

# My fragile future



At 48, Barbara Mahany learned that calcium supplements and exercise are no guarantee against osteoporosis. Then she learned that the 'miracle drug' to treat it may have a devastating side effect.

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s I lay down on the half-table, beneath the panini press of an X-ray machine that would soon peer through to my skeleton, I joked: “Uh-oh, Judgment Day. My bones are probably hollow.” ■ Ha. ■ Turns out, at 48, I had some pretty powdery bones, all right. Or at least that was the picture in my head that I could not shake—not after I got the call with the bad bone news. ■ You know it’s not good when your trusted doctor, who usually avoids negative adjectives at all costs, dials you up late in the day and begins: “Gotta pen? Your bone density is *not* good.” ■ Seems my spine, especially down in the lower lumbar vertebrae, is especially bad. On a scale with 0 to -1.5 being normal, anything between -1.5 and -2.5 being osteopenic (or borderline soft), and anything beyond that being osteoporosis, my spine measures a bone density of -3.4. Meaning not only do I have porous bones, I’ve got ’em pretty bad.

And that means—way sooner than I ever thought I’d be thinking about my hipbone connecting to my thighbone and my backbone connecting to my neckbone—I had joined the ranks of some 8 million women and 2 million men in this country whose bones are so flimsy we’ve been diagnosed with osteoporosis.

What’s really vexing for all 10 million of us is that in recent months there have been conflicting medical reports about bones and calcium and vitamin D, and some rather unsettling news about Fosamax, the so-called sure-fire prescription that’s supposed to be Agent No. 1 in keeping us from losing the bone battle.

Lately, it’s feeling wobbly out here in the land of see-through bones.

I took the news of my bad bones especially hard because it was the first time I had concrete evidence that I’d done lasting damage back in high school in 1975, when I was among the first of what would become a wave of diagnosed cases of anorexia nervosa, the eating disorder that had me compulsively cutting down calories until I landed in a hospital at under 90 pounds. Add to that the major surgery I’d had the summer before the bone scan, surgery that included a total hysterectomy and the fact that I’d been nursing babies for a total of nearly six years. I was a walking laboratory for osteoporosis risk factors.

Never mind that I’d been taking calcium supplements for years and walking the treadmill without fail, 2½ to 3 miles a day.

Bone density reaches its peak by the time a woman is in her early 20s, and estrogen is a key component in the formula for building bone mass. When you are anorexic, you stop menstruating, which means you neither have the hormones nor, probably, the calcium and vitamin D to build strong bones. I was not building bone in the one short window nature provides; you don’t get to defer bone building until later. There is no second chance.

Besides that, studies show that prolonged nursing sometimes leaches the calcium out

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of bones, and though it can be reversible, I already had one big strike against me. Finally, in the five years immediately postmenopause, when a woman’s hormones plummet to near zero, bone loss is fast and furious. Bing, bing, bing, I was out with three strikes.

I did what any smart patient would do: I listened to my doctor, I did everything she said, and then I dug for more.

Because I’d already done my homework, having contacted the National Osteoporosis Foundation in Washington, D.C., I knew that the one man to talk to in Chicago, when it comes to bones, is Dr. Murray Favus, who runs the bone health program at the University of Chicago. He has been in the business—studying hormone influence on minerals and bones, first as a research fellow at Harvard University, later as founding director of the bone program at the U. of C. in 1984—for nearly 30 years, since way back in the Dark Ages of bone research, when most doctors pooh-pooed osteoporosis as just one of the bothers that come with old age.

“Most medical doctors thought it was nature’s way of telling us to slow down,” recalls Favus, pointing out that such thinking prevailed into the 1990s. What changed it, he says, “was the pressure of some women’s groups who stood up and said, ‘This is important; pay attention to this.’”

Until the mid-1990s, there was no specific treatment for osteoporosis, although hormone replacement therapy was known to protect bones. Again, Favus says, it was women’s groups who put pressure on the U.S. Food and Drug Administration to do something.

