Maternity epilepsy shared care toolkit

Formulated to encourage joint working with women to optimise holistic healthcare.

My full name	
Date of birth	
NHS Number	
Hospital Number	
Name of hospital	
My baby is due on	

This toolkit is designed to help guide your epilepsy management in pregnancy. This can be used for reference or completed and scanned onto your electronic records or stored in your maternity notes. Please complete as much as you can and share it with your maternity epilepsy specialist team. The toolkit incorporates advice from the RCOG epilepsy in pregnancy green-top guideline, Epilepsies in children, young people and adults NICE guideline, MBRRACE-UK, SUDEP Action and recommendations from website womenwithepilepsy.

My multi-professional team contact details.

Title	Name	Contact details
GP		
Community Midwife		
Obstetrician		
Neurologist		
Epilepsy Specialist Nurse		

Booking appointment

The community midwife is advised to action an immediate referral to the Consultant Neurology and epilepsy specialist nurse team (ESN) and consultant obstetrician. The referral should be assessed, and the consultant neurologist urgently contacted if you have significant epilepsy or treatment risk factors.

Please inform the midwife:

- The type of seizures you experience.
- When do they occur: awake or asleep?
- Approximate date/time of your last three seizures.
- Antiseizure medicine (ASM) prescribed. Dosage and time(s) taken.
- If known, name and contact details of your consultant neurologist or epilepsy specialist nurse.

The midwife will provide the following advice:

- If taking ASM, to continue taking **folic acid** daily until 12 weeks gestation (the dosage will depend on the guidance in your NHS Trust).
- To have an antiseizure medicine blood level taken with the booking bloods if requested by your team.
- **Not to miss any doses of antiseizure medicines.** Missed doses can lead to uncontrolled seizures which can potentially be a risk to life.
- **If being sick** affects taking medicines, contact your GP or phone 111 urgently. If your medicine times need adjusting, they will seek urgent advice from your medical, neurology or obstetric team.
- **For 999 to be contacted** if a tonic clonic seizure occurs in pregnancy in order to be promptly assessed.
- **If possible, not to sleep alone** due to the danger of unwitnessed tonic clonic seizures from sleep.
- **Shower but not bath** (leave door unlocked). Avoid hot tubs. Inform the lifeguard about epilepsy/swim with a buddy in a pool. Extreme caution near water's edge (streams, rivers, and the sea) including the bath at home and hospital to reduce risk of drowning.
- **Please log onto the QR codes (page 6):** epilepsy in pregnancy, UK epilepsy and pregnancy register **(please register your pregnancy as soon as possible),** EpSMon-epilepsy self-monitoring app **(please conduct this free risk assessment 3 monthly),** first aid advice for seizures **(share with your family),** contraception, looking after baby, and the maternity epilepsy toolkit website.

The community midwife will see you regularly during pregnancy & postnatal. Appointments with the obstetrician, epilepsy specialist nurse or neurologist will be determined by your risk factors. Please help with this by answering yes/no to the following risk assessment questions:

1. Was your pregnancy unplanned?
2. Did you receive pre-pregnancy counselling?
3. Have you stopped your epilepsy medicine with or without medical advice in the last year?
4. Are your seizures not controlled with antiseizure medicines?
5. Have you had any convulsive seizures lasting more than 5 minutes?
6. Any tonic clonic seizures from sleep?
7. Any injuries sustained because of seizures?
8. Do you have focal epilepsy?
9. Are you prescribed more than one antiseizure medicine?
10. Are you taking sodium valproate or topiramate?
11. Did you have seizures during a previous pregnancy?
12. Do you have limited English language?
13. Is there a history of substance misuse (including alcohol)?
14. Do you smoke?
15. Is there a history of febrile convulsions, brain surgery, lesion, stroke, head injury, meningitis, or encephalitis?
16. Do you have a learning or intellectual disability?
17. Did your epilepsy start in childhood?
18. Do you have additional physical, mental, or social needs?
19. Do you have a history of non-epileptic attack disorder?
20. Any other health conditions, e.g. diabetes or thyroid problems.

