

EPILEPSY IN PREGNANCY

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Disclaimer

When using this document please ensure that the version is the most up to date by checking the Obstetrics & Gynaecology Guidelines on WISDOM

PRINTED DOCUMENTS MUST NOT BE RELIED ON

Guidelines Definition

Clinical guidelines are systematically developed statements that assist clinicians and patients in making decisions about appropriate treatments for specific conditions.

They allow deviation from a prescribed pathway according to the individual circumstances and where reasons can be clearly demonstrated and documented.

Minor Amendments

If a minor change is required to the document, which does not require a full review please identify the change below and update the version number.

Type of change	Why change made	Page number	Date of change	Version 1 to 1.1	Name of responsible person

Equality Impact Assessment Statement

This Procedure has been subject to a full equality assessment and no impact has been identified.

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Aims:

To provide guidance for healthcare staff (including midwives, obstetricians, physicians and general practitioners) on the management of women with epilepsy preconceptually, antenatally, during labour and emergency situations, and postpartum. The importance of multidisciplinary working is emphasised.

1. Introduction and Background

Epilepsy has a prevalence of 0.5–1%. The risk of death is increased ten-fold in pregnant women compared with those without the condition (ref. Edey et al). The MBRRACE report 2020 highlighted that the number of deaths from Sudden Unexpected Death in Epilepsy (SUDEP) had almost doubled compared with the previous three years. Although anti-epileptic drugs (AED's) are associated with teratogenic effects, seizures resulting from poorly controlled epilepsy can also adversely affect the pregnancy. Assessment of the condition in pregnancy should include duration and severity, frequency and type of seizures, and impact of epilepsy on the mother such as driving, accidents, family life and employment.

2. Pre conception:

- Where possible avoid polytherapy (two or more AED's) and treat with lowest effective dose. Avoid sodium valproate (and valproic acid) in girls and women of child bearing age but if risk of seizure deterioration high then epilepsy specialist may need to advise to continue; a pregnancy prevention programme ('Prevent Programme') must be in place. Follow the MHRA safety advice on sodium valproate (2018), including that the use of valproate is contraindicated for epilepsy in pregnancy, unless there are no suitable alternatives. https://www.gov.uk/drug-safety-update/valproate-epilim-depakote-pregnancy-prevention-programme-updated-educational-materials
- If a woman is planning to become pregnant, a specialist experienced in the management of epilepsy must reassess valproate therapy and consider alternative treatment options. Every effort should be made to switch to appropriate alternative treatment prior to conception and before contraception is discontinued. If, under exceptional circumstances, a pregnant woman does receive valproate for epilepsy, she should be referred for a fetal medicine opinion.
- Commence folic acid 5mg/day 3 months prior to conception / 3 months prior to the discontinuation of contraception (RCOG, 2016).

All girls and women with epilepsy of child bearing age should be counselled by their neurologist and GP regarding the importance of good seizure control prior to pregnancy; effective contraception should be prescribed for those not planning a pregnancy. When planning a pregnancy, they can be referred for preconception counselling to their neurologist and the medical antenatal clinic.

Counselling points:

- Counsel patients that risk of congenital malformations if not on antiepileptic drugs (AED) is similar to background risk of 2.8%.
- The incidence of congenital abnormalities in the fetus is dependent on the type, number and dose of AEDs (RCOG, 2016). Least risk of major congenital malformations is with lamotrigine (<300mg per day), and levetiracetam monotherapy.
- Little is known about other, newer AEDs or combination therapies and the absence of data should not be taken as an indication of fetal safety
- The most common congenital malformations associated with AED's are neural tube defects, congenital heart disorders, urinary tract and skeletal abnormalities and cleft palate. The risk is highest with sodium valproate or valproic acid (approximately 10%) and polytherapy.
- Advise not to self-discontinue any of the AED drugs
- Explain there is no association between epilepsy type and major congenital malformation
- Risk of recurrence for major congenital malformation increased in women with previous child with major congenital malformation (approximately 17%)
- No significant effect on neurodevelopment of the fetus, except with valproate

