NHS North West

NORTH WEST GUIDELINE

Care for people with epilepsy before (pre-conception), during pregnancy and postpartum

A collaborative guideline, commissioned by NHS England North West Maternity Team in association with Epilepsy Action and co-developed through extensive contributions from North West maternity providers, North West Maternal Medicine Network and Teams, Obstetricians, Primary Care, Transitional Care Teams and Adult/Pediatric Neurology experts across Cheshire and Mersey, Greater Manchester and Eastern Cheshire and Lancashire and South Cumbria Local Maternity and Neonatal Systems.

Ensuring People with Epilepsy receive optimal care and management across the North West Region

Document Control:

Role	Name	Contact
Owners	North West Maternal Medicine Network	
Catherine Chmiel	Lead Midwife for the North West Maternal Medicine Network	catherine.chmiel@nhs.net
Catherine Owens	Midwifery and Epilepsy Co-Ordinator	cowens@epilepsy.org.uk
Consultant Nurse in Epilepsy	Dr Janine Winterbottom	Janine.winterbottom@nhs.net

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Compliant with:

1.	NICE guideline NG217 Epilepsies in children, young people and adults (2022) Epilepsies in children, young people and adults (nice.org.uk)
2.	NICE Quality Standard QS211 (2023) Epilepsies in children, young people and adults (nice.org.uk)
3.	Royal College of Obstetricians and Gynaecologists (RCOG, Green-top Guideline No.68 2016) Epilepsy in Pregnancy (Green-top Guideline No. 68) | RCOG
4.	NICE guideline 121Intrapartum care for women with existing medical conditions or complications (2019) Intrapartum care for women with existing medical conditions or obstetric complications and their babies (nice.org.uk)

Authors

Catherine Owens	Midwifery and Epilepsy Coordinator, Epilepsy Action cowens@epilepsy.org.uk
Catherine Chmiel	Lead Midwife for the North West Maternal Medicine Network catherine.chmiel@nhs.net
Christine Burness	Consultant Neurologist The Walton Centre Christine.burness@nhs.net
Farhat Mirza	Consultant Obstetrician, Northern Care Alliance farhat.mirza@nca.nhs.uk
Fiona Legg	Consultant Obstetrician University Hospitals Morecombe Bay fiona.legge@mbht.nhs.uk
Mark Clement Jones	Lead Obstetrician North West Maternal Medicine Network mark.clement-jones@liverpool.ac.uk
Naomi McGuinness	Consultant Obstetrician Liverpool Women's Hospital Naomi.McGuinness@lwh.nhs.uk
Janine Winterbottom	Consultant Nurse, The Walton Centre Liverpool janine.winterbottom@nhs.net

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Once fully ratified and endorsed, this guideline will be available for adoption throughout the North West of England to ensure that people with epilepsy and families universally receive consistent, high-quality care before pregnancy (preconception) into pregnancy and postnatal period.

Lyndsey Banks	Quality and Safety Lead for Maternity and Child Health, Wrightington, Wigan and Leigh NHS Foundation Trust
Juthica Bardapure	Consultant Obstetrician Bolton NHS Foundation Trust
Lisa Cook	Maternal Medicine Midwife Preston Hospital
Paul Davies	Epilepsy Specialist Nurse, Dartford and Graveside NHS Trust
Papa Essilfie	Consultant Obstetrician, Wrightington, Wigan and Leigh NHS Foundation Trust
Liz Hayes	Specialist Midwife, Manchester University Foundation Trust
Charlotte Mills	Midwife Bolton NHS Foundation Trust
Andrea Morris	Consultant Obstetrician University Hospitals Morecombe Bay
Louise Morgan Nilsen	Roald Dahl Children & Young People's Epilepsy Transition Nurse Specialist, Alder Hey Children's NHS Foundation Trust
Nicola Parry	Specialist Midwife Manchester University Foundation Trust
Sangeetha Steevart	General Practitioner Warrington
Meghan Taylor	Maternity and Neonatal Voice Partnership representative

Conflict of Interest:

No conflict of interests identified.

Contents

1 Summary / Introduction

The purpose of this clinical guideline is to ensure that women and birthing people with epilepsy (BPWE) at the stages of preconception (reproductive health), into pregnancy (maternity) and postnatal period have in place the best practice clinical guidance, systems, and processors, that address patient safety and deliver a high-quality service.

For this guideline women and birthing people with epilepsy (BPWE) are referred to and includes all young women/women and people.

This guideline has been commissioned by NW Maternity Services and developed in association with Epilepsy Action developed in response to available evidence and reflects the MBRRACE-UK: Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK report (2023) which states that the risk of maternal mortality is 10 times higher for people living with epilepsy when compared to the general population. Furthermore, the mortality risks increase to at least 40% for BPWE living in areas of high deprivation and from Black, Asian and minority backgrounds.

This guideline has been co-produced with midwifery, obstetric, neurology, primary care, epilepsy nurse specialist leads for adults and young persons and service users following a North West Gap analysis of previous maternity epilepsy services, triangulated with national best practice, service user and clinical listening events and North West regional guideline review.

2 Purpose

The purpose of this guideline is to provide clinical guidance that aligns care across the North West Region, and is tailored to BPWE health and social care needs by:

a) Reducing health inequalities
b) Strengthening local expertise and drive improvement.
c) Improving clinical outcomes and reducing risk
d) Providing a positive lived experience for carers and families of BPWE

3 Scope

This guideline will support the care of people with confirmed diagnosis of epilepsy prior to preconception and pregnancy plus a person who develops a new onset of first seizures in pregnancy.

Based on the most recent data collected in 2018 the number of BPWE in the UK is 626,000 people. About 73000 people are living in the Northwest of England which equates to a prevalence of 9.98/1000 people or 1% of the population (Wigglesworth et al, 2023). The prevalence and incidence of epilepsy is at least 40% higher in areas of high deprivation (58.53/1000 people respectively) of which the Northwest of England has multiple areas of the highest levels of deprivation in the UK (MBRRACE, 2023; Epilepsy Action, 2023).

4 Roles and Responsibilities

The care provided for BPWE will be delivered by a multiple disciplinary team in distinct roles and clinical settings across the North West.

The Local Maternity Provider: is responsible for offering maternity care to its local community; there are seventeen maternity providers in the North West. Most BPWE will be able to be cared for by their local provider in partnership with their local epilepsy services and or Local Maternal Medicine Centre (MMC). This will depend on the complexity of the woman's needs, skill set and experience of the maternity and clinical team of the provider. Each provider of maternity or epilepsy services is responsible to notify the NW Maternal Medicine Network (MMN) of any BPWE when pregnant via the NW Electronic MMN referral form and communicate clinical updates between the multi-disciplinary team. A list of local maternity providers can be found in appendix 1.

The local provider is responsible for effectively communicating with the MDT when updates in care have been made or are required. For example, ensure the General Practitioner is notified of the care provided, birth outcomes, and/or any care directives e.g., recommended medication requirements and future follow-up appointments required.

Obstetric Consultant: is the lead professional in maternity care for BPWE who is responsible for providing safe care, in line with the current best maternity practice and for effectively communicating with the MDT when updates in care have been made or are required. This includes providing preconception, pregnancy and postnatal advice relating to maternity care and management.

Community Midwife: is the named midwife and is responsible for providing routine midwifery care during the ante natal, intrapartum and postnatal period where appropriate and effectively communicating clinical updates with the MDT.

Clinician specialising in epilepsy: A clinician refers to a physician with expertise in assessing first seizures and diagnosing epilepsy (usually a consultant neurologist), who is responsible for providing safe care in line with current best practice and for effectively communicating with the MDT when updates in care have been made or are required.

Expertise may be demonstrated by training and continuing education in epilepsy and/or peer review of practice, and epilepsy must be a significant part of their clinical workload (equivalent to at least 1 session per week) [NICE QS211, 2023

Consultant Nurse/Epilepsy Specialist Nurse: is the lead nurse professional who provides clinical advice and support to BPWE in line with best clinical practice and for effectively communicating with the MDT when updates in care have been made or are required. This includes providing appropriate preconception, pregnancy and postnatal advice relating to epilepsy care and management.

Consultant Paediatrician: is the lead professional for paediatric care for young BPWE transitioning from paediatric to adult epilepsy services in line with local policy. The paediatrician consultant and his team are responsible for providing safe care in line with current best for paediatric epilepsy care and for effectively communicating with the MDT when updates in care have been made or are required. This includes providing pre conception, pregnancy and postnatal advice relating to epilepsy care and management.

General Practitioner: Although preconception counselling is every clinician's responsibility who prescribes antiseizure medication (ASM) to BPWE who are of reproductive age or managing people with a history of epilepsy, GPs play a vital role in identification, referral, early management and

provision of epilepsy information, annual review including ASM review, contraception and support for BPWE. GPs also review and manage the treatment of people whose epilepsy care is not complex and who have been discharged by the neurologist. The GP is also responsible for effectively communicating with the MDT when updates in care have been made or are required.

Transitional Care Nurse (specialising in epilepsy) for Young People: is the lead nurse for transitional care and provides care to young people transitioning from long term paediatric health conditions, including epilepsy, to adult care services. The transitional care nurse is responsible for, providing preconception information, supporting the young person through their pregnancy and for effectively communicating with the MDT when updates in care have been made or are required.

The North West Maternal Medicine Network (NW MMN): The NWMMN is responsible for supporting the delivery of preconception, ante natal, intrapartum and postnatal care for people who have significant medical problems that predate or arise in pregnancy within the North West Maternal Medicine Centers (NW MMC).NW MMN consists of 3 Maternal Medicine Centers that are located at one primary provider within each Local Maternity and Neonatal System (LMNS)/region at:

- Liverpool Women's Hospital, NHS Foundation Trust in Cheshire and Mersey LMNS
- Manchester University NHS Foundation Trust at Oxford Road Centre for Greater Manchester and Eastern Cheshire LMNS
- Lancashire Teaching Hospital, NHS Foundation Trust, Preston for Lancashire and South Cumbria LMNS

The NW MMN is responsible for updating the NW MMC, Primary Care Providers and Local Maternity Providers of any national updates, alerts or changes in national guidance related to caring for BPWE predating or during pregnancy.

North West Maternal Medicine Centers: provide the delivery of local, equitable and timely specialist care and advice for all people with complex medical conditions, including epilepsy, before, during and following pregnancy. The specialist team caring for BPWE during pregnancy includes a designated Obstetrician, Neurologist, Epilepsy Specialist and/or Nurse and Maternal Medicine specialist Midwife. The NW MMC also has additional specialist staff to provide care for BPWE who have additional medical conditions and co-morbidities e.g., diabetes.

The NW MMC is responsible for ensuring the local provider and General Practitioner is notified of the care provided, birth outcomes and any care directives e.g., recommended medication requirements.

Maternal Medicine Specialist Midwives: Trained midwives with additional clinical midwifery experience and skillset who provide care to people with maternal medicine conditions, including epilepsy, before and during and after pregnancy. Maternal Medicine Midwives are responsible for the coordination of maternity care for BPWE accessing local joint obstetric and medical or MMC services and for effectively communicating with the MDT when updates in care have been made or are required.

Consultant Neurologist is the lead professional in epilepsy care for BPWE who is responsible for providing safe neurological care, in line with current best epilepsy practice and for effectively communicating with the MDT when updates in care have been made or are required. This includes providing preconception, pregnancy and postnatal advice relating to epilepsy care and management.

Local Emergency Departments and Maternity Triage Units: are responsible to provide urgent care to BPWE during pregnancy following a seizure. It is the responsibility of the lead professional attending the BPWE to refer the person to her named Obstetric Consultant and epilepsy specialist

team for review. The persons named Obstetric and Epilepsy review should be undertaken within 2 weeks following a seizure via local appointment/review system.

5 Preconception and pregnancy pathway of care

Maternal morbidity and mortality are increased in BPWE that pre-dates pregnancy and by complications that arise both during pregnancy and within the first year after delivery (MBRRACE, 2023). Significant changes occur in a BPWE during pregnancy in all aspects of physiology and pharmacokinetics therefore the following recommendations will enable the safest and best care to be delivered across the North West.

This guideline is for:

- All healthcare professionals providing care and support to BPWE of reproductive potential, including primary, secondary, and tertiary care providers.
- Commissioners of maternity service
- All service users, their partners, their family and the public

The clinical guideline recommendations are based on current national clinical guidance which. include:

- NICE guideline NG217 Epilepsies in children, young people and adults (2022) Epilepsies in children, young people and adults (nice.org.uk)
- NICE Quality Standard QS211 (2023) Epilepsies in children, young people and adults (nice.org.uk)
- Royal College of Obstetricians and Gynecologists (RCOG, Green-top Guideline No.68 2016) Epilepsy in Pregnancy (Green-top Guideline No. 68) | RCOG,
- Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries (MBRRACE, 2023) Saving Lives, Improving Mothers' Care (2023) Saving Lives, Improving Mothers' Care 2023 - Lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2019-21 | MBRRACE-UK | NPEU (ox.ac.uk)
- NICE guideline 121Intrapartum care for women with existing medical conditions or complications (2019) Intrapartum care for women with existing medical conditions or obstetric complications and their babies (nice.org.uk)
- NHS England North West Maternal Medicine Network Maternal Medicine Centres | NW Maternal Medicine Network

5.1 Epilepsy diagnosis and assessment

People with a chronic medical condition, including epilepsy require personalised care as described below:
A diagnosis of epilepsy should be made by a medical clinician or paediatrician with expertise in

epilepsy, usually a neurologist (NICE QS211, 2023; RCOG, 2016) following robust clinical assessment, including detailed history taking and examination, video footage, electrocardiogram (ECG), neuroimaging, genetic testing and/or antibody testing as indicated by NICE Clinical Guidance 217: 1.2.5 : Epilepsies in children, young people and adults (nice.org.uk).

Care provided during preconception counselling and pregnancy provides an ideal opportunity to review and where necessary reassess the diagnosis and ensure appropriate care is provided.

5.1.1 People who have their first seizure when pregnant

People, including young people may present with suspected seizures via primary care, emergency department, acute medicine, community midwifery, gynaecology or obstetric services or self-refer. Maternity services are to be informed at the earliest opportunity following presentation and involved in the persons ongoing care as required.

- All people, including young people, presenting with a first suspected seizure in their pregnancy must be notified to the NW MMN, by the referring clinician, following notification of the seizure using the regional electronic notification form pertinent to the LMNS provider (Appendix 3,4 or 5). The person must be assessed by a clinician with expertise in epilepsy within 2 weeks of presentation. [NICE Quality Standards QS211, 2023]. Each MMC has a neurological team attached to the MMC provider

- A clinician refers to a physician with expertise in assessing first seizures and diagnosing epilepsy (usually a consultant neurologist). Expertise may be demonstrated by training and continuing education in epilepsy and/or peer review of practice, and epilepsy must be a significant part of their clinical workload (equivalent to at least 1 session per week) [QS211, 2023]

- A young person under the age of 16 or 18 years (as per local transitional care policy) who is suspected of having a first seizure in pregnancy must also be referred to their local paediatrician with expertise in epilepsy within 2 weeks of suspected seizure presentation. They must also be referred to a named obstetrician within their chosen local provider via the local referral system within 2 weeks of suspected seizure presentation.

