

Women and Epilepsy



Artwork by Studio E participant
Cadence DuBois (details on inside cover)



About the Cover:

Candace DuBois, a Studio E participant with the Epilepsy Foundation of Idaho, created the cover artwork. Studio E is a multi-week art program open to people with epilepsy. Participants use art to creatively express themselves, build confidence, and make friends. Living with epilepsy can be challenging; art therapy may be beneficial in working through how the condition impacts an individual's life. Find out more about the program and where it's available at www.epilepsy.com.

Reflecting upon her artwork, Candace says, "It's nice to feel a sense of community and openness. It was nice to have my doctors here to show support."

Disclaimer:

This publication is designed to provide general information about epilepsy and seizures to the public. It is not intended as medical advice. People with epilepsy should not make changes to treatment or activities based on this information without first consulting their health care provider..



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Women and Epilepsy

If you're living with epilepsy, you probably know a lot about seizures already. As a woman with epilepsy, you may have specific concerns. For example, your hormones and your period (menstrual cycle) may be affecting your seizures. You may want to know more about getting pregnant or going through menopause.

Each woman with epilepsy is different. Knowing about possible issues ahead of time can be helpful. The more information you have, the better you can work with your health care team to stay healthy and control your seizures.

Keep track of your period and seizures.

The hormones that regulate your menstrual cycle can also affect your seizures. Hormones are chemicals in your body that help control things like hunger, sleep, stress, and sexual desire.

Female hormones called estrogen and progesterone control your menstrual period. The amount of these hormones in your body changes during the 28 days or so from one period to the next.

- Changes in the balance between estrogen and progesterone during the menstrual cycle may affect seizures in some women.
- Some women notice more seizures just before or after menstrual bleeding starts.
- Other women may have more seizures when they ovulate, about two weeks before each period.
- If you notice your seizures changing around your menstrual cycle, talk to an epilepsy specialist. Making changes in your seizure medicine or checking hormone levels may help.

Talk with your health care team about your bone health.

It's important to have strong bones throughout our lives. Having weak or thin bones makes it more likely that you will break a bone if you fall.

Some women with epilepsy are at higher risk for having weak bones. This is because some seizure medicines can weaken your bones over time. Your bone strength is also effected by many things, including how much weight-bearing exercise you get, smoking, diet, age, and family history. In women, bones also get weaker after menopause (when menstrual periods stop).

If you are worried about your bone health, talk with your health care provider. Ask if you need to take a calcium supplement, a vitamin D supplement, or other medicine for your bones. You may also want to ask about getting a test to measure the strength of your bones.



Take these steps to keep your bones strong.

Do weight-bearing exercise regularly, like jumping, jogging, weight-lifting, and walking with a weighted vest or backpack. Start with light weights and slow jogging and increase slowly. Check with your health care provider before starting any exercise program.

Get plenty of calcium. The best way to get calcium is to eat foods that are high in calcium. Dairy products (like milk, cheese, and yogurt) and green, leafy vegetables (like broccoli, collards, and kale) as well as fortified products such as orange juice, plant milk, and cereal are good sources. Some women also take calcium supplements (pills), but it's important not to take too much. Check with your health care provider if you're not sure how much you need.

Get enough vitamin D. Many people don't get enough vitamin D, and some seizure medicines can lower your vitamin D level. Ask your health care provider about a blood test to find out if you need to take a vitamin D supplement.

Get your bones tested. A bone density test may help guide your treatment. Ask

your health care provider when and how often this should be done.

Choose a birth control method that works for you.

If you want to use birth control (contraception), be sure to choose a method that works well for you. In the United States, hormone-containing birth control pills are the most popular form of contraception. Other methods of birth control — like a vaginal ring, a shot, or an implant that goes in your arm — also use hormones. Condoms, (male or female), the cervical cap, the diaphragm, and the sponge do not use hormones; they may not be as good at preventing pregnancy. An intrauterine device (“IUD”) is a very effective form of birth control; some types do not rely on hormones, other types do. No one



method of contraception is right for everyone.

It's important to know that some seizure medicines can make hormonal birth control methods less effective at preventing pregnancy. If you are taking one of these, talk with your health care provider. You may decide to.

- Use a diaphragm or condom in addition to birth control pills
- Change your seizure medicine
- Use an intrauterine device (IUD) that does not contain hormones.

If you are on lamotrigine and you are going to start or stop taking a birth control pill, tell your health care provider who may need to adjust your dose to avoid having a seizures or getting side effects.

Ask your primary care, OB/GYN, and neurology providers to work together for the best care for your epilepsy when thinking about birth control.

Find out how menopause may affect your seizures.

Menopause causes a decrease in the level of female hormones in your body which causes your monthly periods to slow down and then stop. This usually happens between ages 45 and 55, but some women with epilepsy go through it earlier. As women reach menopause, the changing levels of estrogen and progesterone can cause some women to have more seizures.

If you're going through menopause and your seizures are getting worse, check with your health care provider. You may need to try another seizure medicine or change the amount of medicine you take.

If you have many hot flashes and other problems during menopause, your health care provider may suggest hormone replacement therapy (HRT) to help you feel better. HRT is not right for everyone and may cause some women to have more seizures.

Menopause is not the only thing that can cause you to have more seizures as you get older. If you notice any change in your seizures, be sure to talk with your health care provider about them.

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Changes in your hormone levels during menopause may cause you to have more seizures, fewer seizures, or no change in seizures at all.

