National Maternity Network

Standards of Care for Women with Epilepsy of Childbearing Age

Developed by

Scottish Government 'Best Start' Obstetric Neurology Working Group

Scottish Perinatal Network MATERNITY

Scottish Government
Riaghaltas na h-Alba
gov.scot

DOCUMENT CONTROL SHEET

Key Information:

Title:	Standards of Care for Women with Epilepsy of Childbearing Age
Date Published/ Issued:	21.02.2023
Date Effective From:	21.02.2023
Version/Issue Number:	1.0
Document Type:	Standard of Care
Document Status:	Final
Owner:	National Maternity Network (NMN)
Approver:	NMN Core Steering Group
Approved by and Date:	NMN Core Steering Group on 26.08.2022
Contact:	nss.perinatalnetwork@nhs.scot
File Location:	\\freddy\DEPT\NSDBCS\09 PCF\NSD\Strategic Networks\Perinatal\Maternity\Workstream\Obs Neuro Guides - Headache and Epilepsy\Epilepsy

Lead authors:

Linda Stephen[1], Emily Frier[2], Yvonne Leavy[3], Iona Duckett[4], Alastair Campbell[5]

[1] Associate Specialist in Neurology (NHS Greater Glasgow & Clyde)
[2] Clinical Research Fellow & Senior Registrar in Obstetrics & Gynaecology (NHS Lothian)
[3] Senior Epilepsy Specialist Nurse (NHS Lothian)
[4] Senior Midwife (NHS Tayside)
[5] Consultant Obstetrician & Gynaecologist (NHS Lothian)

Full membership of the Scottish Government Obstetric Neurology Working Group, who contributed to the development of these standards, can be found in the appendix.

Revision History:

Version:	Date:	Summary of Changes:	Name:	Changes Marked:

Table of Contents

DISCLAIMER

The recommendations in these Standards of Care represent the view of the Scottish Government Best Start Obstetric Neurology Working Group, arrived at after careful consideration of the evidence available. When exercising their clinical judgement, healthcare professionals are expected to take these Standards of Care document fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to follow the Standards of Care recommendations and it remains the responsibility of the healthcare professional to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

Background and Introduction

Epilepsy is one of the most common neurological disorders in pregnancy with a prevalence of 0.3-0.7%[1]. Although most women with epilepsy (WWE)* have straightforward pregnancies and healthy babies, there is an increased risk of complications[1,2].

In the UK between 2017 and 2019, 18 women died due to sudden unexpected death in epilepsy (SUDEP) during or up to a year after the end of their pregnancy[3]. This number was unchanged from 2016-2018 and has more than doubled compared to 2013-2015 when 8 women died of SUDEP[4]. These cases may be partly due to anti-seizure medication (ASM)* adherence and dose optimisation[4]. Physiological changes of pregnancy alter ASM metabolism and doses of ASMs may need to be increased[1], particularly if seizure control deteriorates.

Optimisation of ASM necessitates a balance between seizure control and teratogenic risks of ASM[5,6], which are increasingly well-defined[7]. Data suggests maternal folic acid supplementation confers neurodevelopmental benefits for children born to WWE on ASMs, although optimum dosing requires clarification[8,9].

Current guidelines recommend that advanced planning, including the development of local protocols for care, should be implemented in obstetric units[10]. In the postnatal period WWE require support with issues including seizure control, ASMs, baby feeding, sleep deprivation and contraception[11,12]. Peripartum psychiatric comorbidities may be a significant problem[13].

This Standards of Care document contains pragmatic advice for managing WWE prior to pregnancy and during the antenatal period, labour and birth, and postnatal period. We have considered equality impact assessment throughout; at all stages of care WWE should be provided with information in an accessible format, tailored to individual needs. We believe that implementation of these standards by neurology and obstetric services across Scotland will provide WWE with equitable, timely and proactive clinical care before, during and after pregnancy and ensure optimal outcomes for mothers and babies.

* WWE refers to all pregnant people with active epilepsy, and this guidance reviews standards of care for WWE on treatment. Those in remission (over 5 years without seizures) who no longer need treatment may not require additional visits. Throughout this document, we refer to anti-seizure medication (ASM), rather than previously used terms such as anti-epileptic drugs or anti-convulsants, because we feel that anti-seizure medication best represents the effects of these drugs and is therefore the most appropriate terminology.

Pre-pregnancy care

Pre-pregnancy care offers WWE the opportunity to make informed choices.

