



WALKING BLUES
Tim McQuay at home
with his companion Apaulo.

Boning Up On Multiple Sclerosis

People with multiple sclerosis are at increased risk of bone loss.

Here's what you can do to stay strong.

BY AMY PATUREL, M.S., M.P.H.

When 32-year-old Tim McQuay started walking down the stairs at work, he stumbled and suddenly realized he couldn't move. A strong African-American man working as a heavy machine operator at a recycling company, Tim was the picture of health—until that day. After relaying the incident to the emergency room physician, Tim underwent a battery of tests and was diagnosed with multiple sclerosis (MS).

“At first the doctors didn't know why my legs were buckling beneath me like that,” says Tim, now 37. “They did a lot of x-rays and ultimately discovered that the bone structure in my legs wasn't normal—there were little tears in my bones.”

After being aggressively treated with pulsed steroids for about two years, neurologist Lily Jung, M.D., medical director of the neurology clinic at the Swedish Neuroscience Institute in Seattle, WA, and one of two MS neurologists within the MS Center at the Institute, requested that Tim have a bone-density test. More shocking news: Tim had osteoporosis, which is the medical term for loss of bone density over time. Osteoporosis can lead to bone tenderness and pain, fractures, loss of height, back and neck pain, and stooped posture.

Like Tim, most patients—and even

some neurologists—are unaware that people with MS are at high risk of osteoporosis and osteopenia, which refers to bone density that is lower than normal but not low enough to be classified as osteoporosis. People with untreated osteopenia are at a greater risk of developing osteoporosis. Among the MS population, a whopping 27.2 percent of patients report having low bone density—either osteoporosis or osteopenia—and approximately 16 percent report experiencing a fracture after the age of 13, with nearly half of those reporting multiple fractures. And yet, according to a study published in the medical journal *Neurology*, only half of MS patients are being screened for bone disease.

“The available studies are suggesting that this is more of a problem than we have appreciated,” says Patricia K. Coyle, M.D., professor and acting chair in the department of neurology at State University of New York, Stony Brook. “Particularly as patients get older, there's a concern about vulnerability to fractures and bone-density issues. A fall with a fracture and the subsequent immobility can be catastrophic for these patients.”

MS primarily occurs between the ages of 20 and 50—a time when most patients (and physicians) are unconcerned about bone loss. After all, we're still building bone in our 20s and 30s, not losing it. However, in the case of MS patients—a population that is typically deficient in bone-building

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vitamin D and exposed to high-dose steroids that can compromise bone health—the chances of developing bone disease long before they hit their fifth decade is significantly higher.

WHY THE INCREASED RISK?

MS patients are predisposed to bone loss for a variety of reasons. “More women than men get MS, and women are more inclined to develop osteopenia or osteoporosis than men,” says Dr. Jung. “Add on top of that the mobility issues facing people with more advanced disease and the fatigue and pain associated with MS, all of which make people with MS less likely to be active.” Inactivity makes the disease worse and increases one’s risk of bone loss.

Take 59-year-old Beverly McKinney. When she was diagnosed with osteoporosis about 12 years ago, she was using her electric scooter almost all of the time. “I didn’t do much weight-bearing activity,” says McKinney. “Now I try to exercise more and I’m trying to stand some, but it’s difficult to stay mobile, especially since my bones are more fragile.”

While several studies identify impaired mobility as a primary factor in bone loss, experts agree that inactivity isn’t the only issue. Other key factors: vitamin D deficiency and steroid treatments. Researchers in Australia found that among patients with MS, increasing disability was strongly associated with lower levels of vitamin D and reduced sun exposure (exposure to sunlight prompts the body to make more vitamin D).

“We know that vitamin D deficiency is a significant factor for the development of MS,” says Dr. Coyle. “Vitamin D is fundamental to bone health, but it also has an impact on the immune system. People who are lacking in vitamin D are more vulnerable to infection, for example.”

Indeed, studies show that areas with high sunlight exposure, and thus more exposure to vitamin D, have a low prevalence of MS. The reverse is also true: Areas with low sunlight exposure have a relatively high prevalence of MS.

Research suggests that vitamin D can help regulate the immune system and may impact the onset and progression of multiple sclerosis. The evidence also suggests that vitamin D may play an important role in both the prevention and management of MS.

