



DECIDING ON BIRTH CONTROL: A guide for women with epilepsy

For many women, decisions about starting birth control and picking a birth control method can be challenging. For the over one million women and girls in the US who have epilepsy, these decisions can be even more complex.

Like you, many women with epilepsy have questions about how having epilepsy affects their birth control choices. It does not matter what type of seizures you have, how often you have them, or what medications you take, this guide can help you make an informed birth control choice.

How Will This Guide Help Me?

Are you:

- Considering starting birth control?
- Not sure which birth control method is right for you?
- Curious how other women with epilepsy have picked a birth control method?
- Looking for ways to talk to your doctor about birth control?

If you answered “yes” to any of these questions, this guide can help. Inside you will find:

- Answers to questions women with epilepsy often have about birth control;
- Real life stories of women with epilepsy who have made different birth control choices;
- Exercises to help you figure out what is most important to you when starting or selecting a birth control method; and
- Questions to ask your health care team so they can help you with your decisions.

Keep in mind that this guide should not replace the advice of a doctor. Instead, it will help prepare you to talk to a doctor about your birth control needs and choices.



Can Women with Epilepsy Use Birth Control?

Yes! You can use birth control that prevents pregnancy in the short-term, long-term, or permanently, depending on if and when you want to have children. Before you pick what type of birth control to use, it is important to learn about some common myths and facts about birth control for women with epilepsy.

Myth: There are laws that prevent women with epilepsy from having children.

Fact: In the early 1900s, there were laws saying that women with epilepsy should be forcibly sterilized. Those laws no longer exist. Thankfully understanding of epilepsy has come a long way. Now women with epilepsy can decide for themselves if they want to use birth control or have children.

Myth: It is not safe for women with epilepsy to get pregnant.

Fact: Women with epilepsy can have children and be great mothers. In fact over 90% of women with epilepsy who have children have safe pregnancies and healthy babies that do not inherit epilepsy. To make sure their pregnancies are safe and their babies are healthy, women with epilepsy need to plan their pregnancies and talk to their doctors about their pregnancy plans.¹⁻²

Myth: Epilepsy medications make all birth control methods less effective.

Fact: There are two different types of birth control: non-hormonal and hormonal. Condoms and diaphragms are types of non-hormonal birth control. Birth control pills, the shot, and the ring are types of hormonal birth control.³ Epilepsy medications do not affect non-hormonal methods. But, if you take enzyme-inducing epilepsy medications and hormonal birth control, it could make your birth control less effective at preventing pregnancy.⁴

Myth: All birth control methods increase the chance of seizures in women with epilepsy.

Fact: If you use non-hormonal birth control, it will not affect your seizures.⁵ If you use hormonal birth control, it is hard to tell what impact your birth control will have on your seizures.⁶ Some women say hormonal birth control increases their seizures, but other women find it decreases their seizures. Still other women say hormonal birth control does not affect their seizures at all. There is a lot left to learn about this issue.

Which Birth Control Method is Right for Me?

You have a number of birth control options to choose from. The table on the following pages gives a lot of information about your choices. It even shows how different birth control methods work with epilepsy medications.

What if I have problems with my birth control method?

It is hard to tell which combination of birth control and epilepsy medications will work best for you. You might find the right combination on your first try. Or you might try different combinations before finding the right one. During these trial periods:

- Look for signs that your epilepsy medication is not working. These signs include changes in the number, length, or kind of seizures you usually have. If this happens, take an extra dose of your medication and talk to your doctor.
- Look for signs that your birth control is not working. If you notice missed period, headaches, tender breasts, nausea or lower backaches, and you have been sexually active, these may be early signs of pregnancy. Use a back-up method of birth control (like condoms) and talk to your doctor as soon as possible.

What if my birth control fails and I become pregnant?

- If you would like to have a child or want to consider adoption, talk to your doctor right away about ways to take care of your health for the rest of your pregnancy.
- If you are not ready to have a child, abortion is an option. Abortion is safe, common, and legal. The National Abortion Federation can give you information about abortion, and help you find out where to get an abortion and how to pay for it. You can reach them at www.prochoice.org or at 1-877-257-0012.



How Have Other Women with Epilepsy Made Birth Control Decisions?

The following stories are from women who hoped sharing their own experiences would help other women who have epilepsy.

Danielle is not ready to have a child so she uses the IUD.

