



WOMEN + EPILEPSY Initiative

BONE HEALTH & YOU



Information
for Women
with
Epilepsy



EPILEPSY FOUNDATION®

Not another moment lost to seizures™

This pamphlet is intended to provide basic information about bone health 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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Bone Health & You

Most of us know it's important to have strong bones throughout our lives.

And most of us know that bone health is of special concern for women as they get older.

What isn't so well known is that the risk of thinning bones is higher for women with epilepsy than for other women.

That's because some of the medicines that prevent seizures may make bones become thin.

It doesn't happen all at once.

It may take years.

If you're a woman with epilepsy and you take one or more of these medicines for several years, your bones may get thinner.

That can lead to serious problems.

Most women with epilepsy do not know about this risk.

Many doctors are not aware of it, either.

So women with epilepsy may not be getting the information they need to protect their bones.

NOTE

Most of us know it's important to have strong bones throughout our lives.

This booklet tells you more about epilepsy and bone health so that you can talk about these issues with your doctor — and keep your bones healthy and strong.

About Your Bones

Bones are your skeleton's building blocks, the rigid framework that gives your body strength and form.

Bones are made mostly of calcium. Calcium is a mineral that you get from food and dairy products.

The surface of bones looks smooth. Inside is a lacey but strong network of mineral deposits.

If the network gets too thin, bones are more likely to break.

Broken bones are painful. A broken hip is a serious injury, especially in older people.

Broken or damaged bones in the spine cause pain, loss of height, and changes in the shape of the back.

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What makes bones get thin?

Your bones are constantly changing. Old bone is replaced by new.

Losing bone means the inside structure of the bone gets thinner and the bone loses some of its strength.

When bones have lost density or thickness, the condition is called osteopenia.

When bones have lost a lot of density or thickness, the condition is called osteoporosis.

How many people have bone loss?

About 10 million Americans have some bone loss. Eight out of every 10 people with bone loss are women.

The risk of having thin bones is higher in women over the age of 65.

Other things that raise the risk of bone loss are:

- smoking cigarettes
- having other family members whose bones break easily
- early menopause
- being of white or Asian race
- heavy use of alcohol or caffeine drinks
- lack of exercise
- lack of sunlight
- taking medicines that contain steroids

Why do women with epilepsy have to be concerned about thinning bones?

Because some of the medicines they take to prevent seizures seem to increase bone loss.

Because some of the medicines they take result in side effects such as clumsiness and instability that increase the risk of falling.

Because women who have seizures that make them fall are more likely to break a bone if their bones have become thin.

And because treating bone loss at an early stage may keep it from getting worse.

Women with epilepsy are twice as likely as other women to have had broken bones.

What about men with epilepsy?

Men who have taken some epilepsy medicines for several years are also at higher risk of thinning or breaking bones.

However, their risk is still lower than the risk for women with epilepsy.

Medicines and Bone Health

Some epilepsy medicines have been in use for more than 50 years. Others are newer.

Experts say that thinner bones are most

likely if you are taking one or more than one of these older medicines:

- phenobarbital
- phenytoin (Dilantin, Phenytek)
- primidone (Mysoline)

Taking one or more of other older epilepsy medicines may also lead to thinning bones. These are:

- carbamazepine (Tegretol, TegretolXR, Carbatrol)
- valproate (Depakene, Depakote, DepakoteER)

NOTE
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What about the new epilepsy meds?

So far, so good. None of the epilepsy medicines approved during the past 15 years is known to cause bone loss.

But some are so new that very few studies have been done. More research will help answer this question.

The newer epilepsy medicines include:

- gabapentin (Neurontin)
- lamotrigine (Lamictal)

- levetiracetam (Keppra)
- pregabalin (Lyrica)
- topiramate (Topamax)

I take one of the older meds because it works for me. Should I stop taking it?

No. Not having seizures is important. You don't want to do anything that might make them begin again.

And you should never stop any epilepsy medicine suddenly.

However, it's a good idea to check with your doctor. Ask whether any changes in your treatment need to be made.

And ask about having a test to check on your bone health.

Keeping Bones Strong

The recipe for strong bones includes:

- getting enough calcium and vitamin D
- spending time in sunlight
- doing weight bearing exercise and other exercise
- eating a balanced diet with plenty of dairy products, fruit, and vegetables.

It also includes:

- not smoking cigarettes
- not drinking a lot of alcohol

- not drinking a lot of coffee, tea, or colas that contain caffeine

Why is sunlight important?

Because sunlight on your skin creates vitamin D.

Vitamin D helps your body absorb the calcium that your bones need to stay strong.

If I can't be in the sun that much, how can I get enough vitamin D?