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## What you can do

If my bones are flimsy, my brain is a blur. At least it was while I wondered what to do with all the conflicting bone news. Some of the smartest, most sound advice I got was from Valerie Early, registered dietitian, who specializes in women’s health at her Schaumburg-based practice, Nutrition, Connection, Balance:

Get a good look at your bones. If you’ve had a hysterectomy, an eating disorder or have a history of low hormones, have a thyroid condition, take steroid medications on a regular basis, are over 50, have lost 50 pounds or more or have avoided dark green leafy veggies and dairy foods most of your life, do not delay: Get a DEXA bone scan.

Eat soy every other day. Take your pick of these: 1/3- to ½-cup raw soy nuts; soy protein bar; soy milk or a soy shake.

Eat dark green, leafy vegetables every day. Liberally. Choose these from any grocery store (organic is always better): kale, Swiss chard, spinach, organic salad mixes, broccoli.

Make raw food salads. Blend all the dark green leafies (about ½ cup to 1 cup of each, except for broccoli. Limit that to maybe two florets, its taste will overpower). Add peeled, chopped cucumber to taste. Squeeze lemon juice. Blend in a blender or food processor. “It looks awful; it’ll look like baby food,” says Early. Proceed anyway. Sprinkle with blueberries to sweeten. Add ground flax meal, if you’re really ambitious.

Weight-bearing exercise is a must. “We’re not talking walking,” says Early, who is also a clinical exercise specialist. “Strength training, preferably with free weights or in combination with machines. But not machines only. The women’s workout circuit-training is not enough. It’s a good start, though.”

Make sure you’re getting adequate calcium in a supplement with vitamin D and other co-factors, based on your personal needs. She recommends at least 1,200 to 1,500 mg. calcium citrate, with 800 to 1,000 IU vitamin D3. Check with your health-care practitioner about these, and also magnesium and vitamin K.

Evaluate your hormones, which play an essential role in bone health. While synthetic hormones are no longer recommended for most postmenopausal women, there are options, says Early, including bio-identical hormones and over-the-counter sources such as soy and vitamin D, which work in the body in ways similar to hormones without the side effects.

# “THE CELLS GET REAL BUSY . . . [AFTER MENOPAUSE]. IT’S LIKE TAKING OFF THE DOOR TO THE TIGER’S CAGE.”

—DR. MURRAY FAVUS

In an unprecedented summer session in 1995, the FDA approved a class of drugs known as bisphosphonates, the most familiar of which is sold under the brand name Fosamax.

Until we die, our bones remain dynamic. Two kinds of cells are continually at work on our skeletal micro-architecture, one set breaking down older bone tissue and the other set replacing it with fresh. Fosamax, made and marketed by the pharmaceutical giant Merck & Co., acts, as all the bisphosphonates do, by slowing down the cells that destroy old bone. Fosamax was hailed as a miracle drug that would work against the degeneration of the matrix that keeps us upright and mobile.

With more than some loathing, I had started taking Fosamax every Sunday morning. Because it’s known to do a number on the esophagus and stomach, wearing raw the tender lining of both, I follow strict precautions. I take it first thing in the morning, with two glasses of water. I stand upright for an hour and don’t eat or drink anything until that hour is up. I don’t want to be one of the many who live with rampant heartburn—or worse—trying to keep my bones from breaking.

Turns out, that’s not the worst of it. There have been whispered concerns that while Fosa-

max increases bone density, the new bone that’s laid down is too brittle.

Also, in the last few years, but especially since July 2005, roughly 1,000 cases of jaw necrosis—in which the jawbone rots and dies—have been reported in patients taking Fosamax, whether through infusions or in pill form. While the majority of cases involve cancer patients, who take high-dose infusions, there is some question about the long-term effects on patients like me, who are looking at being on the drug for decades.

Favus is unshakably in the Fosamax camp. “The overwhelming evidence is that the bone that’s made is normal bone,” he says. “If the bone was more brittle, you’d see more fractures. But fractures in patients taking Fosamax, and other drugs in this category, are reduced by 50 percent.”