3. Antenatal:

- WWE (women with epilepsy) should have their initial appointment with the community midwife as soon as possible to ensure appropriate referrals are initiated. Community midwives should initiate the 'Maternity epilepsy shared-care toolkit' with the woman or birthing person file:///C:/Users/re218331/Downloads/Pregnant%20women%20with%20epile psya%20maternity%20toolkit%20updated%20June%202021.pdf
- Midwives should give patient information leaflets as directed in the tool kit, especially the RCOG Epilepsy in Pregnancy patient information leaflet (Appendix 3). Sign-post women to the 'Epilepsy Action: Epilepsy and having a baby' and 'Women with epilepsy' websites (see section 8 'Written information for women' and references).
- Women should be seen in the combined medical antenatal clinic and ensure they are taking folic acid 5mg daily
- Continue folic acid 5mg/day until at least 12 completed weeks of pregnancy, ideally throughout pregnancy
- A multidisciplinary team approach is essential and it is important to ensure close liaison with the neurologist; urgent review is imperative if there is any deterioration in seizure control. MBRRACE 2020 highlighted SUDEP (Sudden Unexpected Death in EPilepsy) as the main cause of death for pregnant women with epilepsy; nocturnal seizures are a 'red flag' for SUDEP and should prompt an urgent referral to a neurologist.
- If unplanned pregnancy, commence folic acid 5mg daily and arrange appointment in Medical Antenatal Clinic (MANC)

- Vomiting may compromise epilepsy medicine absorption: urgently assess need for antiemetic and rehydration, and consider seeking advice from neurologist regarding emergency epilepsy medicine treatment.
- Patients who have remained seizure-free for at least 10 years (with the last 5 years off AEDs) and those with a childhood epilepsy syndrome who have reached adulthood seizure- and treatment-free are considered no longer to have epilepsy. However, the Neurologist / Medical team should confirm resolution of epilepsy individually. These patients can then have low risk care Midwifery Led Care (MLC) if no other risk factors.
- 12 week ultrasound scan and Downs' screening as routine.
- Women with epilepsy on AED are at high risk of depression and anxiety. Therefore, all caregivers (including community midwives, obstetricians and physicians) should assess for signs of anxiety or depression at every visit. If concerned refer to perinatal mental health team
- No need for routine monitoring of AED levels. AED levels to be done depending on patients clinical features (non-adherence, toxicity, intractable seizures) on advice of neurologist. There have however been reports of decreased lamotrigine plasma levels during pregnancy with a potential risk of loss of seizure control. After birth, lamotrigine levels may increase rapidly with a risk of dose-related adverse events. Therefore, lamotrigine serum concentrations in the woman should be monitored before, during, and after pregnancy, including shortly after birth. If necessary, the dose should be adapted to maintain the lamotrigine serum concentration at the same level as before pregnancy or adapted according to clinical response. In addition, dose-related undesirable effects should be monitored after birth (MHRA 2021).
- Women with epilepsy should be regularly assessed during pregnancy for the following: risk factors for seizures, such as sleep deprivation and stress; adherence to AEDs; and seizure type and frequency. (RCOG, 2016)
- Anomaly scan at 18⁺⁰ 20⁺⁶ weeks can identify neural tube defects and major cardiac defects. Refer for fetal echocardiogram if cardiac defect identified on anomaly scan
- Serial growth scan from 28 weeks every 4 weeks as per the Perinatal Institute Growth Assessment Protocol / GROW programme (due to increased risk of growth restriction)
- Women should be advised not to sleep alone at night and advised to bathe themselves in shallow water with assistance to minimise risk (see shared-care toolkit)
- Women can have vaginal delivery if epilepsy well controlled. Induction of Labour (IOL) not indicated for epilepsy per se if well controlled. If IOL is necessary, there are no known contraindications to use of any induction agents in WWE taking AEDs (RCOG, 2016).
- If recurrent or prolonged seizures or high risk of status epilepticus, consider elective caesarean section
- Invitation to join UK Epilepsy and Pregnancy Register (anonymous data collection) <u>http://www.epilepsyandpregnancy.co.uk/</u>

Non-epileptic attack disorder:

• Psychological aetiology. No role for caesarean section or induction. Clear documentation in notes as these patients do not require AED or diazepam if have seizure-like episodes in labour