Summary of recommended epilepsy pregnancy and postnatal care.

Following a positive pregnancy test	Contact your GP practice and epilepsy specialist or neurologist to inform them of the pregnancy as soon as possible. An appointment for booking the pregnancy will be made with your community midwife. See page 1 to guide you with this appointment.
Midwifery support	The community midwife will continue to see you regularly during pregnancy and postnatal. You are likely to require extra appointments with the obstetrician and epilepsy team.
Within 2 weeks of booking	Your epilepsy and risk factors should be assessed by your specialist team. Download the free EpSMon app onto your mobile to do your safety assessment (QR code page 6). Look at the safety advice from Epilepsy Action: https://www.epilepsy.org.uk/living/safety
11-14 weeks	Your dating scan and risk factors to you and your baby will be assessed.
18-21 weeks	Your detailed mid pregnancy anomaly ultrasound scan will be conducted. They will determine if baby requires any additional cardiac scanning and growth scans.
From within two weeks of booking until delivery you will be provided with additional specialist appointments every 4-8 weeks.	Your epilepsy team will review your seizure control, medicine management, safety, and risk management regularly. **Please ask them to complete your management plan: page 9 which can be cut and pasted to the maternity electronic system.** We recommend a discussion to help prepare for birth after your fetal anomaly scan between 20-26 weeks gestation (page 4). Most women will have a normal delivery & not require intervention because of epilepsy.
	There should be regular obstetric surveillance or your pregnancy and baby's health. If growth scans have been recommended, they usually start at 28 weeks.
	Between 28-32 weeks your specialist team are advised to complete your postnatal medicine plan and go through the postnatal checklist (page 5) to help reduce risks to you and your baby. **Notify your epilepsy specialist team urgently if you experience an increase in seizures, side effects from your medicines and when you deliver your baby.**
Starting between 3-7 days postnatal	Postnatal medication review and reduction of these medicines is likely to start from day three to seven postnatal if they were increased in pregnancy. A further reduction medicine plan over the following weeks will be provided by your specialist team (page 4).
6 weeks-1 year postnatal	Risks associated with your epilepsy can increase during the postnatal year with the sleep disruption of caring for a baby, therefore it is important for you to receive on-going support from your specialist team. You should receive accurate contraception advice, and your safety & seizure risks should be assessed at each appointment in the postnatal year.

About your antiseizure medicines

Please do not stop taking your medicine or reduce the dose unless you are advised to do so by a specialist. This is because it can lead to an increase in seizures. In some cases, tonic clonic seizures can be life threatening.

Are you having trouble taking your medicines?

Please ask yourself the following and contact a member of your epilepsy or maternity team urgently. "How many doses have I missed in the last 2 weeks?" "What seems to get in the way of me taking my medicine?" "What was going on when I missed a dose this past week?" "When am I most successful at taking my medicine? Is there a reason that I do not take my medicine? Your pharmacist or specialist team will help you with strategies to remember to take your medicines.

Do you have an emergency management plan?

If yes, ensure that your emergency medicine is in date, your partner/family member has been trained in its' use and your neurology and maternity team informed if you have taken this or had it administered.

Which antiseizure medication were you prescribed when you became pregnant?

Medicine name?	Dose?	What time do you take it?	Total daily dose?

Monitoring antiseizure medicine levels in pregnancy

Your specialist may advise changes to your medicines in pregnancy especially if you are having seizures or taking lamotrigine and sometimes, levetiracetam, zonisamide or oxcarbazepine. This is because the changes that occur during pregnancy can cause the blood levels of these medicines to fall. Your specialist may monitor the serum levels before, during and after pregnancy. **Please check before having routine bloods taken in pregnancy, whether an antiseizure medicine serum blood level has been requested or recommended by the epilepsy team.**

Was a pre-conception medicine serum level obtained: Yes/No

Date reported: Serum level:

Pregnancy serum results for your epilepsy team to complete.

Date	Medication	Serum level	Range

Pregnancy medicine changes for the team to complete.

Date	Medication	Dose change

Most women with epilepsy will have a vaginal delivery and not require induction of labour or caesarean section. However, if there are any concerns about yours or baby's health requiring medical or surgical intervention; be guided by your obstetric team.

