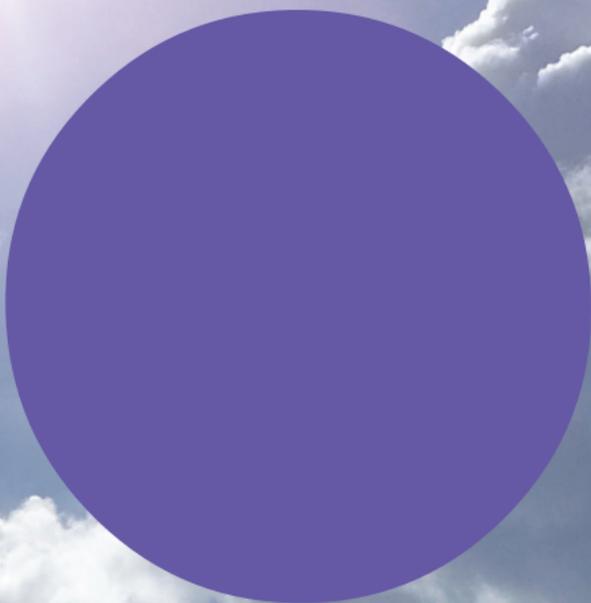




**epilepsy  
society**

# **pregnancy and parenting**

A guide to starting a family



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This symbol means further information is available.

You can find any further updates at [epilepsysociety.org.uk/pregnancy-and-parenting](https://epilepsysociety.org.uk/pregnancy-and-parenting)

## Call us for a large print version

This leaflet was reviewed by Dr Fergus Rugg-Gunn, Consultant Neurologist, Epilepsy Society; and Beth Irwin of the UK, and Irish, Epilepsy and Pregnancy Registers.

## helpline

**01494 601 400**

Confidential, national call rate.

Information and emotional support.

## a guide to starting a family

Each year in the UK around 2,500 women with epilepsy have a baby. Most of these women will have a normal pregnancy and delivery, an unchanged seizure frequency and over a 9 in 10 (90%) chance of having a healthy baby.

If you have epilepsy it doesn't necessarily mean that starting a family will be any more difficult for you than for anyone else. However, it may mean that you have a few more things to consider before, during and after your pregnancy.

This leaflet looks at the issues around pregnancy and parenting that may affect some people with epilepsy.

### getting pregnant

Many people with epilepsy have children and a normal family life. 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 anti-epileptic drugs (AEDs) may reduce the production of sperm for some men, which could lower a man's fertility.



**See the patient information leaflet for your AEDs.**

Some women with epilepsy have irregular periods or a condition called Polycystic Ovary Syndrome (PCOS). PCOS is more common in women who put on weight, and some AEDs have weight gain as a possible side effect.

 **See our leaflet *women*.**

 **Visit [verity-pcos.org.uk](http://verity-pcos.org.uk)**

Reduced sperm production and PCOS are treatable but they can make becoming pregnant more difficult.

Although you may be concerned that AEDs might affect your chances of becoming pregnant, it is important not to stop taking AEDs 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 the side effects of some AEDs.

Both of these problems can be common for people that have focal impaired awareness seizures (previously called complex partial 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.

 **See our factsheet *relationships and sex*.**

## can epilepsy be inherited?

Most parents with epilepsy do not have children with epilepsy, and the chances of inheriting epilepsy 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 5 in 100 (2 – 5%) for most children of parents with epilepsy.

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, passed from parent to child. These include the rare conditions tuberous sclerosis and neurofibromatosis.

### **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.



**See our leaflet *what is 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 to do this *before* you become pregnant. You may have questions about the 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.

Because of the possible effects of AEDs on an unborn baby, having your AEDs reviewed before you get pregnant can help you and your neurologist make sure that you are taking the most appropriate AEDs and at the most suitable dose during your pregnancy.



**See page 10 for more about the effects of AEDs on an unborn baby.**

If you have seizures you are likely to be advised to keep taking your AEDs throughout your pregnancy.

Your doctor may suggest adjusting your AEDs so you take the lowest possible dose that will still control your seizures. However, some AEDs 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 8).

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

Some women prefer not to take AEDs 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 AEDs affecting your baby.



**See page 10 for more about these risks.**

If you have been seizure-free for two or three years, your doctor might suggest slowly stopping your AEDs before you try for a baby. However, if your AEDs are 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. How long you will need to stop driving for may depend on the type and number of seizures you have had.



**See our leaflet *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.

## 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 AEDs as normal;
- ask your doctor to prescribe daily folic acid supplements of 5mg (see page 15); and
- make an appointment to see your neurologist as soon as possible.

### **Could pregnancy affect my epilepsy?**

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 AEDs.

