

Thinking about the future?



FEMALE LIFESTAGES

AND THE EFFECTS OF EPILEPSY

Thinking Ahead Throughout the Lifestages

Epilepsy and its treatment may impact many aspects of the lives of females—from puberty and family planning to menopause.

It's important for you to consider your future plans now, and discuss them with your doctor. So whether you're—

- A teenage girl with a busy schedule
- A young woman hoping to start a family
- A mature woman with a lot to look forward to—this document is designed to help you learn more about your special needs.

Start by Talking to Your Doctor Now

Since people with epilepsy tend to stay on the same medicine for a long period of time, it is especially important to discuss your long-term plans with your doctor now. Even if you're planning to have a family 5 years from now or if menopause is 10 years away, it is never too soon to consider how your epilepsy and the medicines you take to manage your seizures might impact those stages of life.

1. THE HORMONE SEESAW

Female Differences: The Hormone Seesaw

In males, masculine traits (beard growth, voice pitch, etc) are controlled by a fairly constant level of one male hormone called testosterone. In females, however, hormone levels are not constant.

Your reproductive system—all the parts of your body that allow you to have children—is controlled by several female hormones. Two of these, estrogen and progesterone, are especially important. Every month, the levels of estrogen and progesterone go up and down to prepare your body for pregnancy or for menstrual periods. They also affect the nerve cells in your brain.

Estrogen and Progesterone May Affect Your Seizures

As hormone levels go up and down, seizure patterns may change:

- More estrogen may increase seizure frequency
- More progesterone may decrease seizure frequency

Seizures Can Affect Your Hormones

A female with epilepsy is more likely than other women to have problems with her menstrual cycles and fertility. You will learn more about how this works in the next 2 sections.

Anti-Seizure Medicine

Some anti-seizure medicines may lower the amount of the female hormones in your body. Also, some anti-seizure medicines may affect hormones that regulate bone health, leading to thinning of the bones (related to osteoporosis).

Birth Control

Certain types of birth control work by using female hormones to prevent pregnancy. These types of birth control include:

- The daily "pill"
- The vaginal ring
- The weekly patch
- Under-the-skin implants
- A shot given in the doctor's office on a regular basis
- IUDs that include progestin

These treatments work by providing hormones (estrogen and/or progesterone), which prevent the ovaries from releasing an egg, or interfere with the fertilization of the egg. Since some anti-seizure medicines reduce the level of estrogen, this may mean that there is not enough estrogen for these forms of birth control to work properly, which can result in unplanned pregnancy.

If you currently are or want to start using any forms of birth control listed above, ask your doctor about the best treatment plan for you.

Balancing Female Hormones and Epilepsy

As you can see, every female with epilepsy has to balance 3 important concerns:

- Female hormones may affect seizures
- Seizures may affect female hormones
- Some anti-seizure medications can affect female hormones

Important Turning Points in Your Life

At certain times in every female's life, the levels of estrogen and progesterone—and the balance between them—suddenly change. These changes may have a greater impact than usual on the lives of females with epilepsy.

- Puberty
- Menstruation
- Pregnancy
- Menopause

Each turning point is a time to evaluate your health. That's why having a strong relationship with your doctor is so important. To help you enjoy a full life at every age, your doctor needs you as a partner. You are the only one who can describe your day-to-day experiences.

A calendar can help you keep track of seizure activity, side effects, your menstrual cycle, and other events that may affect your seizures. The more you know about the changes to expect in your body at every stage of life, the more help you can offer.

2. PUBERTY CHANGES YOUR BODY

Many Americans with epilepsy will experience their first seizure before the age of 18. That means many people have to manage their seizures while they are also going through puberty.

Puberty is the specific period of time when physical differences between girls and boys suddenly become obvious.

For a young girl, puberty begins when the brain sends a message to her ovaries. The ovaries and other organs react by making hormones. Hormones are chemicals that travel through the bloodstream to reach all parts of her body. She becomes taller and her breasts begin to develop. In fact, her whole body soon changes into a grown-up shape. When a girl has her first menstrual period, puberty is almost complete.

→ DID YOU KNOW...

- **PUBERTY** is a period of time during which specific changes occur in the body; these changes are triggered by hormones
- **IN AMERICAN** girls, puberty may begin as early as age 7
- **ADOLESCENCE** is the stage of development between puberty and maturity

Puberty and Epilepsy

At this age, every girl wants to get good grades, be popular with other kids, and be independent. If you're a teenager, you're also very sensitive to the rapid changes in your body. Almost overnight, you change from a "little girl" into a fully developed woman. You worry a lot about your appearance: Your face. Your hair. Your weight. When you have epilepsy, these normal concerns are magnified and can cause serious problems.

Side effects from some anti-seizure medicines, for example, may include menstrual irregularity, weight gain, unwanted hair growth, and feeling tired or "out of it." It's no surprise that some girls will want to stop taking their medicine, or may "forget" to take them.

Breakthrough Seizures

Skipping or stopping medications can lead to increased seizure frequency. Common teenage behaviors can also create physical stress, which in turn may increase the risk of breakthrough seizures.

- Staying up late (lack of adequate sleep)
- Experimenting with alcohol or drugs
- Cramming for tests

Most doctors want to see teenage girls more often during this time of life. At this age, an increase in dosage may be needed to ensure effective seizure control during growth spurts. The goal is to manage possible changes in seizure pattern and also reduce side effects.

3. PLANNING FOR PREGNANCY

Females with epilepsy face possible challenges around pregnancy:

- You may find it difficult to become pregnant
- If you are pregnant, seizure frequency may increase
- Your risk of pregnancy- and delivery-related complications, premature labor, and cesarean delivery (surgery to deliver a baby from the uterus) are somewhat greater

→ DID YOU KNOW...