Discuss the following with your epilepsy team between 20-26 weeks gestation.

You can adjust or add to this list to meet your individual needs. Consider what you do/do not want and feel you can use this check list to help write your own birth choices to maximise your safety whilst in hospital care.

Date of discussion: **Signature:**

☐ *Complete your own risk assessment in preparation of hospital admission (EpSMon app-QR code page 6).*
☐ *Order and pack an extra supply of your epilepsy medicines in anticipation of admission to hospital.*
☐ *Set reminders for medication times on your mobile.*
☐ *Share your birth choices and this toolkit with the hospital midwife when you go into labour.*
☐ *Identifying emergency call buzzers in all hospital rooms*
☐ *If your birth partner needs to leave the room, ask for a midwife to attend to maximise your safety.*
☐ *Continue your epilepsy medicines as prescribed, even during labour; do not miss dose(s) as this could result in an increased risk of seizures occurring.*
☐ *If you feel sick, ask for an anti-sickness injection to prevent being sick and allow absorption of your epilepsy medicines.*
☐ *Bring a recording of music that helps you to relax.*
☐ *You may find it useful to use relaxation techniques which you practiced antenatally, such as Mindfulness.*
☐ *Stay as mobile as possible and drink enough water in order you are not thirsty but do not overhydrate.*
☐ *Feel supported and listened to and central to shared decision making about your care.*
☐ *Most women with epilepsy are discouraged from using a birthing pool. Ask yourself, would you feel safe if you were to immerse in water during labour; is there a hoist if you needed to get out quickly? Is it possible for someone to always be with you? Is this safe if you were to have a seizure?*
☐ *If you were supported to have a pool labour/delivery stay well hydrated, as it becomes hot in the birth pool room. If you feel at risk of a seizure, inform your birth partner & midwife and be helped out of the pool, safely.*
☐ *Inform your birth partner and midwife urgently if you feel at risk of seizure at any time in the labour.*
☐ *Avoid pethidine as this is converted to norpethidine which evidence suggests has the potential of lowering seizure threshold. Guidelines suggest that Diamorphine is an alternative analgesia if requiring sleep in early labour; this will change your perception of the pain rather than take it away. Please note this can cause drowsiness and vomiting.*
☐ *Gas and air (Entonox) is considered safe for most women with epilepsy. Be careful not to over-breath as this can make you feel dizzy, light-headed, with tingling in your lips, hands and sometimes feet. Following the contraction, if you have these symptoms, the midwife will show you how to relieve these symptoms.*
☐ *If you have a history of absence seizures, avoid hyperventilating (over-breathing) if using Entonox (gas and air) and when baby's head is delivering.*
☐ *Consider epidural if this is your requested form of pain relief or if you require more effective pain relief to allow you to rest. Ordinarily, an epidural is sited when a woman is in established labour. Be guided when to have it by how you are feeling, your level of tiredness, your progress in labour and the expert opinion of the midwives/obstetricians who are caring for you.*
☐ *Ensure your team have completed the postnatal medication management plan below and reassured you about the safety of breast feeding before you go into labour if this is your chosen method of infant feeding.*

Epilepsy medicine post-natal plan: to be completed antenatally.

Date	Medication	Recommended change	Signature

Postnatal advice checklist: discussion with your epilepsy team between 28-32 weeks & following birth.

