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.

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.womenwithepilepsy.co.uk

My baby is due on	

Your multi-professional team emergency contact details

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

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Maternity epilepsy checklist

	Date	Signature

1. GP or Community midwife to action at booking:

- **Booking assessment** (page 3); & action appropriate referral(s).
- Provide details of www.womenwithepilepsy.co.uk website and Epilepsy Action pregnancy & having a baby
- **Issue RCOG** information leaflet: Epilepsy in pregnancy
- **Provide safety advice to optimise well-being:** advise shower rather than bath (leave door unlocked). Avoid Jacuzzis & hot tubs in pregnancy & inform the lifeguard about epilepsy/swim with a buddy in a pool. Extreme caution near any water's edge (including the bath) to reduce risk of drowning if an unexpected seizure occurs at home or in hospital.
- **Issue safety advice:** Epilepsy Action safety leaflet & Caring for baby
- Encourage women to download: EpSMon epilepsy self monitor
- **First aid advice** for partner Epilepsy Action First Aid
- Where possible, please advise women with epilepsy **not to sleep alone**

- **Stress importance adherence with antiepileptic drugs (AED);** a leading cause seizure recurrence. Treatment advice
- **Advise women seek urgent advice from medical/neurology/obstetric team if vomiting is affecting adherence or absorption of AEDs.**
- **Issue** UK Epilepsy & pregnancy registration forms encouraged before 20 week anomaly scan or call 0800 3891248 to register.
- **Women taking sodium valproate,** provide communication material: Gov.UK safety update for Valproate & fast track referral (page 3)
- **Please ask women to maintain seizure diary** (appendix 1)

During pregnancy: multi-professional team advice

2. Provide vigilant, flexible support & monitoring of physical and mental well-being throughout pregnancy continuum.

3. Following dating scan, arrange 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 AED prescribed. **Growth scans** may be required depending on AED regime.

4. Inform Consultant Obstetrician if woman is admitted to hospital.
Avoid hospital admission to a single room unattended; consider family member staying in room overnight.

5. Provide immediate telephone contact/follow-up if any antenatal appointments are missed in case of a deteriorating medical condition.

6. Urgent referral to neurologist/expert in epilepsy, if seizures recur in the pregnancy or the usual seizure frequency/severity increases. 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 & well-being.

7. Ensure women bring **a supply of their own AEDs** for hospital admission(s) and continue to take them at prescribed times, even in labour.

8. Important to **reduce triggers** for seizures in labour including anxiety and sleep deprivation. Ensure woman receives sensitive, holistic care.

9. Advise that although risk of seizures in labour is low, it is recommended that labour/delivery occurs in a suitably equipped obstetric unit.

10. Advise **avoidance of pethidine** as this may lower seizure threshold.

11. Vomiting may compromise AED absorption; urgently assess need for antiemetic, rehydration and emergency AED treatment.

12. Avoid hyperventilating with entonox especially if history of absence seizures.

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Booking assessment   Date: Signature:

GP/community midwife: with consent, please refer all women with epilepsy/history of seizures to Consultant Neurologist/Epilepsy Specialist and Consultant Obstetrician for fetal/maternal medicine for evaluation of current health status.

Fast-track an urgent referral to multi-professional team including Consultant Neurologist/ epilepsy specialist if the answer is yes to any of the following:

1. Recent seizures (active epilepsy) despite taking AEDs Yes/No
2. If AEDs were stopped without seeking medical advice Yes/No
3. If sodium valproate is prescribed Yes/No
4. History of status epilepticus/prolonged seizures Yes/No
5. History of nocturnal convulsive seizures Yes/No
6. Focal onset epilepsy (simple/complex partial/secondary generalised) Yes/No
7. More than one antiepileptic drug is prescribed Yes/No
8. Active epilepsy during previous pregnancy Yes/No
9. If therapeutic drug monitoring is recommended Yes/No
10. Women with limited English language Yes/No
11. If the diagnosis is uncertain Yes/No
12. If there is a history of substance misuse (including alcohol) Yes/No
13. Previous brain surgery Yes/No

Anti-epileptic drug treatment at booking

Medication 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 Partial or Focal: Yes/No Unclassified/Unknown: Yes/No

How many seizures in last nine 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 (appendix 1)*

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Background *woman to complete background information*

If known, age of diagnosis Who diagnosed epilepsy?
Which hospital?

