





# **Greater Manchester and Eastern Cheshire SCN**

# **Epilepsy in Pregnancy Guideline**

FINAL V2 April 2022





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## **Document Control**

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Ownership

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#### 1. Introduction

Epilepsy is one of the commonest neurological conditions in pregnancy affecting 1 in 200 (0.5 -1%) women. Women with Epilepsy (WWE) are at a ten fold increased risk of mortality in pregnancy compared to those without the condition. In the recent MBRRACE-UK report (2016-18) 22 maternal deaths were attributed to epilepsy, 18 of whom died from Sudden Unexpected Death in Epilepsy (SUDEP), a figure which has more than doubled between 2013-15 and 2016-18.

WWE, their families and healthcare professionals should be aware of the different types of epilepsy and their presentations (see appendix 1). Classification is needed to choose appropriate AED, determine prognosis of pregnancy and to identify and prevent seizure deterioration.

The aim of this guideline is to provide information on how and when to refer pregnant WWE within the GMEC region to ensure good quality maternity care. It also covers the obstetric management of epilepsy as well as highlighting SUDEP.

## 2. Joint obstetric and neurology services across GMEC SCN

The joint obstetric and neurology clinic at St Mary's Hospital, Manchester is jointly run by Dr Bullen (Consultant Obstetrician and Subspecialist in Fetal and Maternal Medicine) and Dr Farhat Mirza (consultant neurologist). The clinic is held in the antenatal department at St Mary's Hospital on the second and fourth Thursday of the month.

To refer to this service please refer to Dr Bullen, Consultant Obstetrician, Saint Mary's Hospital Oxford Road, Manchester M13 9WL or telephone 0161 276 6427.

#### 3. Referral Criteria

WWE taking AEDs who become expectedly/unexpectedly pregnant should be advised to continue their AEDs and be urgently referred to neurologist/ANC/joint maternal-antenatal clinic

Pregnant WWE should be seen within 2 weeks for regular planned antenatal care with a designated obstetrician and epilepsy specialist nurse (where available) for early assessment and to plan antenatal care

Pregnant WWE which is complex\* should be seen within 2 weeks for regular planned antenatal care with a designated obstetrician, neurologist and epilepsy specialist nurse (where available) for early assessment and to plan antenatal care.

\*Complex epilepsy includes women on more than 1 AED, women with poorly controlled epilepsy (1 or more seizures in the last 6 months), women on valproate/lamotrigine or women with deteriorating epilepsy).

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Urgent referral can be made at any time in the pregnancy if women have nocturnal seizures or worsening epilepsy symptoms

WWE who are seizure free for at least 10 years and unmedicated for at least 5 years can be managed as low risk

If urgent input is required (including out of hours) then escalation to the local oncall neurology or medical team is advised. Further support can be obtained via the neurology team at Salford.

(see figure 1 for referral pathway)

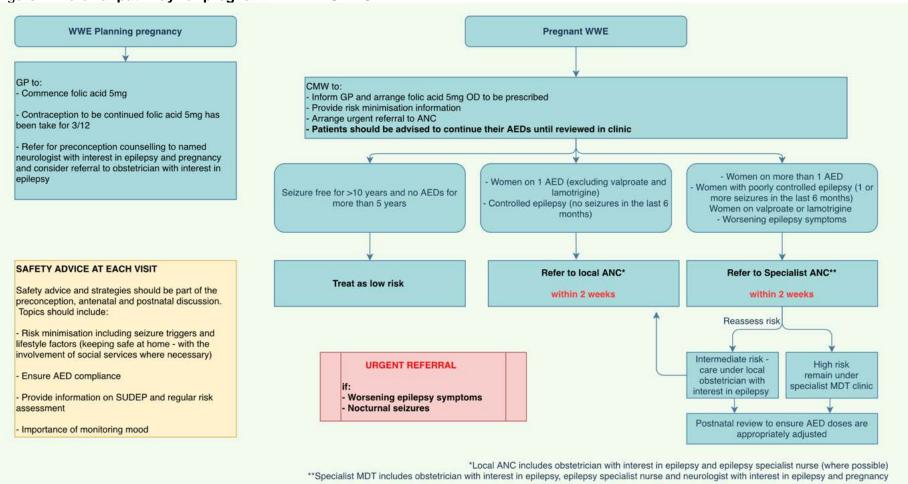
## 4. Pre-pregnancy counselling and support