4. Intrapartum care

- The risk of seizures in labour and 24 hrs after birth is low (1-4%)
- Continue AEDs in labour; if not tolerating orally give parenteral alternative eg phenytoin, phenobarbital, levetiracetam. Please contact pharmacy/neurology for guidance.
- Avoid pethidine as epileptogenic in high doses and consider alternative analgesia (diamorphine should be used in preference to pethidine); consider transcutaneous electrical nerve stimulation (TENS), Entonox[®] (although avoid hyperventilating especially if history of absence seizures), early epidural.
- Good hydration
- Avoid delay if patient is booked for planned elective caesarean section
- If the woman is at high risk of seizures, consider prophylactic clobazam peripartum (dose of 10 mg PO daily can be used, please refer to BNF https://bnf.nice.org.uk/). Use in the short-term only (eg starting at the onset of labour or the day before planned delivery) due to the risk of respiratory depression in the neonate.
- Continuous Cardiotocograph (CTG) if high risk of seizures
- Avoid anaesthetic agents pethidine, ketamine as they are known to lower the seizure threshold.
- Water birth can be considered if the woman is not on AED and has been seizure free for a significant period after discussion with epilepsy specialist. The woman should be counselled re risk of drowning if fits occur. Special equipment like hoists should be available on the unit that provide water birth.

Management of epileptic seizure in labour – see flow chart in appendix

- 1. Maintain left lateral tilt
- 2. Contact team via emergency bleep 2222, state Obstetric and Neonatal Emergency
- 3. Maintain airway and oxygenation (high flow 15 L/min)
- 4. Lorazepam bolus up to 4mg IV and repeat after 10-20mins; Diazepam 5-10mg slow IV is an alternative. Intravenous phenytoin (10-15 mg/kg) or levetiracetam (60 mg/kg, maximum 4500mg) can be given for status epilepticus. If any possibility of eclampsia, give iv magnesium sulphate as per CTMUHB severe pre-eclampsia guideline
- 5. If no IV access give diazepam 10-20mg PR which can be repeated once after 15 minutes, or midazolam 10mg buccal preparation, if continued risk of status epilepticus
- 6. If there is persistent uterine hypertonus consider using tocolytics eg terbutaline 250mcg sc (Abertawe Bro Morgannwg University Health Board, 2018).

- 7. After stabilising the woman continuous CTG. If the CTG does not recover in 5 minutes or seizures are recurrent then expedite delivery, by caesarean section if vaginal delivery not imminent.
- 8. The baby is at risk of neonatal withdrawal with the maternal use of benzodiazepines and AED's so ensure the neonatal team are aware. Refer to the Wales Maternity and Neonatal Network Neonatal Guideline: Management if Babies Born to Mothers Requiring Medication during Pregnancy: https://phwsharepoint.cymru.nhs.uk/whc/NN/NN/Guidlines/Medical%20Gui delines/General%20Guidelines/Management%20of%20Babies%20Born%20to %20Mothers%20Requiring%20Psychotropic%20Medication%20During%20Pr egnancy.pdf

5. Postnatal

- Ensure that triggers for seizure deterioration such as pain, stress, sleep deprivation, missed medication are minimised. Help at night time feed. If the mother breastfeeds, storage of breast milk pumped during the day might be beneficial.
- Advise to bathe themselves and baby in shallow water with assistance to minimise risk
- Review of AED by neurology team within 10 days postpartum if dose was increased in pregnancy, to avoid postpartum toxicity
- If symptoms of toxicity develop (drowsiness, diplopia or unsteadiness) urgent neurological review needed
- Women with epilepsy are at increased risk of depression. Mothers should be informed about the symptoms of depression and provided with contact details / sources of support as subsequent early intervention may improve quality of life.