5.2 A person over the age of 18 years presenting with a first suspected seizure must also be referred to a named obstetric consultant within their chosen local provider via local referral systems within 2 weeks of suspected seizure presentation.

5.1.2 Information and support following a first seizure

Following a first seizure the epilepsy clinician/specialist epilepsy nurse must provide the person, their family and carers if appropriate, with tailored information relating to:

- How to recognise a further seizure

- Seizure First Aid and initial safety guidance in case of another seizure: Epilepsy Action provide an online training session and can be accessed via the following link: First aid - Epilepsy Action

- How to reduce seizure triggers and any changes they can make to reduce their risk of another seizure (refer to section 5.1.3 and 5.1.4)

- Advise who must be contacted if the BPWE has a further seizure while awaiting their appointment for assessment and diagnosis

Ensure all service user information is accessible in an easy read format, culturally sensitive and in multiple languages relevant to the demographic needs of its service user population. A range of epilepsy service user and professional information can be found via the following link: About epilepsy - Epilepsy Action

5.1.3 Assessing the risk of a second seizure

When a BPWE, including young person in pregnancy presents with a first seizure they are at risk of having a further seizure.

An individualised risk assessment of their likelihood of a second seizure must be undertaken.

The assessment should include checking for the following modifiable factors that may increase the risk of a second seizure:

- an underlying mental health problem (such as depression, anxiety, psychosis and alcohol or substance misuse)
- Vascular risk factors (for example, diabetes, hypertension, atrial fibrillation)
- Pathological risks including sepsis and brain tumour
- Stress and sleep deprivation

Using a person-centred approach, discuss with the person, their family and carers if appropriate, their individualised risks for further seizures. This should include any mental, physical and social factors identified as possible risk factors and how these may be modified.

5.1.4 General guidance to reduce risk of further seizures include:

- Do not stop taking or reduce the amount of any anti - seizure medication the BPWE has been prescribed
- Do not stop taking any medication prescribed for any other medical condition unless advised to do so by your clinician
- Avoid becoming sleep deprived by ensuring you do not become over tired and having a relaxing environment to sleep and undisturbed as much as possible.
- Avoid substance or alcohol misuse
- If you are worried about future seizures talk to your GP or epilepsy specialist nurse/midwife
- Report any signs of infection or illness to your GP as this may trigger a seizure

Typically, a diagnosis of epilepsy is made following a second seizure, unless another abnormality is detected during the assessment process. The medical management for BPWE consists of Anti-Seizure Medications (ASMs). Recommended ASMs can be found in NICE Guideline (2022) via the following link: Epilepsies in children, young people and adults (nice.org.uk).

5.3 Preconception care

5.3.1 Preconception counselling and support

Each person of child-bearing age should receive an annual review with their epilepsy care provider (this may be with their GP, Epilepsy Specialist Clinician or Neurologist) and provided with preconception information and advice.

Preconception appointments should be made available as per local preconception services:

a) Preconception appointments should be offered to any BPWE:

- Who is, or who should be, under regular neurological review
- Who is planning to undergo assisted reproduction who has significant risk factors for Epilepsy
- Who has a history of significant complications related to epilepsy during a previous pregnancy or hospital care related to another medical condition
- Who has a history of significant risk related to other comorbidities

b) The preconception consultation should include:

- Assessment and information gathering

- Previous epilepsy history, obstetric history and co-morbidities include:
    - Review of epilepsy diagnosis and seizure classification
    - Previous and current investigations -e.g., ASM Serum levels, EEGs, ECGs, treatment plans
    - Assessment of current epilepsy status

c) Optimisation

- Explain to BPWE who are pregnant or are planning pregnancy the importance of adherence to their antiseizure medications and that they should not stop their medication without medical supervision

- Discuss the relative benefits and risks of adjusting medication with the person planning pregnancy to enable informed decision making. This should include discussing the balance between the risks of poorly controlled seizures and the risks of the baby when antiseizure medicines are taken in pregnancy or while breastfeeding.

- Optimise epilepsy well-being – medical, surgical, or other intervention

- Lifestyle modification- smoking cessation, folic acid and vitamin D supplementation, reduction and avoidance of alcohol and improving physical fitness

- All BPWE are recommended to take Folic Acid daily for a minimum of 3 months before conception (NICE,2022 NG217 amendment in 2024) as per local guidance and individualized review. NICE recommend 5mg (2024) from preconception and throughout the first trimester however further research is required due to opposing reports to the benefit of high dose folic acid and associated reports of childhood malignancy (Vegrim et all (2022), which was deemed as having serious methodological flaws (Wrede et al 2023).

d) Drugs

The teratogenic impact of ASM's can include congenital malformations, neurodevelopmental impairments, and fetal growth restriction (MHRA, 2021; NICE, 2022). Follow NICE guidelines for treatment with antiseizure medications (NG217, 2022), treatment initiation and ASM selection aiming for lowest dose monotherapy to achieve seizure control, starting dose low and slow does increments appropriate for patient need and seizure related risk.

- Undertake personalised risk assessment of which ASM, and any other medications, can be continued in pregnancy and plans for changing any ASM. Risks must include unknown teratogenic risk and uncertainties
- ASMs may need to be stopped or changed prior to pregnancy and reassessed after stopping them

- Refer to NICE guidance: Epilepsies in children, young people and adults (nice.org.uk) and MHRA 'safety advice on antiepileptic drugs in pregnancy' (2021) https://www.gov.uk/drug-safety-update/antiepileptic-drugs-in-pregnancy-updated-advice-following-comprehensive-safety-review

- Specifically, discuss the risks to the unborn child of a BPWE using sodium valproate and topiramate during pregnancy due to high risk of birth defects and development disorders, including the increased risk with higher doses and polytherapy. Follow the MHRA safety advice on valproate and topiramate for people of child-bearing potential. Complete the Annual Risk Acknowledgement Form (ARAF) for valproate and topiramate and ensure the Pregnancy Prevention Programme is fulfilled (MHRA, 2024)

- BPWE should be informed that the risk of congenital anomalies in the fetus is dependent on the type, number and dose of ASM's

- Specifically discuss the potential need for ASM dose adjustment and monitoring in pregnancy; most notably early pregnancy concentration drops with lamotrigine but the potential to influence any ASM clinically may vary. ASM blood monitoring might also support adherence monitoring, therefore have a baseline ASM drug concentration level before pregnancy is beneficial (MHRA 2021)

- Be aware of clinically significant ASM contraception drug interactions: carbamazepine, cenobamate, eslicarbazepine, acetate, oxcarbazepine, peranpamel, phenobarbital, phenytoin, primidone, rufinamide and topiramate (any dose), can impair the effectiveness of hormonal contraceptives; oestrogen-containing hormonal contraceptives and hormone replacement therapy can impair the effectiveness of lamotrigine (GOV.UK 2024).

- Refer to The Faculty of Sexual Health and Reproductive Healthcare guidance: Drug Interactions with Hormonal Contraception (2022) https://www.fsrh.org/Common/Uploaded%20files/documents/drug-interactions-with-hormonal-contraception-5may2022.pdf

e) Information giving

Give the BPWE and their chosen support person/partner/guardian personalised, age specific and current information about the BPWE reproductive health and the associated risks of pregnancy to the person and their fetus/baby (including morbidity and mortality) to enable informed decision making. Information must be age appropriate

NB Members of the person's family should not be used as interpreters.

- Discussion of the risk of seizures and potential risk to the fetus and include how to minimise the risk of seizures (section 5.1.4)
- Provide information about the benefits and how to improve seizure control prior to pregnancy and potential for change to seizure control during pregnancy (may require ASM adjustment)
- Provide patient information about the benefits of preconception folic acid daily
- Outline a plan of management of pregnancy, birth, and postnatal care
- Clear documentation of discussions/information given to the BPWE to facilitate their decision on whether to proceed or not with a pregnancy
- Discussion around any additional issues around assisted conception treatment where relevant
- Information about appropriate contraception including potential ASMs drug interactions. Discuss the importance of delaying pregnancy by re-starting contraception to allow for optimising seizure control and making changes to ASM.
  Information regarding access to contraception options, termination of pregnancy services and how to access care when pregnant
- Providing contraceptive advice and care to young people under the age of 16 years brings legal and ethical considerations. In the event where a young person does not wish to have a parent or guardian Fraser Guidelines and Gillick Competence (Care Quality Commission (CQC),2022) screening must be adhered to.

  https://www.cqc.org.uk/guidance-providers/gps/gp-mythbusters/gp-mythbuster-8-gillick-competency-fraser-guidelines
- Provide information about Sudden Unexpected Death in Epilepsy (SUDEP), including risk factors for SUDEP and how to reduce the risks. Advice on what to do on discovery of becoming pregnant including how nausea and vomiting may affect ASM absorption and increase risk of seizures recurring or increasing the progress of pregnancy care (antenatal care, labour and birth)
- Discuss the digital tool for reducing the risk. EpSMon can help a BPWE understand their own personal risk so a BPWE can make informed decisions. The app is based on the latest epilepsy research and is free. This can be accessed in the app store or via google play
- Provide information about postnatal care: explain that breastfeeding for most BPWE taking ASMs is generally safe and should be encouraged. Support each mother to choose a feeding method that bests suit the BPWE and their family. Include discussion about family/friend support following initial return to home

f) Equity and diversity considerations

BPWE who are older or who have learning disabilities, have other complex needs (such as comorbidities), or do not speak English should have their specific requirements taken in to account. This should include:

- Giving longer appointments to allow more time for discussion
- Offering telemedicine appointments if the BPWE is unable to attend face- to -face
- Providing information in different formats such as easy read prints, large prints, or audio versions
- Providing information that is culturally sensitive and accessible to people who do not speak or read English, and is culturally appropriate
- Involving family members and carers or an advocate if the BPWE wishes
- Sharing information with those involved in the person's care, if appropriate
- Repeating information as BPWE often have memory issues

5.3.2 Preconception counselling for people who do not receive regular neurological care

Preconception counselling should be offered to all BPWE. Some BPWE and young persons do not require regular neurological review at a Neurological centre and their epilepsy care is provided by their GP, Advanced Nurse Practitioner or Practice Nurse or via their local epilepsy services (Adult and paediatric transitional care services). Pregnancy planning is equally important and should be accessed via their GP or Epilepsy Specialist Services at their local hospital. The preconception care discussion provided should mirror that provided by the MMN as noted in section 5.2.1

Preconception care and preconception counselling for BPWE must be provided by a clinician with expert knowledge of contraceptive knowledge and potential impact for BPWE taking ASM and epilepsy specialist knowledge.

Specialist contraceptive advice can be accessed in each LMNS via accessing the links attached in appendix 2.

5.2.3 Contraception for young people

Providing contraceptive advice and care to young people under the age of 16 years brings legal and ethical considerations. In the event where a young person does not wish to have a parent or guardian Fraser Guidelines and Gillick Competence (CQC 2022) screening must be adhered to.

5.4 Termination of pregnancy

Rapid access to termination of pregnancy services should be facilitated for any person seeking abortion care. Multidisciplinary care, including epilepsy services, will be necessary for people around the time of termination of pregnancy as ASM levels may drop from the onset of pregnancy and seizure control affected. For people with complicated and uncontrolled forms of epilepsy, it is important that the termination occurs in an NHS hospital setting, with access to emergency care. Clinicians should recognise the difficulty in making these types of decisions and be supportive of a decision to abort in the context of significant maternal neurological disease.

5.5 Miscarriage

The care of a person who has had a miscarriage requires a multidisciplinary approach, including the appropriate epilepsy clinician, gynecologist, and anesthetist. The MDT should decide with the person the best place and method for the person having a miscarriage. The options for management of miscarriage are surgical evacuation, medical management, or Manual Vacuum Aspiration (MVA). These all have their own risks and benefits. Surgical evacuation requires an anesthetic but has a lower risk of retained products and the timing is more predictable. A person having medical management of miscarriage needs to be managed as an impatient with access to senior clinical staff. MVA performed in a theatre setting (but without an anesthetic) may be a suitable procedure if undertaken less than 9 weeks gestation. If a BPWE miscarries at home, then she should be advised to attend hospital to be assessed.

5.6 Ante Natal Care Pathway for BPWE

This section must be used in conjunction with NICE guidance 201 Ante Natal Care (2021): Antenatal care (nice.org.uk)

5.5.1 North West Maternal Medicine Network

The North West Maternal Medicine Network (NW MMN) is responsible for ensuring that all BPWE in the network's footprint with significant medical problems will receive timely specialist care and advice before, during, and after pregnancy. All constituent providers within the network will be responsible for agreeing and upholding shared protocols on the management and referral of people with medical conditions, including reviewing guidelines and referral pathways.

This model of care will ensure that – where agreed appropriate – an experienced Multidisciplinary Team (MDT) conduct investigation and management.

Most BPWE with complications during pregnancy will continue to be managed by local maternity services. The proportion of a person's care provided by a Maternal Medicine Centre (MMC) will vary according to individual need. For some, a single visit to the MMC or communication with the MMC by the local unit will suffice. For the highest risk and most complex BPWE, it may be that all care will be recommended to be provided within the MMC.

When referring BPWE, be respectful and aware of all religions, languages, cultures, and diversities such as sexuality and gender diversity to ensure best care for all. Please take into consideration the additional challenges faced by those who are from an ethnic minority, have a severe mental illness, learning disability or are socially deprived as they are at a higher risk of poor physical health and poor outcomes, compared with the general population. The perinatal period adds further complexity, therefore please ensure you consider mental health needs and refer to your local perinatal mental health service appropriately.