The need for effective pre-conception counselling is highlighted in the recent MBRRACE report. WWE considering pregnancy should be referred for prenatal counselling either in an obstetric medicine clinic or to their neurologist. The ultimate aim is to optimise treatment so WWE remain seizure free from preconception to postnatal on the lowest effective dose avoiding polypharmacy. Women who are not currently pursuing pregnancy but may do so in the future should be appropriately counselled about the teratogenicity effects of AEDs.

Discussion points for preconception counselling for WWE are outline in table 1. All information should be summarised in a letter to the woman and team of professionals who care for her which should include instructions if she were to become pregnant.

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Figure 1: Referral pathway for pregnant WWE in GMEC



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## 5. Pregnancy care management plan

#### 5.1 Antenatal Care

It is suggested that the majority of poor outcomes associated with women with epilepsy could be prevented by identifying WWE as high risk and offering more specialised care. Patients should be referred to the appropriate clinic within 2 weeks as outline in section 3 – referral criteria. Discussions points for ANC in WWE are outlined in table 1.

Table 1 – Discussions points for preconception counselling and attendance at ANC for WWE (adapted from TOG)

for WWE (adapted from TOG)					
DISCUS	SION POINTS AT PRECONCEPTION COUNSELLING AND ANC				
Dainta anasitis t	APPOINTMENTS				
Points specific t					
	eption counselling are indicated via PC				
	I clinic are indicated via ANC				
Reassure	- Most WWE remain seizure free, have straightforward pregnancies				
woman	and healthy babies  - Most women who are seizure free for >12 months are likely to remain				
	West wellen wile are colleged into the FT2 months are likely to formall				
Inform woman	so if they are compliant with medication				
	- Epilepsy alone is not an indication for IOL/LSCS				
The effect of	- 64% seizure free				
pregnancy on	- 17% increased seizure frequency				
epilepsy	- 16% decreased seizure frequency				
	- 1-4% risk of seizure in labour and 24 hours postnatally				
Factors	- Poorly controlled epilepsy prior to pregnancy				
contributing to	- Seizure frequency >1/month				
deterioration	- Polytherapy				
of epilepsy	- Poor compliance				
during	- Pregnancy specific triggers (tiredness, dehydration, pain)				
pregnancy	- Pregnancy can hormonally induce alteration in seizure threshold				
	- ANC: Review seizure triggers at each appointment and discuss				
	methods of risk reduction				
Aims of	- The need to adjust medication to ensure on lowest effective dose and				
treatment	avoidance of polypharmacy should be explained				
	- PC: WWE with poor seizure control should be advised to				
	postpone pregnancy, use effective contraception and be referred				
	to a specialist neurologist				
Explain to	- Benefits of controlling seizures outweigh risks of AED for mother and				
women	baby				
	- Counsel about SUDEP				
	- Importance of risk assessment and risk minimisation should be				
	discussed with women and their family at each contact				
	- Escalation if concerns about low mood due to epilepsy and AEDs				
	increasing the risk of depression				