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 AEDs?**

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

Although routine monitoring of AED levels in pregnancy is not generally necessary, your neurologist might ask you to have blood tests to make sure that the amount of AED 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 AED in your blood helps your neurologist decide if the dose needs to be changed. If your dose needs 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 AED at this new dose.

### **Can morning sickness affect my AEDs?**

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 AEDs, the medication may not have a chance to work properly.

Changing the time of day you take your AEDs, 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 AEDs.

## **Can seizures affect an unborn baby?**

There is no evidence that the seizure activity in focal aware (previously called simple partial), focal impaired awareness (previously called complex partial), absence or myoclonic seizures are harmful to an unborn baby. However, if you injure yourself during any type of seizure, this can carry risks. 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.

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 AEDs as prescribed, and telling your doctors or midwife about any seizures you have, can be helpful.

## **can AEDs affect an unborn baby?**

If the baby's father has epilepsy and takes AEDs, these will not affect the baby's development because the baby will not come into contact with the father's AEDs.

For a woman with epilepsy who takes AEDs during pregnancy, her baby will be exposed to AEDs 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 AEDs.

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

### **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 different reasons. Birth abnormalities can be classed as 'minor' and 'major'.

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 slightly 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.

### **AEDs and birth abnormalities**

Women with epilepsy who take AEDs during pregnancy also have a slightly higher risk of having a baby with a birth abnormality than women with epilepsy who don't take AEDs.

Different AEDs 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 AED increases the risks, especially if this includes sodium valproate.

- 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 AEDs** will have a baby with a major malformation.
- 4 – 10 women in every 100 (4 – 10%) who have epilepsy and **who take an AED** will have a baby with a major malformation.



- Recent studies show that lamotrigine (Lamictal), and levetiracetam (Keppra) are safer to use during pregnancy than other AEDs, having low rates of physical birth abnormalities, in line with the background risk (2 – 3%). Again, for each drug the risks increase with higher doses.

### **Sodium valproate – an important case**

Sodium valproate (brand names include Epilim, Episenta and Epival) has greater risks in pregnancy than other AEDs, with 7 women in 100 (7%) having a baby with a major malformation, 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 (see page 14).

The Medicines and Healthcare products Regulatory Agency (MHRA) states that sodium valproate should not be prescribed to girls or women who are pregnant, or who may become pregnant in future, **unless** it is the only effective drug for them and they are on a pregnancy prevention programme. They also recommend that treatment with sodium valproate should only be started by a doctor experienced in managing epilepsy.

**If you are taking sodium valproate, do not suddenly stop taking it**, but talk to your doctor as soon as possible about the best treatment options for you. Sodium valproate is an effective drug for epilepsy and, for some women, it is the best or only drug that controls their seizures.

## **Fetal anti-convulsant syndrome**

Some AEDs 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 AEDs.

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 have an autism spectrum disorder.

There are organisations which provide information and support to families affected by Fetal anti-convulsant syndrome.



**See page 23 for contact details.**

## **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 AEDs and dose you take, and other medical conditions.

If you stop taking your AEDs, your seizures may increase, or become more severe. Seizures may cause more harm for you and your baby than any risks associated with the AEDs themselves.

You and your specialist can discuss any specific risks, and the best options, for you individually.

### **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 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 take a higher dose of 5mg 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.

### **What is pre-natal screening?**

Pre-natal screening is the name for a number of different checks that all women have done during pregnancy, to see how their baby is developing in the womb. These 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 combined blood tests that measure a number of things including alphafetoprotein (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 any birth abnormalities. However, it can help to determine the risk of a baby being born with birth abnormalities.

### **The UK, and Irish, Epilepsy and Pregnancy Registers**

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 effects of AEDs on unborn babies, and the effects of having seizures while pregnant. The study lets you speak to an epilepsy nurse and asks questions about your pregnancy and epilepsy. If you would like to join the register you will be asked about your epilepsy and any AEDs that you take, and the register may want to contact you after your baby is born. It is free of charge to be part of the study and over 10,000 women have taken part so far.

Research into epilepsy and pregnancy is ongoing. It is hoped that the findings from the study will provide some answers and guidance for other women in the future.



**To join the UK register call 0800 389 1248, visit [epilepsyandpregnancy.co.uk](http://epilepsyandpregnancy.co.uk) or text 'Join' to 07585 509 789.**

**For the Irish register call 1 800 320 820, or visit [epilepsyregister.ie](http://epilepsyregister.ie)**

## will epilepsy affect the birth?

Your doctors may advise you to give birth in hospital. For 2 – 4 women in every 100 (2 – 4%) who have epilepsy, the stress of labour may trigger a tonic clonic seizure either during the labour or during the 24 hours afterwards, even if they don't normally have tonic clonic seizures. If a seizure happens during labour, your baby's oxygen supply may be reduced. Drugs can usually be given to stop the seizure.

