

Self-advocacy and Discussing Reproductive Health With Your Healthcare Professional

A guide for women living with epilepsy

Developed in partnership with healthcare professionals and patient experts



The discussion guide was funded by UCB. It has been prepared and reviewed by an expert council of patients and healthcare professionals, including: Jessica Smith, Erin Davies, Liz Dueweke, Carolina López, Kimford Meador MD, Gus Baker PhD, Rebecca Bromley DClinPsy PhD, Thomas McElrath MD PhD, Bettina Schmitz Prof Dr Med, Emma Voinescu MD PhD. This guide has had a courtesy review by UCB, but UCB was not involved in the development of the material.



Guide overview

This guide has been developed in collaboration with healthcare professionals and patient experts.

It is intended to support women of childbearing age living with epilepsy:

- make informed, evidence-based decisions about their reproductive health, and
- initiate open conversations with healthcare professionals, covering topics across the motherhood journey, including contraception, pregnancy, and parenting.

This guide contains three parts:



1. Self-advocacy



Guidance on speaking up about treatment and expressing your pregnancy preferences to ensure the best possible care.



2. Finding information



Advice on identifying reliable sources of information, what to do if no information is available, and links to useful resources and tools for epilepsy and pregnancy.



3. Discussion prompts



Suggested questions to ask your healthcare team to prompt discussion about epilepsy and reproductive health.



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Self-advocacy for women of childbearing age living with epilepsy



What is self-advocacy and why is it important?¹

Self-advocacy is having the confidence to speak up about what is important to you and making sure you are being heard.

Your healthcare professionals need to understand your preferences when making decisions, and you should work together to receive the best possible care.

Self-advocacy and epilepsy across the motherhood journey

Many women experience challenges ensuring their preferences are respected across the motherhood journey.² Making decisions about motherhood while having epilepsy can be challenging, and self-advocacy can help inform your decision-making about:

- Whether to have children
- Use of ASMs* and supplements during pregnancy
- Preferences regarding childbirth delivery methods
- Whether to breastfeed
- Other concerns.



Key considerations for self-advocacy³⁻⁵

- Ensure you understand your preferences
- Explore options that are available to you to help establish your preferences
- Consider what additional information you may need to make informed decisions
- Know your rights and what you are entitled to
- Communicate your preferences to your healthcare team
- Keep a record of your conversations with your healthcare team

*Abbreviation:

ASM = antiseizure medication

References:

1. Hagan TL, Medberry E. Patient Education vs. Patient Experiences of Self-advocacy: Changing the Discourse to Support Cancer Survivors. *J Cancer Educ.* 2016;31(2):375-81 ([reference link](#));
2. Mohamoud YA, Cassidy E, Fuchs E, et al. Vital Signs: Maternity Care Experiences - United States, April 2023. *MMWR Morb Mortal Wkly Rep* 2023;72:961-967 ([reference link](#));
3. Rethink Advocacy. Taking Control: A guide to self-advocacy. Available at: <https://www.rethinkadvocacy.org.uk/get-help/self-advocacy/>. Accessed: 4th November 2025; 4. Advocacy Focus. The essential self-advocacy toolkit. Available at: https://advocacyfocus.org.uk/wp-content/uploads/2022/04/The_Essential_Self_Advocacy_Toolkit_1119.pdf. Accessed: 4th November 2025; 5. Carers UK. Being heard self-advocacy guide. Available at: <https://www.carersuk.org/media/4ahpa34k/cuk-self-advocacy-guide-2024-england.pdf>. Accessed: 4th November 2025



Finding reliable information on epilepsy and motherhood



Women living with epilepsy need reliable information to make informed decisions about their health during the motherhood journey. However, it can be difficult to find reliable, up-to-date information.

If you find information that may help to inform or influence your decisions at any point during your journey, consider discussing its reliability with your healthcare team or patient organization.

Key considerations for finding reliable information¹⁻³

- **Does the information come from a reliable and objective source?**

Reliable sources include reputable organizations or charities, healthcare professionals, official guidelines, government websites, national health agencies (e.g., NHS*, CDC*).

- **Has the research been published in a credible, peer-reviewed medical journal?**

Medical journals publish research written by and reviewed by experts. Only information that is considered accurate is released. Credible journals should clearly state how their peer-review process works.