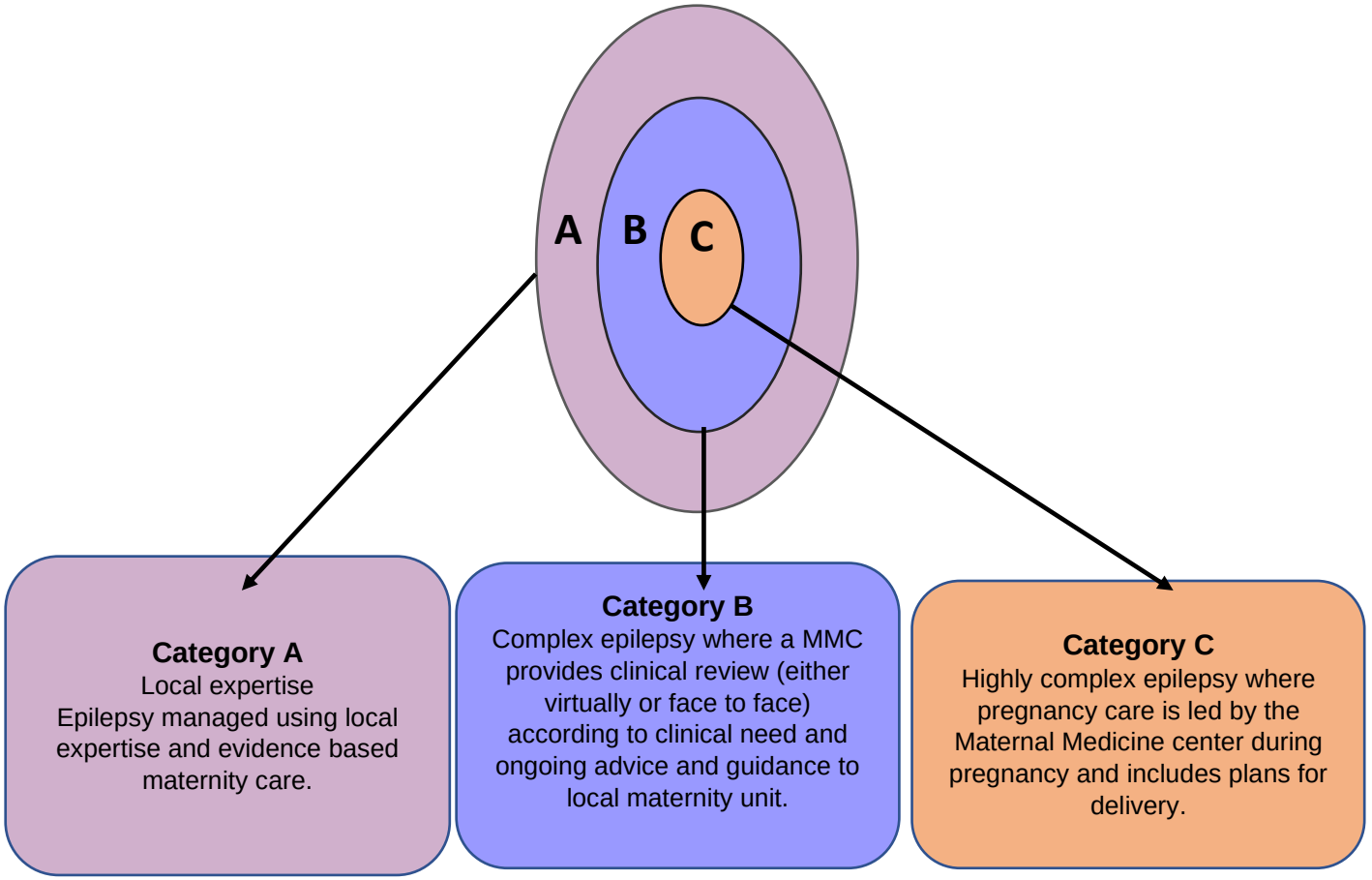
There is a designated MMC in each LMNS that serves the North West region

LMNS	MMC
Greater Manchester and Eastern Cheshire (GMEC)	St Mary's Hospital Manchester
Cheshire & Merseyside (C&M)	Liverpool Women's Hospital (LWH)
Lancashire & South Cumbria (L&SC)	Royal Preston Hospital (RPH)

The three MMC's encompass all maternity providers within the three LMNS's (Appendix 1). The centers function collaboratively as a network enabling coordination to deliver maternal medicine care to people throughout the NW region. This integrated approach ensures equitable expert care.

Each MMC is equipped to facilitate telemedicine across the MMN if it is safe for the BPWE and where it is difficult for a person to attend face to face appointment. Telemedicine can also be used where expertise is required for specific cases and clinicians from several providers need to work together from as an MDT to implement joint care plans.

Most BPWE in pregnancy will be cared for by their local maternity provider dependant on their clinical need and expertise of local clinicians. Care is categorised by the NW MMN as follows:



(Maternal Medicine category pathway (2024)

All BPWE, including young people, must be notified to their local MMC following the maternity booking appointment or following a first seizure; this can be made through the MMN referral system. Each MMC has their own referral form/process that can be accessed through the following hyperlinks below:

1. Notification to C&M MMC at Liverpool Women's Hospital (Appendix 3)
2. Notification to GMEC MMC at St Mary's Hospital (Appendix 4)
3. Notification to LSC MMC at Royal Preston Hospital (Appendix 5)
4. A Patient summary template for referral to MMC can be found in Appendix 7
5. An MDT summary template can be found in appendix 8

If your clinical assessment indicates the BPWE needs to be reviewed by the MMN/MMC please indicate this on the Summary referral form (appendix 7). Following submission of the notification form each referral will be reviewed by the MMN team at their weekly review meeting. Following this review you will be advised of the appropriate plan:

- Care to be provided by the local maternity provider
- Care to be provided by the local maternity provider and MMN to provide additional guidance/support
- All care to be provided by the MMN at the local MMC including recommended place of birth
- If the clinical needs of the BPWE change during the pregnancy the person can be rereferred back to the local MMC for further guidance, support and care

A person who has been seen pre-conceptually may access care directly to contact the neurology team, or the Epilepsy Specialist Liaison Nurse/Maternal Medicine Specialist Midwife who can also refer the BPWE directly to the Obstetric Neurology Clinic, through the referral system.

Any person who presents a history at booking of known or suspected epilepsy should be referred as early as possible for review with an obstetrician to determine their level of risk, and whether onward referral to the local MMC is necessary. Antenatal appointments should provide care specifically for BPWE, in addition to the care provided routinely for healthy pregnant people.

5.5.2 Schedule of appointments

Most BPWE are classified as having a high -risk pregnancy, due to their unknown likelihood of seizures during the pregnancy, and recommended to attend additional appointments throughout their pregnancy:

NG201 Schedule of antenatal appointments (nice.org.uk)

Table 1: Guide for additional care in addition to routine schedule plan for BPWE

All BPWE should follow primiparous pathway as a minimum standard. Appointments may vary depending on clinical assessment and need.

Gestation	Appointment	Epilepsy Specific guide

Before 10 weeks	Prioritise Booking Appointment	• Detailed history to include ascertaining:
		  ➢ Preconception counselling accessed
		  ➢ Type of epilepsy,
		  ➢ Frequency of seizures.
		  ➢ Date of last 3 seizures
		  ➢ Duration of seizures
		  ➢ Antiseizure medication and note if stopped or reduced taking medication in last 12 months
		  ➢ Rescue medication
		  ➢ Any other medical condition
		  ➢ Identify high risk triggers: nocturnal seizures, sleep deprivation, any additional co morbidities, alcohol and drug misuse. Is the person taking Valproate or Topiramate?
		• Notify MMC (appendix 3,4 or 5) and if appropriate request MMC discussion at weekly review panel for future recommendations
		• Refer to Obstetric lead and Epilepsy Specialist for review (to be reviewed by local provider within 2 weeks of booking appointment to plan ante natal care)
		• Refer for dating scan
		• Continue Folic acid up to 12 weeks as per local guidance
		• Take bloods to monitor ASM serum levels to assess ASM concentration and to monitor comparison from preconception and pregnancy levels. The reporting and feedback must be planned to avoid delay of ASM dose adjustment where levels have dropped significantly
		• Continue ASM unless advised by epilepsy specialist to change ASM or dosage
		• Recommend maintaining a seizure diary
		• Assess mental health status
		• Ensure BPWE knows who, how and when to contact maternity/epilepsy services
		• Provide extra time for appointments consider double appointment slot
		• Provide personalised information
		• Refer to national pregnancy register: : Home | UK Epilepsy and Pregnancy Register (appendix 6)
		• Recommend EpSMon app at SUDEP Action helps BPWE understand own personal

		epilepsy risk: EpSMon app - SUDEP Action (more information can be found on appendix 6) • Discuss epilepsy first aid training with the BPWE and their partner/support which can be accessed by the following link: First aid - Epilepsy Action • Confirm ability for face-to-face appointments or need for telemedicine review where possible • Information may need repeating due to memory issues in BPWE • Ensure booking summary is shared with GP, Health Visitor and any other medical profession involved in their care e.g. learning disabilities, mental health, paediatric consultants/therapists/specialist nurses as appropriate
11 – 14 weeks	First trimester screening	• Obstetric Review within 2 weeks of booking appointment to plan AN Care; continue ASM unless advised by epilepsy specialist to change ASM or dosage • Review ASM serum level results and compare with any previous ASM levels • Consider requirement for additional growth scans during the pregnancy re associated risk of growth restriction • Co-develop personalised care and seizure management plan with the BPWE • If a BPWE has a history of status epilepticus or prolonged seizures buccal midazolam (10mg in 2mls) must be included in their seizure management/care plan • Provide personalised safety advice and information to minimise seizures and reduce triggers • Advise BPWE and partner/family re Epilepsy First Aid • Information may need repeating due to memory issues in BPWE
16 weeks	Community Midwife appointment	• Review of all screening results and escalate any anomalies • Ensure all appointments have been made • Information may need repeating due to memory issues in BPWE
18 - 20 weeks	Anomaly Ultrasound Screening Obstetric and Neurology/epilepsy	• Review anomaly scan • Consider requirement for additional growth scans during the pregnancy re associated risk of growth restriction

	specialist review at MMC or Local provider	• Review personalised care and seizure management plan with the BPWE • Review seizure diary • Review mental health needs • Information may need repeating due to memory issues in BPWE • Consider if anaesthetic referral required (dependant on seizure control and additional co morbidities)
25-28 weeks	Community Midwife Appointment	• Review seizure diary • Review mental health needs • Take bloods to monitor ASM serum levels • Continue ASM unless advised by epilepsy specialist to change ASM or dose • Information may need repeating due to memory issues in BPWE
24 – 28 weeks	Glucose tolerance test	• If criteria met
24 – 28 weeks	Anaesthetic Review	• If BPWE has poor seizure control or other comorbidities • Information may need repeating due to memory issues in BPWE
28 weeks	Joint medical appointment • Obstetrician • Epilepsy Clinician/Neurologist • Epilepsy Specialist Nurse/Midwife Or separate obstetric and epilepsy review if joint clinic unavailable	• Review seizure diary • Review ASM serum level results • Review personalised care and seizure management plan with the BPWE • Assess mental health status • Review mental health needs • Review fundal height measurement • Consider requirement for additional growth scans during the pregnancy re associated risk of growth restriction (RCOG 2016) • Continue ASM unless advised by epilepsy specialist to change ASM or dose • Information may need repeating due to memory issues in BPWE
31 weeks	Community Midwife appointment	• Review seizure diary • Review mental health needs • Provide information re preparation for birth including PRN medications to manage seizure triggers e.g. Clobazam • Consider infant feeding referral • Take bloods to monitor ASM serum levels • Continue ASM unless advised by epilepsy specialist to change ASM or dose • Information may need repeating due to memory issues in BPWE

32 weeks	Screening appointment	• Growth Scan if indicated following risk assessment
34 weeks	Joint medical appointment • Obstetrician • Epilepsy Clinician/Neurologist • Epilepsy Specialist Nurse/Midwife Or separate obstetric and epilepsy review if joint clinic unavailable	• Review seizure diary • Review ASM serum level results and compare with previous ASM levels • Review personalised care and seizure management plan with the BPWE • Review mental health needs • Review fundal height measurements • Review fetal growth & consider requirement for additional growth scans during the pregnancy re associated risk of growth restriction (RCOG 2016) • Continue ASM unless advised by epilepsy specialist to change ASM or dose • Information may need repeating due to memory issues in BPWE
35 weeks	Screening appointment	• Growth Scan if indicated following risk assessment
36 weeks	Birth planning appointment	• Include partner/support person • Review personalised care and seizure management plan with the BPWE • When and how to get to hospital • Discuss birth options and analgesic options (avoid pethidine) • Advise to bring in to hospital their own ASM to maintain drug continuity • Advise to continue taking ASM at same times when in hospital to maintain ASM levels • Review preparation for birth and PRN medications to manage seizure triggers e.g. Clobazam/GP correspondence to prescribe/to bring into hospital with other ASMs • Discuss infant feeding options • Discuss support plan at home following the birth • Discuss how to reduce risk of seizure re sleep deprivation • Plan for postpartum ASM dose reduction if ASMs increased during pregnancy, correspondence to GP to support prescription of lower dose tablets for incremental dose reduction plan. • Discuss contraception options • Shared decision making • Give extra time • Information may need repeating due to memory issues in PWE
38 weeks	Screening appointment	• Growth Scan if indicated following risk assessment

38 weeks	Joint medical appointment • Obstetrician • Epilepsy Clinician/Neurologist • Epilepsy Specialist Nurse/Midwife Or separate obstetric and epilepsy review if joint clinic unavailable	• Review birth plan • Review seizure diary • Review fundal height measurements • Review personalised care and seizure management plan with the BPWE • Confirm ASM plan for birth • Confirm postnatal discharge plan including ASM review and management • Assess mental health needs • MDT communication • Information may need repeating due to memory issues in BPWE
40 weeks	Community Midwives appointment	• Review seizure diary • Assess mental health status • Information may need repeating due to memory issues in BPWE
Postnatal	PN care and discharge planning	• **Provide PN care in ward setting to facilitate continuous observation**. If single room requested the person must have another person to alert staff immediately in case of seizure • Review personalised care and seizure management plan with the BPWE • Advise re potential need to remain in hospital for 48 hours dependent on seizure control and home support • Provide care in a room which can be monitored constantly or facilitate a person to stay with BPWE • Obstetric review before discharge • Consider Epilepsy Specialist review before discharge (in management plan) • Confirm ASM management especially if breastfeeding • Safety checklist to reduce seizures • Caring for baby for BPWE • Support the chosen infant feeding methods that best suits the BPWE and her family and provide written information re infant feeding team contact number • Ensure all contact numbers provided and information of how to access services • Inform of following appointments if required • Contraception information and administration (if appropriate) to prevent further pregnancy • Screened for depressive disorder • Information may need repeating due to memory issues in BPWE • Ensure discharge summary is shared with GP and Health Visitor. This must include ASM management plan, contraception advice and required follow up

		• Ensure discharge summary is shared with any other clinician involved in the persons care e.g. learning disabilities, mental health, paediatric consultants/therapists/specialist nurses/midwives

All BPWE should be followed up if they do not attend for an antenatal appointment to ascertain reason for non- attendance and to provide alternative appointment.

5.5.3 Initial booking appointment

At the initial booking appointment, the following epilepsy risk assessment should be used to ascertain where the BPWE maternity care must be undertaken

- Type of epilepsy diagnosed
- History of seizures in last 12 months including type, duration and frequency of seizure and any existing seizure management plan
- ASM and any add on therapy (Vagus Nerve Stimulation)
- Current care provider and setting including Neurologist, Epilepsy physician and or GP, centre of care
- Recent inpatient admissions in last 5 years
- Additional specialist care received
- Complete NW MMN notification form. Each LMNS has its own referral process please refer to the relevant Appendix (3,4 or 5)
- Consider taking baseline serum of ASM concentration to help facilitate dose adjustment where required (dependant on ASM dosage and preconceptual levels) and assess ASM compliance/risk assessment
- Recommend continue taking Folic Acid until the 12 week of pregnancy is completed to reduce the risk of brain abnormalities and neural tube defects
- Recommend the person to register with the national epilepsy and pregnancy register to provide information about the health and development of the BPWE and their child through to 2 years of age. Further information and registration can be found via the following link: Home | UK Epilepsy and Pregnancy Register or via QR code on appendix 6
- Recommend the BPWE to download EpSMon App which is a digital tool to reduce the risk of seizures by helping to understand a person's individual risk, helping to track things, and providing key information. For further information please click on the following link: EpSMon app - SUDEP Action or provided by the information on Appendix 6

BPWE should be prioritised to be cared for in an Enhanced Continuity of Care Team throughout their care to improve clinical outcomes and experience for themselves and their family, in local providers who can support this model of care.