Most women with epilepsy have normal deliveries and healthy babies. 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 AEDs you take and when you take them. Ideally, AEDs 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. There is no evidence that TENS machines are not safe for use in epilepsy, but many manufacturers still include a warning in their instructions and advise women with epilepsy to speak to their doctor before using a TENS machine.

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 any particular triggers. For example, if pain, tiredness or over-breathing 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 (about 1 in 10,000 or 0.01%) are born without enough vitamin K. This can cause nose bleeds, mouth bleeds and in some cases internal bleeding. Some AEDs 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 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 Department of Health 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 AEDs, 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.

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 patient information leaflet that comes with your AED often includes information about breastfeeding and that particular drug. You can also talk to your neurologist, midwife or health visitor about any concerns you may have.

The Breastfeeding Network has a helpline run by pharmacists on a voluntary basis. You may have to leave a message so that they can call you back.



**See page 23 for contact details.**

## **Childcare**

If your seizures (or your partner's seizures) are controlled, then epilepsy may not affect how you look after your child.

However, parents who have seizures may find taking extra safety measures helpful. This depends on the type of seizures and the activity involved.

If you are more likely to have seizures when you are overtired, sharing night time feeds with a partner might help to increase the chance of a good night's sleep.

## **Keeping you and your baby safe**

If your seizures happen suddenly and without warning, the following ideas may be helpful to keep your baby safe. These might not always be necessary, especially if there is someone else around to help you, but they could be helpful if you are with your baby on your own and have a seizure.

- Dressing and changing your baby on the floor means that they would be less likely to fall if you had a seizure.
- Sponging your baby down on a changing mat on the floor is safer than bathing them in water.
- Carrying your baby in a padded carrycot or sling rather than having them in your arms, may help to protect your baby if you fall.
- Using a wrist strap on your baby's pram, or a brake which automatically activates, means that the pram will not roll away if you let it go.

- Feeding your baby in a low highchair may be safer as it is less likely to tip over than a higher one.
- Feeding your baby while you sit on the floor, surrounded by cushions and leaning against the wall, may help to keep your baby safer.

### **Talking to your child about epilepsy**

Children can often be taught at a young age what to do if someone has a seizure. Many children learn what to do from watching other people. As their parent, it is for you to decide when it is the right time to explain your epilepsy and seizures to your child.

During a seizure your child could learn to:

- stay with you, so they don't get lost;
- get help from someone else, for example a neighbour or friend; or
- help you themselves, if they know what to do.



**See our leaflet *first aid* and our factsheet *the recovery position*, or call the helpline for *first aid cards* (see back page for details).**

Some people wear medical jewellery or carry an 'I have epilepsy' card saying what to do if they have a seizure. Even if children are too young to manage seizures, they may be able to tell other people that you have a card or medical jewellery.



**Call our helpline for our '*I have epilepsy*' card.**



**Visit [livingmadeeasy.org.uk](http://livingmadeeasy.org.uk) for medical ID cards and jewellery.**

## What about immunisation?

The Department of Health recommends that every child is immunised (vaccinated) against infectious diseases such as measles, mumps and rubella (MMR). Current research suggests that there is no connection between the MMR vaccine and epilepsy.

If you are concerned about any vaccination your child may need, you can talk about this with your child's doctor or paediatrician. It is your choice whether your child is vaccinated, and having more information might help you to decide.

## further information

### Epilepsy Society information

First aid – card and leaflet

Driving

'I have epilepsy' card

Relationships and sex

The recovery position

What is epilepsy?

Women



## other organisations

### The Breastfeeding Network

Drugs in Breastmilk helpline: 0300 100 0212

**[breastfeedingnetwork.org.uk](http://breastfeedingnetwork.org.uk)**

Provides information on taking prescription drugs while breastfeeding.

### FACS Association

01253 799 161

**[facsassociation.org](http://facsassociation.org)**

UK support group providing help and support to families with children affected by Fetal anti-convulsant syndrome.

### Organisation for Anti-Convulsant Syndrome – OACs

07904 200 364

**[oacscharity.org](http://oacscharity.org)**

UK charity providing help and support to families with children affected by Fetal anti-convulsant syndrome.

### Verity

**[verity-pcos.org.uk](http://verity-pcos.org.uk)**

UK charity for women with Polycystic Ovary Syndrome.

Every effort is made to ensure that all information is correct at the time of printing. Please note that information is intended for a UK audience. This information is not a substitute for advice from your own doctors. Epilepsy Society is not responsible for any actions taken as a result of using this information.

# epilepsy society

[epilepsysociety.org.uk](http://epilepsysociety.org.uk)

A full life for everyone affected by epilepsy.

## research

Pioneering medical research.

## treatment and care

Individualised medical and care services.

## information

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## education

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## connect with us



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## helpline 01494 601 400

Confidential, national call rate.

Information and emotional support.

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