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#### DISCUSSION POINTS AT PRECONCEPTION COUNSELLING AND ANC **APPOINTMENTS** Points specific to: Preconception counselling are indicated via PC Antenatal clinic are indicated via ANC Explain to ANC: Advise delivery in consultant led unit women ANC: It is usual to increase the AED dose during pregnancy. although routine monitoring is not recommended (can be done if seizures increase/likely to increase) The risk of congenital malformations is increased whether or not the Risks to the developing woman takes AED fetus Risk is dependent on the type, number and dose (see appendix 2) Lamotrigine, levetiracetam and carbamazepine most commonly used Highest risk is with sodium valproate (NTD, facial cleft, hypospadias (10%), learning difficulties and autism spectrum (40%). Valproate is contraindicated in all women of childbearing potential unless the conditions of the valproate pregnancy prevention programme are fulfilled (https://www.gov.uk/guidance/valproate-use-by-women-and-Single seizure unlikely to cause serious complications (risk of hypoxia and injury secondary to fall) but repeated seizures and SE are associated with maternal (33%) and fetal (50%) mortality **SUDEP IUGR** ANC: Epilepsy carries increased risk of SGA therefore monitor fetal growth with serial ultrasound scans Increased risk of epilepsy if first degree relative affected Risk of Consider genetic counselling if one partner has idiopathic generalised developing childhood epilepsy (IGE) and a positive family history of epilepsy epilepsy Risk to child: o 5-20% one first degree relative affected with IGE 25% two first degree relatives affected with IGE 3% if one parent has focal seizures Medication Aim for monotherapy on lowest possible dose Advise to continue AEDs until reviewed in clinic and not to stop abruptly 5mg folic acid should be taken for 3/12 prior to conception (need for effective contraception during this time should be discussed) and during the first trimester If on sodium valproate consider weaning and changing under advice from a neurologist PC: 5mg folic acid should be taken for 3/12 prior to conception (need for effective contraception during this time should be discussed) and during the first trimester ANC: Commence/continue folic acid 5mg during first trimester Advise about the EpSMon app to help monitor their epilepsy, risks and Encourage all women wellbeing between appointments www.sudep.org/epsmonv PC: General preconception advice including smoking cessation, stopping/reducing alcohol intake and optimising BMI if overweight ANC: WWE should be provided with information about the UK Epilepsy and Pregnancy Register and invited to register (www.epilepsyandpregnancy.co.uk)

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#### 5.2 Management during antenatal care

- Commence/continue 5mg folic acid throughout first trimester
- Offer screening as per usual practice. Offer USS for dating and fetal anomaly scan and ensure sonographer is aware of woman's additional risks and of AED medication
- Advise delivery in a consultant led unit due to increased risk of seizures in labour and postpartum
- Organise anaesthetic review at 36 weeks if seizures uncontrolled or change in seizure pattern
- Some countries have a stigma surrounding epilepsy therefore it is important that an interpreter is present when required and discussions are had with cultural understanding
- WWE at reasonable risk of seizures should be accommodated in an environment that allows for continuous observation by a carer, partner or nursing staff when in hospital.
- Review seizure triggers at each appointment
- If admitted WWE should **receive the same brand of AED** and not a generic substitution while in hospital
- There is insufficient evidence to recommend giving vitamin K to WWE to prevent postpartum haemorrhage

#### **Monitoring levels**

- No clear-cut relationship between serum levels of AEDs and seizure control in nonpregnant and pregnant WWE therefore routine monitoring of serum AED levels in pregnancy is not recommended
- Indications for monitoring of AED blood levels are:
  - Increase in seizure activity
  - Detection of non-compliance
  - Suspected toxicity
  - Adjustment of phenytoin or lamotrigine dose
  - Changes to bio-availability/elimination/drug interactions
  - Organ failure or SE

#### 5.3 Planning the birth

- Timing/mode of birth should be guided by each individual case.
- Epilepsy is not an indication for induction of labour or caesarean section
- WWE with significant deterioration of seizures, timing and mode of delivery should be discussed with the MDT
- A care plan should be documented at 36 weeks in women where there are special considerations likely to affect birth/postpartum management. These include:
  - Anaesthetic considerations
  - Reduction of seizure related risk factors
  - Ensuring AED are prescribed in labour (even if alternative routes are required)
  - A plan for medications in the immediate postnatal period