“I check vitamin D status in my patients regularly, and I’m amazed at how low those levels are,” says Dr. Jung. “There’s no evidence that supplementing with vitamin D is harmful, and it doesn’t cost a lot of money, so I don’t see how assessing vitamin D levels and supplementing when necessary could be a bad thing for these patients.”

Patients with high skin pigmentation, including African

Americans, are especially vulnerable, as skin pigment decreases the body’s ability to make vitamin D. That’s why Dr. Jung prescribed Tim 5,000 International Units (IU) of vitamin D daily, along with 1,200 mg of calcium.

“I can definitely feel the difference in my bones,” says Tim. “It takes some time and patience, but you can help yourself by taking vitamins, eating right, and exercising.”

Unfortunately, even vitamin D cannot mitigate the devastating toll that MS medications, including repeated courses of steroids, can have on bone health. “Steroids automatically set people up for more bone turnover and put them at greater risk for osteopenia, osteoporosis, and fractures,” says Christine Gerbstadt, M.D., R.D., national spokesperson for the American Dietetic Association. “A lot of the medications neurologists prescribe for MS are immune-system modulating, so even if they’re not steroids, they can still cause the body to lose more bone than it’s building in some cases.”

THE GAP IN MS CARE

Even though MS is a progressive and debilitating disease that causes joint pain, fatigue, and immobility—and carries several risk factors for brittle bones—experts agree that there’s a huge gap in health care for MS patients.

“The typical person who is getting MS is younger and female, probably still in her fertile years,” says Dr. Gerbstadt. “In that case, the neurologist is not likely to screen for low bone mass because they’re so focused on the symptoms of MS. Bone disease is relatively subtle compared to neurological lapses. As a result, MS patients really have to be on top of their bone-density screening from a very young age.” There are no specific recommendations on how often people with MS should receive bone-density screenings, but many experts hope such guidelines will be disseminated soon.

In addition to requesting bone-density screenings, people with MS should ask their health care providers about proper nutrition and exercise.

“We have to be good advocates for ourselves,” says McKinney. “Doctors should discuss supplements like vitamin D and calcium with their patients, but patients should also ask about their vitamin D levels and request bone-density screenings. Having a really good patient/doctor relationship is critical—you have to feel comfortable raising these issues with your doctor.”

Like McKinney, many MS patients don’t visit a primary care physician annually to assess their general health needs. And they’re falling through the cracks as a result, not only in terms of bone health, but also with regard to general health screenings like mammograms, cholesterol, and depression or anxiety.

Boning Up on Calcium and Vitamin D



Both calcium and vitamin D are critical for building bone, but meeting the recommended 1,200 mg of calcium and 1,000 – 2,000 IU of vitamin D is a challenge. In fact, more than half of Americans fall short on both counts. Add MS to the mix and you're destined for osteoporosis, right? Not necessarily.

With the rise in calcium-fortified foods, not to mention tasty pocket supplements like Viactiv, meeting your daily calcium needs is a snap. Three to four servings each day of dairy foods will provide about 1,200 milligrams of calcium (1 serving equals 1 cup of milk or yogurt; 1½ ounces of hard cheese; or 2 cups of cottage cheese). Other calcium-rich foods include canned fish with bones like sardines and salmon; dark, green, leafy vegetables, such as kale, collards and broccoli; fortified breakfast cereals; and nuts.

“Vitamin D is a little trickier since there aren't too many foods that have adequate vitamin D,” says Christine

Gerbstadt, M.D., R.D., national spokesperson for the American Dietetic Association.

Good sources include egg yolks; fatty fish, such as salmon, sardines and mackerel; and fortified cereal and milk products. Sun exposure for about 15 minutes daily works, too.

Salmon is one of the highest natural food sources of vitamin D, with 360

International Units (IU) per 3.5 oz. For some great wild Alaska salmon recipes—such as Alaska Salmon with Horseradish, Walnuts, and Herbs; Alaska Salmon with Champagne-Caper Vinaigrette; and Thai Salmon Cakes with Hot and Sour Sauce—go to cookitfrozen.com or alaskaseafood.org. Or check out cookstr.com for recipes such as Salmon Florentine (with vitamin-packed spinach), Baked Salmon with Cucumber Dill Sauce, or Hot and Sour Salmon with Greens.