BPWE who are not considered to have a high risk of unprovoked seizures can be managed as low risk in pregnancy (RCOG ,2016)

BPWE should have access to regular planned ANC with a designated epilepsy team, obstetrician, midwife and neurologist where appropriate.

BPWE who have experienced seizures in the year prior to conception require close monitoring for their epilepsy. An epilepsy management plan must be made and reviewed in each trimester.

5.5.4 Additional guidance for the ante natal period

The majority of BPWE can experience a healthy planned pregnancy, delivering a healthy baby who they can go on to breastfeed (NICE, NG217, 2022; RCOG 2016).

Obstetric and epilepsy care for BPWE will be provided in a joint clinic where possible, or at an individual obstetric and epilepsy clinics where joint clinics are unavailable.

BPWE may be at increased risk for a range of perinatal complications compared with the general population, including pre-eclampsia, premature delivery, hemorrhage, fetal growth restriction, and stillbirth. (NICE, NG217, 2022; RCOG 2016). The need for additional growth scans should be considered at each obstetric review.

BPWE should be informed that the risk of congenital anomaly in the fetus is dependent on the type, number and dose of ASM's.

It is common for BPWE to be worried about ASM risks. It is important to balance the individual need for ASMs against the safety of the PWE and baby. Sudden withdrawal of ASMs may affect seizure control (especially if in remission for years), personal safety, ability to drive and employment.

It is important to maintain current ASM's until advised accordingly by an epilepsy clinician.

Consider monitoring ASM serum levels in each trimester and findings discussed with the BPWE (NICE, 2022).

The monitoring of ASM blood levels is usually prompted by new seizure activity and BPWE personal needs (fear of seizure relapse):

- Detection of non-adherence to prescribed ASM
- Suspected toxicity
- Adjustment of ASMs (Drug levels can drop significantly for lamotrigine/phenytoin use)
- Management of pharmacokinetic interactions (e.g. changes in bioavailability changes in elimination, and co -medication with interacting drugs e.g. selective serotonin reuptake inhibitors)
- Specific clinical conditions e.g. status epilepticus and organ failure

Teratogenic ASMs are contraindicated in pregnancy. All prescribers must check current MHRA guidance re ASM which includes Valproate and Topiramate.

If a BPWE is taking Valproate or Topiramate at booking advise the person to continue taking the ASM until reviewed by the epilepsy specialist team/neurologist. Arrange urgent review by their specialist prescriber (within days). Additional information on BPWE taking teratogenic ASMs in pregnancy can be found in appendix 10.

When pregnant it is important for BPWE to maintain a seizure diary to help clinicians monitor their epilepsy. PWE often experience memory issues thus maintaining a diary will help with recall and assessment of the impact of the pregnancy and epilepsy. The EpSMon app - SUDEP Action can facilitate this.

Ensure SUDEP awareness, risk assessment and risk minimization are provided as standard care throughout pregnancy (MBRRACE 2023).

Regard nocturnal seizures as a red flag indicating BPWE need urgent referral in to an epilepsy service of obstetrician (MBRRACE, 2023).

Urgent referral should be made to epilepsy services and obstetrician if a BPWE has discontinued or changed her ASM medication dose.

Consider more frequent monitoring reviews for BPWE if on more than one ASM, have a learning disability, aged under 16years, have active epilepsy (seizure within last 12 months, have bilateral tonic-clonic seizures or have modifiable SUDEP risk factors

If dosage of ASM is changed during pregnancy, discuss and make an antenatal plan with the PWE to return her medications to pre-conception dosages. Antiseizure medications should begin to return to pre-conception dosages in the first few days/week after birth. Rapid dose reduction can be a trigger to seizures and must be discussed in AN Planning (to include other triggers, potential toxic effect of ASM and postpartum monitoring plan)

Each provider must provide the appropriate emotional and psychological well-being support and refer to local counselling services where required. The risk of increased mental health concerns is greater in BPWE. Refer to mental health services as per local provision if the BPWE reports deterioration in their mental health to facilitate early intervention.

5.5.5 Personalised care planning

A personalised epilepsy and maternity care plan should be made following appropriate and full MDT review and discussion with each BPWE; the following topics should be included:

- Review date (this is dependent on clinical needs). Minimum standard review and care plan updated must be undertaken in each trimester
- Seizure types and record of seizures
- Triggers that may provoke seizures
- Regular medication, including adherence to ASM, experience of side effects from medication and coping mechanism
- Reducing epilepsy related risks, including advice re SUDEP checklist
- Patient information and support
- Mental Health risk assessment
- When and how to contact the hospital in the AN period
- The NW MMN have developed an MDT Summary template and must be used to document a summary of the MDT meeting following each meeting. (Appendix 8)
- If a BPWE has a history of status epilepticus or prolonged seizures buccal midazolam (10mg in 2mls) must be included in their seizure management/care plan
- The care plan must be reviewed and updated in each trimester as a minimum

5.5.6 Risk factors for seizures

At each AN appointment a BPWE must be assessed for the following risk factors for seizures:

- Sleep deprivation
- Stress
- Alcohol and substance use
- Adherence to ASM’s
- Seizure type and frequency
- Any deterioration in their mental health

5.6.7 Birth planning

An individualised birth plan should be made following a joint discussion with the woman and her partner/support person, the appropriate epilepsy and maternity team, including anaesthetic review no later than 36+6 days gestation and include:

- Hospital and epilepsy specialist contact numbers
- When to contact the hospital
- What to bring to hospital
- Advised to bring their own ASM to hospital with them to ensure their ASM administration is maintained
- Place of birth discussion and recommendation to birth their baby in a hospital setting
- Birth Options
- Ways to optimise normal birth
- Non-pharmacological and pharmacological pain relief options and ensure each WWE is aware of the recommendation to avoid the use of pethidine in labour as this has the potential to interfere with the ASM action
- PRN ASM if after risk assessment BPWE is assessed at increased risk of seizures deteriorating in labour, and sleep deprivation. Discuss the role of PRN clobazam, risks and benefits.
- Care of the newborn including infant feeding and Vitamin K (1mg recommended intramuscularly)
- Management of the third stage
- How your partner /support person can be assisted when in hospital
- Postnatal care (PNC)
- BPWE should be counselled that the risk of seizures in labour is low
- If a BPWE has undergone Vagus Nerve Stimulation (VNS) implantation she should be advised to bring her VNS magnet to hospital with her
- Advised to bring all her ASM medication to hospital to enable continuation of personalised ASM

A birth plan template can be found in Appendix 9.

5.6 Managing risk in the AN period

BPWE must be advised never to stop or change ASM's without an informed discussion with their epilepsy specialist clinician or nurse.

The lowest dose of appropriate ASM should be used.

BPWE should be informed that the introduction of safety precautions may significantly reduce the risk of accidents and minimise anxiety and should be signposted to EpSMon self-monitoring Safety Checklist: https://sudep.org/epilepsy-self-monitor. This includes minimising time spent alone, ASM compliance, first aid training for family members, avoiding sleeping alone and inpatient care should be in an environment where continuous care from a partner or staff can take place. Individuals with unwitnessed seizures are at high risk of SUDEP with nocturnal seizures being an independent factor. Consider the need for rescue medication such as buccal Midazolam.

Table 2: SUDEP risk discussion tool (adapted from SUDEP and MBRRACE

Risk Factor	Risk Minimisation
Seizure related factors	
In last 12 months • Active seizures • Injury • Generalised tonic-clonic seizures • Status epilepticus &prolonged seizures • Nocturnal Seizures • Epilepsy onset <16 years	Discuss the following are key risk factors for mortality • Seizure free<12/12 • Injuries • GTCS • SE • Nocturnal seizures (red flag requires urgent referral) Actions • Provide education about SUDEP • EpSMON app to help track seizure activity
Treatment factors	
• Poor compliance with medication and service • Medication change • Ineffective treatment	Actions: • Review control • Provide education around importance of compliance and engaging with services for regular reviews
Individual factors	
• Living and sleeping alone • Alcohol and substance misuse • Mental health issues • Learning disability • Pregnancy triggers- stress, sleep deprivation & dehydration	

Healthcare professionals should be alert to signs of depression, anxiety and neuropsychiatric systems in BPWE exposed to ASM's and ensure a mental health risk assessment and appropriate referral to maternity mental health teams are completed in each trimester as a minimum standard.

If admission to hospital is required during the AN period BPWE with reasonable risk of seizures should be accommodated in an environment which facilitates continuous monitoring by a carer, partner nurse or midwifery staffing.

5.6.1 People who experience a seizure in the AN period

All BPWE must have a seizure management plan in place during their pregnancy which must also include who and when to contact if they experience any seizure in the antenatal period. The seizure management plan must be reviewed and updated each trimester as a minimum standard.

This plan should be individualised depending on the woman's individual epilepsy history, seizure risk and gestation of the pregnancy. Points of contact include the woman's epilepsy specialist and or Maternity Triage unit.

First Aid for Seizures training can be accessed via the Epilepsy Action website to support families caring for their BPWE outside of a healthcare setting: First aid - Epilepsy Action

5.6.2 Preparation for parenthood

BPWE and their partners/support person should receive individualised support and access to preparation for parenthood classes inclusive of:

- Preparation for birth
- Infant feeding
- How to minimise seizure triggers including the importance of continuing ASM
- Identifying important contacts and support networks
- Mental health and wellbeing
- Caring for a newborn
- Contraception discussion in the ante natal period and consideration for long-acting contraception before leaving hospital
- When, how and who to contact in the event of needing additional help, following a seizure and/or in an emergency
- Epilepsy first aid: First aid - Epilepsy Action
- BPWE are often challenged by memory issues and reduced ability to retain information therefore it is important to provide the information in a range of platforms and in different languages that meets the local demographic needs

5.7 Intrapartum Care

Intrapartum care should be provided to BPWE in conjunction with the following clinical guidelines:

Nice Intrapartum care for women with existing medical conditions or obstetric complications and their babies guideline (ng121,2019): https://www.nice.org.uk/guidance/ng121/resources/intrapartum-care-for-women-with-existing-medical-conditions-or-obstetric-complications-and-their-babies-pdf-66141653845957

And

Epilepsy in Pregnancy guideline (Green-top Guideline No.68, RCOG (2016):

https://www.rcog.org.uk/media/rzldnacf/gtg68_epilepsy.pdf

5.7.1 Birth place setting

Most BPWE will be recommended to birth their baby in their local maternity unit on the consultant led birth suite to facilitate continual observation of the person in labour.

BPWE whose epilepsy is complex, or where their local maternity unit does not have the expertise to care for them will be recommended to birth their baby at their local MMC.

BPWE must be counselled that the risk of seizures in labour is low (3.5%). However, due to this risk BPWE should be recommended to birth their baby in a consultant led birth suite and not be left unattended during labour or within the first 24 hours following the birth of the baby.

5.7.2 Additional Intrapartum care

Adequate analgesia and appropriate care in labour should be provided to minimise risk factors for seizures such as insomnia, stress and dehydration. **Pethidine should be avoided** as this is known to decrease seizure threshold. The use of Trans Electrical Nerve Stimulation (TENS) is not contraindicated for used by BPWE

- Long-acting benzodiazepines such as clobazam (by mouth PRN) can be considered if there is high risk of seizures in the peripartum period
- BPWE should be advised to bring their own ASM in to hospital to ensure timely maintenance of administration. ASM intake should be continued during labour If this cannot be tolerated orally, a parenteral alternative should be administered
- Benzodiazepines are the drugs of choice for the management of self-terminating seizures (focal/non convulsive seizures, tonic clonic seizures less than 5 minutes)
- If a BPWE has a history of status epilepticus or prolonged seizures buccal midazolam (10mg in 2mls) must be included in their seizure management/care plan
- Intravenous access is recommended at the onset of labour
- In individual cases if labour is thought to be likely to precipitate a major seizure or suggestive aura is experienced, the care plan may include use of clobazam 10-20mg orally twelve hourly to reduce the risk
- Continuous fetal monitoring is recommended in BPWE at high risk of a seizure in labour, and following an intrapartum seizure
- There are no known contraindications to use of any induction agents in BPWE taking ASM's
- All BPWE are at potential risk of peripartum seizures and should be advised to birth their baby in a consultant-led unit with facilities for one- to-one midwifery care and neonatal resuscitation
- The decision to use water for analgesia and birth should be made on an individual basis. BPWE who are not taking ASM's and who have been seizure free for a significant period may be offered waterbirth after joint discussion with their epilepsy specialist and named obstetric consultant to clarify birth plan

5.7.3 Intrapartum Seizures

Every maternity unit should have a written guideline on the management of intrapartum seizures and management of intrapartum status epilepticus.

If a BPWE has a history of status epilepticus or prolonged seizures buccal midazolam (10mg in 2mls) must be included in their seizure management/care plan

In individual cases if labour is thought to trigger a tonic-clonic seizure, the care plan may include

administration of clobazam 10-20mg orally, 12 hourly to reduce the risk.

Management of intrapartum tonic-clonic seizures:

- Seizures in labour should be terminated as soon as possible to avoid maternal and fetal hypoxia and fetal acidosis
- Follow all personalised seizure management plans
- In the absence of this follow local seizure management guidance which includes:

a) Initial patient management 0 – 5 minutes

- Call for emergency assistance which will include obstetric/anaesthetic/neonatal team where appropriate in hospital or 999 if in a community setting
- Record time of seizure onset and time the length of seizure
- Airway Breathing Circulation management
- Protect the patient but do not restrain by cushioning head and environmental risks (sharps, abrasive surfaces, electronic cables and devices, water)
- Consider airway adjunct
- Administer high flow oxygen
- Place BPWE in semi prone, left lateral tilt head down
- Gain IV access
- Obtain BM if hypoglycaemic
  Give 150 – 200mls 10% glucose IV Stat
  If seizures continue repeat this step and commence 10% glucose infusion at 100mls/hour
- If suspicious of alcohol excess or malnutrition commence 1 pair Pabrinex IV BEFORE glucose replacement
- If the seizure continues for 5 minutes the status epilepticus guidance should be followed (section
- Continuous fetal monitoring is recommended in women at high risk of seizures in labour and following an intrapartum seizure

Ongoing management:

- Regular observations
- Twelve lead ECG
- Obtain FBC, U&Es, LFTs, Ca2+, Mg2+, clotting studies and if applicable antiepileptic drug levels and blood gas.
- Treat acidosis if severe (discuss with critical care)
- Determine if diagnosed epilepsy, medication history and acute seizure care plan
- Consider neuroimaging and EEG Consider possibility of non-epileptic seizures
- Recommence fetal monitoring by cardiotocography (CTG) monitoring once seizure control has been maintained. If the fetal heart does not recover after 5 minutes or seizures are recurrent expediate delivery

Consider and treat potential causes:

- Underlying hypoglycemia, eclampsia and alcohol withdrawal
- If there is doubt whether a seizure is due to epilepsy or eclampsia, then in addition to the above follow the trust guideline on eclampsia
- Medication related (poor compliance, poor absorption, recent antiepileptic drug changes, medication interactions or subtherapeutic levels)

- Infection
- Electrolyte disturbance
- Toxicity or drug withdrawal (including alcohol withdrawal)
- CNS pathology (tumour, stroke, encephalitis, PRES, neurodegenerative diseases etc.)
- Obstetric consultant review and Labour management plan updated and to include future seizure management plan

5.8 Postnatal Care

Postnatal Care (PNC) should be provided to BPWE in conjunction with the following clinical guidelines:

Post Natal Care NICE Guideline (ng194):
https://www.nice.org.uk/guidance/ng194/resources/postnatal-care-pdf-66142082148037

All babies born to BPWE should be offered 1mg of intramuscular Vitamin k to prevent haemorrhagic disease of the newborn.