- You are advised to consent to baby having an injection of vitamin K following delivery. Some of the antiseizure medicines can affect absorption of this vitamin. However, this is routinely offered to all newborn babies to help prevent a serious disease called haemorrhagic disease of the newborn. We do not recommend it to be given by mouth to baby of mums taking antiseizure medicines as it is less effective.
- If baby has been exposed to antiseizure medicine in pregnancy, we recommend the newborn and infant physical examination (NIPE) is conducted by a senior paediatrician or advanced neonatal practitioner preferably within 24 hours of birth.
- If you are breast feeding and taking antiseizure medicine, please alert a maternity health professional urgently if baby develops difficulty in feeding, jaundice, a skin rash or becomes increasingly drowsy.
- To prepare for your admission following the birth of your baby, determine from your midwife and obstetrician if your birth partner can remain with you on the postnatal ward. We advise showers rather than baths and ensure someone is with you if you feel unsafe or at risk of seizures.
- It is important to reduce risks to you and your baby when you have epilepsy. Please access and read the information from Epilepsy Action: Looking after a baby of young child when you have epilepsy-QR code page 6. You will also be provided with a safer sleeping assessment before discharge from hospital and the community: https://www.lullabytrust.org.uk/safer-sleep-advice/
- If your medicines have been changed during the pregnancy, refer to the epilepsy medication post-natal plan (page 4) as medicine reductions usually start from day three postnatally. After making any changes to your medicines, do let your GP know in order your prescription can be changed. You or your maternity team are advised to contact the epilepsy specialist/neurologist if you need additional medication support.
- Remember to take your antiseizure medication at the prescribed times and try not to miss any doses.
- You are likely to benefit from community midwifery post-natal home visits to reduce the impact of tiredness on seizure control. There should be vigilant monitoring of your physical & mental well-being. When the midwives are planning discharge from midwifery care, it is important you know which specialist to contact in an emergency if there is any deterioration in seizure control or your mental well-being.
- Where possible, you are advised not to sleep alone due to risk of seizures from sleep.
- You should be provided with contraception advice before discharge from maternity care because some of the antiseizure medicines interact with hormonal contraception making them less effective. QR code link page 6 for further information.
- National guidelines currently recommend that you are prescribed folic acid 5 milligrams once daily if there is risk of pregnancy & before future planned pregnancy if you are taking antiseizure medicine. However, the dosage recommendations differ between 400 micrograms and 5 milligrams daily depending on which NHS Trust you come under. Please check this with your GP. Folic acid is usually continued until 12 weeks gestation.
- There should be the opportunity of flexible support for your epilepsy and treatment in the year following birth and before future pregnancies as lack of support can be associated with adverse outcomes.

There should be an urgent postnatal review by a neurologist/epilepsy specialist if:

- There is diagnostic uncertainty or when urgent treatment review is recommended.
- Seizures increased or were uncontrolled during pregnancy.
- If there is a history of prolonged seizures or status epilepticus
- Baby was born with a major congenital malformation.
- If sodium valproate or topiramate were prescribed
- If antiseizure medicine was stopped during pregnancy

Information QR codes to help inform your pregnancy journey.

RCOG: Epilepsy in Pregnancy

UK Epilepsy & pregnancy register

EpSMon-epilepsy
self-monitoring app

First aid for seizures
(Epilepsy Action)

Epilepsy and pregnancy
(Epilepsy Action)

Looking after baby
(Epilepsy Action)

womenwithepilepsy.co.uk
Kim Morley website

Contraception
(Epilepsy Action)

Pregnancy is individual to you.

Pregnancy and having a baby are usually an exciting time and feel reassured that most women's seizure control will remain the same or in some cases, improve. However, others may experience an increase in seizures, a change in seizure pattern or severity. This can lead anxiety and fear and affect quality of life which can be further impacted on eligibility to drive; therefore, it is important you feel supported during this time by your epilepsy neurology team, your GP, and the obstetric and midwifery team.

Can a seizure harm me or baby during pregnancy?

There is a small increased risk of harm to a woman and her developing baby during a tonic clonic seizure. This is especially if the seizure is prolonged. Convulsive (tonic clonic) seizures arising from sleep, particularly if unwitnessed, can be associated with an increased risk of sudden unexpected death (SUDEP). To protect yourself, try to always remember to take your antiseizure medicines and urgently contact your healthcare team if you have a change in seizure control. Please download the EpSMon free app on your mobile available from the app store or google play (QR code page 6) to assess your individual risk factors.