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#### 5.4 Intrapartum care

- WWE should be reassured that the risk of intrapartum seizures is low (3.5%), however, due to this risk women should not be left unattended during labour and 24 hours postpartum
- Delivery in consultant-led unit with IV access on arrival
- Home births are not recommended
- Continuous fetal monitoring is recommended in women at high risk of a seizure in labour, and following an intrapartum seizure
- Seizure triggers should be minimised where possible by:
  - Avoiding dehydration
  - Avoiding stress
  - Avoiding sleep deprivation
  - Providing adequate analgesia TENS, epidural, spinals
    - Pethidine is known to decrease seizure threshold and should be avoided, diamorphine can be used as an alternative.
    - WWE, not on AEDs and seizure free for a significant time can be offered a water birth after discussion with their neurologist
  - Continuing AEDs during labour (use parenteral route if needed)
- In individual cases if labour it thought to be likely to precipitate a major seizure, the care plan may include use of clobazam 10-20mg orally 12 hourly to reduce the risk

#### 5.5 Seizure in labour

Seizures in labour should be treated promptly to reduce the risk of maternal and fetal hypoxia and fetal acidosis.

- Maternal airway and oxygenation maintained
- Left lateral tilt
- Benzodiazepines:
  - If patient has IV access:
    - IV lorazepam 0.1mg/Kg (usually a 4 mg bolus) with the dose repeated every 10–20 minutes (1st line)
    - If not available administer IV diazepam 5–10 mg in slow IV bolus 2mg/min
    - If fails IV phenytoin 10-15mg/kg IV (usual dose is about 1000mg) will need BP and ECG monitoring
  - If no IV access:
    - Midazolam 10mg buccal (10mg in 1ml or 10mg in 2ml) or IM 10mg in 2ml if no contraindications (e.g. anticoagulation)
    - Diazepam 10-20mg PR only if patients on chronic maintenance for refractory epilepsy in the community
- If there is doubt whether a seizure if due to epilepsy or eclampsia, then in addition to the above follow the trust guideline on eclampsia
- If persistent uterine hypertonus then consider tocolytic
- After mother is stabilised continuous CTG should be commenced. If FH does not recover after 5 minutes or seizures are recurrent then expedite delivery
- Differentials of a seizure in pregnancy include eclampsia, drug toxicity, subarachnoid haemorrhage, cerebral sinus thrombosis, cerebral vasculitis, TTP, hypoglycaemia, amniotic fluid embolism, water intoxication/hyponatraemia, vagal episode/faint.

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#### 5.6 Status epilepticus (SE)

Any seizure lasting more than 5 minuets is unusual and represents a high risk of progressing to status epilepticus (defined as 30 minutes of continual seizure activity or a cluster of seizures without recovery).

- Call for help (labour ward co-ordinator, obstetric registrar, anaesthetist, ODP).
   Ensure consultant obstetrician is informed. General medical team can be contacted for advice and support
- Secure the airway
- Obtain IV access if not already done so
- Give lorazepam or diazepam as above
- If seizures are not terminated 20 minutes after onset, despite administration of two doses of benzodiazepines, second line treatment should be administered
- In female patients of child-bearing age, levetiracetam is the first choice
  - IV Levetiracetam 60mg /kg (up to a maximum of 4500mg, patients weighing 75kg and over) infused over 10 minutes (see appendix X), followed by maintenance dose. As levetiracetam is primarily renally cleared, a maintenance dose reduction is required in patients with impaired renal function.

See Northern Care Alliance Status Epilepticus and Prolonged Seizures guideline for management in adults for dosing schedules available at <a href="https://www.srft.nhs.uk/EasysiteWeb/getresource.axd?AssetID=76349&type=full&servicetype=Inline">https://www.srft.nhs.uk/EasysiteWeb/getresource.axd?AssetID=76349&type=full&servicetype=Inline</a>

- Second line treatment Phenytoin is likely to be associated with increased risk of side-effects
- Give usual AED medication if already on treatment.
- Once seizure control is secured commence cardiotocography (CTG) monitoring of the fetus if suspected or known to be above local gestation threshold

