

# 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	



This toolkit is designed to provide a summary of your epilepsy, treatment and management recommendations. **It should be stored securely in your maternity hand-held notes.** A copy should be provided for you to keep after you are discharged from hospital following birth.

Please encourage all members of your multi-professional team to write in and refer to this toolkit during your pregnancy, labour and after you have had your baby. Please ask them to date and sign each written entry they make and click on the links to download further information. This toolkit is designed to be used alongside [RCOG green-top guidelines](#) & [www.womenwithpilepsy.co.uk](http://www.womenwithpilepsy.co.uk)

My baby is due on	
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## Your multi-professional team emergency contact details

Name	Title	Telephone	Email/FAX
	GP		
	Community Midwife		
	Obstetrician		
	Neurologist		
	Epilepsy Specialist Nurse		
	Health visitor		
	Pharmacist		

**GP/Midwife** complete this page at first antenatal booking appointment

**Women with history of seizures or epilepsy**, fast-track urgent multi-professional referral to consultant neurologist/epilepsy specialist, consultant obstetrician/physician

**Answer: yes or no**

- ❖ Seizures in last twelve months (active epilepsy) Yes/No
- ❖ Epilepsy medicine stopped with or without medical advice in last year Yes/No
- ❖ Seizures never controlled with epilepsy medicines Yes/No
- ❖ History of status epilepticus/prolonged seizures Yes/No
- ❖ History of seizures from sleep (tonic clonic) seizures Yes/No
- ❖ Focal epilepsy (with or without bi-lateral tonic clonic seizures) Yes/No
- ❖ More than one epilepsy medicine is prescribed Yes/No
- ❖ Active epilepsy during previous pregnancy Yes/No
- ❖ Women with limited English language Yes/No
- ❖ Diagnosis is uncertain Yes/No
- ❖ History of substance misuse (including alcohol) Yes/No
- ❖ History of brain surgery, lesion, stroke or head injury Yes/No
- ❖ Learning/intellectual disability Yes/No
- ❖ History of non epileptic attack disorder Yes/No
- ❖ Complex physical, mental or social co-morbidities Yes/No

**Ask the following information about epilepsy medication**

Medicine name	Dose taken	What time(s) do you take it?	Total daily dose

Other medication prescribed/over the counter:

Has folic acid been started? Yes/No    Dosage: 5mg /400mcg    Date started:  
*If higher dose folic acid (5mg) not prescribed, contact GP for individual prescribing advice in pregnancy*

**Allergies:** Yes/No    Further details

**Other health conditions:**

**Seizure characteristics:** *woman to complete; she may need to gain information from witness*

Generalised: Yes/No    Focal (partial): Yes/No    Unclassified/Unknown: Yes/No

How many seizures in last twelve months?

Approx. date/time of day of last three seizures:

Is there a warning before seizure (aura): Yes/No

Time to get safe: Yes/No

Awareness lost: Yes/No

Seizure witnessed: Yes/No

What happens?

How long do they last?

Tongue bitten: Yes/No

Symptoms following seizure:

How long to recover?

Seizure diary: Yes/No    *Please ask woman to maintain pregnancy seizure diary (page 6)*