At 20 Danielle was diagnosed with non-convulsive seizures. Not sure if she wanted children in the future, she asked her neurologist for birth control advice. Danielle learned that her epilepsy medications can interfere with many hormonal birth control methods. She decided to use a non-hormonal intrauterine device—or IUD for short. She is happy the IUD does not affect her seizures and is one of the best birth control methods to prevent pregnancy. She said, “I really like this IUD because it is non-hormonal and...you don’t have to deal with it on a daily basis and whatnot.... I think the IUD is great.”

Kelsey uses the pill to regulate her periods and reduce her seizures.

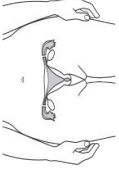
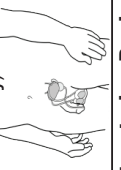


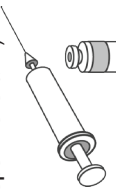


Kelsey was diagnosed with epilepsy when she was very young. At age 29 she continued to have frequent convulsive seizures. She noticed her period was irregular and that her seizures increased around her period. Kelsey asked her neurologist and her gynecologist for advice. They worked together to find a birth control method that would help Kelsey regulate her period and reduce her seizures. Kelsey tried a few different brands of pills and then found one that worked for her. She said, “Being on the pill helps me not have seizures during that time of the month ‘cause that’s one of the times that I’m more likely to get seizures.”


Courtney tried several birth control methods before finding the right one for her.

Courtney was 17 when she was diagnosed with non-convulsive seizures. By the time she was 30 Courtney had tried several epilepsy medications. She also had brain surgery. Then she finally got her seizures under control. But she had trouble finding birth control that worked. She said, “I tried several different birth control pills trying to find one that would work and really agree with me... but, I got pregnant.” Courtney was upset her doctor had not warned her that her epilepsy medication and birth control pills may not work together. She ended up having a miscarriage. After that, she and her husband decided to use condoms.

Wendy’s husband had a vasectomy to permanently prevent pregnancy.

At 35 Wendy had been living with epilepsy for 17 years. Despite taking epilepsy medications, she continued to have both convulsive and non-convulsive seizures several times a week. Wendy and her husband had one teenager. They decided not to have more children because they did not want to do anything that might increase Wendy’s seizures. They decided vasectomy was a good option because it prevents pregnancy and does not affect Wendy’s seizures. She said of their decision, “It was mutual.... After we weighed all the pros and cons, we knew it was something that we had to do.”

Birth Control Method	# of Pregnancies Expected per 100 Women per Year	Benefits	Risks	Considerations for Women with Epilepsy
Female Sterilization (Tubal ligation) 	1	<ul style="list-style-type: none"> One-time procedure Very safe Very effective No lasting side effects Helps protect against pelvic inflammatory disease 	<ul style="list-style-type: none"> Permanent decision that must be carefully considered Does not protect against HIV or other STDs/STIs 	<ul style="list-style-type: none"> Female sterilization does not affect seizure activity Epilepsy medications do not affect efficacy of sterilization
Male Sterilization (Vasectomy) 	1	<ul style="list-style-type: none"> One-time procedure Very safe Very effective No lasting side effects 	<ul style="list-style-type: none"> Permanent decision that must be carefully considered Does not protect against HIV or other STDs/STIs 	<ul style="list-style-type: none"> Male sterilization does not affect seizure activity Epilepsy medications do not affect efficacy of sterilization
Intrauterine Devices (IUD, Mirena™, ParaGard™) 	1	<ul style="list-style-type: none"> Easy to use Mirena: use up to 7 yrs, reduces cramps and bleeding Paragard: use up to 12 yrs, non-hormonal method Helps protect against endometrial cancer Fertility returns quickly after IUD removal Can be used while breastfeeding 	<ul style="list-style-type: none"> Mirena may cause spotting between periods for first 3-6 months Paragard may increase cramps and cause heavier bleeding Does not protect against HIV or other STDs/STIs 	<ul style="list-style-type: none"> IUDs do not affect seizure activity Epilepsy medications do not affect the efficacy of the IUD
The Implant (Implanon) 	1	<ul style="list-style-type: none"> Lasts up to 3 years Helps protect against pelvic inflammatory disease Fertility returns quickly after removal Can be used while breastfeeding 	<ul style="list-style-type: none"> May cause irregular bleeding (spotting, no periods, heavy periods) May cause headaches, abdominal pain, weight changes, breast tenderness, dizziness, nausea, and mood changes Does not protect against HIV or other STDs/STIs 	<ul style="list-style-type: none"> It is unknown how the implant affects seizure activity Some epilepsy medications may decrease the efficacy of the implant
The Shot (Depo-Provera™) 	1 - 3	<ul style="list-style-type: none"> Each shot works for 12 weeks Helps protect against endometrial cancer Can be used while breastfeeding 	<ul style="list-style-type: none"> May cause spotting, no period, hair or skin changes, weight gain, headaches, dizziness, abdominal bloating and discomfort, mood changes, or change in sex drive Does not protect against HIV or other STDs/STIs 	<ul style="list-style-type: none"> Use of the shot may help decrease seizure activity⁵ Epilepsy medications do not affect the efficacy of the shot
The Ring (Nuvaring™) 	1 - 8	<ul style="list-style-type: none"> Inserted once a month Can make periods more regular and less painful Ability to become pregnant returns quickly after stopping the ring 	<ul style="list-style-type: none"> Can increase headaches, vaginal discharge, and vaginitis May cause spotting the first 1-2 months of use Does not protect against HIV or other STDs/STIs 	<ul style="list-style-type: none"> It is unknown how the ring affects seizure activity Some epilepsy medication may decrease the efficacy of the ring
The Patch (Ortho Evra™) 	1 - 8	<ul style="list-style-type: none"> Applied once a month Can make periods more regular and less painful Ability to become pregnant returns quickly after stopping the patch 	<ul style="list-style-type: none"> Can irritate skin under the patch, cause headaches, nausea, vomiting, breast tenderness, vaginitis, and abdominal pain May cause spotting the first 1-2 months Does not protect against HIV or other STDs/STIs 	<ul style="list-style-type: none"> It is unknown how the patch affects seizure activity Some epilepsy medication may decrease the efficacy of the patch