Ensure family/friends are aware of appropriate first aid (QR code page 6). Where possible, avoid sleeping alone and shower rather than bath. Be cautious around water's edge including leaning over the bath. Your family are advised to urgently obtain help by dialling 999 (in the UK) if you start having tonic clonic seizures in the pregnancy; if this is a first seizure; if it is a convulsive seizure lasting 5 minutes or two minutes longer than the usual time of your seizure; if you have a convulsive seizure but do not regain consciousness before having a further seizure; if you have suffered harm or if additional help is needed. If you have a history of prolonged seizures or repetitive seizures (clusters), please ensure your doctor or epilepsy specialist formulates a management plan and information session for you and your family about the administration of emergency medication.

Please ensure that your own healthcare team are informed if you have recurrence of seizures in pregnancy. Depending on what happened, they will advise whether it is necessary for you to be seen urgently for monitoring of you and your developing baby. If you are admitted to hospital during the pregnancy or postnatal year, the epilepsy/neurology team and maternity/obstetric team should be informed.

How can I reduce the triggers for seizures?

As well as the influence pregnancy has on the way your body processes antiseizure medicines, forgetting to take them, lack of sleep and stress are the most common reasons seizures may recur. To reduce these triggers, it is important to find out whether your antiseizure medicine dosage needs adjusting in the pregnancy; please discuss this with your specialist team and ask them to complete page 3. Using medication reminder techniques will help reduce the risk of forgetting to take your epilepsy medication. Please look at the information on Epilepsy Society and look at their strategies & tools for taking epilepsy medication.

Infections are more common during pregnancy due to the unique changes that occur in your body. Please ensure that you report any signs of infection to your care providers as soon as possible and take extra safety precautions with your epilepsy as infection can be a trigger for seizures. Only about 3 in 100 people with epilepsy have photosensitivity. If you have this condition please obtain further advice to protect yourself from this potential trigger of seizures from: Epilepsy Action: Photosensitive epilepsy. Many pregnant women have sleep disturbance; this can be particularly troublesome for women with epilepsy as it can increase the risk of seizures. Please ask your midwife or epilepsy specialist for advice and support. **If there are on-going concerns about your risk from seizures, a risk assessment can be made by social care occupational therapists. They may suggest adaptations to the home or safety aids of alarms. Further information is available from: Social-care-and-support-guide. Please speak to your GP or epilepsy team for a referral.**

Can my medicines harm my baby during pregnancy or whilst breast feeding?

The risk of antiseizure medicines will depend on the type and number prescribed; the dosage; family history of birth defects and other conditions such as thyroid disease and diabetes. When women are prescribed sodium valproate or topiramate, they should be under specialist epilepsy care and be supported with a pregnancy prevention programme. All women taking antiseizure medicines are advised to have their epilepsy and antiseizure medicines reviewed before stopping contraception and planning a pregnancy to ensure they are taking the safest regime in preparation of future pregnancy. A safety leaflet on epilepsy medicines and pregnancy to help patients and their families understand the risks is available from GOV.UK.

Please talk to your epilepsy team about any fears you have about your medicines.

They will provide evidence-based safety information from the UK teratology information service www.uktis.org and information about your medicines and breast feeding from LactMed: https://www.ncbi.nlm.nih.gov/books/NBK501922/.

Record dates and the time of any seizures that have occurred in pregnancy or the postnatal year. Obtaining video recordings or a witness's mobile video recording helps with diagnostics and classification of seizures. Talk to your team about how a seizure can be recorded and shared whilst protecting your data.

Please make notes about any concerns or questions about your epilepsy or treatment you would like to discuss with your maternity epilepsy team below:

This peer reviewed toolkit reflects more than two decades of experience in providing a pre-conception and pregnancy specialist service for women with epilepsy. It was updated on 31/8/2024 to reflect guidelines and research: Epilepsies in children, young people and adults NICE guideline [NG217] NICE Published: 27 April 2022; MBRRACE-UK (2023) Saving Lives, Improving Mothers' Care - Lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2018–20; Anti-epileptic drugs: review of safety of use in pregnancy (2021) MHRA.

