Q. I have a question about supplemental vitamins. I have been told that because I have celiac and Addison’s, I should be taking many supplemental vitamins. I see a nutritionist and belong to a support group for celiac and I get a lot of mixed messages. The biggest problem I have is that it seems no one, even my doctors, know that much about Addison’s. It has been a year since I was diagnosed with Addison’s and a year and a half with celiac disease. I work a stressful job and feel that I need to retire or find another job, as I have many times when my sodium level has been low. I now know when to recognize this so that I do not have to be hospitalized each time. Any help you can give me would be appreciated. Thank you.

A. There is no specific vitamin regimen necessary for Addison’s disease. However, I usually suggest a general multivitamin/mineral supplement to a good healthy diet. Extra calcium is very important, especially for post-menopausal women. The celiac disease tends to cause a malabsorption of vitamin D. I suggest that anyone with celiac disease have a serum 25-OH vitamin D level checked. If it is low, adding extra vitamin D is essential. Doses of 800 to 1200 U per day are useful for normal to slightly low D levels. If the blood test shows very low levels (below 20), then prescription strength vitamin D should be given and monitored by your doctor.

It was very refreshing to read in the last NADF newsletter about how well some of our members are doing. It is incredible to believe what Dusty is undertaking! No matter what, she is a winner! I was an advocate of exercise and played various sports prior to acquiring Addison’s disease. I have the secondary type due to developing severe adult onset asthma and being given high doses of steroids over a long period of time. This has drastically changed my life. I can no longer play sports and have gained over 100 pounds from the steroids. I have had many complications from the steroids, some of which include: having to have both hips replaced; osteoporosis; multiple stress fractures; steroid-induced cataracts; and myopathies and neuropathies, to name a few. I also easily go into crisis and
am often on increased doses of Prednisone to stop the oncoming crash. I remain thankful that we have the technology and medications available to treat most of these side effects as well as the Addison’s Disease itself. I am sure that, as with any other disease, people have varying degrees of severity and different complications. For example, there are four of us in my support group who have underlying conditions and complications associated with Addison’s that have drastically affected our lives. For most of us, sports have sadly become things of the past. I am genuinely happy for all of you who are doing well and living the lifestyle you want. It is good that the disease does not keep you down or dominate your life. I just wanted to make you aware that there is unfortunately another side of the coin. Some of us have had to put our sport shoes away, and continue to deal with limiting complications on a daily basis.

From: NADF News®, VOL. XXII, No. 2 • 2007

Q & A
By Paul Margulies, M.D., FACE, FACP

Q. I have read calcium supplements are not needed by males, but with this condition is it a good idea to take them (and vitamin D)? If so, what is the recommended dosage, assuming a normal diet with one glass of milk/day?

A. For men I suggest a good multivitamin that contains some calcium (usually 200-300 mg) and vitamin D (usually 400 units). If he must be on higher than usual steroid doses, this should be increased to vitamin D 800 to 1200 units plus extra calcium such as Caltrate 600, one to two per day. These doses would also be needed by anyone found to have osteoporosis, where other medication to build bone (such as Fosamax, Actonel or Boniva) would be prescribed in addition to the calcium and vitamin D

RARE DISEASE FORCES YOUNG WOMAN TO FIND OWN ANSWERS
By Paula Evans Neuman – The New Herald
(reprinted using the Fair Use Act)

There is a saying in the medical profession that says, “When you hear hooves, look for horses, not zebras.” Well, in my case, there were definitely stripes,” said Dayna Chlebek, 24, of Lincoln Park.

The saying means, of course, that doctors should seek the most common causes of symptoms before they look for rarities. A practical approach that surely works best most of the time. But for Chlebek, it was a rarity. Cushing’s disease, that was the cause of her symptoms. And nearly three years of misdiagnoses made it even worse for her.

The young woman found she had to overcome her frustration, muster her courage and advocate for herself to get the treatment she desperately needed. “I had to fight for myself,” Chlebek said. “And being a 23-year-old girl telling doctors who’ve been practicing for decades that they are wrong was not easy.”

Her symptoms began showing up about three years ago, when she started to gain weight and become increasingly irritable. She tried to eat healthier and exercise more. But her weight and the mood swings continued to increase, so she sought medical help. Her doctor diagnosed her with an under-active thyroid gland, and put her on medication, to no avail. Chlebek continued to gain weight and began to suffer from anxiety, so an appetite suppressant and an antidepressant were pre-
“Weeks went by with no improvement, and I started noticing other strange symptoms,” Chlebek said. She developed acne on her normally clear skin and was unable to sleep for days on end.

“When I slipped one day in my back yard and was immediately covered in black bruises, I knew something was seriously wrong,” Chlebek said. She went back to the doctor. “He took my blood pressure and it was through the roof,” Chlebek said. She was prescribed blood pressure medication, blood was drawn for tests, and she was asked to come back for a follow-up. By the next appointment, my feet had swelled to the size of cinder blocks,” Chlebek said.

More blood work. Another prescription, this time for a diuretic. The blood work results indicated hormonal problems, and Chlebek was told to stop taking birth control pills. “This only caused my symptoms to get worse,” she said. “I gained another 15 pounds. I was beginning to see purple markings that looked like thick vines all over my abdomen and thighs, and my blood pressure kept getting worse and worse.”

She grew increasingly frustrated with the medical profession’s seeming inability to help her. So Chlebek, who is an accountant and a graduate student at Wayne State University, started doing her own research. She spent frantic hours searching the Internet for a cause of her symptoms. “I came across a Web site called Cushing’s-help.com, which had a long list of symptoms, of which I have about 90 percent,” she said. She begged to be tested for the rare disorder, and a few more tests were done. But before the results came back, her condition worsened dramatically. One night, her blood pressure skyrocketed, and her boyfriend rushed her into the emergency room, fearing she’d have a stroke. She was admitted and spent six days in the hospital having test after test, again to no avail. Once she was released, she sought out a new endocrinologist on her own.