Combined-oral Contraceptives (COCs, the pill) 	<p>1 - 8</p>	<ul style="list-style-type: none"> • May make periods more regular and less painful, improve PMS symptoms, decrease acne, lower risk of endometrial cancer, protect against pelvic inflammatory disease, and decrease symptoms of endometriosis and PCOS • Ability to become pregnant returns quickly after stopping the pills 	<ul style="list-style-type: none"> • May cause nausea, weight gain, headaches, breast tenderness, dizziness, nausea, mood changes, and change in sex drive – but these can be relieved by changing to a new brand • May cause spotting the first 1-2 months • Does not protect against HIV or other STDs/STIs 	<ul style="list-style-type: none"> • Mixed evidence for impact of COCs on seizure activity—some studies show no impact, others an increase, and still others a decrease⁶ • Some epilepsy medications may decrease the efficacy of COCs
Progestin-only Pills (POPs, the mini-pill) 	<p>3 - 9</p>	<ul style="list-style-type: none"> • Ability to become pregnant returns quickly after stopping the pills • Can be used while breastfeeding 	<ul style="list-style-type: none"> • Often cause spotting, which may last for many months • May cause headaches, dizziness, mood changes, breast tenderness, abdominal pain, and nausea • Does not protect against HIV or other STDs/STIs 	<ul style="list-style-type: none"> • Use of POPs with some epilepsy medications may increase seizure activity⁵ • Some epilepsy medications may decrease the efficacy of POPs
Diaphragm 	<p>6 - 16</p>	<ul style="list-style-type: none"> • Can last several years • May protect against some STDs/STIs (NOT HIV) • Can be used while breastfeeding 	<ul style="list-style-type: none"> • Frequent use of spermicide nonoxonyl-9 may raise the risk of getting HIV • Raises risk of bladder infection 	<ul style="list-style-type: none"> • The diaphragm does not affect seizure activity • Epilepsy medications do not affect the efficacy of diaphragms
Male Condom 	<p>2 - 15</p>	<ul style="list-style-type: none"> • Available over the counter • Protects against HIV and other STDs/STIs • Can be used while breastfeeding 	<ul style="list-style-type: none"> • Can decrease sensation • Can break or slip off 	<ul style="list-style-type: none"> • Condoms do not affect seizure activity • Epilepsy medications do not affect the efficacy of condoms
Female Condom 	<p>5 - 21</p>	<ul style="list-style-type: none"> • Available over the counter • Protects against HIV and other STDs/STIs • Can be used while breastfeeding 	<ul style="list-style-type: none"> • May be noisy • May be hard to insert • May slip out of place during sex 	<ul style="list-style-type: none"> • Female condoms do not affect seizure activity • Epilepsy medications do not affect the efficacy of female condoms
Fertility-based Awareness Methods 	<p>25</p>	<ul style="list-style-type: none"> • No side effects • Does not involve taking or applying any medication • Can be used while breastfeeding 	<ul style="list-style-type: none"> • One of the least effective methods if used incorrectly • Does not protect against HIV or other STDs/STIs 	<ul style="list-style-type: none"> • Fertility-based awareness methods do not affect seizure activity • Epilepsy medications do not affect the efficacy of fertility-based awareness methods
Emergency Contraception (Plan B® One-Step, Next Choice™, etc.) 	<p>Cuts risk by 75 - 95%</p>	<ul style="list-style-type: none"> • Available at many pharmacies, health centers, or health care providers if 17 and over • Can be used while breastfeeding • Must be used within 72 hours of unprotected intercourse to achieve 75% reduction in risk of becoming pregnant 	<ul style="list-style-type: none"> • May cause nausea, vomiting, spotting or bleeding • Does not protect against HIV or other STDs/STIs 	<ul style="list-style-type: none"> • It is unknown how emergency contraception affects seizure activity • Some epilepsy medications may decrease the efficacy of emergency contraception
Spermicide (Cream, gel, sponge, foam, inserts, film) 	<p>15 - 29</p>	<ul style="list-style-type: none"> • Available over the counter • Can be used while breastfeeding 	<ul style="list-style-type: none"> • Frequent use may raise the risk of getting HIV • May irritate vagina, penis • Cream, gel, and foam can be messy 	<ul style="list-style-type: none"> • Spermicide does not affect seizure activity • Epilepsy medications do not affect the efficacy of spermicide

