



Epilepsy during and after pregnancy

This leaflet explains what complications may occur, how your pregnancy will be monitored and who is available to support you during your pregnancy. If you have any questions or concerns, please speak to your midwife or doctor.

What does having epilepsy mean for me and my baby/babies?

Epilepsy is a relatively common condition. Most women who have epilepsy remain free of seizures throughout their pregnancy 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/babies. Therefore, planning your pregnancy and having extra care during your pregnancy can reduce the risks (RCOG 2022). If you are pregnant and nausea or vomiting makes it difficult to keep your epilepsy medication down, talk to your GP, midwife or epilepsy specialist. (RCOG 2022).

Planning for pregnancy

If you are reading this before becoming pregnant, then you should speak to your GP or epilepsy specialist regarding your current epilepsy medication before conceiving. You can have a review with an epilepsy specialist to ensure that you are on the lowest safest dose of medication before you try to conceive. This is also an opportunity to review your seizure control before becoming pregnant. Current advice suggests that for those taking Sodium Valproate (Epilim) a specialist review is needed and alternative medications discussed where appropriate.

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 communications, language skills and behaviour. If you are taking sodium valproate your epilepsy specialist may 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. (RCOG)

Never stop taking your anti-epilepsy medication unless under the guidance of your neurologist or epilepsy specialist nurse.

The Epilepsy Clinical Nurse Specialist Service offers pre-conception counselling, which is a good opportunity to plan your pregnancy as safely as possible.

Folic acid

A folic acid supplement of five milligrams (5 mg) once daily is recommended to pregnant women with epilepsy. This is a higher dose and cannot needs a prescription from your GP.

Folic acid may interact with some anti-epileptic drugs such as: phenytoin, phenobarbital and primidone, making them less effective. For this reason, if you are taking any of these anti-epileptic drugs, **it is important to seek advice from your doctor or the Epilepsy Clinical Nurse Specialist before taking folic acid supplements.**

Ideally, you should start taking folic acid approximately three months before you start trying to conceive and stop after the first trimester of pregnancy (after 3 months).

Certain 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. 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 may reduce this risk.

Major congenital malformations (MCMs)

For any woman there is a small (background) risk that her baby may be born with a birth abnormality or malformation. Women with epilepsy have a higher chance of having a baby with a birth abnormality than women who do not 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 some types of anti-seizure medications (Epilepsy Society September 2023). 'Congenital' means a condition that a baby is born with. MCMs include malformations of the spinal cord and spine (spina bifida), the heart (such as a hole in the heart), the ribs, the bladder, the sexual organs and the fingers and toes (such as un-separated fingers). Babies born with MCMs may need surgery after their birth.

Minor malformations

There is also a slightly higher risk of your baby having minor malformations. Minor malformations do not necessarily require medical treatment and may not be permanent. Examples of minor malformations include small fingers and toes with small nails, facial features such as wide-set eyes, low-set ears and a short neck. The exact risk of minor malformations due to anti-epileptic drugs (AEDs) is unknown.

Scans and tests during pregnancy

There are a number of tests, such as scans and blood tests, available for all pregnant women. Some tests can check the development of the baby's heart, head and spine as well as look for abnormalities of the baby's face, such as a cleft lip (when the top of the baby's mouth does not develop properly). Other tests can only tell you if your baby has a high or low risk of having a birth defect such as spina bifida (when the baby's spine does not develop properly). These tests can be particularly helpful if your baby has a higher risk of having a birth defect due to the mother having epilepsy and anti-epileptic drugs.

It is up to you to decide whether you want these additional tests or not. Some find knowing about these conditions can help them to prepare, while others choose to wait until after birth to find out.

If you would like to find out more about scans and tests that can be done while you are pregnant, speak to your midwife or obstetrician (doctor specialising in pregnancy and birth).

Seizures during pregnancy

You may find you have more seizures when pregnant, sometimes tiredness is a factor. It is important to take your medication regularly and if necessary set alarms to remind you. If you find your seizures are increasing, you should consult your epilepsy team.

