Belfast Health and Social Care Trust
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FOI/33893

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Management of Epilepsy in Pregnancy

The confidential enquiry into maternal deaths has highlighted the increased risk of maternal morbidity and mortality in women with epilepsy during pregnancy. This survey aims to enhance our understanding of the services currently in place to manage these women.

We will be very grateful for your completion of the attached survey. If you have any queries, please do not hesitate to contact us.

Freedom of Information Questionnaire – Epilepsy in Pregnancy Services

Hospital Name: Royal Jubilee Maternity Services

Trust: Belfast H&SC Trust

Maternity Medicine Network:

Secondary/Tertiary Care:

Pre-pregnancy planning in women with epilepsy		
1a	Do women with epilepsy have access to a pre-pregnancy counselling clinic in your centre?	☐ Yes ☒ No – designated clinic
1b	If pre-pregnancy counselling is available in your centre, who delivers this/these services? **(Please tick all that apply)**	☒ A neurologist/ epilepsy specialist doctor ☒ A neurology specialist nurse/ epilepsy specialty nurse ☐ An obstetrician with an interest in neurology/ a maternal-fetal medicine obstetrician ☐ An obstetrician physician ☒ An epilepsy specialist midwife

1c	If you have selected more than one practitioner in question 1b do they work separately or as part of a joint clinic?	☐ They work separately ☒ They work together in a joint clinic
1d	How are patients transferred into the pre-pregnancy clinic? **(Please tick all that apply)**	☐ From their General Practitioner (GP) ☐ From their secondary care epilepsy service ☐ Other – please state: No pre-pregnancy clinic exists. Pre-pregnancy counselling provided at request of consultant or if patients are accessed by Epilepsy Specialist Midwife/Nurses via Epilepsy Helpline (all women of childbearing age are given counselling by Epilepsy Midwives/Nurses)

Antenatal management		
2	Do your patients have access to written information on the management of epilepsy in pregnancy?	☒ Yes – Epilepsy Action resources on Pregnancy and Safety in caring for child. ☐ No
3a	Do women with epilepsy in your centre have access to regular planned antenatal care with a designated epilepsy care team?	☒ Yes ☐ No
3b	If yes, which of the following healthcare professionals deliver the service? **(Please tick all that apply)**	☒ A neurologist/ epilepsy specialist doctor ☒ A neurology specialist nurse/ epilepsy specialist nurse ☒ An obstetrician with an interest in neurology/ a maternal-fetal medicine obstetrician ☐ An obstetric physician ☒ An epilepsy specialist midwife
3c	If you have selected more than one practitioner in questions 3b do they work separately or as part of a joint clinic?	☐ They work separately ☒ They work together in a joint clinic
3d	How do women with epilepsy enter the service?	☐ Identified at their booking appointment

	(Please tick all that apply)	☒ From their General Practitioner (GP) ☒ From their secondary care epilepsy service ☐ Other – please state: Self-referral to maternity services
3e	If yes, how often are they reviewed in your epilepsy pregnancy clinic?	☐ Fortnight ☐ Monthly ☐ Bimonthly ☐ Once per trimester ☒ Other – please state: 12 weeks, 20 weeks, 28 weeks, 4 weekly thereafter until delivery. Seen by community teams in between GP/Community Midwives.
4	Are women with epilepsy risk stratified in your antenatal service?	☒ Yes ☐ No
4b	If yes, how is the risk assessment done?	☐ Using a risk stratification tool : please state which ☒ Other – please state: Individualised as per patient.
4c	If so do those women considered 'higher risk' have a different care pathway to those considered 'lower risk'	☒ Yes ☐ No If yes, please detail how these pathways differ: Monitored more closely.

Medication management		
5	How does your service manage folic acid use in women with epilepsy?	☒ Recommend 5mg folic acid for three months prior to pregnancy and throughout pregnancy ☐ Recommend 5mg folic acid for three months prior to pregnancy and for the first trimester of pregnancy, then drop to 400mcg for the remainder of the pregnancy ☐ Recommend 400mcg for three months prior to pregnancy and for the first trimester of pregnancy ☐ Recommend 400mcg for three months prior to pregnancy and throughout pregnancy ☐ Other – please state

6	How does your service manage titration of antiseizure medications in pregnancy? **(Please tick all that apply)**	☐ Using drug levels ☐ Using clinical symptoms ☒ Using both drugs levels and clinical symptoms ☐ Other – please state: Accurate Hx, Individualised to patient.
7	Does your centre routinely measure drug levels in women with epilepsy?	☒ Yes ☐ No
8a	Do you use long-acting benzodiazepines, such as clobazam, in the peripartum period for women with 'high risk' of seizures during this period?	☒ Yes – only if required – active epilepsy ☐ No
8b	If yes, what is your routine drug/dose/regimen	Individualised to patient - lowest possible dose, to achieve best possible seizure control, especially tonic clonic seizure which carry potential risk of harm/SUDEP.
8c	If yes, what are the criteria for women being considered 'high risk'?	Active uncontrolled Epilepsy - esp. frequent Tonic clonic seizures

Postpartum follow up for women with epilepsy		
9	How are women with epilepsy in your service followed up postpartum?	☐ In a postpartum pregnancy clinic ☒ In their usual epilepsy clinic – 12-16 weeks postnatal ☐ By their GP ☐ There is no routine follow-up