6. Baby and Breastfeeding

- Offer 1mg Vitamin K IM as a single dose at birth to the neonate, for the prevention of haemorrhagic disease of the newborn.
- Monitor babies for postpartum withdrawal symptoms (lethargy, difficult feeding and inconsolable crying). Discuss with Paediatricians re the need for measurement of serum levels of AED. Refer to the Wales Maternity and Neonatal Network Neonatal Guideline: Management if Babies Born to Mothers Requiring Medication during Pregnancy:
- https://phwsharepoint.cymru.nhs.uk/whc/NN/NN/Guidlines/Medical%20Gui delines/General%20Guidelines/Management%20of%20Babies%20Born%20to %20Mothers%20Requiring%20Psychotropic%20Medication%20During%20Pr egnancy.pdf
- General advice: Change baby on floor, supervised shallow baths, nursing the baby on the floor, lay the baby down if warning aura. Use a carrycot while taking baby up and down the stairs
- Encourage women to breastfeed, as based on current evidence, the risk of adverse cognitive outcomes is not increased in children exposed to AEDs through breast milk. Infants are exposed to lower levels of medication through

breastmilk than they are during pregnancy, and in addition to the other benefits of breastfeeding, it can reduce the chance of withdrawal symptoms in the baby. Mothers should be advised to observe their babies for sleepiness and poor feeding and that risks are increased with multiple medications. There is no need to time breastfeeds around medication. If a mother is taking a nonslow-release AED and baby is sleepy or has to be woken for feeds, consider advising mother to feed before rather than after taking her AED to help avoid peak serum, hence breast milk, levels.

Excessive tiredness can be a seizure trigger and mothers may need support to care for their babies overnight. This may mean another adult supervising or supporting breastfeeds or some mothers may choose to combination feed. Mothers can be referred to an Infant Feeding Coordinator if needed to make an individual feeding plan. <u>epilepsy-and-breastfeeding.pdf</u> (websitehome.co.uk)

7. Contraception

Copper intrauterine devices (Cu-IUDs), the levonorgestrel-releasing intrauterine system (LNG-IUS) and medroxyprogesterone acetate (DMPA) injections should be promoted as reliable methods of contraception that are not affected by enzyme-inducing AEDs (see table below) (RCOG, 2016)

Women should be counselled that the efficacy of oral contraceptives (combined hormonal contraception, progestogen-only pills), transdermal patches, vaginal ring and progestogen-only implants may be affected if they are taking enzyme-inducing AEDs. (RCOG, 2016). FSRH Clinical Guidance: Drug Interactions with Hormonal Contraception- Link: https://www.fsrh.org/documents/ceu-clinical-guidance-drug-interactions-with-hormonal/

All methods of contraception may be offered to women taking non-enzymeinducing AEDs (RCOG, 2016)

- For women on enzyme inducing AEDs (and for 4 weeks after stopping) Copper Intrauterine Contraceptive Device (Cu-IUD) preferred choice for emergency contraception (the IUD can be fitted up to 5 days after unprotected sex, or up to 5 days after the earliest time the woman could have ovulated, for it to be effective)(FSRH, 2022). Ulipristal acetate should not be used. Levonorgestrel (double dose) 3mg single dose within 72 hrs of unprotected sexual intercourse (UPSI).
- If the woman prefers to be on oral contraceptive, then increase dose of oestrogen to 50mcg. Consider tricycling packs (taking 3 packs back-to-back) or reducing the pill-free interval from 7 to 4 days.
- Use barrier contraception additionally if on Combined Oral Contraceptive (COC), Progesterone Oral Contraceptive (POP), transdermal patches, vaginal rings, or progestogen only implants.
- Caution: Oestrogen-containing contraceptive reduces lamotrigine levels (for further information please refer to FSRH

file:///C:/Users/re218331/Downloads/drug-interactions-with-hormonalcontraception-5may2022%20(1).pdf).

• Avoid unplanned pregnancy

Table: List of hepatic enzyme-inducing and non-enzyme-inducing AEDs

Enzyme inducing AED	Non enzyme inducing AED
Carbamazepine	Acetazolamide
Eslicarbazepine	Clobazam
Oxcarbazepine	Ethosuximide
Perampanel (at doses of 12mg daily or	Gabapentin
more)	Lamotrigine (caution as can interact with
Phenobarbitone / phenobarbital	oestrogen-containing contraceptives with
Phenytoin	potential increase in seizures)
Primidone	Lacosamide
Rufinamide	Levetiracetam
Topiramate (at a dose of 200mg daily or	Perampanel (at doses of less than 12mg
more)	daily)
	Pregabalin
	Sodium valproate
	Tiagabine
	Topiramate (at dose of less than 200mg
	daily) seizures)
	Vigabatrin
	Zonisamide