Steroid treatments, **vitamin D deficiency**, and inactivity due to impaired mobility may all contribute to bone loss in people with MS.

“It’s not unusual for the MS patient to view their neurologist as their primary care physician,” says Dr. Coyle. “So if a patient is not plugged into an appropriate health maintenance program, including screening for bone density, it’s our responsibility to take care of those issues or nudge them to see someone else.”

BRIDGING THE GAP IN MS CARE

Over the years, researchers have learned that immobility, poor nutrition and nutrient deficiencies, and steroid medications all take a significant toll on the health and well being of MS patients. When it comes to bone health, an area where MS patients are at a distinct disadvantage, perhaps the single most important thing MS patients can do is weight-bearing exercise, such as weight lifting, swimming, and even walking.

“There are still a lot of antiquated ideas out there about exercise not being good for MS patients,” says Dr. Jung. “But there’s certainly a lot of evi-

dence coming down the pipeline that exercise is critical for both bone health and general health.” So exercise is priority number one. For Tim, that means getting around on forearm crutches, walking, lifting weights, and stretching.

“You don’t have to exercise to the point where you strain yourself, you just have to do a little bit a few times a week,” he says. “I don’t limit myself because I have MS. If you sit around and think about the MS, it’s going to slow you down. You just have to keep moving.”

Next comes diet. Both calcium and vitamin D are critical bone-building nutrients, but most Americans—with or without MS—are deficient in both of them (see page 29 to learn how to get more of these important nutrients into your diet). As

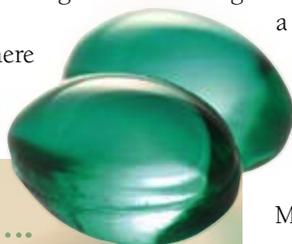
a result, some neurologists are prescribing calcium and vitamin D supplements to their MS patients, in addition to recommending a diet rich in fruits, vegetables, whole grains, fish, nuts, seeds, and olive oil. Dr. Jung often prescribes the low-fat, high-fiber diet recommended by the National Multiple Sclerosis Society.

“There are currently no practice guidelines, but I think that any patient with MS should have their vitamin D levels checked, and anyone who is deficient should have it replaced,” says Dr. Coyle. “Vitamin D is not only important for bone health, but also for immunological functioning.”

Some neurologists are moving in that direction. A recent survey of the National MS Society’s medical board found that at least some members routinely screen patients for vitamin D deficiency. And while vitamin D level isn’t directly linked with bone health, it is a good indicator of problems, and is required for the body to absorb calcium.

Sure, MS patients may be at a disadvantage in terms of bone health, but biology isn’t destiny. There are measures you can take to help stave off bone loss, even if they aren’t a formal set of recommendations yet. “This is where health care reform is heading—to a preventive focus,” says Dr. Coyle. “I expect that we’re going to ultimately have some more formal guidelines that are widely accepted with regard to following long-term MS patients.” But don’t wait: Talk to your doctor about bone health. NN

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Vitamin D

There are no formal guidelines for vitamin D supplementation among MS patients. These recommendations were developed for the National MS Society by Allen C. Bowling, M.D., Ph.D., medical director of the Multiple Sclerosis Service, director of the Complementary and Alternative Medicine Service at the Colorado Neurological Institute (CNI), and clinical associate professor of neurology at the University of Colorado Health Sciences Center. However, before taking any supplements, check with your own neurologist.

- ▶ **LOW DOSE** Supplement with 1,000 International Units (IU) of vitamin D daily for blood levels between 20 and 35–40 ng/mL (nanograms per milliliter).
- ▶ **HIGH DOSE** Supplement with 2,000 IU daily for levels below 20 ng/mL.
- ▶ **GO FOR D3** Select vitamin D3 over vitamin D2. Relative to vitamin D2, vitamin D3 is more active biologically, raises blood levels more effectively, and is more stable on the shelf.
- ▶ **CALCIUM** Take calcium supplements with vitamin D. Experts typically recommend daily doses of 1,000–1,200 mg of calcium.

Note: In some regions, such as the Pacific Northwest, higher doses of vitamin D may be necessary due to the lack of sunlight. The official standards, which are controversial, state that the safe upper limit for regular use is 2,000 IU daily for vitamin D. However, most experts agree that the upper tolerable limit should be increased.