#### 5.7 Postnatal care

#### **Mother**

- Higher risk of seizures in immediate postpartum period
- Can be due to triggers (sleep deprivation, stress, altered AEDs) therefore should be well supported to ensure they are minimised
- All women with epilepsy should be monitored for 24 hours after delivery
- Any woman who had a seizure during labour should be observed closely for the next 72 hours
- Postnatal WWE at reasonable risk of seizures should be accommodated in single rooms only when there is provision for continuous observation by a carer, partner or nursing staff
- Continue AN AED dosage for the first 24 hours post delivery then reduce gradually to pre-pregnancy dose over the next 3-4 weeks to avoid toxicity
- As per the recent MBRRACE-UK prompt postnatal review is required to ensure AED doses are appropriately adjusted (see appendix 3)
- Postpartum safety advice and strategies should be part of the antenatal and postnatal discussions. It should cover for example avoiding co-sleeping, 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 and not bathing baby alone
- Ensure the same brand of AED is provided at discharge

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#### **Breastfeeding**

WWE who are taking AEDs should be encouraged to breastfeed as concentration
of AEDs in breastmilk is minimal (see appendix 2). Prescribers should review
individual drug advice in the BNF.

#### **Baby**

- All babies born to WWE taking enzyme-inducing AEDs should be offered 1 mg of intramuscular vitamin K to prevent haemorrhagic disease of the newborn
- Babies of WWE on phenobarbitone often experience withdrawal and should be monitored for fits

### 6. SUDEP

SUDEP is defined 'sudden, unexpected, witnessed or unwitnessed, non traumatic and nondrowning death in patients with epilepsy with or without evidence for a seizure and excluding documented status epilepticus, in which postmortem examination does not reveal a toxicologic or anatomic cause for death'.

The recent MBRRACE-UK report showed a that the number of women who died from SUDEP more than doubled between 2013-15 and 2016-18. The majority had clear risk factors for SUDEP, however, had no pre-pregnancy counselling, specialist review in pregnancy and little documented evidence that SUDEP in pregnancy was discussed or risk assessment and minimisation strategies put in place.

SUDEP is more common in pregnancy and occurs more frequently in chronic epileptics with poorly controlled seizures. WWE should be informed that the introduction of a few safety precautions may significantly reduce the risk of accidents. This includes minimising time spent alone, AED compliance, first aid training for family remembers, avoiding sleeping alone and inpatient nursing should be in an environment in which continuous care from a partner or nursing staff can take place. Individuals with unwitnessed seizures are at high risk of SUDEP, with nocturnal seizures being an independent risk factor.

The need for guidance on SUDEP risk assessment and minimisation was highlighted in the recent MBRRACE report. SUDEP Action have produced tools which can be used to minimise risk including an app to help monitor their epilepsy, risks and wellbeing between appointments (EpSMon app information available at <a href="www.sudep.org/epsmonv">www.sudep.org/epsmonv</a>) and the SUDEP seizure safety checklist tool. It is a very useful tool which advise trust request for use. Is available from <a href="https://sudep.org/checklist">https://sudep.org/checklist</a>. Table 2 highlights risk factors that can be discussed to assess risk and highlights areas where risk can be reduced, however, it is not a replacement for the original checklist.

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#### 6.1 What are the risk factors?

The severity of someone's epilepsy is the most reliable risk factor. Generalised tonic-clonic seizures make a person more likely to experience SUDEP and the risk increases with the number of convulsive seizures per year. It should be noted, however, that there are deaths every year in people who suffer infrequent seizures too.

Other risk factors include:

- Nocturnal seizures
- Young adult age
- Poor compliance
- Earlier age of epilepsy onset (before 16 years of age)
- Longer duration of epilepsy
- Symptomatic epilepsy

#### 6.2 Can SUDEP be prevented?

Recommendations to reduce the risk of SUDEP involve optimization of seizure control and being aware of the potential consequence of nocturnal seizures.