Most types of seizures will not cause any harm to you or your baby. To reduce risks to you it is advisable to take showers rather than baths and ideally to have someone else in the house when you wash. You should avoid standing at the edge of the platform when waiting for a train and think about the potential risks when completing high risk activities.

A very rare but serious complication of poorly controlled epilepsy is sudden unexplained death in epilepsy (SUDEP), which may occur more frequently in pregnancy. To reduce the risks to you and your baby/babies, it is advisable to aim to be as seizure-free as possible during your pregnancy. You can help to do this by taking your anti-epileptic drugs as prescribed and talking to the healthcare team about any seizures you have. If you have more seizures, seizures at night or uncontrolled seizures you should contact your epilepsy team urgently.

Giving birth

Providing your pregnancy is uncomplicated your epilepsy should not affect you having the labour and delivery you choose, including a vaginal delivery. You will generally be advised to have your baby in the Delivery Suite, which is consultant led care, where a team that includes both midwives and doctors is available to look after you. You should take your anti-epileptic drugs (AEDs) to the hospital with you and take them at the usual time, even during labour. You could ask your midwife or birth partner to help you to remember to take your medication at the right time.

Pain management

Your midwife will talk to you more about different ways to manage any pain during your labour and birth. You will be given information about a range of non-medical and medical options. It is important to know which of these can be used alongside your epilepsy.

- **TENS machines** can be used for pain management during labour, and these can be used safely if you have epilepsy.
- **Gas and air (Entonox)** is safe to use with epilepsy. It is important to only use as directed and do not over-breathe when you are using it, as over-breathing can trigger seizures in some people.
- An epidural anaesthetic can be used if you wish. However, it is important that the anaesthetist who gives you this knows that you have epilepsy and which anti-epileptic drugs you are taking (if any).
- **Diamorphine injections** are safe to use with epilepsy.
- **Pethidine** is not safe to use, as it can make seizures more likely.

Vitamin K

Vitamin K is important for making our blood clot. Levels are low in all newborn babies, which puts them at risk of bleeding, which is why they are offered a Vitamin K injection or oral tablets after birth. Some anti-epileptic medication can further lower vitamin K levels. If you take an enzyme-inducing drug (carbamazepine, Oxcarbazepine, phenobarbital, phenytoin, primidone or Topiramate) when you are pregnant, your baby may be at a higher risk of having Vitamin K deficiency. To prevent this, it is recommended that your baby should have an injection of one milligram of Vitamin K at birth.

A very small number of babies will be born with a Vitamin K deficiency which can lead to a rare bleeding disorder called haemorrhagic disease of the newborn (HDN). Vitamin K deficiency can cause HDN so you might also hear people call HDN vitamin K deficiency bleeding (VKDB). This can cause them to bleed in different parts of their body, any time in the first few weeks of life. For example, they may have nose or mouth bleeds, or start to bleed from their umbilical stump or their bottom. They may also have bleeding in their brain. Bleeding in newborn babies can be very serious and can cause brain damage and even death.

Breastfeeding

WHO and UNICEF recommend that babies receive breastmilk (colostrum) within the first hour of birth and be exclusively breastfed for the first 6 months of life*. If you choose to breastfeed it is important to be aware that AEDs can pass into your breast milk in small amount, which would then pass to your baby and could cause excessive sleepiness (making it harder to feed) or allergic skin reactions. You can discuss breastfeeding with an epilepsy specialist or nurse, or an infant feeding adviser.

If you would like to discuss breastfeeding and specific anti-epileptic drugs, please contact the Epilepsy Helpline, 0808 800 5050 or visit www.breastfeedingnetwork.co.uk

However, you decide to feed your baby it is likely that your night-time sleep will be broken regularly. If lack of sleep is a trigger for your seizures, you may need to arrange for someone else to feed your baby at night either with expressed breast milk or formula. Another solution would be for someone else to care for the baby to give you a daytime break, so that you can catch up on missed sleep.

In the UK, some parents with epilepsy may be entitled to Disability Living Allowance to pay towards a helper while their baby is very young.

Caring for children when you have epilepsy

If your seizures are not controlled, there are some precautions you can take. These will help to make sure a baby or child in your care is as safe as possible in the event of you having a seizure.

- If possible, share the care of a baby, especially at night, so you do not become too sleep deprived. Some people with epilepsy find that lack of sleep or feeling very tired can trigger their seizures.
- When feeding a baby from a bottle or your breast, you could sit on the floor on a towel or a rug, so that if you have a seizure your baby does not have far to fall.

- When a child is taking more solid food, you could put them in an appropriate low chair on the floor and sit next to them when feeding them.
- When a child is using a highchair, make sure you could not knock the chair over if you had a seizure.
- Never bathe a baby or child on your own. Instead give them a simple sponge bath or seek the support of another adult.
- Change a baby's nappy on the floor. Changing units are not recommended, as the baby could roll off if you had a seizure.
- When carrying a baby up or down stairs, use a car seat to provide protection from a fall.
- Use safety gates and fixed fireguards around the home, to keep a baby or child safe if you have a seizure.
- Use a pram with a brake that comes on when you release the handle. REMAP can provide advice on safety brakes for prams. Contact them directly for further details.
- **Tel: 01732 760209 (UK only). Website: www.remap.org.uk**
- When you take a child out, use reins that are attached to you and them, to prevent the child wandering off if you have a seizure.
- Teach a child as soon as possible what to do if you have a seizure. Epilepsy Action has a range of information available that can help you explain epilepsy to young children. Contact the Epilepsy Helpline for more information **0808 800 5050**
- As with all medicines, make sure all your anti-epileptic drugs are locked away from children at all times.

Inheriting epilepsy

You may be worried about your child inheriting epilepsy. Less than 1 child in every 10 born to a parent with epilepsy will develop epilepsy. There are three different ways in which epilepsy can be inherited:

- A person's low epileptic seizure threshold may be passed to the next generation through the genes.
- Some types of epilepsy seem to run in families. These include benign rolandic epilepsy, juvenile myoclonic epilepsy and a rare type of temporal lobe epilepsy. Epilepsy can be one of the symptoms of another inherited medical condition, for example tuberous sclerosis.

If you are worried that your child might be at risk of inheriting epilepsy, speak to your GP or epilepsy specialist. They may refer you to a genetic counsellor. A genetic counsellor will look at information such as who in the family has epilepsy, their seizure type, age at which it started and the results of any tests. They will also look at any other medical conditions present in the family. They will use this information to try to work out the risk of your child developing epilepsy.

Contraception

If you want to take precautions against having another baby, it is important to understand how your epilepsy and anti-epileptic drugs may have an effect on your choice of contraception. The Epilepsy Clinical Nurse Specialist will be able to advise on suitable contraception methods. Speak to your GP or family planning nurse for more information.

Further information

- Speak to your midwife or obstetrician.
- Speak to your neurologist.
- Contact the Epilepsy Clinical Nurse Specialist on **0118 322 8486** or email [**rbft.adultepilepsyspecialistnurses@nhs.net**](mailto:rbft.adultepilepsyspecialistnurses@nhs.net)

References

1. Epilepsies in children, young people and adults NICE guideline [NG217] Published: 27 April 2022 <https://www.nice.org.uk/guidance/ng217>
2. Epilepsy Action www.epilepsy.org.uk
3. <https://www.epilepsy.org.uk/living/having-a-baby>
4. Royal College of Obstetricians and Gynaecologists (2016)
5. <https://www.rcog.org.uk/globalassets/documents/patients/patient-information-leaflets/pregnancy/pi-epilepsy-in-pregnancy.pdf>
6. <https://www.rcog.org.uk/guidance/browse-all-guidance/green-top-guidelines/epilepsy-in-pregnancy-green-top-guideline-no-68/>

To find out more about our Trust visit www.royalberkshire.nhs.uk

Please ask if you need this information in another language or format.

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Reviewed: February 2024

Next review due: February 2026

Our Maternity Strategy and Vision

'Working together with women, birthing people and families to offer compassionate, supportive care and informed choice; striving for equity and excellence in our maternity service.'

You can read our maternity strategy here