5.8.1 Maternal guidance

BPWE and their caregivers:

- Need to be aware that although the overall chance of seizures during and immediately after delivery is low, it is relatively a higher risk period than during pregnancy.
- Must be advised to continue their ASMs postnatally.
- Must be well supported in the postnatal period to ensure any triggers of seizure deterioration such as sleep deprivation, stress and pain are minimised
- If a BPWE has a history of status epilepticus or prolonged seizures buccal midazolam (10mg in 2mls) must be included in their seizure management/care plan
- **Do not routinely offer a single room** due to risk of unwitnessed seizures
- Any BPWE who has had a seizure 1 month prior to pregnancy, during pregnancy and labour should be observed closely for 72 hours
- All women with seizure in the last 2 years should be observed for 48 hours post delivery/birth
- Any increase in drugs during pregnancy will be continued for 24-48 hours post delivery, but then needs to be decreased to pre pregnancy levels (if effective) over the next 3-4 weeks to avoid risk of toxicity.
- Postpartum safety advice and strategies should be part of the antenatal and postnatal discussions. It should cover for example avoiding co-sleeping with baby, minimising excessive tiredness as well as practical measures including placing the baby in a cot/playpen if mother feels unwell, feeding/changing/bathing baby on the floor, transporting the baby upstairs in a car seat and not bathing baby alone

Be advised that breastfeeding for most BPWE taking ASM's is generally safe and should be encouraged. Support each person to choose a feeding method that bests suit the person and their family.

Must be screened for depressive disorder in the puerperium. BPWE should be informed about the symptoms and provided with contact details for any assistance.

Prescribers should consult individual drug advice in the SPC and the BNF or BNF for children when prescribing antiseizure medications for BPWE who breast feed. Decisions about antiseizure therapy and breastfeeding should be made between BPWE and prescriber and consider the benefits alongside the potential risks of the ASM affecting the child.

All providers must provide a suitable environment which enables a partner/support person to stay in hospital with the BPWE and facilitates continuous observation by carer, partner or midwifery staff.

5.8.2 Neonatal guidance

- All babies born with BPWE taking enzyme-inducing AEDs should be offered 1 mg of intramuscular vitamin K to prevent hemorrhagic disease of the newborn
- Babies of BPWE on phenobarbitone (rare) often experience withdrawal; they are jittery and irritable and should be monitored for seizures.
- Leaflet: “Tips for looking after a baby or young child when you have epilepsy”; Epilepsy action (https://www.epilepsy.org.uk/info/caring-children) can be provided

5.8.3 Discharge plan when returning home

Discharge home planning should commence in the antenatal period last trimester and initial plan reviewed by the epileptic specialist team and obstetrician following the birth of the baby and prior to discharge where required.

If BPWE has had their ASMs changed during pregnancy they must be reviewed by their epilepsy specialist within 7-10 days as per RCOG guideline (2016) to avoid potential ASM toxicity.

Any BPWE who has developed complications during pregnancy should be offered a debriefing appointment by the appropriate obstetric clinician/specialist midwife.

BPWE must be offered contraceptive advice to avoid an unplanned pregnancy.

BPWE must be provided with the contact details of who and when to call if any concerns for themselves or their baby or if they have a seizure when returned home. These include their local or MMC Maternity Triage, Infant feeding support, Epilepsy Specialist team/ specialist nurse and midwife.

Where the birth of the baby has taken place at a MMC, a woman will be discharged with one of the following discharge plans:

- Follow up by local hospital physician or GP as appropriate (this should include access to epilepsy services, and epilepsy nurse/midwife specialist)
- Follow up at MMC (this will only be for very complex medical conditions – or intercurrent problems have developed)

All BPWE should be followed up if they do not attend their postnatal appointment or unable to gain access at a home visit to ascertain reason for non- attendance and to provide alternative appointment.

5.8.4 Postnatal contraception advice

Prior to being discharged from hospital BPWE must be offered contraceptive advice to prevent an unplanned pregnancy.

Contraceptive advice must be provided by a health professional with expert knowledge of how ASM’s may interact with each contraceptive option as per MHRA safety recommendations and NICE

contractive:

Clinical Guidance: Drug Interactions with Hormonal Contraception:

https://www.fsrh.org/Common/Uploaded%20files/documents/drug-interactions-with-hormonal-contraception-5may2022.pdf

and

https://bnf.nice.org.uk/treatment-summaries/contraceptives-interactions/

PWE can also be signposted to Epilepsy Action website for patient information on contraception via;

https://www.epilepsy.org.uk/living/sex-and-contraception/contraception-an-epilepsy

6 Non pregnancy specific related epilepsy care

6.1 Vagus Nerve Stimulation

Vagal nerve stimulation (VNS) is a surgical treatment option for patients with pharmacoresistant epilepsy. VNS therapy is considered an option for selected people, with the aim of reducing seizure frequency and intensity and improving quality of life, although it is unlikely to result in seizure freedom. A pulse generator is surgically implanted with electrodes applied to the left vagus nerve. The VNS therapy device then delivers repeated electrical stimulations to the vagus nerve.

VNS therapy is an implanted device which may reduce the frequency, length and severity of seizures by stimulation of the vagus nerve.

Disabling the devise is not usually required and can carry risks of seizures worsening in severity or risk of side effects when stimulation re-starts. In the rare event the VNS device needs to be deactivated temporarily, the woman's VNS magnet can tape over the implanted generator, removal of the magnet resumes stimulation. If required to be switch off or following surgical procedures including diathermy a VNS FU should be arranged as soon as appropriate for the patient, this service is typically provided by the epilepsy nurses.

The patient and their family/carers are instructed on the use of the VNS, the use of magnet and how to temporarily deactivate, additional information available through LivaNova UK https://www.livanova.com/epilepsy-vnstherapy/en-gb/hcp

6.2 Status epilepticus, repeat or cluster seizures, and prolonged seizures

Status Epilepticus is a life-threatening emergency defined as tonic-clonic seizures lasting more than 5 minutes. Evidence is based on NICE NG217, 2022.

All seizures require timing to determine if prolonged and commencement of emergency treatment required.

If a BPWE has a history of status epilepticus or prolonged seizures buccal midazolam (10mg in 2mls)

must be included in their seizure management/care plan

6.2.1 Initial treatment for generalised convulsive status epilepticus

Provide resuscitation and immediate emergency treatment for BPWE, including young people who have convulsive status epilepticus (seizures which last 5 minutes or more).

- **If the person with convulsive status epilepticus has an individualised emergency management plan that is immediately available, administer medication as detailed in the plan**

- **If the person with convulsive status epilepticus does not have an individualised emergency management plan immediately available:**

Follow your local status epilepticus guidance

If your provider does not have local guidance follow the guidance below as per NICE (ng217, 2022):

Note: a status epilepticus algorithm can be found in appendix 11

b) Initial patient management 0 – 5 minutes

- Emergency medical call for assistance which will include corporate emergency team and or obstetric/anaesthetic/neonatal team where appropriate
- Airway Breathing Circulation management
- Protect the patient from injury but do not restrain by cushioning the head, protecting from environmental risks e.g. sharps, cables, water
- Consider airway adjunct
- Administer high flow oxygen
- Place BPWE in semi prone, left lateral tilt head down
- Gain IV access
- Obtain BM if hypoglycaemic
  Give 150 – 200mls 10% glucose IV Stat
  If seizures continue repeat this step and commence 10% glucose infusion at 100mls/hour

- If suspicious of alcohol excess or malnutrition commence 1 pair Pabrinex IV BEFORE glucose replacement

c) First Line Treatment 5 – 15 minutes

- Give a benzodiazepine (buccal midazolam 10mg or rectal diazepam) immediately as first-line treatment in the community or

I. If person has iv access:

- **Dose 1**: Use intravenous lorazepam 0.1mg/kg (usually 4mg bolus) if intravenous access and resuscitation facilities are immediately available.
- **Wait 5 minutes**
- **If no response following 1st administration of benzodiazepine**
  Call emergency services in community (999)
  Or
  seek expert hospital guidance (corporate emergency team) if not already in attendance
- **Dose 2:** intravenous lorazepam 4mg bolus
- **Wait 5 minutes**

II. If no IV access:

- **Dose 1** Buccal midazolam 10mg or IM midazolam 10mg
- Rectal diazepam 10mg should be reserved for patients with refractory epilepsy , who have diazepam prescribed as their usual rescue therapy in the community

  Wait 5 minutes
- **Dose 2** Buccal midazolam 10mg or IM midazolam 10 mg
- **Wait 5 minutes**

III. Ongoing management:

- Regular observations
- Twelve lead ECG
- Obtain FBC, U&Es, LFTs, Ca2+, Mg2+, clotting studies and if applicable antiepileptic drug levels and blood gas.
- Treat acidosis if severe (discuss with critical care)
- Determine if diagnosed epilepsy, medication history and acute seizure care plan
- Consider neuroimaging and EEG Consider possibility of non-epileptic seizures

If convulsive status epilepticus does not respond to the first dose of benzodiazepine, seek expert medical assistance.

Consider and treat potential causes:

- Underlying hypoglycemia, eclampsia and alcohol withdrawal
- Medication related (poor compliance, poor absorption, recent antiepileptic drug changes, medication interactions or subtherapeutic levels)
- Infection
- Electrolyte disturbance
- Toxicity or drug withdrawal (including alcohol withdrawal)
- CNS pathology (tumour, stroke, encephalitis, PRES, neurodegenerative diseases etc.).

Seizure terminated:

- **Airway, Breathing, Circulation, Disability and Exposure (ABCDE)** assessment of patients at regular intervals. Consider escalation to Critical Care setting if indicated Start supportive medical care and look for underlying cause of status epilepticus
- Recommence continuous fetal monitoring. If fetal heart has not recovered within 5 minutes expediate delivery

d) Second Line treatment 15 minutes onwards

If convulsive status epilepticus does not respond to 2 doses of benzodiazepine, give any of the following medications intravenously as second- line treatment under expert guidance:

- Levetiracetam (note this may be quicker to administer and have fewer side effects)
- Phenytoin
- Sodium Valproate (Follow the MHRA safety advice on valproate use by women and girls)

IV or IO access:

- Escalate to critical care as per local policy
- Dose 3
- IV levetiracetam 60mg/kg, (Table 3) maximum 4500mg (in 100ml sodium chloride 0.9% or glucose 5% over 10 minutes
- Levetiracetam is primarily renally cleared therefore a maintenance dose reduction is required for people with renal impairment (Table 4)

OR

- **IV Phenytoin** 20mg/kg, maximum dose of 2g (rate 50mg/min, 25mg/min for elderly patients with cardiac history, given undiluted

OR

- **IV Sodium Valproate** 40mg/kg, maximum 3000mg (in 100ml sodium chloride 0.9% or glucose 5% over 5 minutes

Caution – phenytoin administration requires cardiac monitoring and wide bore IV access due to risk of extravasation

Table 3 Levetiracetam loading dose by weight:

Table 1 – Levetiracetam Loading dose

Weight (kg)	Dose	Volume of 100mg/mL vials
20-24kg	1200mg	12mL
25-29kg	1500mg	15mL
30-34kg	1800mg	18mL
35-39kg	2100mg	21mL
40-44kg	2400mg	24mL
45-49kg	2700mg	27mL
50-54kg	3000mg	30mL
55-59kg	3300mg	33mL
60-64kg	3600mg	36mL
65-69kg	3900mg	39mL
70-74kg	4200mg	42mL
75kg and over	4500mg	45mL

Table 4: Maintenance dose

eGFR	Maintenance dose/interval
>80ml/min	1500mg BD started 12 hours after loading dose
50-79ml/min	1000mg BD started 12 hours after loading dose
30-49ml/min	750mg BD started 24 hours after loading dose
<30ml/min, PD, HD patients (see below if HD)	500mg BD started 36 hours after loading dose

Levetiracetam in hemodialysis (HD) patients

- Administer 250mg levetiracetam after each HD if the next dose is not immediately due

- If HD occurs within 36 hours of the initial loading dose, begin the maintenance dose immediately after dialysis

If ongoing seizures following the completion of the infusion consider second IV antiepileptic drug infusion of a different drug from the same list (levetiracetam, phenytoin, sodium valproate as above).

OR

Phenytoin

- Phenytoin can be given 20mg/kg as a single dose, max. rate 100mg/min (Maximum dose 2g). infused at a rate of 25-50mg/min (max 50mg/min) followed by maintenance dose of 100mg TDS commenced 24 hours following loading dose.
- Serum concentration should be measured 2 hours after initial loading dose and then rechecked every 5-7 days. Levels should be checked sooner if there are concerns of toxicity or poor response.
- Phenytoin should be avoided in the elderly because of increased risk of cardiovascular complications, as well as in those at risk of drug interactions (patients on chemotherapy, anticoagulation with warfarin)

Table 5 Phenytoin Loading Dose

Weight	Dose (Half this dose in elderly or cardiac disease	Volume of 250mg/5mL vials	Minimum dilution volume of sodium chloride 0.9%
35 - 39kg	700mg	14mL	100mL
40 - 44kg	800mg	16mL	100mL
45 – 49kg	900mg	18mL	100mL
50 – 54kg	1000mg	20mL	100mL
55 – 59kg	1100mg	22mL	250mL
60 – 64kg	1200mg	24mL	250mL
65 – 69kg	1300mh	26mL	250mL
70 – 74kg	1400mh	28mL	250mL
75 – 79kg	1500mg	30mL	250mL
80 – 84kg	1600mg	32mL	250mL
85 - 89kg	1700mg	34mL	250mL
90 -94kg	1800mg	36mL	250mL
95 – 99kg	1900mg	38mL	250mL
100kg or above	200mg	40mL	250mL

OR

Sodium Valproate

- IV Sodium Valproate 40mg/kg (up to maximum of 3000mg, patients weighing 75kg and infused over 10 minutes followed by maintenance dose of 600mg three times per day (TDS) commencing 8 hours following the loading dose.

- **Valproate should be avoided in people of childbearing potential (up to 55 years) who are potentially pregnant unless alternatives are ineffective**. Consult the MHRA guidance before administering this group of patients. Use with caution in patients with liver disease, check LFTs and serum ammonia in 24 hours.

Table 6: Sodium Valproate Loading Dose

Weight (kg)	Dose
20 – 24kg	800mg
25 – 29kg	1000mg
30 – 34kg	1200mg
35 – 39kg	1400mg
40 – 44kg	1600mg
45 - 49kg	1800mg
50 – 54kg	2000mg
55 – 59kg	2200mg
60 – 64kg	2400mg
65 – 69kg	2600mg
70 – 74kg	2800mg
75kg and over	300mg

Dilute with sodium chloride 0.9% or glucose 5%. There is no recommended concentration for dilution but a minimum volume of 50mL is advised.