Name of previous epilepsy medicines (AEDs) prescribed:

Do you smoke? Yes/No How many daily? What is your BMI?

Any previous babies exposed to AEDs Yes/No AED name(s):

Any congenital malformations? Yes/No Any delay reaching milestones? Yes/No

Specialist Assessments

Obstetric Signature Date
Epilepsy Signature Date

Is emergency medicines management of seizure recommended?

If yes, please provide care plan and administration advice for clobazam or buccal midazolam.

Therapeutic drug monitoring recommended: Yes/No

AED serum levels are not routinely tested. However, the epilepsy specialist may recommend therapeutic AED monitoring in addition to clinical monitoring, especially if lamotrigine or levetiracetam are prescribed. This is due to the possible impact on seizure control from falling AED serum levels in pregnancy.

Preconception level: Yes/No Date reported: Serum level:

Pregnancy results:

Medication	Date	Serum level	Range	Signature

AED changes during pregnancy

Date	Medication	Recommended change	Signature

AED post-natal plan

Date	Medication	Recommended change	Signature

Post-natal advice checklist

Checklist	Date/signature
1. Advise mothers who take AEDs consent to vitamin K (1 mg) 1/M for baby following delivery. 2. Babies exposed to AEDs-recommend expert paediatric examination post delivery. • Advise breast feeding mothers who take AEDs to alert health professional urgently if baby develops difficulty in feeding, jaundice, a rash or becomes increasingly drowsy. 3. Advise women complete **Epilepsy Society risk assessment** to optimise their safety whilst in hospital care. Advise showers rather than baths. **4. Provide information about reducing risks when caring for children** **Epilepsy Action: caring for a baby & young children**	
5. Refer to AED post-natal plan 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. 6. Remind women to take epilepsy medication at prescribed times 7. Where possible, provide post-natal home visits to reduce impact of tiredness on seizure control. There should be vigilant monitoring of physical & mental well-being. 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. 8. Where possible, advise women not to sleep alone due to risk of nocturnal seizures 9. Provide contraception advice before discharge from maternity care. Refer to the BNF for individual drug advice on interactions with AEDs with hormonal contraception.	
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 AEDs. This is usually continued until 12 weeks gestation. 11. Ensure women receive the opportunity of flexible support for their epilepsy in the year following birth and before future pregnancies.	

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
- If there is a history of prolonged seizures or status epilepticus
- Baby was born with a major congenital malformation
- If the woman is taking sodium valproate
- If the woman stopped anti-epileptic drugs 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 and Women with epilepsy

The author

Kim Morley is an award winning epilepsy specialist nurse/midwife practitioner at Hampshire Hospitals Foundation Trust. She is a registered nurse, midwife, independent nurse prescriber specialising in the management of antiepileptic drugs & advanced clinical practice. She is the founder of Women with epilepsy, a website designed to complement this toolkit; a free resource for women and the professionals who care for them.

The toolkit

This has been 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), with the ethos of promoting multi-professional working, continuity of carer, working across boundaries and safer, personalised care. The toolkit has been peer reviewed and future research is planned to assess the effectiveness of its use in clinical practice. For further information and support, contact: kim.morley@nhs.net

Appendix 1: Pregnancy seizure diary: *woman with epilepsy or witness of seizure to complete*

Date & time	**Seizure description**	**Symptoms before seizure (aura)**	**Symptoms following seizure**	**Missed medication or other trigger?**

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