- **How long ago was the information published?**

Check the publication date of the resource – information from a few years or even months ago might now be out of date.

- **Who authored the information, and is it based on their personal experiences or opinion?**

Consider if the author is an expert, such as a healthcare professional, scientific researcher, patient expert, or someone working for an organization. Do they have specific goals or an agenda in sharing information (e.g., promoting a product)? Who is funding the research?

*Abbreviations:

CDC = Centers for Disease Control and Prevention; NHS = National Health Service

References:

1. National Institutes of Health. How To Find Reliable Health Information Online. Available at: <https://www.nia.nih.gov/health/healthy-aging/how-find-reliable-health-information-online>. Accessed: 4th November 2025;
2. The Patients' Association. Finding trustworthy information online. Available at: <https://www.patients-association.org.uk/finding-trustworthy-information-online>. Accessed: 4th November 2025;
3. Patient. How to find reliable health information online. Available at: <https://patient.info/news-and-features/how-to-find-reliable-health-information-online>. Accessed: 4th November 2025



Finding reliable information on epilepsy and motherhood



What to do if you cannot find information

Information may not be available on some topics of epilepsy and the motherhood journey. This may reflect a lack of research. For example, information on epilepsy and WoCBA* is limited regarding the following:

- The effectiveness of taking certain contraception and ASMs together
- The safety of certain ASMs during pregnancy and breastfeeding
- The risk of complications during and after pregnancy (e.g., preeclampsia, postpartum depression).

It also takes time for new evidence to become available on accessible platforms. **Speak to your healthcare team or a patient organization** to understand the most recent information for WoCBA and consider asking them to check for updates.

Find trusted resources and organizations recommended by our experts at the end of this guide.

*Abbreviations:

ASM = antiseizure medication; WoCBA = women of childbearing age



Contributing data to inform discussions on epilepsy and motherhood



What is a registry?

Registries collect and store clinical information about patients' health and the care they receive in the real world, outside of clinical trials. This information helps to improve our understanding of the effects of treatments and disease on patients.¹

Speak to your healthcare team if you are interested in participating in a registry. Examples of epilepsy and pregnancy registries are listed at the [end of this guide](#).

Why are registries important for pregnancy and epilepsy?

Some registries collect information about epilepsy and ASMs across the motherhood journey. These data are used by medical experts to better understand the safety of epilepsy and ASM treatment for a WoCBA and her child during pregnancy and motherhood. The information collected may include²⁻⁴:

- Patient history with epilepsy and ASM treatment
- ASM(s) taken during pregnancy
- Patient health during and after pregnancy
- The health of the child during and after pregnancy.

This information is crucial to help inform future healthcare practices, ensuring that women living with epilepsy can receive the best possible care.²⁻⁴

Abbreviations:

ASM – antiseizure medication; WoCBA = women of childbearing age

References:

1. OrthoInfo. What is a clinical data registry? Available at: <https://orthoinfo.aaos.org/en/treatment/what-is-a-clinical-data-registry/>. Accessed: 4th November 2025;
2. EURAP. Why a pregnancy registry? Available at: <https://eurapinternational.org/home/patient-enrolment/>. Accessed: 4th November 2025;
3. Epilepsy Foundation. North American AED Pregnancy Registry. Available at: <https://www.epilepsy.com/treatment/medicines/pregnancy/north-american-aed-pregnancy-registry>. Accessed: 4th November 2025;
4. The North American Antiepileptic Drug Pregnancy Registry. Available at: <https://www.aedpregnancyregistry.org/history/>. Accessed: 4th November 2025