- Women with epilepsy are faced with several additional issues to consider in pregnancy, including seizure control, ASM and folic acid supplementation.
- Unplanned pregnancies in WWE are common, reported in 55% of women, compared to 48% of women without epilepsy[1].
- Anti-seizure medication adherence issues occur in approximately 40-59% of WWE during pregnancy[1,14].

Standard 1

All WWE:

1.1 should have access to pre-pregnancy counselling which facilitates informed decision making about contraception and pregnancy, from adolescence, or at the point of diagnosis.

1.2 should be encouraged to plan pregnancies and to have at least one pre-pregnancy counselling appointment with an epilepsy specialist nurse, neurologist or expert in epilepsy to have their diagnosis and ASM reviewed, and seizure control optimised.

1.3 who are trying to conceive should be encouraged to optimise health, including stopping smoking, minimising alcohol consumption and optimisation of BMI (in keeping with general pre-pregnancy advice).

1.4 taking ASM should be advised to take folic acid 5mg daily, if actively trying to conceive, and for at least the first 12 weeks of pregnancy.

1.5 should be encouraged to avoid pregnancy whilst prescribed sodium valproate. When sodium valproate is the most effective ASM to manage a woman's epilepsy, she will require specific assessment and counselling, in line with current MHRA recommendations.

1.6 who receive pre-pregnancy counselling should have an assessment of the impact of epilepsy, including ASMs, on their pregnancy, and the impact of the pregnancy on epilepsy, including seizure control and risk of SUDEP.

1.7 should have a trough level of their ASM obtained prior to pregnancy as this may be helpful to guide management during pregnancy, which might include dose adjustment during and/or after pregnancy.

Impact of implementation of these standards

For patients:

- women will be able to make informed choices prior to, and early on in pregnancy
- women receiving sodium valproate will be reviewed on a regular basis

For service providers:

- primary care providers will offer opportunistic pre-pregnancy counselling and contraceptive advice during routine contact with WWE
- secondary care providers will proactively provide pre-pregnancy counselling during patient contact, documenting advice and providing information in an accessible format

Antenatal care

Women with epilepsy should be reassured that the majority will have a straightforward pregnancy and birth, but there are some risks to consider[7]. During pregnancy, WWE have an increased risk of maternal and perinatal complications[1]. There may be associations between epilepsy in pregnancy and complications including gestational hypertension, pre-eclampsia, fetal growth restriction, postpartum haemorrhage, obesity, anxiety, depression and eating disorders[1].

Fetal exposure to ASM can be associated with congenital malformations and neurodevelopmental impairment[6,7]. Folic acid supplementation may confer benefit[8,9]. Physiological changes during pregnancy affect metabolism of ASM, and ASM doses may need to be increased, particularly if seizure control deteriorates. Status epilepticus rates may be higher during pregnancy and SUDEP remains the primary cause of death in WWE[1,7].

Standard 2

All pregnant WWE:

2.1 should be managed in a joint obstetric/neurology setting, by a named neurologist/epilepsy specialist nurse, community midwife and consultant obstetrician. In regions where there is wide geographical spread, areas are remote, or due to caseload, virtual patient consultations should be used to implement multidisciplinary care.

2.2 who have active epilepsy, should be reviewed by an epilepsy specialist nurse/neurologist/epilepsy specialist midwife within 14 days of referral to neurology services and at least twice during pregnancy. Referral to neurology services should be expedited by the midwife conducting the booking appointment.

2.3 should have at least one contact with an epilepsy specialist nurse in their first trimester, and frequency of future reviews agreed.

2.4 should have a primary named midwife who co-ordinates care, in line with recommendations from The Best Start 5-year plan for maternity and neonatal services.

2.5 should be advised regarding the importance of ASM adherence, including the risks of seizures to mother and baby.

2.6 should be advised there is potential for some ASM drug serum levels to fall in pregnancy but the impact of this on seizures is unclear.

2.7 should be supported to discuss the potential impact of seizures on their lifestyle including personal safety, driving, caring responsibilities and employment.

2.8 should be given the option to have repeat ASM trough levels obtained throughout the pregnancy, particularly ASMs which levels are known to alter during pregnancy (such as lamotrigine, levetiracetam and oxcarbazepine). Ideally these levels should be compared with a pre-pregnancy trough level to help inform decisions about ASM dose adjustment.