The following stages must occur with anesthetic input, airway support and early arrangements for transfer to ITU.

e) Third Line treatment 30 minutes onwards (Refractory Status)

General anaesthesia- induction and maintenance
The properties of each drug should be considered when selecting induction and maintenance agents (these may be different).

Drug	Induction	Maintenance
Propofol	1-2mg/kg bolus	Up to 4mg/kg/hour titrated to effect, continuous infusion for min 24 hours
Thiopental sodium	3-5mg/kg bolus	3-5mg/kg/hour titrated to effect, continuous infusion for min24 hours
Ketamine	3mg/kg bolus	1mg/kg/hour titrated to effect maximum10mg/kg/hour, continuous infusion for min 24 hours
Midazolam	0.2mg/kg bolus	0.05mg/kg/hour titrated to effect, continuous infusion for min 24 hours.

- General anesthesia maintenance is typically with propofol and/or midazolam in the first instance
- If the first maintenance agent is unsuccessful at terminating seizures a second anesthetic agent should be used
- As a minimum, intermittent **EEG** to be performed aiming for suppression of electrographic epileptic activity
- Maintenance doses of **antiepileptic drugs** (commence 10-14 hours after loading dose to allow regular ongoing dosing)

Caution:
Midazolam exhibits multiple drug interactions which must be considered please refer British National Formulary (BNF)
BPWE who receive propofol should be monitored for PRIS propofol infusion syndrome metabolic acidosis, rhabdomyolysis, renal failure, hypertriglyceridaemia, refractory bradycardia and cardiac failure.

Ongoing management in critical care:

- At point of admission to ITU all patients should have an up-to-date ECG
- Ensure regular antiepileptic drugs are prescribed alongside any additional treatment as part of this pathway
- It is important to document why treatment decisions have been made and ensure detailed communication with next of kin regarding treatment plans and prognosis

f) Fourth line treatment 24+ hours (Super -Refractory Status)

- Seizures that continue or recur 24 hours after third line treatment are considered Super Refractory Status Epilepticus. Treatment at this stage should be guided by specialists

using an MDT approach. There is no high quality randomised controlled trial evidence to guide treatment decisions.

- Look for an **underlying cause and treat** (e.g., infectious/autoimmune encephalitis, systemic infection, electrolyte disturbance, toxicity)
- **Neurosurgical intervention** (e.g., lesional resection)
- If no underlying cause is identified in the first presentation of seizures, **immunotherapy** can be considered: high dose steroids, IVIG and /or therapeutic plasmapheresis
- **Alternative treatments** at this stage include therapeutic hypothermia, ketogenic diet, and magnesium infusion. Treatments considered to be ineffective should be discontinued to minimise the risk of adverse effects.

After an episode of convulsive status epilepticus, the neurologist and BPWE must agree an emergency management plan with the person if they do not already have one and there is concern that status epilepticus may recur.

6.2.2 Repeated seizures or cluster seizures

Manage repeated or cluster seizures (typically 3 or more self-terminating seizures in 24 hours) as a medical emergency.

a) **If a person has repeated or cluster seizures:**

- follow their individualised emergency management plan, if this is immediately available or
- consider giving a benzodiazepine, such as clobazam or midazolam, immediately if they do not have an individualised emergency management plan immediately available.

b) Seek expert guidance if the person has further episodes of repeated or cluster seizures

c) Agree an individualised emergency management plan with the person after repeated or cluster seizures if they do not have one already and there is concern that repeated or cluster seizures may recur

6.2.3 Prolonged seizures

For convulsive seizures that continue for 5 minutes or more, follow the recommendations in section 6.2 on status epilepticus.

Manage prolonged convulsive seizures (any convulsive seizure that continues for more than 2 minutes longer than a person's usual seizure) as a medical emergency.

6.3 Co dependencies with other services

There is a higher prevalence of mental health difficulties, learning disabilities, neurodevelopmental comorbidities (for example, attention deficit hyperactivity disorder and autism spectrum disorder) and dementia, and a higher risk of suicide in people with epilepsy compared with the general population (NICE 2022).

The following comorbidities and associated safeguarding risks are increased in BPWE in pregnancy should be integrated in to maternity epilepsy guidelines and pathways including:

6.3.1 Mental health care

BPWE with epilepsy are at an increased likelihood of developing or having Mental Health Issues, two times more likely to suffer depression and three times more likely to suffer anxiety than in the general population (NICE NG217,2022).

BPWE should have direct access to local mental health services and have their mental health needs assessed in each trimester and following the birth of the baby.

Further advice on the coordination of care for BPWE with mental health problems and learning disabilities can be found via NICE guideline (NG54, 2016): https://www.nice.org.uk/guidance/ng54

6.3.2 Learning difficulties and disabilities

BPWE can have developmental difficulties and cognitive impairment and may need additional support from a wider multidisciplinary team. Maternity providers must develop robust communication pathways across the relevant services involved to agree and plan care across services.

Further advice on the coordination of care for BPWE with mental health problems and learning disabilities can be found via NICE guideline (NG54, 2016): https://www.nice.org.uk/guidance/ng54

Facilitate individualised joint epilepsy specialist nurse- midwife-led sessions when providing preparation for parenthood education inclusive of how to keep well and safe following the birth of the baby when providing maternity and epilepsy care to young people with epilepsy. The information should be repeated at different time slots to establish the young person understands and should also be available across different platforms and available in different languages.

Maternity care for BPWE and learning disabilities during pregnancy should be undertaken in an Enhanced Continuity of Care model.

6.3.3 Care for young persons with epilepsy

During transition of young people with epilepsy to adult services, including maternity services, the paediatric and adult multidisciplinary teams should jointly review the young person's diagnosis and management plan, taking a young person-centred approach that involves the young person, and their family or carers as appropriate, in planning and decisions about their maternity care (NICE 2022).

Ensure that information about the young person's management plan and support for transition to adult services is discussed with the young person with epilepsy and shared in an accessible format that meets their needs and uses language they understand. Repeat this information at different time points to establish that the young person understands their care plan and the support that will be provided.

Facilitate individualised joint epilepsy specialist nurse- midwife-led sessions when providing preparation for parenthood education inclusive of how to keep well and safe following the birth of the baby when providing maternity and epilepsy care to young people with epilepsy. The information should be repeated at different time slots to establish the young person understands and should also be available across different platforms and available in different languages.

Maternity care for young people with epilepsy during pregnancy should be undertaken in an Enhanced Continuity of Care model.

6.4 Additional Information and epilepsy support agencies

Additional information, support and advice for BPWE and health professionals can be accessed at the following organisations:

Epilepsy Action

Epilepsy action have an extensive library of professional and patient information to access Epilepsy and maternity - Epilepsy Action and includes:

- Professional information and educational resources
- Professional online training programmes
- First Aid for Seizure First aid - Epilepsy Action
- Latest drug watch information
- Patient, family, and carer information
- Helpline

Young Epilepsy

Work with children and young people to ensure their voices and rights are protected. They also provide service user and professional advice and support and can be accessed via their website: Support for you | Young Epilepsy

Sudden Unexplained Death from Epilepsy (SUDEP)

- Aspires to stop preventable deaths from epilepsy@ Home | SUDEP Action
- Offers Bereavement Support to families who have lost a family member to epilepsy
- Provides epilepsy safety information for BPWE, their families and health professionals
- Designed a digital tool for reducing risk and can be accessed via their website at EpSMon app - SUDEP Action

7 References and links

Care Quality Commission GP myth buster 8: Gillick competency and Fraser guidelines 2022: https://www.cqc.org.uk/guidance-providers/gps/gp-mythbusters/gp-mythbuster-8-gillick-competency-fraser-guidelines

GOV.UK 2024 Antiepileptic drugs in pregnancy: update advice following comprehensive safety review: https://www.gov.uk/drug-safety-update/antiepileptic-drugs-in-pregnancy-updated-advice-following-comprehensive-safety-review

Knight M, Bunch K, Felker A, Patel R, Kotnis R, Kenyon S, Kurinczuk JJ (Eds.) on behalf of MBRRACE-UK. Saving Lives, Improving Mothers' Care Core Report - Lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2019-21. Oxford: National Perinatal Epidemiology Unit, University of Oxford 2023.

NICE guideline NG217 Epilepsies in children, young people and adults (2022) Epilepsies in children, young people and adults (nice.org.uk)

NICE Quality Standard QS211 (2023) Epilepsies in children, young people and adults (nice.org.uk)

Royal College of Obstetricians and Gynecologists (RCOG, Green-top Guideline No.68 2016) Epilepsy in Pregnancy (Green-top Guideline No. 68) | RCOG,

Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries (MBRRACE, 2023) Saving Lives, Improving Mothers' Care (2023) Saving Lives, Improving Mothers' Care 2023 - Lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2019-21 | MBRRACE-UK | NPEU (ox.ac.uk)

NICE guideline 121Intrapartum care for women with existing medical conditions or complications (2019) Intrapartum care for women with existing medical conditions or obstetric complications and their babies (nice.org.uk)

NHS England North West Maternal Medicine Network Maternal Medicine Centres | NW Maternal Medicine Network

Vegrim HM, Dreier JW, Alvestad S, Gilhus NE, Gissler M,Igland J, et al. Cancer risk in children of mothers with epilepsy and high-dose folic acid use during pregnancy. JAMA Neurol. 2022;79(11):1130–8.

Wrede, RV; Witt,J.A; Auvin,S; Devlin, A. Lagae; L. Marson, A.; Meador, K.J., O'Brien, T.J. Park, J.; Surges, R.; Trinka, E. ; Wiebe, S. Helmstaedter, C. (2023) Unjustified allegation on cancer risks in children of mothers with epilepsy taking high-dose folic acid during pregnancy—No proof of a causal relationship. *Epilepsia* 2023;64:2239–2243.

Wigglesworth , S., Neligan, A., Dickson, J.M., Pullen, A., Ye;;and, E., Anjuman, T., Reuber,M. (2023) The incidence and prevalence of epilepsy in the United Kingdom 2013 – 2018: A retrospective cohort study of UK primary care data Seizure European Journal of Epilepsy 105 (2023) 37-42

8 Monitoring / Audit

This guideline has been peer reviewed by the North West:

- Regional Guideline Group
- Maternal Medicine Network Team including MMN leads in obstetrics and neurology,
- All maternity providers
- Clinical leads to epilepsy care.

The guideline will be reviewed by the maternal medicine network team in 12 months from the guideline ratification. This will then be returned to the regional guideline group to review and approve any

updates.

9 Details of attachments (e.g. list of appendices)

Appendix 1: List of North West Maternity Providers

Appendix 2: Specialist advice centres for contraceptive advice within each LMNS

Appendix 3: Cheshire and Mersey LMNS electronic notification form/ link to access C&M MMC

Appendix 4: Greater Manchester and Eastern Cheshire LMNS electronic notification form/ link to access GMEC MMC

Appendix 5: Lancashire and South Cumbria LMNS electronic notification form /link to access LSC MMC

Appendix 6: National UK Epilepsy and Pregnancy Register information sheet

Appendix 7: North West MMC referral summary template

Appendix 8: North West Maternal Network MDT summary template

Appendix 9: North West Maternal Network Birth Plan summary template

Appendix 10: Potential teratogenic impact of taking ASMs

Appendix 11: Status Epilepticus Algorithm

Appendix 1 North West Matertiy Providers

LMNS	Cheshire and Mersey	Greater Manchester and Eastern Cheshire	Lancashire and South Cumbria
MMC	**Liverpool Women's Hospital NHS FT** *works with Liverpool University NHS FT to provide joint cardiac and obstetric care*	**Manchester University NHS FT** St Mary's Hospital Oxford Road Campus	**Royal Preston Hospital** *In LSC Obstetric Cardiology referrals for review/advice at the MMC will be led by Blackpool Teaching Hospital*
Provider Trust	Countess of Chester Hospital NHS FT Mid-Cheshire Hospital NHS FT (Leighton) Mersey and West Lancashire Teaching Hospitals NHS Trust St Helens and Knowsley Hospital Mersey and West Lancashire Teaching Hospitals NHS Trust and Southport and Ormskirk Warrington and Halton Teaching Hospitals NHS FT Wirral University Teaching Hospital NHS FT	Bolton NHS FT East Cheshire NHS Trust (Macclesfield) MFT North Manchester Hospital MFT Wythenshawe Hospital Northern Care Alliance NHS FT Stockport NHS FT Tameside and Glossop NHS FT Wigan Wrightington and Leigh NHS FT	East Lancashire Hospital NHS University Hospital Morecombe Bay NHS FT (Furness) University Hospital Morecombe Bay NHS FT (Lancaster) Blackpool Teaching Hospital NHS FT

Appendix 2 : Specialist Advice centres for contraception

Greater Manchester and Eastern Cheshire	Sexual and Reproductive Health team at The Hathersage Centre on telephone no. 0161 701 1555 Alternatively, patients can identify their nearest clinic using the following link https://mft.nhs.uk/mri/services/northern-sexual-health-service/
Cheshire and Merseyside	Specialist contraceptive advice can be obtained through Axess sexual health clinic (0300 323 1300). Patients with a Liverpool GP can also self-refer to the PCN hub (clpcn.co.uk). Alternatively, patients can identify their nearest clinic using the following link https://www.axess.clinic/find-service/
Lancashire and South Cumbria	Patients can identify their nearest clinic using the following link https://lancashiresexualhealth.nhs.uk/find-nearest-centre/

Appendix 3 : Cheshire and Mersey Notification Process to Liverpool Women's Hospital MMC

All referrals to a C&M MMC can be made through the following referral system. This can lead to the following:

1) Response specifying opinion/view of MMC team
2) Discussion at MMC MDT with written response to the referring provider
3) Review of Specialist clinic
4) Transfer of care

C&M MMC at Liverpool Women's Hospital	
Maternal Medicine MDT meeting	Wednesday 12:00-13:00 via Teams
MDT/MMC team	Maternal.medicine@lwh.nhs.uk
Referral form	https://forms.office.com/pages/
EMERGENCY ADVICE	On call Consultant Obstetrician: switchboard 0151 708 9988 ask for Obstetric consultant or call Bleep 100

Appendix 4 Greater Manchester and Eastern Cheshire Notification process to St Marys Hospital MMC

All referrals to a GMEC MMC can be made through a referral system. This can lead to the following:

1) Response specifying opinion/view of MMC team
2) Discussion at MMC MDT with written response to the referring provider
3) Review in Specialist clinic
4) Transfer of care

GMEC MMC at St Mary's Hospital	
Maternal Medicine MDT meeting	Thursday 13:00-14:00 via Teams
MDT/MMC team	Email: maternal.medicine@mft.nhs.uk
Referral form	https://forms.office.com/e/NKekE9Fu31
EMERGENCY ADVICE	On call Consultant Obstetrician: Switchboard: 0161 2761234 ask for Obstetric Consultant on call Bleep 6000 or via Vocera

Appendix 5 Lancashire and South Cumbria Notification process to Preston Hospital and MMC

All referrals to L&SC MMC can be made through the following referral system. This can lead to the following:

1) Written response specifying opinion/view of MMC team
2) Discussion at MMC MDT with written response to the referring provider
3) Review in Specialist clinic
4) Transfer of care

L&SC MMC at Lancashire Teaching Hospital (Preston)	
Maternal Medicine MDT meeting	Wednesday 14:00-15:00 via Teams
MDT/MMC team	Email: maternal.medicine@lthtr.nhs.uk
Referral process	For patients on Badgernet use maternal medicine referral form in each patients notes For patients not on Badgernet email: maternal.medicine@lthtr.nhs.uk
EMERGENCY ADVICE	On call Consultant Obstetrician: Switchboard: 017727 16565 Bleep 4371

Appendix 6: National Uk Epilepsy and Pregnancy Register and EpSMon SUDEP information sheet

Website: Home | UK Epilepsy and Pregnancy Register **Freephone: 0800 389 1248**

UK epilepsy & pregnancy REGISTER

WHO WE ARE

We are a group of doctors, nurses, psychologists, researchers and women with epilepsy who are interested to know how to make pregnancy as safe as possible for women with epilepsy and their babies.

