

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.womenwiththeepilepsy.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.womenwithpilepsy.co.uk website
- **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.
- **Issue safety advice:** [Epilepsy Action safety leaflet](#) & [Caring for baby](#)
- Suggest women download app: [EpSMon epilepsy self monitor](#)
- **First aid advice** for partner [Epilepsy Action First Aid](#)

- **Stress importance adherence with antiepileptic drugs (AED);** a leading cause seizure recurrence. [Treatment advice](#)
- **Issue UK Epilepsy & pregnancy registration forms.** Registration encouraged before 20 week anomaly scan via website: www.epilepsyandpregnancy.co.uk or call 0800 3891248
- **Women taking sodium valproate,** provide communication material: [Gov.UK safety update for Valproate](#)
- **Please ask women to maintain seizure diary** (appendix 1)

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

3. Arrange dating then high-resolution anomaly scan with fetal medicine expert ultrasonographer at 20 weeks. Additional scan may be requested if valproate/more than one antiepileptic (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 this referral is actioned immediately by phoning neurology & obstetric team. Midwife/GP to be in regular contact with woman to monitor her health; with an emphasis on safety advice & 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.

Recommend anti-emetic if nausea/vomiting in labour to optimise AED absorption. Avoid hyperventilating with entonox especially if history of generalised absence seizures.

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. History of status epilepticus/prolonged seizures | Yes/No |
| 4. History of nocturnal convulsive seizures | Yes/No |
| 5. Focal epilepsy (simple/complex partial) | Yes/No |
| 6. More than one antiepileptic drug is prescribed | Yes/No |
| 7. Active epilepsy during previous pregnancy | Yes/No |
| 8. If therapeutic drug monitoring is recommended | Yes/No |
| 9. Women with limited English language | Yes/No |
| 10. If the diagnosis is uncertain | Yes/No |
| 11. If there is a history of substance misuse (including alcohol) | Yes/No |
| 12. 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:

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)*

Background *woman to complete background information*

If known, age of diagnosis
Which hospital?

Who diagnosed epilepsy?

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:

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:

| Date | Medication | Date obtained | Date reported | Serum level | Signature |
|------|------------|---------------|---------------|-------------|-----------|
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AED changes during pregnancy

| Date | Medication | Recommended change | Signature |
|------|------------|--------------------|-----------|
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| | | | |
| | | | |

AED post-natal plan

| Date | Medication | Recommended change | Signature |
|------|------------|--------------------|-----------|
| | | | |
| | | | |

Post-natal advice checklist

Date/signature

1. Advise mothers 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. Provide contraception advice before discharge from maternity care. Refer to the BNF for individual drug advice on interactions with AEDs with hormonal contraception.

9. Recommend GP prescribes folic acid 5 milligrams once daily if risk of pregnancy/at least 3 months before future planned pregnancy if woman is taking AEDs; continue until at least 12 weeks gestation.
10. 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 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 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
