

Epilepsy in Pregnancy

This information is for you if you have epilepsy and want to know more about epilepsy in pregnancy. It may also be helpful if you are a partner, relative or friend of someone who has epilepsy and is pregnant or planning a pregnancy.

The information here aims to help you better understand your health and your options for treatment and care. Your care will be provided by a specialist team who are here to support you in making decisions that are right for you.

What does having epilepsy mean for me and my baby?

Epilepsy is a relatively common condition. Most women who have epilepsy remain free of seizures throughout pregnancy and they have straightforward pregnancies and healthy babies.

It is important to continue taking your medication because having frequent seizures during pregnancy can be harmful for you and your baby. Therefore, planning your pregnancy and having extra care during your pregnancy can reduce the risks to you and your baby.

For me

Some women with epilepsy may have more seizures when they are pregnant. Around 1 woman in every 3 with epilepsy will have seizures during pregnancy and 2-4 in 100 women will experience a seizure during labour or within the first few days after birth. This is usually because they have stopped taking their medication or are not taking it regularly. Pregnancy itself or tiredness can also increase the number of seizures. If this happens to you, you should consult your healthcare professional.

In any pregnancy there is a very small risk of death for a mother and this risk is slightly higher for those with epilepsy. However, the vast majority of women with epilepsy will remain well during their pregnancy and give birth to a healthy baby.

For my baby

With any pregnancy there is a small chance that your baby may not develop normally in the womb. The risk of this happening may be slightly higher with certain epilepsy medications. The risk depends on the type and amount of medication you are taking, and it increases if you are taking more than one medication for epilepsy. The most common problems for your baby linked to these medications include spina bifida, facial cleft or heart abnormalities. Taking folic acid reduces this risk.

The epilepsy medication sodium valproate is known to cause harm to developing babies. This includes physical problems and an increased risk of developmental delay, a condition that can affect communication, language skills and behaviour.

If you are taking sodium valproate your epilepsy specialist should change this to an alternative medication before you become pregnant. You should speak to them to make a plan for your pregnancy before you stop your contraception.

If you become pregnant unexpectedly while taking sodium valproate do not stop the medication yourself but tell your GP and epilepsy specialist straight away so they can discuss the safest options for treatment with you.

Care during my pregnancy

Epilepsy Medications

Your epilepsy medications are important for your safety and wellbeing and you should not stop taking them without taking advice from your specialist team.

Will my epilepsy medication be changed during my pregnancy?

Your specialist team will support you to manage your epilepsy medications during your pregnancy. The team may recommend that you have blood tests to monitor the levels of medication in your blood and based on these results, may recommend a change in your medication dose.

The risk of complications to your baby's development from taking your epilepsy medications is much smaller than the risk to your baby of not taking your epilepsy medications and having seizures in pregnancy.

We strongly recommend that you do not stop your epilepsy medications without seeking medical advice first.

All pregnant women are advised to take folic acid as it helps to reduce the risk of their baby having spina bifida. It may also reduce the risk of heart or limb defects. Your doctor will advise you to take a daily dose of 5mg of folic acid. This is higher than usual and will need to be prescribed for you. This higher dose is needed because of your epilepsy medication, which can increase the risk of your baby being born with spina bifida.

If you are planning to have a baby, it is worth continuing contraception until you have seen a neurologist or epilepsy specialist and have taken folic acid for 3 months. As most of your baby's development takes place in the first 3 months of pregnancy, you should ideally be taking folic acid for 3 months before you conceive and continue to take it until you reach your 13th week of pregnancy

If you have difficulty taking your medications during pregnancy, for example if you are sick during early pregnancy, please speak to your doctor, midwife or epilepsy specialist nurse as soon as possible.

Seizures and safety during my pregnancy

There is no indication that focal seizures or altered state of awareness seizures cause harm to your baby. If you have a generalised tonic clonic seizure there is a slight risk to the baby if you fall, as there would be with any fall during pregnancy.

There is a risk if you have a prolonged generalised seizure which lasts over five minutes; this would start to compromise your own health and your baby. We will discuss your typical seizure pattern in clinic with you.

What is SUDEP?

A very rare but serious complication of epilepsy is sudden unexplained death with epilepsy (SUDEP), which may occur more frequently in pregnancy.

Each year, roughly 1 in 1000 people with epilepsy will die suddenly with no obvious cause. The risk may be greater for a small number of people, which is why it's important to talk to your medical team about your own condition.

SUDEP usually occurs at night or during sleep. It's often the case that the affected person will have had a seizure just before their death, although this isn't universal. Researchers are still investigating the causes of SUDEP and it's unlikely that there is a single cause.