WHAT DO WE DO

We recruit women with epilepsy who are pregnant to find out about their health and then later, the health and development of their child.

WHAT IS THE PURPOSE OF THIS RESEARCH?

To date we have enrolled over 11,000 women and their babies, finding out about the babies at birth. However, we are now running this study to test whether it is possible for us to follow up women and their babies for longer, to learn about the development of the children through to 2 years of age.

WHO IS ABLE TO TAKE PART?

You can take part if you have a diagnosis of epilepsy and are currently pregnant. You can be taking medications or not taking medication for your seizures. Participation in this study is completely voluntary and choosing not to take part will not affect you or your medical care in any way. You can also choose to withdraw your participation at any time, without giving a reason, and your care will continue as usual.

Around 2,500 women with epilepsy will have a baby each year in the UK. If you are one of these women, read on to find out how you can help. **Importantly, you do not need to change your medicines to take part.**

You can **join the register** using the QR code or see page 4 of this information sheet.

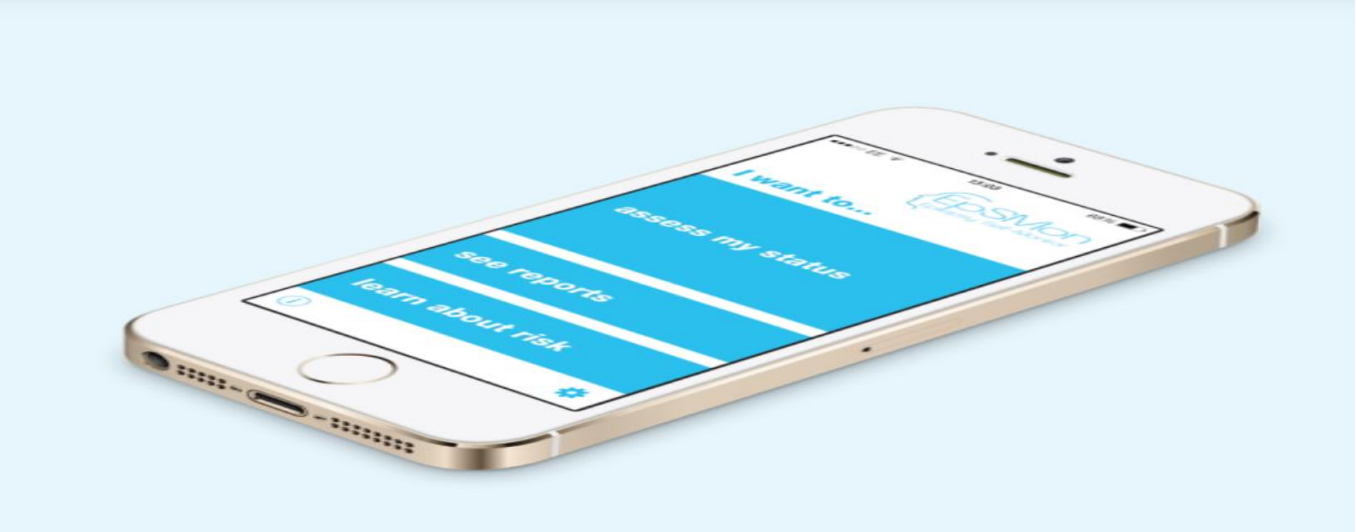
UK Epilepsy and Pregnancy Register 1
Information Sheet Version 2 25/04/2023 IRAS 298187

EpSMon App SUDEP Information sheet

SUDEP Action

General enquiries: 01235 772 850

[EpSMon app - SUDEP Action]



Download on the App Store

GET IT ON Google play

A digital Tool for reducing risk

Living with epilepsy is not easy but EpSMon can help you understand your own personal epilepsy risks so you can make informed decisions about when to book GP/clinician appointments and review your care plan.

Seizures are different for everyone. This easy-to-use app will help you track things, providing key information for you and your GP/clinician. Self-monitoring will not eliminate risk but will reduce them.

Research has shown there are key risk factors that can affect your seizure control and safety – and that these change over time. EpSMon app provides key information for you and your clinician- helping you to better understand your condition and when you need to take positive action to live more safely.

Appendix 7: Patient Summary Template at referral

Patient%20Summary%20Template%20for

Appendix 7 Patient Summary Referral Template

Patient Summary Referral Template		
Referrer name		
Job Role		
Referring organisation		
Date		
Reason for referral	Notification of maternal medicine condition	**Yes / No**
	Referral for MMN MDT Review	**Yes / No**

Patient Details	**Name**	
	Address	
	NHS Number	
	DOB	
	Contact number:	
	Patient aware of referral?	**Yes / No**
First Language		
Interpreter required	**Yes / No**	
Obstetric History	**Gravida** **Parity**	
	Relevant Obstetric history	
	EDC	**Gestation**

	EDC	Gestation
	BMI	Smoking Yes / No
	Mental health concerns	Yes / No
	Learning difficulties	Yes / No
	Other Maternal Medicine conditions Current medication	Please State
Reason for Referral	Medical condition: Epilepsy	
Under care of: Please circle	GP Epilepsy Specialist Clinician Neurologist	
Name of clinician/neurologist/epilepsy nurse		
Organisation of named epilepsy clinician		
Type of Epilepsy		
Current Anti - Seizure Medication (Name and dose)		
Has the person stopped or changed her ASM?	Yes / No	
Seizure history Type and frequency of seizures	Date of last seizure Duration of seizures Frequency of seizures Is this first their first seizure? Yes / No	
History of nocturnal seizures	Yes / No	
Recent investigation reports	ASM Levels Other recent screening results	
MMN MDT referral reviewed by		
Date referral reviewed		
Plan	Remain under care of local provider	Yes / No
	Shared care with local provider	Yes / No
	Full care provided by MMN team	Yes / No
	To birth at MMC	Yes / No

Appendix 8 MDT Summary template

NW%20MMN%20M
DT%20Summary%20

NORTH WEST MATERNAL MEDICINE NETWORK

MDT Summary

Name	
DOB	
Hospital No	
MDT attendees	
Diagnosis Include: Parity, Condition, Medication	
Investigations	
MDT Discussion	Plan: Actions: Outcome:
Antenatal Plan	
Intrapartum recommendations **(include place of delivery)**	
Postpartum recommendations	
Anaesthetic considerations	
Neonatal considerations	
Outstanding actions/investigations	

Plan in the event of an emergency	
Contact details	Generic MMC e-mail: MMC midwife: MDT co-ordinator:

Appendix 9 Birth Plan Template

Birth%20Plan%20template.docx

Birth Plan

The majority of BPWE will be cared for in their local maternity unit

Patient Name:	
Hospital & NHS Number	
Address	
Date of Birth	
Allergies:	
Condition/Diagnosis Type of epilepsy **Seizure history including date & time of last seizure**	
EDD	
Obstetric History including CS	
Medical/Surgical History	

Planned place and mode of birth **Date of ELCS or date of IOL** **MDT informed of birth preference**		**Yes /No**
Staff Alert: On call Consultant Obstetrician and Labour ward coordinator to be informed on admission for all **Red** and **Amber** patients		Please circle the tick as appropriate: ✓ **Red Cat A**: inform all on call staff immediately on admission, immediate HDU care ✓ **Amber Cat B**: Inform on call team within 4 hours ✓ **Green Cat C**: routine care with attention to care plan
Birthing seizure management plan		
ASM Plan **Named Neurologist/Epilepsy specialist nurse**		
Haemodynamic Goals		
Anaesthetic review and recommendations		**Avoid Pethidine**
LSCS	**Indication**	**If labours spontaneously**
Location	**Location post op**	**Location**

Induction	**Location**	
	Oxytocin regime	
	Considerations/recommendations **Fluids** **Additional Monitoring and frequency** **Thromboprophylaxis plan**	
Vaginal Birth	**Special considerations:** **First Stage** **Second stage** **Third stage** **Drugs to be used with caution**	
Post birth please circle as appropriate and add comments	**ICU**	**Yes / No**
	Stay on labour ward (How long)	**Yes / No**
	Stay in hospital (How long)	**Yes /No**
	Staying with partner	**Yes / No**
	Daily examination by Dr	**Yes / No**
	State investigations before discharge	**Yes / No**
PN Seizure management plan		**Yes / No**

	Epilepsy Specialist review before discharge **Epilepsy Specialist review within 10 days**	**Yes /No**
PN ASM plan		
Additional Medication plan		
PN follow up required	**Yes / No**	
Debrief appointment required	**Yes / No**	
Contact details	**Generic MMC email:** **MMC Midwife** **Community Midwife**	

Appendix 10 Potential teratogenic impact of taking ASM

Teratogenic ASMs are contraindicated in pregnancy

Alert: BPWE must be advised to continue all ASM prescribed until reviewed by an epilepsy specialist prescribing.

Adherence to Medicine and Healthcare Regulatory Authority (MHRA)/NICE Guidelines concerning Valproate:

Valproate is contraindicated in female patients aged under 55 years, unless two specialists independently consider and document that there is no other effective or tolerated treatment and the conditions of Valproate Pregnancy Prevention Programme (PPP) Valproate pregnancy are fulfilled.

https://www.gov.uk/drug-safety-update/valproate-pregnancy-prevention-programme-actions-required-now-from-gps-specialists-and-dispensers

Inform the BPWE not to stop valproate and explain the reasons (e.g. their condition may become worse)

It is the responsibility of all healthcare professionals seeing BPWE who may be prescribed valproate to be aware of the MHRA Guide for Healthcare Professionals and their professional Actions, (MHRA, Dec 2023), to ensure this is within the terms of the Pregnancy Prevention Programme (PPP, PREVENT), and knowledgeable of their responsibilities detailed by MHRA. Completion of a risk acknowledgement form is designed to make sure patients are fully “aware the risks of using valproate during pregnancy and the measures needed to reduce the risks” and “to consult their GP to be referred to a specialist prescriber as soon as they start thinking about becoming pregnant, to make sure they have time to switch to another treatment before they withdraw contraception”(MHRA, Dec, 2023).

Preconception / pre-pregnancy – All woman taking Valproate are required to complete an Annual Risk Acknowledgment form (ARAF), this includes discussing the risks and benefits of continued treatment with valproate and questions about changes to their circumstances such as relationship and family planning. Completing an ARAF is an ideal opportunity to enquire about pregnancy intentions in the next 12 months and beyond, which allows care planning to commence. Healthcare professionals should provide BPWE with the MHRA patient guide and share links to NHS England decision-support-aid-valproate.

Female patients who are pregnant taking Valproate:

Refer the patient to their specialist prescriber and ask for them to be seen urgently (within days).

BPWE who are pregnant should have their treatment switched to another ASM treatment whenever possible.

BPWE who must continue Valproate treatment in pregnancy (i.e., if two specialists independently consider and agree that switching to another treatment is not possible) should be referred to a specialist experienced in prenatal medicine for appropriate monitoring. Actions for Gynaecologists/obstetricians, Midwives and Nurses (MHRA, Dec 2023)

Risk acknowledgement and counselling (MHRA healthcare professional guide)

Provide a copy of the patient information leaflet counselling on methods of contraception and pregnancy planning. BPWE and their partners need to be informed of the possible adverse impact on

long-term neurodevelopment of the newborn following in-utero exposure to valproate

• Provide information about the risks of using valproate during pregnancy.

• When a patient consults for pregnancy, urgently refer the patient to be seen (within days by their specialist prescriber and to a specialist experienced in prenatal medicine for evaluation and counselling regarding the exposed pregnancy All PWE with epilepsy presenting pregnant while taking valproate require urgent epilepsy specialist referral (within days), and their follow-up planned to avoid any PWE left unsupported on discovery of her pregnancy while taking valproate. The risks include potential non-adherence, seizures deteriorating risking status epilepticus and SUDEP.

Patients deprescribed valproate preceding current pregnancy.

BPWE who had been appropriately prescribed valproate and who's seizures have been well controlled, who have withdrawn from valproate for a planned pregnancy are at an increased risk of seizure relapse before conceiving and during pregnancy. Valproate is most effective for managing idiopathic generalised epilepsy and switching to alternate antiseizure medications can result in seizure relapse (refer to NICE guidelines for treating generalised epilepsies NG217, (2022), and SANADII (Standard and New Antiepileptic Drugs) Valproate is superior to lamotrigine and levetiracetam.

An awareness of risks for this group of patients is vital, including knowledge of juvenile myoclonic epilepsy at all stages of preconception, pregnancy and postpartum. For some BPWE postnatal recommencement of valproate is appropriate and the epilepsy specialist prescriber should provide an individual patient treatment plan.

Valproate taken by male partners

Controversial information and studies associated with the cognitive development of babies born from men taking valproate have yet to be explored further.

Topiramate – MHRA New safety measures (June 2024)

https://www.gov.uk/drug-safety-update/topiramate-topamax-introduction-of-new-safety-measures-including-a-pregnancy-prevention-programme

Due to the accumulating data on the teratogenic harms, further restrictions are being introduced with regards to the use of topiramate in BPWE of childbearing potential and in pregnancy.