Discussing epilepsy and reproductive health with your healthcare team

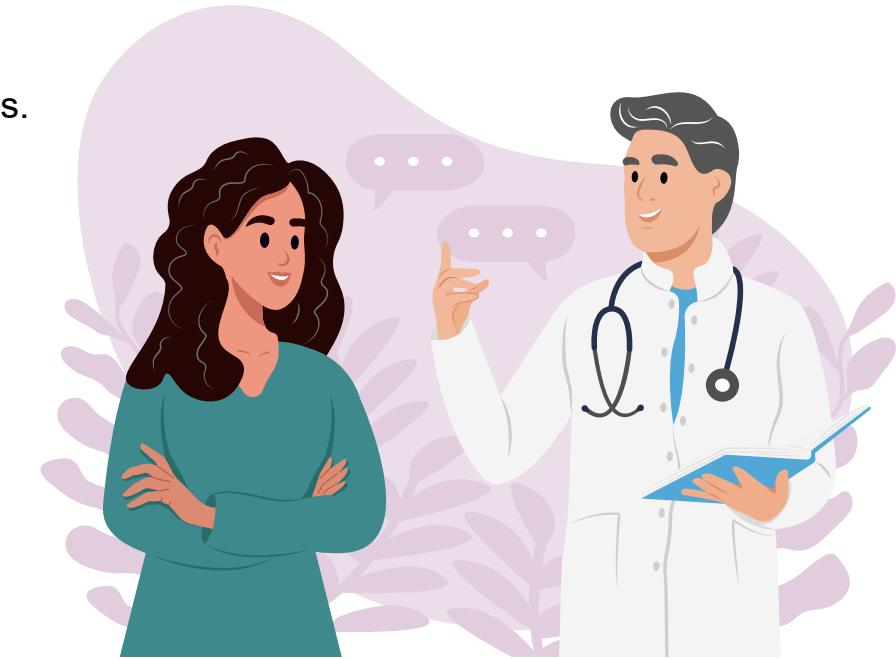
Advocating for your preferences allows you and your healthcare team to work together to support a safe and healthy motherhood journey while living with epilepsy. Bringing a partner, family member, or friend to appointments can help ensure you cover all topics and perspectives. Ideally, it is helpful to take notes or document your discussion for future reference.

To help you start conversations with your healthcare team, this section provides discussion prompts/questions for use at different points along the motherhood journey:

1. Contraception and planning
2. Epilepsy management during pregnancy
3. Childbirth, postpartum, and parenting.



Scan and print a list of discussion questions for your next healthcare visit!



Discussion prompts – contraception and planning



Contraception / Birth control

- What contraception is appropriate for me?
- Will my ASM and contraception interact and cause the other to be less effective?
- Will taking the morning after pill impact the effectiveness of my ASM?
- What should I do should I become pregnant?

Pregnancy planning

- What if the medication controlling my seizures is considered high-risk during pregnancy?
- Am I less likely to conceive due to my epilepsy or my medication?
- If I need IVF*, will my IVF medication and ASM interact and cause the other to be less effective?
- When should I talk to my neurologist about pregnancy planning?
- How will different types of clinicians be involved in coordinating my care? What will their roles be?
- Can epilepsy be passed on to my children?
- When should I start taking supplements (e.g., folic acid) to improve the health of my pregnancy?
- What are the risks and benefits of changing my ASM(s) to improve pregnancy outcomes?
- Should I change my ASM(s) to improve pregnancy outcomes? If so, when?

*Abbreviations:

ASM = antiseizure medication; IVF = in-vitro fertilization



Discussion prompts – epilepsy management during pregnancy



Early pregnancy

- Will pregnancy and hormone changes impact control of my seizures?
- What is the risk of breakthrough seizures during pregnancy and what can I do to prevent them?
- Can I use seizure rescue medication during pregnancy?
- How may seizures or ASM(s) affect my child's development and neurodevelopment (e.g., developmental delays, autism)?
- Are there any pregnancy and epilepsy registries or research studies collecting data, and how can I contribute?
- What should I start considering to help support parenthood (e.g., who takes time off work and duration, options for professional and financial support and how to access/apply, planning for childcare, including nighttime support)?



Mid pregnancy

- Are screening tests for developmental or neurodevelopment abnormalities available to me during pregnancy?
- Am I at higher risk of certain complications during pregnancy (e.g., preeclampsia, high blood pressure, mood disorders, or HELLP* syndrome)?
- Is there a high-risk pregnancy support group I can join?

*Abbreviations:

ASM = antiseizure medication; HELLP = hemolysis, elevated liver enzymes, and low platelets



Discussion prompts – delivery, postpartum, and parenting



Delivery

- What is the risk of having seizures during labor and delivery, and what can I do to prevent them?
- What are my options for delivery? Are there potential risks?
- How may epilepsy affect my ability to give birth vaginally or unassisted by medication?
- If anesthesia is needed, can it have any impact on my ASM effectiveness?