My baby's birth

You will have the opportunity to discuss your preferences for your baby's birth with your specialist team and to develop a personalised plan in the antenatal period.

The risk of having a seizure during labour is 1-2%. We recommend that your baby is born at the hospital delivery suite, where there is a team on hand to provide emergency care if you were to have a seizure.

What are my options for pain relief in labour?

You will have the option of gas and air (Entonox), hypnobirthing techniques, a TENS machine, remifentanyl patient-controlled analgesia or an epidural. Pethidine (a strong painkiller) is not advised if you have epilepsy as it can trigger seizure.

After my baby is born

Your body goes through many changes after you have had your baby; tiredness combined with some hormonal changes mean you are at more risk of having a seizure. For this reason, we recommend that you remain in hospital for at least 24

hours after giving birth. You will be offered a bed in an open bay so that the midwives can observe closely for any signs of seizures.

We recommend that you initially continue taking your epilepsy medications as you were throughout your pregnancy, unless told otherwise by your doctor. We will offer you a follow-up appointment your GP, Neurologist or Epilepsy Specialist Nurse to further discuss your anti-epileptic medications. If you have increased your medications throughout pregnancy, they might need further adjustment or reduction after your baby is born.

Breastfeeding

There are many benefits of breastfeeding for you and your baby. Epilepsy medications can pass into breast milk but the amount is usually so small that it is not harmful. Breastfeeding is safe even if you are taking epilepsy medication.

Contraception

The contraception you choose after your baby is born will depend on factors such as the epilepsy medications you take, whether you are breast-feeding and your own personal preferences. Please speak to your healthcare team for more information.

Epilepsy and Pregnancy Register

You are invited to register with the UK Epilepsy and Pregnancy Register UK (<http://www.epilepsyandpregnancy.co.uk/>). This was set up in 1996 to collect information about the epilepsy medication that women take during pregnancy.

Future Pregnancies

We recommend that you speak to a member of your healthcare team, eg your Epilepsy Specialist Nurse, GP or neurologist before trying to conceive your next baby. This will give the team an opportunity to review your epilepsy and epilepsy medications and ensure you are on the safest drugs for you and your future baby. Advice and recommendations will depend on your individual circumstances.

We recommend that in preparation for your next pregnancy you take Folic Acid 5mg daily before you become pregnant and continue this until you are at least 12 weeks into your new pregnancy. This higher dose needs to be on prescription from your GP or hospital doctor. Taking Folic Acid reduces the risk of your baby having congenital abnormalities.

What can I do to stay safe during pregnancy and once my baby is born?

It is important that you do not forget to take your epilepsy medications. You might benefit from using an alarm on your phone as a reminder.

Be aware of triggers that could cause you to have a seizure and try and reduce the risk of this happening. For example, not getting too tired (share care of your baby

with your partner or family so you can get some sleep), ensure regular meals and avoiding stress as much as possible.

Washing yourself and your baby – We recommend that you shower and do not bathe alone. Don't take the baby into the bath with you unless someone else is present. Do not bathe the baby without someone else being present.

Feeding your baby – Try to feed your baby on the floor sitting with your back well supported and on a soft surface, such as a rug, especially if you are alone.

Changing your baby – We advise that you change your baby on the floor and not at a height, for example don't use a high changing table or on a bed. Take a mat out with you in public so you can cleanly use a floor surface if needed.

Sleeping – Never co-sleep with your baby in bed or on a sofa if you have epilepsy. Ideally have your partner, other family member or trusted friend to be around at night, especially for the first few days after you have your baby.

Carrying your baby – Take care with stairs when carrying your baby; if your seizures cause you to fall your baby could come to harm. Additionally measures such as safety brakes can be fitted to pushchairs (see epilepsy action website below for more information). Always ensure your baby is in a safe place on the floor or crib if you feel unwell or experience aura.

Further Information

Consider using EpSMon, a smartphone app to help you regularly assess and monitor your epilepsy, risks and wellbeing so you are aware of any changes.

Find out more at www.epsmon.com and www.sudep.org/checklist

Epilepsy Action: <https://www.epilepsy.org.uk/info/caring-children>

Epilepsy Society: <https://www.epilepsysociety.org.uk>

UK Epilepsy and Pregnancy Register: <http://www.epilepsyandpregnancy.co.uk/>

For information on epilepsy medications during and after pregnancy

BUMPS – Best Use of Medications in Pregnancy:
<http://www.medicinesinpregnancy.org>

Breast-feeding network: <https://www.breastfeedingnetwork.org.uk>