The use of topiramate is now contraindicated:

In BPWE of childbearing potential unless the conditions of the Pregnancy Prevention Programme are fulfilled (for all indications)

For all new BPWE of childbearing potential prescribers must:

Assess the BPWE potential for pregnancy and discuss the recommendation to join the Pregnancy Prevention Programme

Ensure that a pregnancy has been excluded, by means of a negative pregnancy test, prior to starting treatment with topiramate

Inform BPWE of the potential risks of topiramate use in pregnancy and counsel WWE on treatment options

Discuss the need to use highly effective contraception throughout treatment and for at least four weeks after the last dose of topiramate. https://cks.nice.org.uk/topics/epilepsy/management/women-of-childbearing-age/

Complete the Topiramate Risk Awareness Form with the patient, parent, guardian or person who holds duty of care: https://www.medicines.org.uk/emc/rmm/3083/Document

Provide a copy of the Topiramate Patient Guide to the patient, parent, guardian or person who holds duty of care: https://www.medicines.org.uk/emc/rmm/3081/Document

For existing patients, prescribers must:

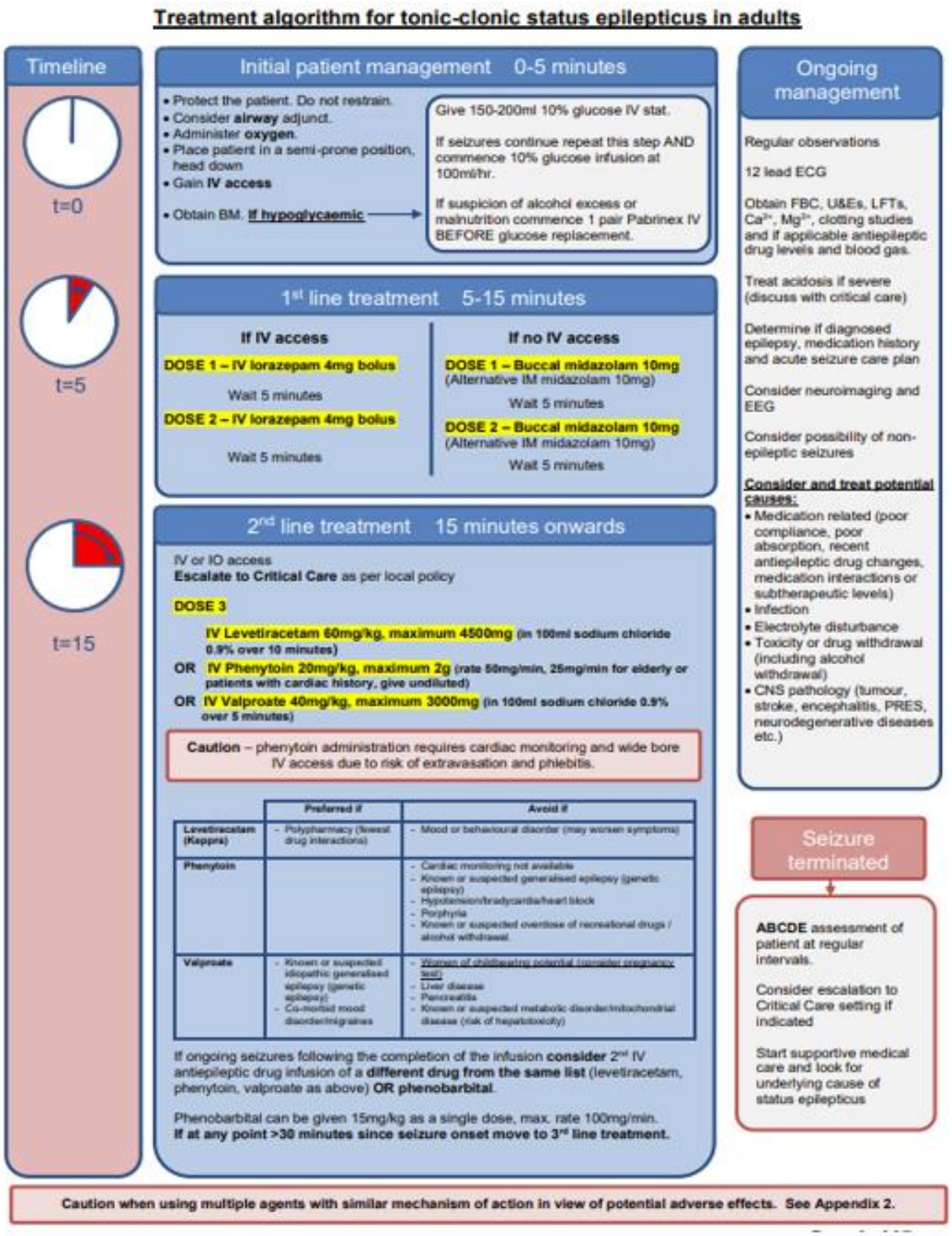
Topiramate must not prescribed to BPWE in pregnancy for epilepsy unless there is no other suitable treatment. Further information can be found on the MHRA website link

Identify all BPWE of childbearing potential on topiramate and invite them in for review

Complete the Topiramate Risk Awareness Form with the patient or parent/guardian/ person holding duty of care and appropriate physician/ at each annual review: https://www.medicines.org.uk/emc/rmm/3083/Document

Provide a copy of the Patient Guide to the patient or parent/guardian/person holding duty of care in pregnancy for prophylaxis of migraine: https://www.medicines.org.uk/emc/rmm/3081/Document

Appendix 11 Status Epilepticus



Treatment algorithm for tonic-clonic status epilepticus in adults (cont.)

t=30

The following stages must occur with anesthetic input, airway support and early arrangements for transfer to ITU.

3rd line treatment 30 minutes onwards (Refractory Status)

General anesthesia – induction and maintenance.

The properties of each drug should be considered when selecting induction and maintenance agents (these may be different).

	Induction	Maintenance
Propofol	1-2mg/kg bolus	up to 4mg/kg/hour titrated to effect, continuous infusion for min. 24 hours
Thiopental sodium	3-5mg/kg bolus	3-5mg/kg/hour titrated to effect, continuous infusion for min. 24 hours
Ketamine	3mg/kg bolus	1mg/kg/hour titrated to effect maximum 10mg/kg/hour, continuous infusion for min. 24 hours
Midazolam	0.2mg/kg bolus	0.05-0.5mg/kg/hour titrated to effect, continuous infusion for min. 24 hours

- General anaesthesia maintenance is typically with propofol and/or midazolam in the first instance.
- If first maintenance agent is unsuccessful at terminating seizures a second anaesthetic agent should be used.
- As a minimum, intermittent **EEG** to be performed aiming for suppression of electrographic epileptic activity.
- Maintenance doses of **antiepileptic drugs** (commence 10-14 hours after loading dose to allow regular ongoing dosing).

24hrs+

4th line treatment 24+ hours (Super-Refractory Status)

Seizures that continue or recur 24 hours after third line treatment are considered Super Refractory Status Epilepticus. Treatment at this stage should be guided by specialists using an MDT approach. There is no high quality randomised controlled trial evidence to guide treatment decisions.

- Look for an **underlying cause and treat** (e.g. infectious/autoimmune encephalitis, systemic infection, electrolyte disturbance, toxicity)
- **Neurosurgical intervention** (e.g. lesional resection)
- If no underlying cause identified in a first presentation of seizures, **immunotherapy** can be considered: high dose steroids, IVIG and /or therapeutic plasmapheresis
- **Alternative treatments** at this stage include therapeutic hypothermia, ketogenic diet and magnesium infusion.

Treatments considered to be ineffective should be discontinued to minimise risk of adverse effects.

Ongoing management in Critical Care Unit

At point of admission to ITU all patients should have an up-to-date ECG.

Ensure regular antiepileptic drugs are prescribed alongside any additional treatment as part of this pathway.

It is important to document why treatment decisions have been made and ensure detailed communication with next of kin regarding treatment plan and prognosis.

Caution

midazolam exhibits multiple drug interactions which should be considered: See appendix 2

Patients on **propofol** should be monitored for PRIS - propofol infusion syndrome (metabolic acidosis, rhabdomyolysis, renal failure, hypertriglyceridaemia, refractory bradycardia and cardiac failure)

Interpretation of processed EEG monitoring such as bispectral index (BIS) may become unreliable when using **ketamine** infusion.

Caution when using multiple agents with similar mechanism of action in view of potential adverse effects. See Appendix 2.

10 Details of other relevant or associated documents (including links)

North West Service Specification: Caring for people with epilepsy during pregnancy and including preconception care (in draft format waiting for regional sign off)

Clinical%20panel%20draft%20service%20s

11 Supporting references & national guidance

Royal College of Obstetricians and Gynaecologists (RCOG, Green-top Guideline No.68, 2016) Epilepsy in Pregnancy (Green-top Guideline No. 68) | RCOG,
National Institute of Clinical Excellence (NICE, Guidance 217, 2022) Epilepsies in children, young people and adults (nice.org.uk) ,
Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries (MBRRACE, 2023) Saving Lives, Improving Mothers' Care 2023 - Lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2019-21 | MBRRACE-UK | NPEU (ox.ac.uk),
MHRA "safety advice on antiepileptic drugs in pregnancy" (2021). https://www.gov.uk/drug-safety-update/antiepileptic-drugs-in-pregnancy-updated-advice-following-comprehensive-safety-review

12 Definitions / glossary

ASM Anti seizures medication: medication used to treat epilepsy and other seizure disorders

BMI Body Mass Index

Clinician: A clinician refers to a physician with expertise in assessing first seizures and diagnosing epilepsy (usually a consultant neurologist), who is responsible for providing safe care in line with current best practice and for effectively communicating with the MDT when updates in care have been made or are required.

Epilepsy A neurological condition where sudden bursts of electrical activity in the brain cause seizures. The type of epilepsy is determined by the type of seizure: generalised epilepsy includes subtitles of myoclonic seizures, tonic clonic seizures and atonic seizures; focal epilepsy original in a specific area of the brain and further classified as temporal lobe or frontal lobe epilepsy.

Cluster seizures is a group of seizures that occur more than often within a certain time span

Focal seizure starts in one hemisphere of the brain. During a focal seizure the person is fully aware of their surroundings even if they can-not move or respond

Myoclonic seizures present with sharp uncontrollable muscle movements

Tonic Clonic Seizure is a generalised seizure that produces bilateral convulsive tonic (stiffening) and clonic (jerking) muscle contractions

SE Status Epilepticus a single seizure lasting more than 5 minutes or 2 or more seizures within 5 minutes without the person returning to normal in between

IV Intravenous

LMNS Local Maternity and Neonatal System

MDT Multiple Disciplinary Team

North West MMN NW Maternal Medicine Network

NW MMC Maternal Medicine Centres are hosted in the North West maternity providers of Liverpool Women's Hospital in Cheshire and Mersey LMNS, St Marys Hospital, Oxford Road campus, Manchester in Greater Manchester and Eastern Cheshire LMNS and Preston Hospital in Lancashire and South Cumbria LMNS

Refractory Status Epilepticus is defined as a life-threatening neurological emergency when status epilepticus continues or reoccurs within 24 hours despite anaesthetic treatment

13 Consultation with Stakeholders

Extensive stakeholder events held with Service Users, Regional Maternity Team MDT clinicians, neurology leads, primary care, epilepsy leads and agencies:

- NW Regional Midwifery Team
- All NW maternity providers including Directors of Midwifery, Maternal Medicine Teams including obstetric, epilepsy and neurological leads and clinical epilepsy teams.
- NW MNVP Leads
- Epilepsy Action
- Young Epilepsy
- Th Walton Centre
- North West CYP transformational care and epilepsy leads.

14 Equality Impact Assessment

Section 1: Equality Impact Assessment (EIA) Form

The EIA process allows the group to identify where a policy or service may have a negative impact on an individual or particular group of people.

Information Category	Detailed Information
Name of the strategy / policy / proposal / service function to be assessed:	Care for people with epilepsy before (preconception) during pregnancy and postpartum care
Directorate and service area:	North West Regional Guideline
Is this a new or existing Policy?	New Guideline
Name of individual completing EIA (Should be completed by an individual with a good understanding of the Service/Policy):	Catherine Owens Midwifery and Epilepsy Coordinator, Epilepsy Action
Contact details:	*cowens@epilepsy.org.uk*

Information Category	Detailed Information
1. Policy Aim - Who is the Policy aimed at? (The Policy is the Strategy, Policy, Proposal or Service Change to be assessed)	*This is a North West Guideline aimed at all health care providers who provide care to women/BPWE before the birth of their baby, during pregnancy and in the postnatal period.* *The guideline also aligns itself to the wider NHS Maternity agenda and other maternal medicine guidelines.*
2. Policy Objectives	• *To align epilepsy care across the North West region and ensure care is tailored to BPWE, health and social care needs.* • *Reduce Health inequalities.* • *Strengthen local expertise.* • *Improves clinical outcomes and reduces risk.* • *Provides a positive lived experience for BPWE.* • *Recommend for national roll out of policy*
3. Policy Intended Outcomes	*Embed the policy across the North West* *Improve data reporting for BPWE.* *Improve clinical outcomes.* *Improve service user experiences.*
4. How will you measure each outcome?	*Undertake a clinical audit of epilepsy care across the North West*
5. Who is intended to benefit from the policy?	*People with epilepsy accessing maternity services within their local maternity provider or at the regional maternal medicine center*

Information Category	Detailed Information
6a. Who did you consult with? (Please select Yes or No for each category)	• Workforce: *Yes* • Patients/ visitors: *Yes* • Local groups/ system partners: *Yes* • External organisations: *Yes* • Other: *Yes*
6b. Please list the individuals/groups who have been consulted about this policy.	NHS E Regional Midwifery Team All North West Maternity Providers inclusive of midwifery, obstetric, epilepsy specialist teams at provider site The Walton Centre: regional neurology centre of excellence Epilepsy Leads Paediatric Neurologists Transitional Care nurses across the North West North West and National Maternity and Neonatal Voice Partnership Leads Northwest and national service users including young persons Epilepsy Action Young Epilepsy North West Transitional care and epilepsy leads NHS E Digital and North West Business Intelligence Managers North West Primary Care teams EpiSafe National Study team Please record specific names of individuals/ groups:
6c. What was the outcome of the consultation?	*Building collaborative partnerships to co-produce this guideline. The guidelines are also aligned to the work being undertaken by the North West Maternal Medicine Network*
6d. Have you used any of the following to assist with your assessment?	**National or local statistics, audits, activity reports, process maps, complaints, staff, or patient surveys** NICE guideline NG217 Epilepsies in children, young people and adults (2022) Epilepsies in children, young people and adults (nice.org.uk) NICE Quality Standard QS211 (2023) Epilepsies in children, young people and adults (nice.org.uk) Royal College of Obstetricians and Gynaecologists (RCOG, Green-top Guideline No.68 2016) Epilepsy in Pregnancy (Green-top Guideline No. 68) | RCOG NICE guideline 121Intrapartum care for women with existing medical conditions or complications (2019) Intrapartum care for women with existing medical conditions or obstetric complications and their babies (nice.org.uk)

7. The Impact
Following consultation with key groups, has a negative impact been identified for any protected characteristic? Please note that a rationale is required for each one.

Where a negative impact is identified without rationale, the key groups will need to be consulted again.

Protected Characteristic	(Yes or No)	Rationale
Age	*No*	*Any person of childbearing age*
Sex (male or female)	*Yes*	*Inclusive language Person with Epilepsy*
Gender reassignment (Transgender, non-binary, gender fluid etc.)	*Yes*	
Race	*Yes*	
Disability (e.g. physical or cognitive impairment, mental health, long term conditions etc.)	*Yes*	
Religion or belief	*No*	*Not references /relevant to policy content*
Marriage and civil partnership	*Yes*	
Pregnancy and maternity	*Yes*	
Sexual orientation (e.g. gay, straight, bisexual, lesbian etc.)	*No*	

A robust rationale must be in place for all protected characteristics. If a negative impact has been identified, please complete section 2. If no negative impact has been identified and if this is not a major service change, you can end the assessment here.

I am confident that section 2 of this EIA does not need completing as there are no highlighted risks of negative impact occurring because of this policy.

Name of person confirming result of initial impact assessment: