

Pregnancy, birth and postnatal information for women who have epilepsy

This leaflet is for pregnant women with epilepsy. It 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?

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. Therefore, planning your pregnancy and having extra care during your pregnancy can reduce the risks to you and your baby (RCOG 2016). The majority of women with epilepsy have healthy pregnancies and give birth to healthy children.

Planning your pregnancy

If you are planning to become pregnant then you should speak to your general practitioner regarding your current epilepsy medication. It will be recommended that you 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 should be sought and alternative medications discussed where appropriate. Never stop taking your anti-epilepsy medication unless under the guidance of your neurologist or epilepsy specialist nurse. The Berkshire West Epilepsy Clinical Nurse Specialist 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 than most pregnant women will be advised to take and cannot be obtained from a pharmacy without a prescription. However, 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 before you try to conceive and carry on taking it throughout your pregnancy.

Unplanned pregnancy

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 support you. If you are not taking folic acid already you should start taking it. 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. (RCOG 2016).

Major congenital malformations (MCMs)

For every baby that is born to women with epilepsy, 1-2 in every 100 will have a major congenital malformation (MCM). '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. The risk of having a baby with MCMs is related to the mother having epilepsy and to any anti-epileptic drugs (AEDs) she takes during pregnancy.

Minor malformations

Babies born to mothers who have epilepsy also have a slightly higher risk of 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. At the time of writing, the exact risk of minor malformations in babies born to mothers who take 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.

Some women choose not to have any tests to check the development of their baby. Some women have some tests but not others. It is up to you to decide. Parents who find out that their baby has a birth defect before they are born, and choose to continue with the

pregnancy, may be better prepared to look after the baby after the birth. Parents who are not expecting a baby with a birth defect may find it more difficult to come to terms with.

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

Many women will not experience a change to seizure frequency during pregnancy.

However, some women will have fewer seizures and around one third will have more

seizures. ***Current advice is to use the shower rather than the bath when you have a diagnosis of epilepsy. NEVER take a shower when you are alone in your home.**

If you have more seizures, your doctor, neurologist or epilepsy CNS may suggest that you change the dosage to your drugs to ensure that you experience the least number of seizures possible during pregnancy and labour. Unborn babies are rarely harmed by their mothers having a seizure, unless the mother falls and injures herself. To reduce the risks to you and your unborn child, 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.

Giving birth

Providing you and your baby are well, your epilepsy should not prevent you from having a normal labour and delivery. You will generally be advised to have your baby in the Delivery Suite in hospital, where a team that includes both midwives and doctors is available to look after you. Remember to 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 companion to help you to remember to take your medication at the right time. Also, set a reminder on your phone to aid memory in the weeks leading up to your birth.

Pain relief

TENS machines are often used for pain relief during labour and these can be used safely if you have epilepsy.

An epidural anaesthetic can be used to provide pain relief 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).

Gas and air is safe, so long as you do not over-breathe when you are using it, as over-breathing can trigger seizures in some people.

Diamorphine injections are safe to use in women with epilepsy. Pethidine is not, as it can make seizures more likely, although this is not routinely used in RBH.

Vitamin K

Vitamin K is important for making our blood clot. A very small number of babies don't have enough Vitamin K in their body when they are born. 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.

When a newborn baby doesn't have enough Vitamin K, it is called Vitamin K deficiency. This is a rare disease but it can be prevented by giving the baby extra Vitamin K shortly after birth, either by an injection or by mouth. 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.

Breastfeeding

If you take anti-epileptic drugs (AEDs) and you want to breastfeed, it is important to be aware that AEDs can pass into your breast milk, which would then pass to your baby. For this reason, it is advisable to discuss breastfeeding with a medical adviser who has access to information about AEDs, before your baby is born. This may be an epilepsy specialist, epilepsy nurse, a midwife with an interest in epilepsy or an infant feeding adviser.

Generally speaking, mothers who take AEDs are encouraged to breastfeed. The majority of AEDs, which pass into your breast milk in small amounts, may have very little effect on your baby, so there is no reason why you can't breastfeed while taking them. Rarely, AEDs may cause problems for your baby, such as excessive sleepiness (which may lead to difficulties in feeding) or allergic skin reactions. When you decide whether or not you want to breastfeed, you will need to consider the benefits that are associated with this and the risks that are associated with the AEDs that you are taking.

If you would like to discuss breastfeeding and specific anti-epileptic drugs, please contact the Epilepsy Helpline, Freephone 0808 800 5050.

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 a friend or family member to give you a daytime break, so that you can catch up on missed sleep.

When you are feeding your baby, you could sit on the floor on a towel or a rug, so that if you have a seizure the baby does not have far to fall.

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

Many people with epilepsy successfully care for babies and young children. 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 exhausted. 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 a bouncer chair or car seat on the floor and sit next to them when feeding them.
- When a child is using a high chair, 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: 08451 300 456 (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, Freephone 0808 800 5050 or email helpline@epilepsy.org.uk
- As with all medicines, make sure all your anti-epileptic drugs are locked away from children at all times.

Inheriting epilepsy

Many parents with epilepsy worry that their children might inherit their epilepsy. The question of whether your child will inherit epilepsy or not is complicated and depends on a number of factors. 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. (More information about these is available from Epilepsy Action.)

- 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 family doctor 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.
- The Epilepsy Clinical Nurse Specialist can be contacted on: 0118 322 8486 or 0776 967 1062.

Acknowledgements

Taken from the epilepsy action leaflet 'Mothers in Mind'.

References

1. NICE Guideline 70 Epilepsy
2. Epilepsy Action (women) www.epilepsy.org.uk
3. Royal College of Obstetricians and Gynaecologists (2016) <https://www.rcog.org.uk/globalassets/documents/patients/patient-information-leaflets/pregnancy/pi-epilepsy-in-pregnancy.pdf>

This document can be made available in other languages and formats upon request.

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