2.9 who have their ASMs increased during pregnancy should:

- be informed that there is a lack of data regarding neurodevelopmental outcomes for babies who have been exposed to increased doses of ASM *in utero*, and
- have a clearly documented plan for ASM doses to be reduced in the postnatal period, which should be shared with the woman and her GP.

2.9 should be advised to take folic acid 5mg daily for at least the first 12 weeks of pregnancy.

2.10 who are taking ASM should be offered serial growth scans from 28 weeks onwards.

2.11 should have mental health and psychosocial needs assessed regularly and offered referral to appropriate services as required.

2.12 should create a personalised obstetric management plan with their named midwife, obstetrician and neurology team. This should cover an ASM plan (including any additional medication during labour and management of acute seizures), analgesia and plans for mode and place of birth.

2.13 should be counselled about postnatal issues including breastfeeding, safe baby care, sleep deprivation, mood alteration, seizure control and contraception.

2.14 should be informed of the UK Epilepsy and Pregnancy Register and the International ASM and Pregnancy Registry.

2.15 who experience a deterioration in seizure control:

- For self-limiting convulsive or other prolonged seizures should be advised to contact obstetric triage and should be managed via rapid neurological referral pathways.
- For ongoing convulsive or other prolonged seizures should be taken to the emergency department where an obstetric emergency call should be made to the obstetrician on call.
- For other self-limiting seizures should be advised to contact their epilepsy specialist nurse or neurologist during office hours and if concerned to contact obstetric triage out with office hours for support and advice.

2.16 who are admitted to hospital should - *see flowchart*:

- be given a bed in a bay which allows for observation and regular monitoring by staff,
- be prescribed their usual ASMs, which should be taken regularly including during labour,
- be encouraged to bring their own medications into hospital with them, to avoid delays in dosing,
- have their neurology team informed of admission,
- shower only, not bathe.

2.17 in status epilepticus should be managed according to an agreed, up-to-date health board protocol.

Impact of implementation of these standards

For patients:

- WWE will benefit from early senior input and resultant expertise
- proactive review of diagnosis (where required) will lead to earlier appropriate management

For service providers:

- improved coordinated working between obstetric and neurology services will enhance communication and collaborative patient care
- rapid neurological care pathways will streamline care for pregnant WWE

Intrapartum care

The risk of intrapartum seizures for WWE is low but birth in a consultant-led unit is recommended[7] in view of the increased risks associated with pregnancy and birth[1].

Standard 3

For all WWE admitted to hospital in active labour or for scheduled delivery (induction of labour or planned Caesarean birth) - *see flowchart*:

3.1 the most senior obstetrician on site (ST3 or above) should be informed regarding admission.

3.2 the woman's obstetric management plan should be reviewed on arrival, including

- analgesia (certain analgesia should be avoided, for example tramadol and pethidine),
- fetal monitoring,
- postnatal ASM dosing plan, and
- postnatal contraception.

3.3 her usual ASMs should be prescribed in the drug chart. She should receive her usual ASMs even if fasting, and an alternative administration route/formulation should be offered if necessary. No doses of ASM should be missed.

3.4 it is particularly important they are prescribed postnatal analgesia and anti-emetics before transfer to a postnatal ward.

All WWE in active labour or at the time of Caesarean section should:

3.5 have one to one midwifery care.

3.6 not be left on their own.

3.7 be formally reviewed by the on call anaesthetist and the most senior obstetrician on site (ST3 or above).

Impact of implementation of these standards

For patients: WWE will benefit from early senior input and resultant expertise, as well as one-to-one midwifery care.

For service providers: effective communication within obstetric, midwifery and anaesthetic teams will improve outcomes for mothers and babies.

Postnatal care

The postnatal period can be a difficult time for WWE and there is a lack of robust evidence to inform management strategies. Concentrations of ASMs may increase as the physiological changes of pregnancy reverse[1]. Postnatal depression and anxiety can occur[10]. Sleep deprivation and stress may impact negatively on seizure control. Breastfeeding confers benefits to mothers and babies and should be encouraged, where possible. Breastfeeding does not adversely affect neurocognitive function of children born to WWE taking ASMs[12].

Standard 4

4.1 In the 72 hours post-delivery WWE should be cared for in a bay, within sight of the midwifery/nursing staff. For any WWE nursed in a single room, their partner or family member should be in waking attendance at all times.

4.2 WWE, including those on ASMs, should be encouraged to breastfeed. Advice about expressing breast milk should be given to facilitate sleep.