As for reports of jawbones deteriorating after simple dental procedures, such as tooth extraction, Favus says that a thousand or two cases out of the millions of patients who have taken the drugs would be scant reason for concern.

“Overall, our advice on bisphosphonates is, tell your dentist, tell your oral surgeon [you’re taking it],” he says. “It should not be a reason why you don’t go to a dentist or an oral surgeon.”

And Favus emphasizes that he doesn’t think the jaw problem is enough of a risk to stop taking the drugs.

However, in early April a class-action lawsuit was filed in Florida against Merck, alleging that the firm not only knew of the jaw necrosis risk but refused to study it further. Moreover, the suit charges, Merck ignored FDA requests back in 2004 to warn consumers.

The lawsuit set off what some defenders of Merck termed “ambulance chasing,” with attorneys running ads seeking Fosamax patients who believed they had symptoms of jaw necrosis. In all, some 15 class-action lawsuits against Merck have been filed around the country.

“This is a once-in-a-decade case,” says Pensacola, Fla., attorney Tim O’Brien, who specializes in pharmaceutical litigation and filed the initial class-action suit in federal court last April. “This is so rare that you can actually trace back the injury to the cause of the injury. Dentists and oral surgeons call it ‘fossy jaw.’ It’s a signature injury.”

He advises Fosamax patients to pay close attention to their teeth and gums, and to seek a full mouth scan if they’re experiencing any jaw or face pain, especially under the eyes, a telltale sign, he says.

O’Brien estimates that there are between 5,000 and 15,000 cases of jaw necrosis among the 3 million to 4 million patients taking Fosamax orally. He has no quarrel with the efficacy of Fosamax, he says; rather, he has a quarrel with Merck’s failure to warn patients of possible side effects.

Merck counters by asserting that most reported cases of necrosis of the jaw have been in the cancer patients receiving high-dose infusions—although the company does concede that cases have occurred in patients with postmenopausal osteoporosis.

In a statement, Merck said the cause of jaw necrosis is not well understood and that its own studies of 17,000 Fosamax patients had not turned up any cases of the disease. The statement acknowledged that Merck did get a request from the FDA in January 2005 to include a warning about jaw necrosis on its label, and that it had complied by July 2005.

O’Brien, the Florida litigator, responds that the precaution is buried deep in fine print, not even in the section marked “Warnings,” and that until now most doctors prescribing the drug have been unfamiliar with the side effect.

Merck executives directed me to Dr. Robert Heaney, whom many consider to be the top expert on bones in the United States. Heaney, professor of medicine at Creighton University School of Medicine in Omaha, has been studying bone biology, and the role of calcium in bone formation, since 1955, when he was at the National Institutes of Health. Heaney, who says he has not been paid by Merck but admits to taking honoraria from the company for several speeches, insists there’s no cause for alarm over Fosamax.

“You’ve got much more chance of being struck by a meteorite” than getting jaw necrosis from the drug, he says, a possibility he rates as “one in a million.” He’s more concerned that the lawsuit and news reports will chase away people who are being helped by Fosamax and have no reason to stop taking it.

But O’Brien says there’s more than jaw necrosis for Fosamax users to consider. He directed me to a study, published last February in the European Journal of Obstetrics & Gynecology and Reproductive Biology, which concluded that Fosamax caused “significant” DNA damage in white blood cells in 32 postmenopausal women over a 12-month period. White blood cells are key components of the body’s immune system. The long-term implications of the study’s findings are unclear, but even the possibility of such a side effect is troubling.

Heaney, the driving force behind the creation of the prestigious Osteoporosis Research Center at Creighton in the mid-1960s, argues that if Fosamax caused DNA damage, the FDA would be urging Merck to include a warning on their label. But, again, O’Brien argues that Merck has a history of ignoring the FDA.