To assess the effectiveness of the toolkit's use in clinical practice, a research study was conducted: Morley K (2020) Reducing risks for pregnant women with epilepsy: A qualitative study exploring experiences of using a toolkit at the antenatal booking appointment. Epilepsy & Behavior

Reference for toolkit: Morley K (2024) Maternity epilepsy shared care toolkit (PDF). Available from: www.womenwithepilepsy.co.uk

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Appendix 1: Example of management plan to complete and scan onto electronic system, e.g. Badgernet

Situation

• Type of epilepsy, last seizure date, last seizure type, current treatment, dosage.
• Other treatments, including folic acid and vitamin D.
• Name of epilepsy specialist neurology team and contact details if known.

Background

• Birth and childhood history, first seizure date, trajectory of epilepsy.
• Diagnostic details, investigations, treatment history. Any family history of epilepsy?
• Menstrual, gynaecological, and obstetric history, any history of antiseizure medicine exposure in previous pregnancies? If so, were there any birth abnormalities or neuro-developmental delay? Other co-morbidities.
• Social history including smoking, alcohol, and substance misuse. Impact of epilepsy?

Assessment

• Current seizure control.
• Adherence with antiseizure medicine and any side effects?
• Last blood results and date of testing
• Woman's knowledge of personal risks from her seizures and the potential toxicity of her current medicine regime. Provide information from: www.uktis.org and https://www.ncbi.nlm.nih.gov/books/NBK501922/.
• Woman's view about therapeutic drug monitoring in addition to clinical monitoring.

Recommendations

• Clinical monitoring and particularly if taking lamotrigine, offer therapeutic drug monitoring.
• If woman consents, obtain antiseizure medication serum level at booking and requested gestation thereafter.
• If poor or non-adherence antiseizure medicines and there is a risk of tonic clonic seizures, sensitively question decision making and urgently refer woman to consultant neurology team and put safeguards in place, including an urgent referral for a Needs Assessment: https://www.gov.uk/apply-needs-assessment-social-services. Also, discuss impact on eligibility to drive. Further information: https://www.gov.uk/epilepsy-and-driving.
• Complete sudden unexpected death in epilepsy checklist: https://sudep.org/checklist. Alternatively, ask woman to complete free EpSMon assessment three monthly: https://sudep.org/epilepsy-self-monitor.
• Ensure woman is aware of safety advice regarding her epilepsy, inside and outside the home. Available from: https://epilepsysociety.org.uk/safety-and-risk.
• Ensure woman's partner/family aware of seizure first aid; Available from: https://epilepsysociety.org.uk/about-epilepsy/first-aid-epileptic-seizures/seizure-first-aid.
• Provide patient information leaflet from RCOG, epilepsy in pregnancy: epilepsy-in-pregnancy.pdf (rcog.org.uk)
• Encourage self-registration to UK Epilepsy and Pregnancy Register: https://www.epilepsyandpregnancy.co.uk.
• Record an individualised pregnancy medicine management plan and if the medicines have been increased in pregnancy, a postnatal medicine reduction plan antenatally in preparation of birth (see page 3).
• Advise birth is usually recommended in Consultant Led maternity unit. If requesting care outside of guidelines, refer for senior midwifery assessment.
• Screen mental health at each pregnancy & postnatal appointment.
• If admitted at any stage, avoid admission to a single room unattended. If seizure related, inform the consultant obstetrician and epilepsy team, urgently.
• Avoid baths and being in pool room in hospital care. If care requested outside this guidance, ensure individual risk assessment and care plan in place to optimise safety.
• Ensure antiseizure medicines continued at prescribed times during labour and postnatally. If nausea/vomiting, offer antiemetic to optimise absorption of medicines.
• Avoid pethidine in labour as it has the potential to lower seizure threshold.
• Advise NIPE conducted by senior paediatrician or Advanced Neonatal Nurse Practitioner if baby exposed to antiseizure medicines. If pregnancy exposed to valproate or topiramate, Yellow Card MHRA.
• If possible, arrange home postnatal visits by community midwifery team to reduce impact of tiredness getting out for early morning appointments.
•If medicines increased in pregnancy, epilepsy specialist/neurology team to review antiseizure medicines in first week postnatal; and provide on-going antiseizure medicine management support. Regular assessment of safety and risks should be made in the postnatal year.