4.3 If ASM doses were increased during pregnancy, dose reduction may be required as detailed in the woman's postnatal dosing plan. Urgent neurological review should be sought if seizure control deteriorates or if signs of ASM toxicity develop.

4.4 WWE should be offered postnatal contraception prior to discharge, such as insertion of long-acting reversible post-partum contraception at the time of delivery or immediately afterwards. Any potential interactions of postnatal contraception with ASMs should be taken into consideration.

4.5 The woman's neurologist/epilepsy specialist nurse should be informed of her discharge from hospital by the maternity team.

When a WWE is discharged from hospital:

4.6 she should have contact details for their epilepsy specialist nurse/neurologist, community midwife and GP. She should be encouraged to make contact if she has any concerns about seizure control.

4.7 it should be ensured that there is postnatal community continuity of midwifery care, with comprehensive guidance and information on baby care, infant feeding and safety in the home. The midwifery team should ideally have specialist knowledge of epilepsy.

4.8 epilepsy specialist nurse review should take place around 6 weeks or earlier after birth, and at least twice during the first postnatal year in order to review issues including seizure control, ASMs, signs of ASM toxicity, baby feeding and care, and contraception.

Impact of implementation of these standards

For patients: WWE will be closely monitored for seizures postnatally. Mothers and babies will benefit from breastfeeding where possible, and WWE will leave hospital with a contraceptive plan. Effective community midwifery support and timely neurology follow up will allow continued physical and mental health monitoring for WWE.

For service providers: A contraceptive pathway will facilitate discussion surrounding contraceptive choices. Enhanced liaison between secondary care and community teams will improve patient care.

Useful resources on epilepsy for patients and healthcare professionals

Clinical Guidelines: **- SIGN** **- RCOG**	Diagnosis and Management of Epilepsy in Adults Epilepsy in Pregnancy
Report on WWE & pregnancy	Management of epilepsy in pregnancy: a report from the International League Against Epilepsy Task Force on Women and Pregnancy
Pregnancy & epilepsy	Pregnancy & epilepsy (Epilepsy Society)
- UK epilepsy & pregnancy register **- International registry of ASMs & pregnancy**	UK epilepsy and pregnancy register International Registry of Antiepileptic Drugs and Pregnancy
Epilepsy & having a baby	Epilepsy and having a baby – During pregnancy (Epilepsy Action)
Safety of ASMs in pregnancy: **- Advice & information** **- Safety leaflet** - **Risks of Sodium Valproate**	Epilepsy Medicines & Pregnancy (Epilepsy Society) Epilepsy Medicines & Pregnancy (Medicines and Healthcare products Regulatory Agency) Valproate medicines (Epilim▼, Depakote▼): contraindicated in women and girls of childbearing potential unless conditions of Pregnancy Prevention Programme are met Sodium Valproate and pregnancy – Factsheet (Epilepsy Scotland)
Research on ASM management in pregnancy	Support for Researchers (Epilepsy Action)
Epilepsy & giving birth, including pain relief	Labour, birth and after the baby is born (Epilepsy Action)
WWE after the birth - what to expect **Looking after your baby safely for WWE**	Labour, birth and after the baby is born (Epilepsy Action) Looking after a baby or young child when you have epilepsy (Epilepsy Action)
Epilepsy & breastfeeding	Breastfeeding and epilepsy (Epilepsy Society)
Contraception & ASMs	Contraception (Epilepsy Action)
Epilepsy Charities providing helpful information for patients and clinicians	Epilepsy Scotland Epilepsy Action Epilepsy Society
Mental health support	Breathing Space Samaritans

