EpiKNOW

EPILEPSY KNOWLEDGE AND RESOURCES FOR WOMEN FROM PRECONCEPTION TO POSTPARTUM

Supporting conversations between women with epilepsy and their PRIMARY CARE TEAM

Checklist for appointments with your **PRIMARY CARE TEAM** (GP and Practice Nurse)

OVERVIEW OF WHAT THIS CHECKLIST COVERS:

OUTSIDE OF CONCEPTION	FAMILY PLANNING	DURING PREGNANCY
☐ Fertility	☐ Referral	☐ Referral to epilepsy specialist and maternity care teams
☐ Contraception	☐ Planning ahead	☐ Pregnancy sickness
☐ Folic acid	☐ Preconception counselling	☐ Changes in seizure frequency
☐ Valproate and Topiramate		☐ Blood tests

1. Outside of conception

☐ Epilepsy itself is not a reason for infertility but you need to consider issues such as medication, seizure safety and potential for seizures when planning to start a family requires a few more considerations (i.e., review of medications, seizure safety and potential for seizures).

Contraception:

☐ The potential for becoming pregnant and each woman's needs for contraception depending on circumstances, should be assessed.

☐ Contraception options and information on how they interact with epilepsy medication should be made available to you. This is because contraception effectiveness may be reduced by some Anti-Seizure Medications (ASMs). Further information can be found via the Epilepsy Ireland website.

☐ Folic acid should be prescribed to women of childbearing potential. The specific dosage and usage will be determined by your epilepsy specialist team.

☐ It is no longer advised to prescribe Valproate and Topiramate for women of childbearing potential, unless other treatments are ineffective or not tolerated. Find out more about Valproate via the HPRA website.

For those whom Valproate or Topiramate is the only effective treatment, advice should be provided on the use of effective contraception and the risks of congenital malformations and neurodevelopmental disorders to children exposed to Valproate during pregnancy. You should share any plans for pregnancy with a healthcare professional at the earliest convenience.

2. Family planning

Family planning should be discussed at the consultation. If you are planning to start a family, you should be referred to the epilepsy specialist team for a medication review.

Be cautious that assumptions may be made (for example, if a woman is not married) about whether someone is thinking about starting a family. No matter the stage of life, you should contact the epilepsy team if you are thinking about starting a family in the next 12 months.

☐ It should be highlighted that starting a family can take time (sometimes 12 months or more), especially if ASMs need to be changed. You do not need to be planning a pregnancy in the next year to get this information and it is advised to plan ahead as much as possible.

Note: changes to ASMs could impact your seizure frequency, which could affect your lifestyle i.e., driving or spending long periods alone. Although it is not necessary, it may be useful to inform workplaces or friends/family.

☐ Preconception counselling should be offered, or given if you ask for it. In this counselling, details about the risks (including safety advice and cautioned about the risk of SUDEP - Sudden Unexpected Death in Epilepsy) and outcomes of pregnancy with epilepsy will be explained.

3. During pregnancy

Immediately after a positive pregnancy test:

- ☐ You should contact the GP and epilepsy specialist team to plan the next steps and appropriate referrals onto the maternity care team. Epilepsy medication should not be stopped.
- ☐ Should you experience pregnancy sickness; this could interfere with medication adherence. Get in contact with the GP or the epilepsy specialist and maternity care team should this happen to seek further advice. For more general information on pregnancy sickness, please see the HSE website.
- ☐ Seizure patterns can change during pregnancy. As a general rule, one-third of women may have fewer seizures, one-third may stay the same, and one-third may have more seizures. Any changes in seizure frequency or concerns should be checked by the epilepsy specialist and maternity care teams.
- ☐ Throughout the pregnancy there should be regular blood tests taken by the primary care team. This is for drug levels to be assessed by the epilepsy specialist team. Depending on results, the epilepsy specialist team may alter your medications. Medication levels can change at a quicker pace during pregnancy. If there are any concerns that seizure frequency is changing, contact the epilepsy specialist and maternity care teams.
- ☐ The team should encourage preconception advice be sought before planning another pregnancy.

4. Key questions to consider by women with epilepsy during these stages

Can I still have children?
Epilepsy itself is not a reason for infertility and considerations to start a family are still appropriate, but this process requires a few more considerations (i.e., review of medications, seizure safety and potential for seizures).

What type of contraception is the most suitable for me?
Suitable contraception options are dependent on the type of antiseizure medications. For more information, please see the Epilepsy Ireland website.

When should I consider information on family planning?
At your earliest convenience. Even if you are not planning a family now, medication adjustments can take up to and beyond 12 months of planning, so it is best to start conversations earlier to be prepared.

What do I need to consider during family planning?
Each medication's safety should be considered, and information about it should be given to you. Any changes to medication and how they might affect seizure frequency and safety during pregnancy should also be explained. This checklist can help with preparing what to think about and ask.

What are my considerations during pregnancy?
Managing epilepsy during pregnancy may require additional blood tests, and changes in medication or doses and maintaining a healthy lifestyle (e.g., good sleep hygiene) to reduce seizure risks. You must not stop taking your epilepsy medication during pregnancy.

Your notes

This research was funded by the Health Research Board APA-2022-014, with co-funding from Epilepsy Ireland and the HSE National Women and Infants Health Programme

RCSI UNIVERSITY OF MEDICINE AND HEALTH SCIENCES

National Women & Infants Health Programme

HRB Health Research Board

Epilepsy Ireland