Postpartum

- Will my ASM(s) affect whether I can or should breastfeed?
- How will a lack of sleep postpartum impact my seizure risk? How can I help lower that risk?
- When do I need to resume contraception/birth control?
- When is it safe to plan for another pregnancy?
- How should I get back to my previous ASM dose (before pregnancy)?
- Am I more likely to be diagnosed with certain conditions after pregnancy (e.g., postpartum depression)?
- Where can I find more information and support?



Parenting

- How can I keep my child and myself safe since I am at risk for seizures postpartum?
- What additional resources should I consider to help support me at home with parenting and managing my seizure risk?



Child development

- What should I keep in mind about child development?
- Are there any early intervention or screening clinics for neurodevelopmental conditions (e.g., autism) available to my child?
- Should I tell my pediatrician about the ASM(s) I used during pregnancy?

Resources for epilepsy and the motherhood journey



The following organizations and resources were recommended by the experts that co-created this document:



Organizations

- **International Bureau for Epilepsy (International):**
<https://www.ibe-epilepsy.org/>
- **My Epilepsy Story (International):**
<https://myepilepsystory.org/>
- **International League Against Epilepsy (International):**
<https://www.ilae.org/>
- **Epilepsy & Pregnancy Medical Consortium (US):**
<https://epilepsypregnancy.com/>
- **Epilepsy Foundation (US):**
<https://www.epilepsy.com/>
- **Epilepsy Action (UK):**
<https://www.epilepsy.org.uk/>

Contraception and planning

- **Contraception and antiseizure medication:**
<https://www.nice.org.uk/indications/ind78-contraception-advice-for-people-taking-anti-seizure-medication>
- **Planning for pregnancy with epilepsy:**
<https://utswmed.org/medblog/epilepsy-pregnancy/>
- **Planning for pregnancy with epilepsy:**
<https://epilepsyfoundation.org.au/managing-epilepsy/women-and-epilepsy/pregnancy-planning/>
- **Planning for pregnancy with epilepsy:**
<https://epilepsypregnancy.com/resources-tools/>
- **Planning for pregnancy with epilepsy:**
<https://www.epilepsy.com/lifestyle/family-planning/preparing-pregnancy>
- **Family planning:**
<https://www.epilepsy.com/lifestyle/family-planning>
- **Family and epilepsy:**
<https://livingwellwiththeepilepsy.com/family-epilepsy>

This list is not comprehensive and may not cover all topic areas.
Tips on finding information are provided earlier in this guide.

Resources for epilepsy and the motherhood journey



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Disease management during pregnancy

- **Epilepsy and pregnancy toolkit:**
<https://www.womenwithepilepsy.co.uk/pregnancy-toolkit/>
- **Epilepsy and pregnancy guidelines (UK):**
<https://www.rcog.org.uk/guidance/browse-all-guidance/green-top-guidelines/epilepsy-in-pregnancy-green-top-guideline-no-68/>
- **Epilepsy treatment guidelines (US):**
<https://aesnet.org/about/aes-press-room/press-releases/guideline-issued-for-people-with-epilepsy-who-may-become-pregnant>
- **Suitable antiseizure medications during pregnancy:**
<https://media.epilepsypregnancy.com/wp-content/uploads/2023/10/what-we-know-asmss-pregnancy-epilepsy-EPMC.pdf>
- **Epilepsy and pregnancy guidance:**
<https://www.nhs.uk/pregnancy/related-conditions/existing-health-conditions/epilepsy/>
- **Epilepsy and pregnancy guidance:**
<https://www.mayoclinic.org/healthy-lifestyle/pregnancy-week-by-week/in-depth/epilepsy/art-20048417>

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Childbirth, postpartum, and parenting

- **Labor and delivery:**
<https://epilepsypregnancy.com/pregnancy-journey-topics/labor-and-delivery-with-epilepsy/>
- **Postpartum care:**
<https://epilepsypregnancy.com/pregnancy-journey-topics/post-partum-and-epilepsy/>
- **Sleep and epilepsy:**
<https://www.epilepsy.com/complications-risks/sleep>

Registries and research studies

- **Pregnancy and antiseizure medication registry (Europe):**
<https://eurapinternational.org/>
- **North America antiepileptic drug pregnancy registry (North America):**
<https://www.aedpregnancyregistry.org/>
- **Epilepsy and pregnancy register (UK):**
<https://www.epilepsyandpregnancy.co.uk/>

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Abbreviations:

HCP = healthcare professional; WoCBA = women of childbearing age

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