References

1. Stephen LJ, Tomson T, Harden C, Brodie MJ. Management of epilepsy in women. Lancet Neurology 2019; 18: 481-491
2. Royal College of Obstetricians & Gynaecologists. Epilepsy in Pregnancy. Green-top Guideline No. 68, June 2016. https://www.rcog.org.uk/globalassets/documents/guidelines/green-top-guidelines/gtg68_epilepsy.pdf
3. Knight M, Bunch K, Tuffnell D, et al (Eds.) on behalf of MBRRACE-UK. Saving Lives, Improving Mothers' Care - Lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2017-19. Oxford: National Perinatal Epidemiology Unit, University of Oxford 2021. MBRRACE-UK_Maternal_Report_2021_-_FINAL_-_WEB_VERSION.pdf (ox.ac.uk)
4. Knight M, Bunch K, Tuffnell D, et al (Eds). Saving Lives, Improving Mothers' Care. Lessons learnt to inform maternity care from the UK and Ireland confidential enquiries into maternal deaths and morbidity 2016-2018. Oxford: National Perinatal Epidemiology Unit, University of Oxford; 2020. Accessed 11th November 2021. MBRRACE-UK_Maternal_Report_Dec_2020_v10_ONLINE_VERSION_1404.pdf (ox.ac.uk)
5. Tomson T, Battino D, Bromley R, et al. Management of epilepsy in pregnancy: a report from the International League Against Epilepsy Task Force on Women and Epilepsy. Epileptic Dis 2019; 21: 497-517
6. Sen A, Nashef L. New regulations to cut valproate-exposed pregnancies. Lancet 2018; 392: 458-60
7. Bhatia, M, Adcock, JE, Mackillop, L. The management of pregnant women with epilepsy: a multidisciplinary collaborative approach to care. The Obstetrician & Gynaecologist 2017; 19: 279– 88. DOI: 10.1111/tog.12413
8. Scottish Intercollegiate Guideline Network. Epilepsy and women's health. In: Diagnosis and management of epilepsy in adults. May 2015. Accessed November 11th, 2021. http://www.sign.ac.uk/assets/sign143.pdf
9. Meador K, Pennell P, May RC, et al. Effects of preconceptual folate on cognition in children of women with epilepsy. NEAD Study. Neurology 2020; Feb 18; 94 (7) e729-e740. DOI: 10.1212/WNL.0000000000008757
10. National Institute for Health and care Excellence. NICE Pathways. Special considerations for women and girls with epilepsy. 30 July 2021. Accessed November 11th, 2021. epilepsy-special-considerations-for-women-and-girls-with-epilepsy.pdf
11. Veiby G, Bjork M, Engleson BA, Gilhus NE. Epilepsy and recommendations for breastfeeding mothers with epilepsy. JAMA Neurol 2020; 77: 441-50
12. Binbaum AK, Meador KJ, Karanam A, et al. Antiepileptic drug exposure in infants of breastfeeding mothers with epilepsy. JAMA Neurol 2020; 77: 441-50
13. Bjork MH, Veiby G, Reiter SC, et al. Depression and anxiety in women with epilepsy during pregnancy and after delivery: a prospective population-based cohort study on frequency, risk factors, medication, and prognosis. Epilepsia 2015; 56: 28-39
14. Askarieh A, MacBride-Stewart S, Kirby J, Fyfe D, Hassett R, Todd J, Marshall AD, Leach JP, Heath CA. Delivery of care, seizure control and medication adherence in women with epilepsy during pregnancy. Seizure. 2022 Aug;100:24-29. doi: 10.1016/j.seizure.2022.06.002. Epub 2022 Jun 9.

Appendix

Membership of the Scottish Government's Best Start Obstetric Neurology Group

Name	Profession	Health Board/ Organisation
Richard Davenport	Consultant Neurologist	NHS Lothian
James McDonald	Consultant Neurologist	NHS Fife
Alastair Campbell	Consultant Obstetrician	NHS Lothian
Callum Duncan	Consultant Neurologist	NHS Grampian
Chris Derry	Consultant Neurologist	NHS Lothian
Corinne Love	Consultant Obstetrician	NHS Lothian / SG
Rosamunde Burns	Consultant Anaesthetist	NHS Lothian
Yvonne Leavy	Senior Epilepsy Specialist Nurse	NHS Lothian
Eleanor Arthur	Epilepsy Clinical Nurse Specialist	NHS Greater Glasgow & Clyde
Sarah Stobbs	Consultant Anaesthetist	NHS Lothian
John Paul Leach	Consultant Obstetrician	NHS Greater Glasgow & Clyde
Emily Frier	Clinical Research Fellow & O&G Registrar	NHS Lothian
Tara Fairley	Consultant Obstetrician	NHS Grampian
Kirsteen Guthrie	Interim Lead Midwife	NHS Borders
Iona Duckett	Senior Midwife	NHS Tayside
Mhairi Macfarlane	General Practitioner – Holburn Medical Group	NHS Grampian
Janet Brennand	Consultant Obstetrician	NHS Greater Glasgow & Clyde
Linda Stephen	Associate Specialist in Neurology	NHS Greater Glasgow & Clyde

Pregnant or postnatal WWE admitted to hospital - Flowchart