8. Written information for women

Women with epilepsy should be given written information during pregnancy:

- Epilepsy Action: <u>http://www.epilepsy.org.uk/info/women</u> has useful information leaflets to download.
- RCOG patient information leaflet: <u>https://www.rcog.org.uk/for-the-public/browse-all-patient-information-leaflets/epilepsy-in-pregnancy/</u>
- 'Women with epilepsy' website https://www.womenwithepilepsy.co.uk/

9. Auditable standards

Standards for audit of practice should include the following:

- Provision of written information on the effects of epilepsy and AEDs on pregnancy outcomes and seizures (100%).
- Multidisciplinary input into prepregnancy, antenatal, intrapartum and postnatal care of WWE (100%).

Standards for audit of documentation should include the following:

- Written protocols for management of status epilepticus in all obstetric units (100%).
- Documented discussion on risks to the mother and baby from epilepsy and AEDs in the short and long term (100%).
- Proportion of women enrolled in the UK Epilepsy and Pregnancy Register (100%).

10.References

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- CTMUHB (2021). Guidelines for the Management of Hypertensive Disorders in Pregnancy. Available at: http://ctuhbintranet/Policies/_layouts/15/WopiFrame.aspx?sourcedoc={01E00962-D03E-4AD4-A09B-B661113E6B8C}&file=Management%20of%20Hypertensive%20Disorders%20in% 20Pregnancy%20Guideline.docx&action=default (Accessed May 2022).
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- Handbook of Obstetric Medicine 6th edition; Nelson-Piercy, Catherine; CRC Press; Boca Raton; 2020; Chapter 9 (pages 168-196)
- IBM Micromedex (2022). Levetiracetam. Available at: https://www.micromedexsolutions.com/micromedex2/librarian/PFDefaultAction Id/evidencexpert.DoIntegratedSearch?navitem=topHome&isToolPage=true# (Accessed 19/07/2022).
- Maternity epilepsy shared-care toolkit: <u>file:///C:/Users/re218331/Downloads/Pregnant%20women%20with%20epilepsy</u> <u>-a%20maternity%20toolkit%20updated%20June%202021.pdf</u>
- Medicines and Healthcare Products Regulatory Agency April 2018, January 2021 <u>https://www.gov.uk/drug-safety-update/valproate-epilim-depakote-pregnancy-prevention-programme-updated-educational-materials</u>
- Medicines and Healthcare Products Regulatory Agency 7 January 2021 updated advice on anti-epileptic drugs in pregnancy following a comprehensive safety review by the Commission on Human Medicines
- 2020 MBRRACE Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries in UK
- NICE Guidance for Epilepsy 2012, updated 2018
- RCOG Green Top Guideline No. 68 June 2016 'Epilepsy in Pregnancy' https://www.rcog.org.uk/media/rzldnacf/gtg68_epilepsy.pdf
- UK Epilepsy and Pregnancy Register http://www.epilepsyandpregnancy.co.uk/
- Wales Maternity and Neonatal Network Neonatal Guideline: Management if Babies Born to Mothers Requiring Medication during Pregnancy:

https://phwsharepoint.cymru.nhs.uk/whc/NN/NN/Guidlines/Medical%20Guideli nes/General%20Guidelines/Management%20of%20Babies%20Born%20to%20M others%20Requiring%20Psychotropic%20Medication%20During%20Pregnancy.p df

• Women with epilepsy

Appendix 1

Flow Chart of Management of Epileptic Seizures in Labour

(NB. In women with no prior history of epilepsy, eclampsia is the most common cause of seizures in labour)



Commence IV levetiracetam over 10 minutes (60 mg/kg, max 4500 mg) If levetiracetam unavailable or if already on regular levetiracetam, give IV Phenytoin 10-15mg/kg slowly (rate not exceeding 50mg per minute) Continuous ECG, arterial blood gases