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Pregnancy and Parenting

Most women with epilepsy can have normal pregnancies and healthy babies. You will need to take some extra steps to stay healthy, control seizures, and keep the baby safe.



If you have epilepsy, your children will have a slightly higher chance of developing epilepsy compared with kids whose parents do not have epilepsy. Still, it is much more likely that your children **will not** develop epilepsy. If you're worried, ask your health care provider about talking to a genetic counselor.

Talk with your health care provider before getting pregnant.

Before you get pregnant, make an appointment to see your health care provider. Having a seizure while you are pregnant could be dangerous for you and your unborn baby. So, controlling your seizures through some kind of treatment is very important. It is also important to know that some seizure medicines may increase a baby's risk of birth defects (problems with physical or intellectual development). You and your health care provider can talk about the risks and benefits of taking your current seizure medicine during pregnancy. Your health care provider may be able to lower chances of birth defects by lowering the dosage or number of medications you use before you get pregnant.

Ask your health care team about ways to lessen your baby's risk of birth defects, such as:

- Taking fewer medicines, if you currently take more than one
- Taking a lower dose of seizure medicine
- Switching to a different seizure medicine that is safer for the baby

- Stopping your seizure medicine (if your seizures are well controlled)

Also, ask your health care provider if you need to take prenatal vitamins or folic acid (also called folate) before or during pregnancy.

Changes in your body during pregnancy can change the way seizure medication is absorbed. You may need to regularly check the level of medicine in your blood or make changes in the amount of medicine you take.

Some women will need to increase their dose of medicine during pregnancy. If this is true for you, remember to ask your health care provider about whether you need to change it back after you give birth.



Never stop taking seizure medicine on your own — even if you think you are pregnant. Always check with your health care provider first.

If you are having trouble getting pregnant, talk with a specialist.

If you have been trying to have a baby for a long time, see a fertility specialist who is familiar with treating women with epilepsy to find out why you are having trouble getting pregnant.

The most common cause of infertility in North America is called polycystic ovary syndrome (PCOS), a health condition that affects a woman's hormones and fertility. Women with epilepsy are more likely to have PCOS than women who do not have epilepsy.

Having PCOS means that your ovaries may not release an egg every month which makes it harder to get pregnant.

These are some of the signs of PCOS:

- Irregular, heavy periods
- Weight gain, especially in your belly
- Hair growth on your face and body
- Acne or pimples and oily skin

If you have noticed these signs, talk to your health care provider. Tests may be done to see if you have PCOS or other reasons for infertility. If you do have PCOS, your health care provider may suggest a change in seizure medicine or give you a hormone medicine to help.

Have a healthy and safe pregnancy.

Take these steps during pregnancy to keep you and your baby healthy and safe.

- Eat healthy foods, stay active, and get enough sleep.
- Take the vitamins your health care provider recommends, including folic acid.
- Take steps to prevent seizures. Know and avoid your seizure triggers — and take your seizure medicine every day.
- If your seizures make you fall, avoid stairs and high places as much as possible.
- Make the most of your health care provider visits. Ask questions and share any concerns you have.
- Get your blood tests on time.
- Make a plan for how you will safely care for your new baby.
- Ask for help if you need it — having a new baby is exciting, but it can also be stressful.

Talk with your doctor about breastfeeding your baby.

Most women with epilepsy who take seizure medicines can breastfeed. There may be some seizure medicine in your breast milk, but it's a smaller amount than the baby got from your blood during pregnancy.

Talk to your doctor about the benefits and possible risks of breastfeeding. Your doctor may suggest you don't breastfeed if you are taking a medicine that could make the baby too sleepy.

If not getting enough sleep is a seizure trigger for you, keep in mind that breastfeeding can interfere with your sleep. Your doctor may suggest you bottle feed instead. Or you may be able to breastfeed during the day and have your spouse or another family member feed the baby with a bottle at night so you can sleep.

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To make breastfeeding easier, I kept my daughter in a crib next to my bed at night. Sometimes I also used a breast pump before going to bed so my husband could feed the baby breast milk from a bottle while I slept.

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Take steps to keep your baby safe.

There are many things you can do to keep yourself and your baby safe. Depending on the type of seizures you have, you may not need to take all these steps. Your doctor or nurse may also suggest some other steps for you to take.

To care for your baby safely:

- Give the baby a sponge bath on the floor when you're alone.

- Only give the baby a bath in a baby tub when other people are with you.
- Sit on the floor to feed the baby.
- Change the baby on a pad on the floor.
- Warm the bottle in the kitchen and bring it to the baby in another room.
- Use a stroller to move the baby from room to room.
- Take extra care to childproof your house.
- Don't be afraid to ask for help!

Remember, these are just examples of ways to keep your baby safe. Based on the type of seizures you have and how well your seizures are controlled, you and your doctor can decide which steps make sense for you.

To learn more about women and epilepsy, visit <http://www.epilepsy.com/women> or call 1-800-332-1000.

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About the Epilepsy Foundation

The Epilepsy Foundation, and its network of 50 organizations throughout the United States, leads the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures, and save lives. As an unwavering ally for individuals and families affected by epilepsy and seizures, the Epilepsy Foundation connects people to treatment, support and resources; leads advocacy and awareness efforts; funds innovative research and the training of specialists; and educates the public about epilepsy, Sudden Unexpected Death in Epilepsy, and Seizure First Aid. To learn more, please visit epilepsy.com.



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