the patient information leaflet that comes with your ASM, which often includes information about breastfeeding and that particular drug. You can also talk to your neurologist, ESN, midwife, or health visitor about any concerns.

Some drugs, such as phenobarbital and primidone, can pass more easily into breastmilk and can make a baby sleepy, so it may be a good idea to alternate between formula milk and breastfeeds.

The Breastfeeding Network has a helpline run by volunteers.

Visit breastfeedingnetwork.org.uk

Can my child inherit epilepsy?

Most parents with epilepsy do not have children with epilepsy, and the chances of inheriting the condition are generally low.

The risk for any child to develop epilepsy by the age of 20 is around 1 in 100 (1%), and the risk may increase to around 2 to 10 in 100 (2 – 10%) for most children whose parents have epilepsy. There is a slighter higher risk of developing the condition if the mother has epilepsy than if the father has the condition.

However, the chances of your child inheriting epilepsy may depend on various factors, including: whether your epilepsy has a genetic cause, what type of epilepsy you have, at what age it started, and whether your partner or another child of yours has epilepsy. Your neurologist may be able to give you more information about your epilepsy.

Epilepsy can be a symptom of an inherited medical condition, that is passed from parent to child. These include the rare conditions tuberous sclerosis and neurofibromatosis.

Genetic testing can help identify if a person's epilepsy has a genetic cause or if they are likely to pass it on to their children.

Seizure thresholds

Another genetic factor is our 'seizure threshold', which is the brain's natural resistance to seizures and part of our genetic make-up. As we all have a seizure threshold, any of us could have a seizure under certain circumstances.

If a child inherits a low seizure threshold they are more likely to start having seizures. If they inherit a high seizure threshold then seizures are less likely to start unless an outside factor happens, for example a severe head injury.

Visit epilepsysociety.org.uk/what-epilepsy

Further information

NICE (National Institute for Health and Care Excellence)
nice.org.uk/Guidance/cg137
NICE provides guidance on the diagnosis and treatment of epilepsy.

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For a printed copy of this information contact our helpline.

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