- Aim for prompt referral of people with uncontrolled seizures to a specialist epilepsy team
- Ensure/encourage adherence with AEDs
- Talk to patients and their family members about SUDEP and ways of reducing risk
- There is some evidence that nocturnal supervision in the form of room sharing or monitoring devices may reduce the risk of SUDEP, although further research is required to support this

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

Table 2: SUDEP risk discussion tool – (adapted from SUDEP Action and MBRRACE)				
Risk Factor	Risk Minimisation			
Seizure related factors				
In the last 12 months:  - Active seizures  - Injury  - Generalised tonic-clinic seizures (GTCS)  - Status epilepticus (SE) and 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 requiring urgent referral)  Actions:  - Provide education about SUDEP  - EpSMon app to help track seizure activity			
Treatment factors				
<ul> <li>Poor compliance with medication and services</li> <li>Medication change</li> <li>Ineffective treatment</li> </ul>	Actions: - Review control - Provide education around importance of compliance and engaging with services for regular reviews			
Individual factors	-			
<ul> <li>Living/sleeping alone</li> <li>Alcohol and bubstance misuse</li> <li>Mental health</li> <li>Learning disability</li> <li>Pregnancy triggers – stress, sleep deprivation, dehydration</li> </ul>	Action:     Discussion with GP/referral to community service.     Social services can help plan safe accommodation for WWE     MDT discussion with carers     Support to minimise seizure triggers and education for patient and family			

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## 7. Contraception

WWE should be informed about the risks of future pregnancies and the importance of preconception care when planning future pregnancies. WWE should also be advised on how to access the services rapidly if they do become pregnant again.

WWE should be informed that AEDs can reduce the efficacy of hormonal contraceptives resulting in contraceptive failure. A summary of interactions is provided in the table below. Further information can be found via the FSRH.

**Table 3: Contraception and AEDs** 

Type of contraception	Enzyme inducing* AEDs	Non-enzyme inducing AEDs**	Lamotrigine
Combined contraceptive pill	Not advised – recommend an alternative method	No clinical interaction	Potential interaction  – caution required. Risk of reduced seizure control whilst taking COCP and for toxicity during CHC- free week
Progesterone only pill	Not advised – recommend an alternative method	No clinical interaction	Potential interaction  – caution required.  May increase lamotrigine levels – monitor for side effects
Progesterone subdermal implant	Not advised – recommend an alternative method	No clinical interaction	No clinical interaction
DMPA	No clinical interaction	No clinical interaction	No clinical interaction
LNG-IUS	No clinical interaction	No clinical interaction	No clinical interaction
CU-IUD	No clinical interaction	No clinical interaction	No clinical interaction

<sup>\*</sup> carbamazepine, eslicarbazepine, oxcarbazepine, phenobarbital, phenytoin, primidone, rufinamide, topiramate

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<sup>\*\*</sup>sodium valproate, levetiracetam, gabapentin, vigabatrin, tiagabine, zonisamide, gabapentin and pregabalin

### 8. Resources for women

Below are links to patient information leaflets for WWE.

- 1) 'Epilepsy in pregnancy' RCOG patient information leaflet available at <a href="https://www.rcog.org.uk/globalassets/documents/patients/patient-information-leaflets/pregnancy/pi-epilepsy-in-pregnancy.pdf">https://www.rcog.org.uk/globalassets/documents/patients/patient-information-leaflets/pregnancy/pi-epilepsy-in-pregnancy.pdf</a>
- 'Epilepsy and having a baby' from Epilepsy Action available at <a href="https://www.epilepsy.org.uk/sites/epilepsy/files/P021-BOOKLET-EPILEPSY\_AND\_HAVING\_A\_BABY.pdf">https://www.epilepsy.org.uk/sites/epilepsy/files/P021-BOOKLET-EPILEPSY\_AND\_HAVING\_A\_BABY.pdf</a>
- 3) 'Tips for looking after an infant when you have epilepsy' from Epilepsy Action available at <a href="https://www.epilepsy.org.uk/info/caring-children">https://www.epilepsy.org.uk/info/caring-children</a>
- 4) SUDEP information leaflets for patients available at <a href="https://sudep.org/free-information-downloads-0">https://sudep.org/free-information-downloads-0</a>

