

# Information for you

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## Epilepsy in pregnancy

### About this information

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.

### 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. 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.

There are different types of seizures and your doctor should give you information on the type of epilepsy you have and possible effects on you and your baby. Most types of epilepsy will not cause any harm to you or your baby. Medications for epilepsy should never be discontinued or changed without consulting your healthcare professional.

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

## 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 of medication you are taking and the dosage, 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 carries the highest risk to your baby; it also increases the risk of developmental delay, a condition that can affect communication, language skills and behaviour. The condition may only become apparent as the child grows.

# **I have epilepsy. What should I think about before becoming pregnant?**

## **Talk to your GP**

Most women with epilepsy have healthy babies. It is important that you let your GP know that you are planning to have a baby. You may be referred to a neurologist or epilepsy specialist for advice who will be able to talk to you about what pregnancy will mean in your individual situation.

They will talk to you about the medication you are on and what can be done to reduce the risks to you and your baby. You may be advised to stay on your current medication but alter the dose. Sometimes you may be advised to change your medication. Changing the medication or its dose may affect your ability to drive.

Although it is not needed routinely, sometimes your healthcare professional will arrange for blood tests to measure the level of the medication before altering the dose.

## **Start taking folic acid at the higher dose of 5 mg daily**

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 5 mg 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. Your GP or family planning service can advise you on which contraception is best for you if you are unsure.

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.

# I was not planning a baby but I have found out I am pregnant

- Do not stop your medication. Epilepsy medication itself only carries a small risk to your baby, whereas stopping your medication could pose a serious risk to both you and your baby. Talk to your GP or epilepsy nurse as soon as possible. They will arrange for you to see an obstetrician or neurologist who will be able to give you advice.
- If you are not taking folic acid already, you should start taking it now. You should take the higher dose of 5 mg daily. See your GP, who will prescribe this for you.

If nausea or vomiting makes it difficult to keep your epilepsy medication down, talk to your GP, midwife or epilepsy specialist.

## What extra care will I need during pregnancy?

Your midwife will refer you for a hospital antenatal clinic appointment early in your pregnancy. You will be under the care of a specialist healthcare team, which will usually include an obstetrician, a midwife and a specialist healthcare professional.

At your first visit you will be given information about:

- ways to reduce the risk of having seizures, for example by making sure that you take your medication and by trying to get as much sleep/rest as possible
- the UK Epilepsy and Pregnancy Register. This was set up in 1996 to collect information about the epilepsy medication that women take during pregnancy and the health of their babies. It also gives advice about epilepsy medication(s) taken during pregnancy. You will be invited to join the Register. You can also contact the Register directly on Freephone 0800 3891248.

Having epilepsy will usually mean more clinic visits at the hospital. Your team will discuss your general health with you, and whether you have had any seizures recently. You may be advised to increase or alter your medication if the number of seizures you are having has increased.

Like all pregnant women, you will be offered routine ultrasound scans to check how your baby is developing. This includes checking your baby's spine and heart. You may be offered additional scans to monitor the growth of your baby if you are taking medication for epilepsy.

Taking your medication as advised and extra precautions such as taking showers rather than baths can reduce your risk of any accidents such as drowning.

## **Where should I have my baby?**

You will be advised to give birth in a consultant-led maternity unit with a special care baby unit so that you and your baby can get extra care if needed.

## **Will I need to have my baby early?**

Having epilepsy, particularly if it is well controlled, is not by itself a reason to need to give birth early.

## **How will I have my baby?**

You will be able to discuss your birth plan with your midwife and obstetrician. Most women with epilepsy are able to have a vaginal birth. Epilepsy on its own does not require a planned caesarean section or induction of labour. If you would like to have a water birth, you should discuss this with the team looking after you.

## What happens in labour?

The risk of having a seizure during labour is very small, especially if your epilepsy is well controlled. However, being tired, dehydrated and in pain can increase the risk, so make sure that you have as much support, rest and pain relief as possible.

You should bring your epilepsy medication to hospital with you and take it as you normally would during your labour.

Gas and air, TENS machines and an epidural are all suitable for pain relief. Injections of a strong pain reliever such as diamorphine can also be used. Pethidine (another type of pain relief) is not recommended, because in high doses it has been linked with seizures.

## What happens after my baby is born?

Your baby will usually stay with you unless they need extra care.

### Vitamin K

You will be offered an injection of vitamin K for your baby. Vitamin K is needed for blood to clot properly. Levels are low in all newborn babies, which puts them at risk of bleeding. Some anti-epileptic medication can further lower vitamin K levels.

### Seizures

You may have more seizures after giving birth because of tiredness, stress and anxiety. Get as much rest and help with your baby as you can.

### Medication

Missing medication also increases the risk of seizures. Forgetting to take medication after your baby is born is very common. Some women set an alarm on their phone or use an app to help them remember to take their medication on time.

If you have been taking more medication during your pregnancy, you may be able to go back to your previous dose. Talk to your specialist healthcare professional before your baby is born so that you have a plan in place.

## Advice to keep your baby safe

Your midwife and epilepsy nurse will talk to you about ways of keeping your baby safe if you have a seizure, including:

- getting plenty of help and rest
- using very shallow baby baths
- nursing your baby on the floor
- laying your baby down if you have a warning aura.

## Contraception

It is a good idea to have a plan for contraception. You can discuss this with your healthcare professional before you leave hospital.

## Can I breastfeed my baby?

Breastfeeding is best for babies. Epilepsy medication can pass into breast milk but the amount is usually so small that it is not harmful. Breastfeeding is considered safe even if you are taking epilepsy medication.

## Key points

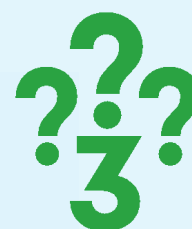
- Most women who have epilepsy do not have a seizure during pregnancy and have healthy pregnancies and healthy babies.
- If you are planning a baby, let your GP or epilepsy specialist know. They will review your medication and discuss with you the best way to prepare for a pregnancy. This will include taking folic acid at the higher dose of 5 mg daily.
- A specialist team will look after you and your baby during pregnancy.
- You must not stop or change your epilepsy medication unless so advised.

- You should be able to have a vaginal birth.
- You are at increased risk of having seizures during labour and after birth. Taking your medication regularly and getting enough rest lowers this risk.
- Breastfeeding is safe even if you are taking epilepsy medication.

## Making a choice

### Shared Decision Making

If you are asked to make a choice, you may have lots of questions that you want to ask. You may also want to talk over your options with your family or friends. It can help to write a list of the questions you want answered and take it to your appointment.



#### Ask 3 Questions

To begin with, try to make sure you get the answers to three key questions if you are asked to make a choice about your healthcare.

1. What are my options?
2. What are the pros and cons of each option for me?
3. How do I get support to help me make a decision that is right for me?

\* Ask 3 Questions is based on Shepherd HL, et al. Three questions that patients can ask to improve the quality of information physicians give about treatment options: A cross-over trial. *Patient Education and Counselling*, 2011;84: 379-85



<https://www.aquanw.nhs.uk/SDM>

## Further information

Epilepsy Action: *Epilepsy and having a baby* ([www.epilepsy.org.uk/info/women/having-baby](http://www.epilepsy.org.uk/info/women/having-baby))

Epilepsy Society: *Pregnancy and parenting* ([www.epilepsysociety.org.uk/pregnancy-and-parenting](http://www.epilepsysociety.org.uk/pregnancy-and-parenting))

UK Epilepsy and Pregnancy Register: [www.epilepsyandpregnancy.co.uk](http://www.epilepsyandpregnancy.co.uk)



## Sources and acknowledgements

This information has been developed by the RCOG Patient Information Committee. It is based on the RCOG Green-top Clinical Guideline *Epilepsy in Pregnancy*, which contains a full list of the sources of evidence we have used. You can find it online at: [www.rcog.org.uk/en/guidelines-research-services/guidelines/gtg68](http://www.rcog.org.uk/en/guidelines-research-services/guidelines/gtg68).

This leaflet was reviewed before publication by women attending clinics at the Royal Victoria Infirmary, Whipps Cross University Hospital, Wrexham Maelor Hospital, Raigmore Hospital, St Thomas' Hospital, St Mary's Hospital, St Bartholomew's Hospital, Royal London Hospital, Birmingham Women's Hospital, University Hospital Birmingham and Birmingham and Solihull Mental Health NHS Foundation Trust, by the RCOG Women's Network and by the RCOG Women's Voices Involvement Panel.

The RCOG produces guidelines as an educational aid to good clinical practice. They present recognised methods and techniques of clinical practice, based on published evidence, for consideration by obstetricians and gynaecologists and other relevant health professionals. This means that RCOG guidelines are unlike protocols or guidelines issued by employers, as they are not intended to be prescriptive directions defining a single course of management.

A glossary of all medical terms is available on the RCOG website at: [www.rcog.org.uk/en/patients/medical-terms](http://www.rcog.org.uk/en/patients/medical-terms).