Freedom of Information Request: Our Reference CTMUHB_208_25

You asked:

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 below survey.

Hospital Name: Princess of Wales Hospital

Health Board: Cwm Taf Morgannwg University Health Board

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 we do not have a pre-pregnancy counselling 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:

Antenatal management		

2	Do your patients have access to written information on the management of epilepsy in pregnancy?	√ Yes ☐ 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 √ 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 (Epilepsy specialist nurse and Obstetrician)
3d	How do women with epilepsy enter the service? **(Please tick all that apply)**	√ Identified at their booking appointment ☐ From their General Practitioner (GP) √ From their secondary care epilepsy service ☐ Other – please state:
3e	If yes, how often are they reviewed in your epilepsy pregnancy clinic?	☐ Fortnight ☐ Monthly ☐ Bimonthly ☐ Once per trimester √ Other – please state: The frequency of the visit depends on their clinical need. They are usually seen at least once every 4 weeks. Patients are seen more frequently if clinical need arises.
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: By clinical assessment jointly by the Epilepsy Specialist Nurse and Obstetric Medicine Obstetrician.
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:

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:
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 ☐ No
8b		

	If yes, what is your routine drug/dose/regimen	If the woman is at high risk of seizures, consider prophylactic clobazam peripartum (dose of 10 mg PO daily can be used, please refer to BNF https://bnf.nice.org.uk/). Use in the short-term only (eg starting at the onset of labour or the day before planned delivery) due to the risk of respiratory depression in the neonate.
8c	If yes, what are the criteria for women being considered 'high risk'?	As above.

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 - by Epilepsy Specialist Nurse with Neurologist input if required. ☐ By their GP ☐ There is no routine follow-up

Hospital Name: Prince Charles Hospital (PCH)

Health Board: Cwm Taf Morgannwg University Health Board

Please note: We do not have a Maternity Epilepsy Clinic at Prince Charles Hospital. Epilepsy patients are referred onwards to a Neurologist, who then advises on their management. However, their care is generally orchestrated by the epilepsy team, i.e. Epilepsy Specialist Nurses or consultants. Medical Antenatal Clinic and Epilepsy Clinics are separate.

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
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: Usually from Community Midwives

Antenatal management		
2	Do your patients have access to written information on the management of epilepsy in pregnancy?	√ Yes ☐ No
3a	Do women with epilepsy in your centre have access to regular planned antenatal care with a designated epilepsy care team?	☐ Yes √ No they attend the Medical Epilepsy Clinic. There is no joint epilepsy clinic for maternity currently at PCH.
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 As in 3a service is split between medical antenatal clinic and epilepsy clinic
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? **(Please tick all that apply)**	√ Identified at their booking appointment ☐ From their General Practitioner (GP) ☐ From their secondary care epilepsy service

		☐ Other – please state: At booking – community midwives
3e	If yes, how often are they reviewed in your epilepsy pregnancy clinic?	☐ Fortnight ☐ Monthly ☐ Bimonthly ☐ Once per trimester ☐ Other – please state: 1-2 times per trimester
4	Are women with epilepsy risk stratified in your antenatal service?	☐ Yes √ No they attend the Medical Clinic
4b	If yes, how is the risk assessment done?	☐ Using a risk stratification tool : please state which ☐ Other – please state:
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: patients are referred onwards to a Neurologist, who then advises the clinic on management.

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 - guided by Epilepsy Team.
6	How does your service manage titration of antiseizure medications in pregnancy?	☐ Using drug levels ☐ Using clinical symptoms

	(Please tick all that apply)	√ Using both drugs levels and clinical symptoms ☐ Other – please state:
7	Does your centre routinely measure drug levels in women with epilepsy?	☐ Yes ☐ No Not always
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 ☐ No We would be guided by Epilepsy Team.
8b	If yes, what is your routine drug/dose/regimen	As above.
8c	If yes, what are the criteria for women being considered 'high risk'?	

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 ☐ By their GP ☐ There is no routine follow-up

Under the terms of the Health Board's Freedom of Information policy, individuals seeking access to recorded information held by the Health Board are entitled to request an internal review of the handling of their requests. If you would like to complain about the Health Board's handling of your request please contact me directly at the address below. If after Internal Review you remain dissatisfied you are also entitled to refer the matter to the Information Commissioner at the following address:

- Information Commissioner's Office - Wales
  2nd Floor, Churchill House, Churchill Way, Cardiff, CF10 2HH
- Telephone: 0330 414 6421 / Email: wales@ico.gsi.gov.uk
- https://ico.org.uk/

You should note, however, that the Information Commissioner would normally expect you to have exhausted our internal complaints procedures before dealing with such an application. Further guidance may be found on the Information Commissioner's website click here.

Cwm Taf Morgannwg University Health Board routinely publishes details of all Freedom of Information Act requests received in its disclosure log. The Disclosure Log can be found at https://ctmuhb.nhs.wales/use-of-site/freedom-of-information/disclosure-log/

Please do not hesitate to contact me if you have any queries.

Yours sincerely

The Freedom of Information Team /Y Tîm Rhyddid Gwybodaeth