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# Appendix 1: Clinical presentation of seizures (adapted from RCOG and NECN)

Clinical presentation of seizures and their effect on the mother and baby						
Common types of seizures	Presentation	Effects on mother and baby				
Tonic-clonic seizures	Sudden impaired consciousness, muscle stiffening and rhythmic muscle contractions followed by postictal phase	Sudden loss of consciousness, uncontrolled fall, without warning. Associated with variable period of fetal hypoxia. Highest risk of SUDEP.				
Focal seizures	Symptoms are variable depending, depending on area of the brain affected. The attacks are recognisable and stereotypical on a typical individual. May impair consciousness.	Impairment of consciousness increases risk of injury (fracture, burns). Can have "epileptic aura" while remaining conscious. Can be associated with a variable period of hypoxia and risk of SUDEP.				
Juvenile myoclonic epilepsy (JME)	Myoclonic jerks (sudden unpredictable movements) often precede a generalised tonic-clonic convulsion.	Occurs more frequently with sleep deprivation. Sudden jerky movements may lead to falls or to dropping of objects including the baby.				
Absence seizures	Generalised seizures that consist of brief blank spells associated with unresponsiveness, followed by rapid recovery.	Effects mediated through brief loss of awareness of surroundings (like a burning flame). Worsening absence seizures places the women at high risk of tonic-clonic seizures.				

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## Appendix 2: Antiepileptic drugs and pregnancy – adapted from TOG

The choice of AEDs in women of childbearing age is predominantly determined by the epilepsy type. In regards to congenital malformations oral clefts are the predominant malformation seen in WWE, particular association with lamotrigine. The older AED gave been associated with the fetal anticonvulsant syndrome. It is recommended to avoid sodium valproate in all women with epilepsy of childbearing age, if possible. With sodium valproate the risk of congenital malformation is high (up to 10%) and increased risk of neurodevelopment disability including lower IQ and autism spectrum disorder (40%). If it is to be commenced patients should be enrolled in the pregnancy prevention programme (PPP) which includes a signed risk acknowledgment which reviewed from form is annually (accessed https://www.gov.uk/guidance/valproate-use-by-women-and-girls).

	Pregnancy	Congenital malformation No AEDs 2-2.3%	Breastfeeding
Enzyme inducing			
Carbamazepine	Considered safe	Cardiac and facial clefts (2-5%)	Safe
Oxcarbamazepine	Relatively safe	Cardiac and facial clefts (1-3%)	Safe
Phenytoin	Relatively safe	Facial clefts, poor neurodevelopment (1-2%)	Safe
Topiramate	Less safe – avoid if possible	Cardiac, facial clefts (4-6%)	Safe
Non-enzyme induc	cing AEDs		
Lamotrigine	Considered safe. May need dose adjustment in third trimester	Cardiac and facial clefts (2-5%)	Caution but benefits may outweigh risks. No side effects in most infants. Monitor infant for apnoea, rash, anaemia, drowsiness or poor suckling, May need levels to exclude toxicity.
Levetiracetam	Considered safe	Cardiac and NTD (1-2%)	Safe
Sodium valproate	Avoid	NTD, Facial cleft, Hypospadias, poor (6-10%) learning difficulties and autism spectrum (40%)	Safe
Clobazam/ clonazepam	Considered safe but can sedating for mother and neonate		Can contribute to respiratory depression

Be aware of the potential of other medications to alter AED levels e.g. some antibiotics

Risk of malformation	•
Monotherapy	3 - 5%
Polytherapy	6 - 8%
Polytherapy with valproate	Up to 10%

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## Appendix 3: Postnatal Discharge Letter

