



WOMEN + EPILEPSY Initiative

HORMONES & YOU



Information
for Women
with
Epilepsy



EPILEPSY FOUNDATION®

Not another moment lost to seizures™

This pamphlet is intended to provide basic information about hormones in epilepsy to the general public. It is not intended to be, nor is it, medical advice. Readers are warned against changing medical schedules or life activities based on this information without first consulting a physician.

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Hormones & You

"Doctor, I'm sure that my periods have something to do with my seizures. Right before my period, every time, I have a seizure. Why is that?"

Does that question sound familiar?

Does it sound like something you've said, or you've heard a friend say?

The fact is, it's a question that some women have been asking for a long time. Often, the answer has been:

"We just don't know why your seizures are happening around your period."

"It's probably a coincidence."

But things have changed.

Now when women with epilepsy ask why seizures happen right around their periods, the answer is more likely to be:

"Hormones!"

Hormones? Yes. Scientists have found out that some female hormones can trigger seizures. Others may prevent them.

Even more surprising, we're learning that seizures themselves can affect hormones.

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Scientists have found out that some female hormones can trigger seizures.

Just two more reasons why epilepsy affects women in so many different ways.

A Special Kind of Epilepsy

When seizures almost always happen at the same point in a woman's monthly cycle, it's likely that hormones are involved.

Doctors call it catamenial epilepsy. It's what this booklet is all about.

Let's look at what happens, step by step.

About Hormones

Hormones are chemical substances that your body makes and your blood carries to all areas of your body.

There are different types of hormones. Some are sex hormones which govern physical appearance and sexual differences.

The three sex hormone groups which affect some women with epilepsy are:

- estrogens
- progestogens
- androgens

What else do hormones do?

Hormones affect our bodies and our minds.

The sex hormones control how large our muscles are and the strength of our bones.

They control male and female fertility.

They affect our emotions and, to some extent, our behavior.

Hormones also control the menstrual cycle in women.

What is the menstrual cycle?

The menstrual cycle is the bodily changes that women of child-bearing age experience each month.

Steps of the cycle include the release of an egg from the ovaries (ovulation), the preparation of the womb to receive a fertilized egg, and the monthly bleeding that happens during the menstrual period if the egg is not fertilized.

Seizures and Hormones

Seizures happen when there are changes in how brain cells (called neurons) send electrical messages to each other.

Cells that are working properly turn on, fire off an electrical charge, and then turn off.

If cells keep firing and can't turn off for a while, the result is a seizure.

How do hormones affect seizures?

Scientists have found that the female hormone estrogen can make brain cells more likely to keep firing.

NOTE

Estrogen acts on the brain in a way that makes a seizure more likely to happen.

In other words, estrogen acts on the brain in a way that makes a seizure more likely to happen.

However, another female hormone, called progesterone, seems to work the other way.

Progesterone has a calming effect. It seems to make brain

cells less likely to keep firing.

That makes a seizure less likely to happen. This may apply only to natural progesterone and not synthetic (man-made) progestins such as are in birth control pills.

So whether or not a person has a seizure may depend on how much of each hormone is in the brain at any one time.

What kinds of seizures are affected by hormones?

Seizures that happen in the part of the brain called the temporal lobe are most likely to be affected by estrogen.

People with these kinds of seizures are said to have temporal lobe epilepsy.

Seizures that start in the temporal lobe are called simple or complex partial seizures.

They produce odd sensations, uncontrolled movements, feelings of confusion, or brief blackouts that look like sleepwalking.

Is temporal lobe epilepsy the only kind that hormones affect?

Probably not. They can also affect generalized seizure disorders.

Adolescence, when people become sexually mature, is a time of major hormone change for both men and women. It's also a time when some types of epilepsy begin and others stop.

Menopause, when there are also changes in the levels of sex hormones, is another time of life when a woman's seizures may start, stop, or change.

It's possible that all these events are affected by hormones.

Seizures and the Monthly Cycle

Some women with epilepsy have seizures just before or just after their periods start.

Other women are more likely to have seizures in the middle of the cycle, when an egg is released (ovulation).

Why do seizures happen at those times?

Probably because of changing levels of female hormones during the cycle.

Research shows that levels of estrogen (which may trigger seizures) go up before a period starts.

Levels of progesterone (which may protect against seizures) go down sharply before a period starts.

It is also possible that hormone changes make a woman's body use up more of the epilepsy medicine right before her period begins.

If that makes the level of medicine in her blood get too low, a seizure may happen.

What about men? Do hormones affect their seizures, too?

Men have the same hormones that women do, but in different amounts.

Male hormone levels may be lower than normal in perhaps 3 out of 10 men with epilepsy. This may lower their level of sexual interest and sexual function as well as energy and strength. Testosterone supplements may be helpful.

Testosterone, like progesterone, is a hormone. It has anti-seizure benefits but how useful they are in actually preventing seizures is not yet known.

More research is needed to get better answers to this question.

Hormones and Pregnancy

Research shows that some women with epilepsy find it harder than others to get pregnant.

Again, women with epilepsy whose seizures start in the temporal lobe areas of the brain are more likely than other women to be affected in this way.

That's because the temporal lobes are linked to other areas of the brain that regulate hormones, including the ones involved in pregnancy.

These areas are the hypothalamus and the pituitary gland.

When seizures happen in the temporal lobes, they may affect these special areas as well.

When that happens, it may change the levels of the various hormones in your body. Some of these may affect the ability to become pregnant.

Some epilepsy medicines may also affect hormones.

How do hormone levels affect pregnancy?

One effect is that a woman with epilepsy may find it more difficult to get pregnant if her level of the hormone androgen is too high.

Women with high levels of androgen may develop a condition called polycystic ovary syndrome, or PCOS.

It means that cysts (small, benign growths) develop on the ovaries, which produce a woman's eggs.

Having PCOS makes it more difficult to get pregnant because women with PCOS do not ovulate (release an egg) regularly.

Other signs that a woman may have PCOS include weight gain, acne on the face, and growth of facial hair and hair on other parts of the body.

This condition affects many women, but is more common in women with temporal lobe epilepsy. Some of the medicines used to treat epilepsy may also produce PCOS.

Fortunately, this condition, once recognized, can be treated.

Keeping Track

All this new information means that it's more important than ever to find out whether your hormones and your seizures are linked.

Knowing that hormones are involved may offer you and your doctor some new ways of treating and preventing seizures.

As we've already seen, there are some signs to suggest that your hormones may be out of balance.

These include seizures at the same time every month, weight gain, and acne and heavier than usual hair growth on your face and body.

Having very few or no periods are also clues that hormones are out of balance.

How can I find out for sure?

Only your doctor can tell you for sure. But you can help by using a calendar to track what's happening to your body.

NOTE

It's more important than ever to find out whether your hormones and your seizures are linked.

Mark every day you have a seizure. Mark the days when you have your period.

Do this for two or three months, compare the results, and ask yourself some questions:

- Do my seizures happen around the same time each month?
- Do they happen when I have my period?
- Do they happen at the mid point of my cycle, when ovulation (release of an egg) usually takes place?
- Or am I not having regular periods at all?

Answering “Yes” to one or more of these questions is a good reason to see your doctor.

How do I know when I ovulate?

Some women take their temperature every morning before getting out of bed or having any food. A rise in your temperature by about a degree for 7-10 days starting mid-cycle is a sign that you have ovulated.

What else should I write down?

You should write down other things that might be making you have a seizure.

These are things like missing your medication. Or not sleeping well. Or feeling unusually tired. Or going through a really stressful time.

Working with Your Doctor

Share the records you've been keeping with your doctor or the health care team that's treating your seizures.

Your doctor may order blood tests to measure your hormone levels. He or she may order other tests to measure the level of epilepsy medicine in your blood.

Your doctor may also suggest that you have an ultrasound test that will show an image of your pelvis and whether or not there are cysts in your ovaries.

This test will show if there are other conditions besides hormone changes that might be making you have irregular periods.

If hormones are affecting my seizures, do I need to see a special doctor?

That is certainly something to consider.

If it looks as if hormones are affecting your seizures, your doctor may suggest — or you may ask — that you see a neuroendocrine specialist or a gynecologist with an interest in epilepsy.

A neuroendocrine specialist has special training in hormone disorders and their effects on the brain.

A neuroendocrine specialist may try treating

you with hormones to bring your system into better balance and to prevent seizures.

If my doctor doesn't give me a referral, where would I find a doctor like that?

Neuroendocrine specialists are usually found at university hospitals or special epilepsy centers.

Your local Epilepsy Foundation may have information about specialists who can help you.

Will my insurance cover that kind of care?

It depends on what kind of insurance you have. Check with your primary care doctor or your neurologist and your insurance plan.

For More Information

Find out about the Epilepsy Foundation's Women and Epilepsy Initiative. It will tell you more about all the different ways in which epilepsy affects women and what you can do about it.

You can get Information about the Women and Epilepsy Initiative from the Epilepsy Foundation 888-886-EPILEPSY or its website (www.epilepsyfoundation.org).

Also, ask your local Epilepsy Foundation about their programs for women.

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