Some foods, especially fatty fish, are high in vitamin D. Salmon and mackerel are good sources of vitamin D.

You can also get vitamin D by taking cod liver oil or other fish oils.

In the United States, milk, bread, and cereal have vitamin D added to them.

If you don't think you are getting enough vitamin D naturally, you can buy vitamin D supplements.

How much calcium is needed to keep bones healthy?

The average teenager or young adult needs 1200-1500 mg of calcium each day to keep bones strong.

The average woman between 25 and 55 years of age needs 1000 mg a day. If she is pregnant or nursing she should be getting between 1200-1500 mg each day.

After menopause, women need to take more calcium. That's because their levels of estrogen fall.

Estrogen is the hormone that protects bones.

After menopause, the average woman needs 1500 mg of calcium each day.

Do I need extra calcium if I have epilepsy?

You may need to take more calcium because some epilepsy medicines make it harder for your bones to get the calcium they need.

If you have been taking epilepsy meds for more than six months, experts say you should be getting between 1000-1500

mg of calcium every day, regardless of age.

What should you do if you don't know how much calcium you're getting from food?

If you're not sure whether your diet is giving you enough calcium, you can buy

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If you have been taking epilepsy meds for more than six months, experts say you should be getting between 1000-1500 mg of calcium every day.

calcium supplements. Check with your doctor first.

It is also a good idea, if you are buying supplements, to get calcium that includes 400 IU (international units) of vitamin D per tablet.

Again, that's because vitamin D helps your body absorb the calcium so it gets where it's needed — into your bones.

Always tell your doctor if you plan to take any vitamin or mineral supplements or herbal products of any kind.

Tracking Bone Health

The only way to know whether your bones have become thin is to have a test done.

If you are a woman with epilepsy and you've been taking epilepsy meds for several years, having a bone density test would be a good idea. You can also get levels of vitamin D and calcium drawn.

You should get a bone density test if you are over 65 or have broken a bone recently.

Ask your doctor about ordering a bone density test to check on your bone health.

What kind of test would I need?

There are several tests, but the one most often used to check for thinning bones is called a DXA scan. DXA stands for 'dual energy x-ray absorptiometry.'

A DXA scan is a painless type of x-ray. It measures how dense your bones are.

Your doctor will compare your results with scans of normal bone density and the scans of other people your age.

If the DXA scan shows I have bone loss, can it be treated?

Yes. There is no cure, but there are medicines that may slow or even stop the bone loss.

These medicines include: hormones, calcitonin, biphosphonates, parathyroid hormone and a group of substances called selective estrogen receptor modulators. It is important to talk to a doctor who treats bone loss before taking these medications as they aren't for everyone.

What kind of doctor treats bone loss?

A doctor who treats people for bone loss is called an endocrinologist.

Endocrinologists are trained in internal medicine with extra study of hormone systems and how they affect health.

Endocrinologists also treat diabetes and thyroid disease.

What else can I do to stay healthy?

Another way of looking after yourself is to prevent broken bones.

Falling is the most common direct cause of a broken bone.

Look around the house.

Do you see things that might make you stumble, trip and fall?

It's a good idea to get rid of loose rugs, electric cords, and discarded personal items in areas where you walk.

Take care on slippery floors. Hold hand rails when going up or down steps.

If your epilepsy medicine sometimes makes you feel lightheaded, clumsy, dizzy, or unsteady on your feet, check with your doctor.

A change in when you take your medicine, or how much you take, may help.

What else can I do to keep from falling?

For people with epilepsy, the most common cause of a fall is having a seizure.

Taking your epilepsy medicine every day will help prevent seizures, falls and broken bones.

If you still have seizures that cause falls,

pregnancy • birth control
menopause • breast-feeding
hormones • genetics • osteo
catamenial seizures • safe
intrauterine devices • e
mood • talking to your do
maternal seizures • auras
counseling • progesterone
• prenatal care • monthly
exercise • genetic counsel
• parenting • antiepileptic
special concerns • suppor
babies • adolescence • understa
hormonal changes • cosm
• lifestyle • vitamins • anti
menstrual • hormones • sexual dysfunction • balanc
adolescence • adjustment

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think about putting carpet and padding in your house, including the bathroom.

If floors are carpeted and sharp edges are padded, you are less likely to break a bone if you do fall.

For More Information

Epilepsy affects women in many special ways. Learn more about them and the Epilepsy Foundation's Women and Epilepsy Initiative by calling 888-886-EPILEPSY or visiting www.epilepsyfoundation.org.

Check with your local Epilepsy Foundation about their programs for women.

You can also find out more about bone health and its treatment from the National Osteoporosis Foundation, 1232 22nd St. NW, Washington, DC 20037; (202)223-2226 or www.nof.org.

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