The new doctor reviewed her previous test results. “You have Cushing’s,” he told her, circling the high levels for ACTH (adrenocorticotropic hormone), a hormone released by the pituitary gland located just below the brain, on her blood test results.

Too much ACTH stimulates the adrenal glands (located just above the kidneys) to release an excess of cortisol, another hormone. Cortisol normally helps the body respond to stress in various ways, including regulating blood sugar, metabolism and blood pressure. A tumor of the pituitary gland causes Cushing’s disease, which leads to excessive levels of cortisol being produced over a long period of time. “The amount of cortisol running through my body was the cause of all of my symptoms, and would cause many more in the next few months,” Chlebek said. She was referred to a neurosurgeon, a Cushing’s specialist, at the University of Michigan Medical Center in Ann Arbor. But her HMO refused to pay for her treatment there. She petitioned her insurance company and waited, while her symptoms worsened. Her menstrual cycles ceased and she suffered hot flashes, as well as high anxiety, loss of concentration and terrible mood swings and depression. Eventually, Chlebek found a recently arrived neurosurgeon at Henry Ford Hospital in Detroit, where her insurance was valid.

More tests were done seeking a pituitary tumor that was causing her problems. The tests were inconclusive, but the gland was slightly enlarged on one side, so the surgeon went up through her nasal cavity and removed the left side of Chlebek’s pituitary. No tumor was found. After six days in the hospital, she was released, despondent and seriously ill. “Over the next three months, I confined myself to my home,” Chlebek said. “My symptoms were worsening.” She suffered from “excruciating back pain,” which she attributed then to her abdominal weight gain. She later learned, however, that the pain was from a fractured vertebrae due to the beginning stages of osteoporosis — another malady caused by Cushing’s disease. Her endocrinologist believed a tiny benign tumor was still there in
her pituitary, but removing the whole gland would prevent her from ever having children. He suggested removal of her adrenal glands — a dramatic step that the surgeons she saw were reluctant to take.

So more tests were done, again to no avail. “I felt ruined, ugly and extremely depressed,” she said. Chlebek had to go “doctor shopping” once again, and at last found a laparoscopic surgeon at another hospital who was willing to perform a bilateral adrenalectomy.

She had the operation March 7, after nearly three years of seeking answers and effective treatment. Chlebek will have to take replacement hormones for the rest of her life, and medication for the diabetes insipidus that developed as a result of her disease and treatment. It’s unknown at this point if she’ll ever be able to become pregnant. But in the four months since the surgery, she’s been able to return to work and school. Her anxiety is fading and she’s lost 25 pounds.

Chlebek knows a full recovery will take time, and she is active with support groups to help others with her rare disorder get proper treatment. “My best advice is to know your own body and be your own advocate,” she said. “I’m bound and determined to get back to living a normal life and someday, hopefully, have a family to tell my story to.”

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Excerpt from: Brittle Bones Can Affect Older Men As Well
Fractures less common but more lethal for men than for women, experts say.
By E.J. Mundell
HealthDay Reporter
(Reprinted using the Freedom of Information Act.)

Then there’s diet and exercise.

“In general, men over the age of 50 should be getting 1,200 mg of calcium a day from diet, or diet and supplements combined,” Weber said. Lane advises men to use calcium citrate — not bicarbonate — supplements, because the bicarbonate formulation raises risks for kidney stones.

The current recommended daily allowance for another bone-strengthener, vitamin D, is 400 International Units (IU) per day for older men, but Weber said that level is currently under review and will no doubt be revised.

“I think maybe upwards of 800 to 1,000 IU can be safely recommended for men,” he said. Many foods, including milk, come fortified with vitamin D (check the label) and cod liver oil capsules are particularly high in the nutrient.

Skin also manufactures vitamin D under strong sunlight. “It has to do with the sun’s angle, though, so go out there between 10 a.m. and 2 p.m. rather than taking a walk in the early morning,” Weber said.
CALCIUM AND VITAMIN D FOR STRONG BONES
by Melanie Wong

To maintain healthy bones, people must get adequate calcium, Vitamin D and physical activity, especially women over 50.

Is it possible that this is even more important for people with adrenal insufficiency? (The jury is still out on this one.)

While reading the first paragraph in this article, how many of you remember reading Vitamin D? Do you just remember calcium? Many people don’t know about the importance of Vitamin D for good bone health.

Vitamin D is necessary because it helps the body absorb calcium from ingested food. It allows calcium to leave the intestines and enter the bloodstream. Vitamin D also works in the kidneys to help absorb calcium that might otherwise be excreted.

It is very difficult, almost impossible, to get the required amount of Vitamin D from ingested food. It is found only in a limited number of foods, such as certain cereals, various dairy products, oysters and fatty fish such as sardines and salmon. Milk has long been fortified with Vitamin D. Now fortified orange juice can be added to the short list.

Of course, Vitamin D is manufactured in the human body after sun exposure, but heat from the sun might be something Addisonians don’t necessarily enjoy or tolerate well.

A supplement might be needed for people to achieve an adequate amount of Vitamin D in their diet. Note: Too much Vitamin D is dangerous; talk to your doctor.

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NADF does not engage in the practice of medicine. It is not a medical authority, nor does it claim to have medical knowledge. In all cases, NADF recommends that you consult your own physician regarding any course of treatment or medication.