Method	Key in	formation & guidance	Additional Information
CHC (combined		Contraceptive effectiveness could be	Users of enzyme-inducing drugs should always be advised
pill, patch or	N	reduced.	to use an alternative effective contraceptive method that is
vaginal ring)		Use not advised during use of the enzyme	not affected by enzyme induction.
		inducer and for 28 days after stopping it. Recommend an alternative effective	Users of enzyme-inducing drugs (except the potent enzyme inducers rifampicin/rifabutin) for whom alternative effective contraception is not acceptable may, in exceptional circumstances, consider use of two ethinylestradiol (EE) monophasic combined oral contraceptive pills together containing a total of 50µg of EE (30µg + 20µg). These should be used in a continuous regimen (or tricycled with a shortened hormone-free interval of 4 days).
			The user should be aware that contraceptive effectiveness is not guaranteed and that there could be increased risk of thrombosis if exposure to EE is increased. Use of two combined contraceptive patches or two combined contraceptive rings together is not recommended.
РОР		Contraceptive effectiveness could be	Use of two progestogen-only pills together is not
(traditional	•	reduced.	recommended in this situation.
POP, DSG POP		Use not advised during use of the enzyme	
and DRSP POP)		inducer and for 28 days after stopping it.	
		Recommend an alternative effective method.	
ENG-IMP	63	Contraceptive effectiveness could be	Use of two implants together is not recommended.
		Use not advised during use of the enzyme inducer and for 28 days after stopping it. Recommend an alternative effective method.	
DMPA		No expected effect on contraceptive	Serum progestogen levels are expected to remain
		effectiveness.	adequate.
		No need for extra precautions	
LNG-IUS		No expected effect on contraceptive	Local progestogen effect on endometrium unaffected by
		effectiveness.	enzyme induction.
		No need for extra precautions	
Cu-IUD		No effect on contraceptive effectiveness.	Unaffected by enzyme induction.
	-	No need for extra precautions	The Cu-IUD is the most effective method of emergency contraception.
LNG-EC	0	Effectiveness for emergency	Double dose LNG-EC (2 x 1.5 mg LNG tablets taken
		contraception <i>could</i> be reduced.	together) can be offered within 96 hours of unprotected
		Offer a Cu-IUD if appropriate. If Cu-IUD	sexual intercourse in cu-iop is declined or unsuitable.
		not appropriate or not acceptable,	The effectiveness of 3 mg oral LNG for emergency
		consider offering double dose LNG-EC.	contraception in this situation is unknown.
UPA-EC	?	Effectiveness for emergency contraception <i>could</i> be reduced.	Use of double dose UPA-EC is not recommended.
		Offer a Cu-IUD if appropriate	The effectiveness of UPA-EC compared to that of double- dose (3mg) LNG in this situation is unknown

Appendix 2: Enzyme Inducing Drugs and Contraception Quick Guide (FRSH, 2022).

No interaction: method suitable Potential interaction: caution required Nown interaction: avoid and advise alternative method Contraceptive methods: CHC, combined hormonal contraception; Cu-IUD, copper intrauterine device; DMPA, progestogen-only injectable: depot medroxyprogesterone acetate; DRSP POP, drospirenone progestogen-only pill; DSG POP, desogestrei progestogen-only pill; EC, emergency contraception; IMP, progestogen-only impiant; LNG-IUS, levonorgestrei-releasing intrauterine system; POP, progestogen-only pill; LNG, levonorgestrei; UPA, ulipristal acetate. Appendix 3: RCOG Epilepsy in Pregnancy Patient Information Leaflet 'Information for You'



Royal College of Obstetricians & Gynaecologists

Information for you

Published in June 2016. Updated in November 2020

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.

The information here aims to help you better understand your health and your options for treatment and care. Your healthcare team is there to support you in making decisions that are right for you. They can help by discussing your situation with you and answering your questions.

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

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.



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 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.

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. Most 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?

How you choose to feed your baby is a very personal decision. There are many benefits of breastfeeding for you and your baby. 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.

Making a choice



Further information

Epilepsy Action: Epilepsy and having a baby www.epilepsy.org.uk/info/women/having-baby Epilepsy Society: Pregnancy and parenting www.epilepsysociety.org.uk/pregnancy-and-parenting

UK Epilepsy and Pregnancy Register 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.

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.