Date		
Dear Community Midwife/Go	eneral Practitioner	
RE:		Hospital No
DOB//		NHS No
MOD		
This patient is currently	days postnatal and has	been discharged on//
In view of her epilepsy she r	equires close monitoring	
Discharged on medication Y	ES/NO	
DRUG	DOSE	FREQUENCY
Pre-pregnancy medication of	lifferent YES/NO	
DRUG	DOSE	FREQUENCY
<ul><li>achieve pre-pregnancy level</li><li>Maintain pregnancy</li><li>Provide TTO's for 1 v</li></ul>	ls. dose for first 24 hours postpar week with gradually reducing of after 1 week to reduce dose	
Hospital follow up YES/NO	/ If yes when and v	where
patient information leaflets: - Risk minimisation an - SUDEP - Adaptations to care of		discussed and supported with
Name	Signature	Date//

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#### References

National Institute for Health and Care Excellence (2012). *Epilepsies: diagnosis and management* (NICE Guideline 137). Available at <a href="https://www.nice.org.uk/guidance/cg137">https://www.nice.org.uk/guidance/cg137</a> [Accessed 8th March 2021]

Royal College of Obstetricians and Gynaecologists (2016). *Epilepsy in Pregnancy* (Green top Guideline 68). Available at

https://www.rcog.org.uk/globalassets/documents/guidelines/green-top-guidelines/gtg68 epilepsy.pdf [Accessed 8th March 2021]

The Faculty of the Sexual & Reproductive Healthcare (2017). FSRH CEU Guidance: Drug interactions with hormonal contraception. Available at <a href="https://www.fsrh.org/standards-and-guidance/documents/ceu-clinical-guidance-drug-interactions-with-hormonal/">https://www.fsrh.org/standards-and-guidance-drug-interactions-with-hormonal/</a> [Accessed 10<sup>th</sup> March 2021]

Northern England Clinical Networks (2017). *Epilepsy in pregnancy*. (NECN/Maternity/Epilepsy/001 V1.1). NHS northern England clinical networks.

Knight, M., Bunch, K., Tuffnell,. D, Shakespeare, J., Kotnis, R., Kenyon, S., & Kurinczuk, J. J. (Eds.). (2019). Saving lives, improving mothers' care: Lessons learned to inform maternity care from the UK and Ireland confidential enquiries into maternal deaths and morbidity 2016-18. Avaiable at <a href="https://www.npeu.ox.ac.uk/assets/downloads/mbrrace-uk/reports/maternal-report-2020/MBRRACE-UK\_Maternal\_Report\_Dec\_2020\_v10.pdf">https://www.npeu.ox.ac.uk/assets/downloads/mbrrace-uk/reports/maternal-report-2020/MBRRACE-UK\_Maternal\_Report\_Dec\_2020\_v10.pdf</a> [Accessed on 7th March 2021]

SUDEP Action (2021). *SUDEP resources for professionals*. Available at <a href="https://sudep.org/sudep-resources-professionals">https://sudep.org/sudep-resources-professionals</a> [Accessed 11<sup>th</sup> March 2021]

Bhatia, M., Adcock, J. and Mackillop, L (2017). *'The management of pregnant women with epilepsy a multidisciplinary collaborative approach to care'*. The Obstetrician and Gyanecologist, 19 pp 279-88.

Government UK (2021). *Valproate use by women and girls*. Available at <a href="https://www.gov.uk/guidance/valproate-use-by-women-and-girls">https://www.gov.uk/guidance/valproate-use-by-women-and-girls</a> [Accessed 12th March 2021]

Northern Care Alliance NHS Group (2020). Status epilepticus and prolonged seizures guideline for management in adults. Available at <a href="https://www.srft.nhs.uk/EasysiteWeb/getresource.axd?AssetID=76349&type=full&servicetype=lnline">https://www.srft.nhs.uk/EasysiteWeb/getresource.axd?AssetID=76349&type=full&servicetype=lnline</a> [Accessed 18<sup>th</sup> March]

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