All images, rates of efficacy, benefits, and risks from Reproductive Health Access Project, 2012 or World Health Organization, 2012. All considerations for women with epilepsy from CDC, 2010 unless otherwise noted.

Weighing Your Birth Control Options

The following exercise is designed to help you think through what is most important to you when starting or picking a birth control method. Below you will find things women with epilepsy think about when making birth control decisions. Please circle a number to show how important these things are to you.

How important to you is.....

	not at all important				extremely important
1. How often you have to take or use your birth control (frequency)?	1	2	3	4	5
2. The potential that a birth control method affects your seizures?	1	2	3	4	5
3. The possible benefit that your birth control could help regulate your period?	1	2	3	4	5
4. Whether you need a prescription from your doctor to get your birth control?	1	2	3	4	5
5. How well your birth control will prevent pregnancy?	1	2	3	4	5
6. Protection from sexually transmitted infections and HIV?	1	2	3	4	5
7. Choosing a birth control that your sex partner(s) is OK with?	1	2	3	4	5
8. Cost and/or insurance coverage for birth control?	1	2	3	4	5

9. What other benefits of birth control are important to you? (Please specify any other benefits and rate their importance to you.)

a. _____

b. _____

c. _____

10. What other reasons are important to you when thinking about why you might not want to take birth control? (Please specify any risk you have considered and rate their importance to you.)

a. _____

b. _____

c. _____

Use this space to list the things that you rated highly (4 or 5).

You can use these results to talk with your doctor about what is important to you. You can also show the results to other people in your life who are part of your birth control decisions.

Talking with Your Doctors

The most important thing to remember when talking with doctors is that you are the expert on you. Your participation and input are essential. Keep your doctor up to date about your desire for birth control or pregnancy. That way she or he can provide you with the best care possible.

Which doctor you talk to about birth control is up to you. Some women like to talk to a gynecologist. Others talk with their neurologist. And still other women reach out to their primary care physician or a nurse who is an expert in birth control issues. You could talk to just one of your doctors or to everyone on your health care team. You might have to search to find the right doctor who can help you with your birth control decisions. If your doctor says that there are no good birth control options for women with epilepsy, or you are unhappy with your doctor for other reasons, you can:

- Use this guide to start a conversation with your doctor about your birth control needs;
- Switch to a new doctor who might be more helpful; or
- Add another doctor to your health care team who can help you with your birth control decisions.

The important thing is to pick a doctor that you trust, who listens, and who can help you. Your doctor's answers to the questions in the checklist below can help you figure out if you have found the best doctor for you.