Alas, the Fosamax controversy is not the only one rattling the bone box. Last winter, as I busily consumed my share of cheese sticks and yogurt and downed my 10 capsules a day of high-dose calcium and vitamin D, there came reports that all that popping of calcium and D might be pointless.

In mid-February, data from the Women’s Health Initiative, a long-term study of 36,282 women between the ages of 50 and 79, suggested that daily intake of 1,000 milligrams of calcium carbonate and 400 international units of vitamin D3 resulted in only “modest benefit in preserving bone mass and preventing hip fractures,” and did not prevent other types of fractures.

Closer examination of the data, though, shows that more than half the participants in the study failed to take the intended number of pills. Heaney says the report was pretty much meaningless. “Stay the course,” he advises, meaning 1200 to 1500 mg. of calcium per day, preferably from food, not supplements.

More important than calcium, he claims, is vitamin D3. “Absolutely essential,” he says, adding that most of us need at least 1,000 international units per day, well above the recommended daily allowance. If we don’t have enough vitamin D, we can’t absorb calcium.

“The No. 1 thing I’d look at is what is the source of the calcium,” says registered dietitian Valerie Early, of Schaumburg-based Nutrition, Connection, Balance, which specializes in nutrition and women’s health. She contends that in older patients, who tend to have decreased levels of stomach acid, a key to absorbing vitamins and minerals, calcium citrate is better than calcium carbonate.

Favus says the supplements controversy misses the point about bone loss. “Calcium alone, or exercise alone, or both, do not stop osteoporosis in postmenopausal women,” he says. “It sounds good: ‘Here are ways to control your destiny.’”

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“The bad news is it may not work that way. The cells [that break down the bone] get real busy when the estrogen is gone” after menopause, he says. “It’s like taking off the door to the tiger’s cage.”

He likens the effect of these break-down cells to digging a ditch in your bones. It takes a mere 10 days to dig the ditch, he says, and a whole three to four months for the build-up cells to fill in the ditch. “If you’ve got a lot of these battles all over your skeleton, you’re going to have bone loss.”

If you’re taking adequate amounts of calcium, taking more will not make much difference, Favus emphasizes. It’s not like your body banks the extra, or builds more bone because you’ve swallowed more calcium. In fact, the extra calcium flushes right through your kidneys on the way out. The only thing extra calcium will get you is the chance for kidney stones. Ouch.

At one point in my research, I was introduced to the confounding notion, mentioned by a bone doctor’s nurse practitioner, that the rampant vitamin D deficiency that I and millions of others share might be due to the sunscreen we have been slathering on our bodies in hopes of beating back melanoma, a skin cancer that is plenty scary itself.

The American Academy of Dermatology dismisses the idea that sunscreen is blocking us from getting adequate beta rays on our skin to activate vitamin D, but Favus argues that it’s a contributing factor to the

widespread vitamin D deficiencies. He and Heaney both suggest going outside without sunscreen for the first 15 minutes, and then slathering it on. Favus also makes the point that in Chicago there’s no way from October to mid-March that anyone can get the beta rays we need from the sun. The slant of the sun makes it impossible to get what our skin needs to kick-start the vitamin D into the form our bodies can use.

The sad ending to this story is that there’s no danger-free zone for me and my bones.

I’m 49, with two sons, one aged 5 and the other 13. I don’t want a future where I am hunched like a walking letter “C,” or confined to a walker. I don’t want to crack a rib cleaning out the bathtub. And I don’t want to be deathly afraid of icy patches on sidewalks, or riding my bicycle into the wind.

God willing, I want to dance at my boys’ weddings.

And I hope never to look in a mirror and see a woman without a jaw looking back.

So this, for now, is the plan: I’ll be exercising as long and as hard as I can. I’ll be the Dairy Queen, and the Dark Leafy Green Queen too. I’ll shake and I’ll rattle. Whatever it takes. And come Sunday morning, when it’s time to pop that next Fosamax, I’ll pray, as I always do, that down the road I won’t regret what I just swallowed. □

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