<b>GP/Midwife: action at first antenatal/booking appointment</b>	Date Signature
<p>Provide the following:</p> <ul style="list-style-type: none"> <li>• Details of <a href="http://www.womenwithepilepsy.co.uk">www.womenwithepilepsy.co.uk</a> website</li> <li>• Information booklet: <a href="#">Epilepsy Action pregnancy &amp; having a baby</a></li> <li>• RCOG information leaflet: <a href="#">Epilepsy in pregnancy</a></li> <li>• <b>Provide safety advice to optimise well-being:</b> advise shower rather than bath (leave door unlocked). Avoid Jacuzzis &amp; hot tubs &amp; inform the lifeguard about epilepsy/swim with a buddy in a pool. Extreme caution near water's edge (including the bath) to reduce risk of drowning if unexpected seizure occurs at home or in hospital.</li> <li>• <b>Information leaflets:</b> <a href="#">Epilepsy Action safety</a> &amp; <a href="#">Caring for baby</a></li> <li>• Encourage women to download: <a href="#">EpSMon epilepsy self-monitoring</a> app</li> <li>• <b>First aid advice</b> for partner <a href="#">Epilepsy Action First Aid</a></li> <li>• Where possible, please advise women with epilepsy <b>not to sleep alone</b></li> </ul>	
<ul style="list-style-type: none"> <li>• <b>Stress importance adherence with epilepsy medication;</b> not taking medication is a leading cause seizure recurrence. <a href="#">Treatment advice</a></li> <li>• <b>Is vomiting affecting absorption/adherence of epilepsy medication? Advise women seek urgent advice</b> from medical/neurology/obstetric team</li> <li>• Issue <a href="#">UK Epilepsy &amp; pregnancy registration forms</a> encouraged before 20 week anomaly scan or call 0800 3891248 to register.</li> <li>• <b>Women taking sodium valproate,</b> provide <a href="#">Valproate Patient Booklet</a> &amp; patient letter <a href="#">NHS England</a></li> <li>• Discuss information from MHRA: <a href="#">Epilepsy in pregnancy leaflet</a></li> </ul>	
<p><b>Action: multi-professional team antenatal checklist</b></p> <ul style="list-style-type: none"> <li>• Provide vigilant, flexible support &amp; monitoring of physical &amp; mental well-being</li> <li>• <b>Following dating scan, arrange</b> detailed ultrasound in line with NHS Fetal Anomaly Screening Programme standards between 18-22 weeks (RCOG 2016). Additional scan may be requested if valproate/more than one epilepsy medication is prescribed. <b>Growth scans</b> may be required depending on epilepsy medication.</li> </ul>	
<ul style="list-style-type: none"> <li>• <b>Inform Consultant Obstetrician</b> if woman is admitted to hospital.</li> <li>• <b>Avoid hospital admission to a single room unattended; consider family member staying overnight.</b></li> <li>• <b>Provide immediate telephone contact/follow-up if any appointments are missed</b> in case of a deteriorating medical condition.</li> </ul>	
<ul style="list-style-type: none"> <li>• <b>Urgent referral to neurologist/epilepsy specialist if seizures recur in the pregnancy or the usual seizure frequency or severity increases.</b> Ensure referral is actioned immediately by phoning neurology/obstetric team. Midwife/GP to be in regular contact with woman to monitor health; emphasis on safety &amp; well-being.</li> <li>• Complete <b>management plan</b> (page 8) &amp; ensure women bring <b>a supply of epilepsy medicines</b> for any hospital admission and follow their usual dosing regimen.</li> <li>• Important to <b>reduce triggers</b> for seizures in labour including anxiety and sleep deprivation. Ensure woman receives sensitive, holistic care.</li> <li>• Advise that although risk of seizures in labour is low, it is recommended that labour/delivery occurs in a suitably equipped obstetric unit</li> </ul>	
<ul style="list-style-type: none"> <li>• Advise <b>avoidance of pethidine</b> as this may lower seizure threshold.</li> <li>• <b>Vomiting may compromise epilepsy medicine absorption:</b> urgently assess need for antiemetic, rehydration and emergency epilepsy medicine treatment.</li> <li>• Avoid hyperventilating with entonox especially if history of absence seizures.</li> </ul>	

## Complete: first antenatal appointment

If known, age of diagnosis:

Who diagnosed epilepsy?

Which hospital?

Name of previous epilepsy medicines prescribed:

Do you smoke: Yes/No

How many daily?

What is your BMI?

Any previous babies exposed to epilepsy medicine: Yes/No/N/A

Medicine name(s):

Congenital malformations: Yes/No

Delay reaching milestones? Yes/No

## Obstetrician/physician & Epilepsy Specialist to complete:

- Complete pregnancy/birth management plan: *page 8*
- Emergency medicines management of seizure recommended: Yes/No *If yes, provide Epilepsy Action [buccal midazolam care plan template](#) and administration advice*
- Provide information: breast feeding and contraception with epilepsy medicine regime
- Therapeutic drug monitoring recommended: Yes/No
- Valproate prescribed: complete [Annual risk acknowledgement form](#)
- SUDEP risk: complete SUDEP Action: [SUDEP and safety checklist](#)

*Epilepsy medication serum levels are not routinely tested. However, the epilepsy specialist may recommend therapeutic epilepsy medication monitoring in addition to clinical monitoring, especially if there is adherence uncertainty or lamotrigine or levetiracetam are prescribed. Note falling epilepsy medication serum levels in pregnancy may impact on seizure control.*

Preconception level: Yes/No

Date reported:

Serum level:

### Pregnancy results

Medication	Date	Serum level	Range	Signature

### Epilepsy medicine changes during pregnancy

Date	Medication	Recommended change	Signature

### Epilepsy medicine post-natal plan: complete antenatally

Date	Medication	Recommended change	Signature

<b>Multi-disciplinary team:</b> discuss antenatally & following birth <b>Post-natal advice checklist</b>	Date/signature
<ol style="list-style-type: none"> <li>1. Obtain informed consent to administer vitamin K (1 mg) 1/M for baby following delivery if taking epilepsy medication.</li> <li>2. Babies exposed to epilepsy medication-recommend expert paediatric examination post delivery.</li> </ol>	
<ul style="list-style-type: none"> <li>• Advise breast feeding mothers who take epilepsy medication to alert health professional urgently if baby develops difficulty in feeding, jaundice, a rash or becomes increasingly drowsy.</li> </ul> <ol style="list-style-type: none"> <li>3. Advise women complete <a href="#">Epilepsy Society risk assessment</a> to optimise safety whilst in hospital care. Advise showers rather than baths.</li> <li>4. <b>Provide information about reducing risks when caring for children from:</b> <a href="#">Epilepsy Action: caring for a baby &amp; young children</a></li> </ol>	
<ol style="list-style-type: none"> <li>5. Refer to epilepsy medication post-natal plan (page 4) for medication advice. Encourage woman to alert GP promptly if any changes to medication are made. Advise contacting epilepsy specialist if additional medication support is required.</li> <li>6. <b>Remind women to take epilepsy medication at prescribed times</b></li> </ol>	
<ol style="list-style-type: none"> <li>7. <b>Where possible, provide post-natal home visits</b> to reduce impact of tiredness on seizure control. There should be vigilant monitoring of physical &amp; mental well-being. <b>When considering discharging a woman from midwifery care, ensure woman knows who to contact in an emergency if there is any deterioration in her seizure control or mental well-being.</b></li> <li>8. Where possible, <b>advise women not to sleep alone due to risk of nocturnal seizures</b></li> </ol>	
<ol style="list-style-type: none"> <li>9. <b>Provide contraception advice before discharge from maternity care.</b> Refer to <a href="#">BNF</a> for individual drug advice on interactions with epilepsy medication &amp; hormonal contraception. <a href="#">FPA: long acting reversible contraception</a> <a href="#">FPA drug interactions</a></li> </ol>	
<ol style="list-style-type: none"> <li>10. National guidelines recommend GP prescribes folic acid 5 milligrams once daily if risk of pregnancy/at least 3 months before future planned pregnancy for women taking most epilepsy medication. This is usually continued until 12 weeks gestation.</li> <li>11. Ensure women receive the opportunity of flexible support for their epilepsy in the year following birth and before future pregnancies.</li> </ol>	

### Arrange urgent postnatal review by neurologist/epilepsy specialist if:

- There is diagnostic uncertainty or when urgent treatment review is recommended
- Seizures increased or were uncontrolled during pregnancy
- There is a history of prolonged seizures or status epilepticus
- Baby was born with a major congenital malformation
- The woman is taking sodium valproate
- The woman stopped epilepsy medication during pregnancy

### How can you provide optimal care?

Please refer to your local and [RCOG green-top guidelines, epilepsy in pregnancy](#). If your PCT or local hospital has an epilepsy specialist nurse, make urgent contact with them if further support is required. Encourage women to become experts in their own condition by obtaining further information from: [Epilepsy Action](#), [Epilepsy Society](#), [Women with epilepsy](#), [SUDEP Action](#) and [Epilepsy Scotland](#)

Reference: Morley K (2021) Maternity epilepsy shared care toolkit (PDF). Available from: [www.womenwithepilepsy.co.uk](http://www.womenwithepilepsy.co.uk)

This peer reviewed toolkit was designed to support recommendations from: NICE, Epilepsies: diagnosis & management, 2012; Diagnosis & management of epilepsy in adults –SIGN (2015); RCOG, green-top guidelines, Epilepsy in pregnancy (2016); MBRACE-UK and the National Maternity Review, Better Births, Improving outcomes of maternity services in England (2016). The toolkit was updated in 2021 to reflect findings from: MBRACE-UK (2020) Saving Lives, Improving Mothers' Care - Lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2016–18 and Anti-epileptic drugs: review of safety of use in pregnancy (2021) [MHRA](#). To assess effectiveness of the toolkit's use in clinical practice, research study published in 2020. For further information and support, contact: [kim.morley@nhs.net](mailto:kim.morley@nhs.net)



## Checklist to discuss in pregnancy to help you prepare for birth

Discuss your birth choices with your midwife and have the knowledge that you can adjust to meet your individual needs. Consider what you do/don't want and feel you can use this check list to help you write your birth choices to maximize your safety whilst in hospital care.

### Example:

- Complete your own risk assessment in preparation of your hospital admission*
- 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*
- Identifying emergency call buzzers in all hospital rooms*
- If your partner needs to leave the room, ask for a midwife to attend to maximize 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 nauseous, ask for an anti-sickness injection to prevent vomiting/allow absorption of epilepsy medicines.*
- Bring a recording of your favourite 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.*
- Feel supported and listened to and be 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 be with you at all times? 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 excessive drowsiness and vomiting.*
- Gas and air (entonox) is considered safe for most women with epilepsy. Be careful not to over-breathe 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, tell the midwives and they will be able to 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 analgesia (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 (page 4) in this maternity epilepsy toolkit and reassured you about the safety of breast feeding before you go into labour, if this is your chosen method of infant feeding.*

## **Pregnancy management and agreed birth plan:**

*Multi-professional team to complete with woman and file at front of maternity notes*

**Signature**

Situation		
Background		
Assessment		
Recommendations		