- **TAKING** only one anti-seizure medicine (monotherapy) may lower the risk of birth defects during pregnancy
- **BEFORE** you get pregnant, or especially if you are already pregnant, make sure that your epilepsy healthcare professional and OB-GYN discuss the best treatment plan for you

Plan Ahead

Before getting pregnant, be sure to ask your doctor about all of the medicines you are taking. Also, to help reduce the risk of certain birth defects, it can be beneficial to take vitamins with folic acid prior to and throughout pregnancy. After you become pregnant, be sure to visit your doctor often to help ensure a successful pregnancy.

Ask About Joining a Pregnancy Registry

Many questions remain about the effects of epilepsy and anti-seizure medicines on pregnancy. If you are pregnant or plan to become pregnant and take anti-seizure medicine, you can help. Ask your doctor to enroll you in an antiepileptic drug (AED) pregnancy registry specific to your medicine.

The purpose of AED pregnancy registries is to keep track of problems that may occur while taking an AED during pregnancy. Your name and other personal information are kept confidential. It's important to enroll as soon as possible after getting pregnant.

The information collected in the pregnancy registry can inform doctors so they can help protect the future health of other females with epilepsy—and their babies. The more females who enroll, the more answers researchers will have.

→ HOW TO ENROLL IN A PREGNANCY REGISTRY

- **ASK** your doctor for information about a pregnancy registry specific to your anti-seizure medicine
- **YOU** can learn about the North American Pregnancy Registry by visiting www.massgeneral.org/aed or enroll by calling toll-free: 1-888-233-2334

4. MENOPAUSE JUST WHEN YOU HAD IT ALL FIGURED OUT

What most people call “menopause” is actually divided into 3 stages:

- Perimenopause—the several years leading up to menopause. Perimenopause often starts when a female is in her early 40s
- Menopause—when menstruation has stopped completely. The average age of menopause is 51, although some females with epilepsy may enter menopause at an earlier age
- The stage following the final menstrual period is called postmenopause. For about 5 years, hormone production continues to fall until it reaches a permanent level. Bone loss can accelerate during this time

Female Hormones Start to Fall

During perimenopause, the ovaries gradually begin to make less estrogen and progesterone. Blood levels of the 2 hormones start falling, often in a kind of seesaw pattern. For females with epilepsy, this erratic reduction in one hormone, then the other, can have dramatic effects:

- Seizure frequency may increase or decrease
- Medicines may have to be changed
- Ovulation is unpredictable; unplanned pregnancy can occur

Epilepsy After Menopause

Unfortunately, epilepsy has no age limit. In fact, about 25% of all new cases occur in females and males over the age of 60, possibly due to age-related changes in blood flow through the brain. Blood flow to the brain may be reduced in older persons because of hardening of the arteries, which may be caused by high cholesterol, high blood pressure, diabetes, and smoking. Seizures in aging adults may also be related to stroke, heart attack, brain surgery/tumors, and degenerative diseases such as Alzheimer’s disease.

If you first develop epilepsy in your later years, you may already be taking several medicines for other health problems—such as high blood pressure or elevated cholesterol. It’s important to talk to your doctor to make sure that other medicines or dietary supplements you may be taking will not interfere with your anti-seizure medicine.

DID YOU KNOW...

- **BONE** loss, meaning your bones become less dense, may occur earlier in females who take certain anti-seizure medications long-term
- **SEVERE** bone loss can lead to a dangerous condition called osteoporosis, in which thin, brittle bones may break easily
- **IT’S IMPORTANT** for females with epilepsy to take extra calcium and to exercise throughout their lives to preserve bone health

Please take the time to answer the questions to the right, and discuss your responses with your doctor.



- The Treatment Satisfaction Questionnaire can help your doctor develop a treatment plan that’s right for you. It asks you questions about problems people with epilepsy may potentially experience. Some of these may be symptoms of epilepsy itself, others may be related to the medication you take for your seizures, and still others may be unrelated

NOTES

WOMEN AND GIRLS WITH EPILEPSY HAVE SPECIAL NEEDS

By providing your doctor with more information about you, you can help him or her select a treatment that’s right for you. If any of the following circumstances apply to you, now or in the near future, please talk to your doctor:

- Entering puberty
- Having irregular periods
- Becoming sexually active
- Using birth control
- Planning a pregnancy
- Going through menopause

If you do become pregnant

- Tell your doctor immediately; together you can make a plan to manage your seizures during and after pregnancy
- Ask your doctor about how you can enroll in a pregnancy registry

TREATMENT SATISFACTION QUESTIONNAIRE

Name	Date		
		yes	no
1. Do you feel that your seizures are adequately controlled? <i>Specify:</i>		<input type="radio"/>	<input type="radio"/>
2. Are you having difficulty thinking clearly? <i>(For example, problems concentrating, communicating, or remembering things)</i> <i>Specify:</i>		<input type="radio"/>	<input type="radio"/>
3. Are you bothered by changes in your physical appearance? <i>(For example, changes in weight, hair loss or unusual hair growth, acne or rash, gum problems)</i> <i>Specify:</i>		<input type="radio"/>	<input type="radio"/>
4. Are your feelings or moods out of the ordinary? <i>(For example, sadness, anger, nervousness, too much or too little energy)</i> <i>Specify:</i>		<input type="radio"/>	<input type="radio"/>
5. Do you find that you have problems with coordination? <i>(For example, you feel dizzy or unsteady)</i> <i>Specify:</i>		<input type="radio"/>	<input type="radio"/>
6. Do any of the above symptoms you described or other problems you may be experiencing interfere with your daily activities or life goals? <i>(For example, it has affected your job performance, schoolwork, or your relationships with family or friends)</i> <i>Specify:</i>		<input type="radio"/>	<input type="radio"/>