Questions For Your Doctor

This checklist will help you keep track of questions to ask your doctor. Be sure to add your own questions to the list as well.

- Some doctors are not sure how to help women with epilepsy pick a birth control method. What experience do you have helping women with epilepsy pick a birth control method that works for them?
- Some women with epilepsy like to work with a team of doctors, like a neurologist and a gynecologist. What is your experience working with other health care providers to find a birth control method that will work for women with epilepsy?
- One part of deciding to start birth control is deciding whether to have children. What are the risks involved with pregnancy or raising a child for me?
- I know there might be a relationship between my hormones and seizures, but I would like to learn more about it. How are hormones and seizures related?
- Given the relationship between my hormones and seizures, how might my period affect my seizures? What types of birth control can help with seizures that occur around my period? What types of birth control can help with any problems I have with my period?
- Birth control methods have lots of benefits and risks. What can you tell me about the benefits and risks of different birth control methods?
- Some types of birth control interact with some epilepsy medications. What can you tell me about interactions between my epilepsy medications and different birth control methods?
- Some women's seizures get worse when they use hormonal birth control, some women's get better, and some women's seizures are not affected. What can you tell me about how my seizures might be affected by using hormonal birth control?
- I have thought about my birth control preferences (as shown in the Weighing Your Birth Control Options exercise). What birth control method will meet the preferences I have picked?
- Other _____
- Other _____

My Support

Doctors are not the only ones who can support you in your decision to start or pick out a birth control method. Your partner, friends, family, and other women with epilepsy could all be important sources of support. Use the space below to write down the people whose opinions matter most to you when you make these decisions:

For More Information



Ibis Reproductive Health aims to improve women's reproductive autonomy, choices, and health worldwide. To learn more about the research on the reproductive health of women with epilepsy that helped create this guide, you can contact Ibis.

Phone: (617) 349-0040

Email: admin@ibisreproductivehealth.org

Website: www.ibisreproductivehealth.org



The Epilepsy Foundation of America[®] works to ensure that people with seizures are able to participate in all life experiences. They have a number of resources about how epilepsy affects women, including information on birth control, pregnancy, and parenting for women with epilepsy. To learn more about their programs, or to connect with other people with epilepsy, you can contact the Epilepsy Foundation.

Phone: 1-800-332-1000

Email: ContactUs@efa.org

Website: <http://www.epilepsyfoundation.org/index.cfm>

References

1. Harden CL, et al. Management issues for women with epilepsy-Focus on pregnancy (an evidence-based review): I. Obstetrical complications and change in seizure frequency: Report of the Quality Standards Subcommittee and Therapeutics and Technology Assessment Subcommittee of the American Academy of Neurology and the American Epilepsy Society. *Epilepsia*. 2009;50(5):1229-36.
2. Harden CL, et al. Management issues for women with epilepsy-Focus on pregnancy (an evidence-based review): II. Teratogenesis and perinatal outcomes: Report of the Quality Standards Subcommittee and Therapeutics and Technology Subcommittee of the American Academy of Neurology and the American Epilepsy Society. *Epilepsia*. 2009;50(5):1237-46.
3. The American College of Obstetricians and Gynecologists (ACOG). Frequently asked questions about contraception. ACOG. 2011. Available from: <http://www.acog.org/~media/For%20Patients/faq021.pdf?dmc=1&ts=20120221T1257021614>.
4. Centers for Disease Control and Prevention (CDC). U.S. medical eligibility criteria for contraceptive use, 2010. *Morbidity and Mortality Weekly Report (MMWR)* 2010. Available from: <http://www.cdc.gov/mmwr/preview/mmwrhtml/rr59e0528a1.htm>.
5. Dutton C, Foldvary-Schaefer N. Contraception in women with epilepsy: pharmacokinetic interactions, contraceptive options, and management. *International Review of Neurobiology*. 2008;83:113-34.
6. Reddy, DS. Clinical pharmacokinetic interactions between antiepileptic drugs and hormonal contraceptives. *Expert Review of Clinical Pharmacology*. 2010;3(2):183-192.
7. Reproductive Health Access Project. Fact sheets. 2012. Available from: http://www.reproductiveaccess.org/fact_sheets.htm.
8. World Health Organization (WHO). Decision-making tool for family planning clients and providers. WHO. 2005. Available from: http://www.who.int/reproductivehealth/publications/family_planning/9241593229/index/en/index.html.