Alternative Medicine and Dietary Supplements—Should I Talk with My Doctor About Them?

What is complementary and alternative medicine?
Complementary and alternative medicine (CAM) is a group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine. CAM includes such products and practices as herbal and vitamin supplements, meditation, yoga, Tai Chi, behavioral therapies, massage, chiropractic manipulation, and acupuncture.

Do you tell your health care providers if you use CAM?
According to a 2007 national survey conducted by the National Institutes of Health’s National Center for Complementary and Alternative Medicine (NCCAM) and the American Association of Retired People (AARP), two-thirds of people aged 50 and older are using some form of CAM. However, among this group, 69 percent are not discussing the use of CAM with their physicians.

Respondents of the NCCAM/AARP survey cited the most common reasons why doctor-patient dialogue is lacking as:
- The physician never asked (42%).
- They did not know they should (30%).
- There was not enough time during the office visit (19%).

Why tell your health care providers about CAM use?
To ensure safe, coordinated care among all conventional and CAM therapies, open discussion is needed between health care providers and their patients. This will allow fully integrated care, and it also minimizes risks of interactions with a patient’s conventional treatments.

Some CAM practices (e.g., types of Tai Chi) have been scientifically proven to support wellness at certain stages of treating and coping with vestibular disorders, others have not. A lack of scientific proof that a CAM treatment is effective in treating vestibular (continued)
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disorders does not necessarily mean that it isn’t helpful for some people. For example, since stress often exacerbates symptoms of a vestibular disorder, CAM treatments that reduce stress (e.g., meditation) may be helpful. However, if the form of stress-reducing meditation involves holding a yoga pose that increases ear pressure, reducing stress with that particular CAM practice may be inappropriate for a person recovering from perilymph fistula surgery.

When patients tell their providers about their CAM use, they can more effectively manage their health. When providers ask their patients about CAM use, they can help patients make the wisest health care decisions possible.

What should I know about dietary supplements?

Today’s dietary supplements are not only vitamins and minerals, they also include other less-familiar substances, such as herbals, botanicals, amino acids, enzymes, and animal extracts. Some dietary supplements are well understood and established in usage, but others need further study.

Federal regulations for dietary supplements are very different from those for prescription and over-the-counter (OTC) drugs. For example, a dietary supplement manufacturer does not have to prove a product’s safety and effectiveness before it is marketed. Consumers might also note that if a dietary supplement package label includes the words “FDA registered,” it does not mean that the U.S. Food and Drug Administration (FDA) has reviewed and/or approved of the supplement. Rather, it means that the registered manufacturer has simply disclosed

to the government that it processes and/or distributes the supplement, as it is required to do under the Drug Listing Act of 1972.

Also, unlike drugs, supplements are not intended to treat, diagnose, prevent, or cure diseases. But some supplements can help assure that you get an adequate dietary intake of essential nutrients; others may help you reduce your risk of disease. Some older people, for example, are tired due to low iron levels. In that case, their doctor may recommend an iron supplement.

At times, it can be confusing to tell the difference between a dietary supplement, a food, or OTC medicines. This is because supplements come in a variety of forms that resemble these products, such as tablets, capsules, powders, energy bars, or drinks. One way to know if a product is a dietary supplement is to look for the Supplement Facts label on the product.

Are there any risks to taking dietary supplements?

Many supplements contain active ingredients that have strong biological effects in the body. While certain products may be helpful to some people with certain health histories, there may be circumstances when these products may not benefit a person’s health or they may create unexpected risks. For example:
Are you taking both medicines and supplements or substituting one for the other?
Taking a combination of supplements, using supplements together with medications (whether prescription or OTC), or substituting them in place of medicines your doctor prescribes could lead to harmful, even life-threatening results. Be alert to any advisories about these products. For example, Coumadin (a prescription medicine), ginkgo biloba (an herbal supplement), aspirin (an OTC drug), and vitamin E (a vitamin supplement) can each thin the blood. Taking any of these products alone or together can increase the potential for internal bleeding or stroke. In another case, St. John’s Wort may reduce the effectiveness of prescription drugs for heart disease, depression, seizures, certain cancers, or HIV.

Are you planning surgery? Some supplements can have unwanted effects before, during, and after surgery. It’s important to fully inform your healthcare professional, including your pharmacist, about the vitamins, minerals, herbals, and any other supplements you are taking, especially before surgery. You may be asked to stop taking these products at least 2–3 weeks ahead of the procedure to avoid potentially dangerous supplement/drug interactions—such as changes in heart rate, blood pressure, or bleeding risk that could adversely affect the outcome of your surgery.

Is taking more of a good thing better?
Some people might think that if a little is good, taking a lot is even better. But taking too much of some nutrients, even vitamins and minerals, can also cause problems. Depending on the supplement, your age, and the status of your health, taking more than 100% of the daily value (see the Supplements Facts panel) of certain vitamins and minerals, e.g. vitamin A, vitamin D, and iron (from supplements and food sources like vitamin-fortified cereals and drinks) may actually harm your health. Large amounts can also interfere with how your medicines work. Your combined intake from all supplements (including multivitamins, single supplements, and combination products) plus fortified foods, like some cereals and drinks, could harm your health.

As someone with a vestibular disorder, do you find yourself saying...

“Even if a product may not help me, it at least won’t hurt me.” It’s best not to assume that this will always be true. Some product ingredients, including nutrients and plant components, can be harmful or toxic based on their activity in your body. Some products may become harmful when consumed in high enough amounts, for a long enough time, or in combination with certain other substances.

“But I only use natural herbal remedies.” The term “natural” does not always mean “safe.” Do not assume this term assures wholesomeness or that these products have milder effects, making them safer to use than prescribed drugs. For example, many weight-loss products claim to be “natural” or “herbal” but this doesn’t necessarily make them safe. The products’ ingredients may interact with drugs or may be dangerous for persons with certain medical conditions.

“But my doctor doesn’t know about some new products that are supposed to be really good for treating vestibular disorders.” There are numerous sources that provide information about dietary supplements. These include TV, radio, newspapers, magazines,

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store clerks, friends, family, and the Internet. It is important to question recommendations from people who have no formal training in nutrition, botanicals, or medicine. While some of these sources, like Web pages, may seem to offer a wealth of accurate information, these same sources may contain misinformation that is not obvious. It is OK to do your own research (see related story on page 5) and then ask your doctor about information you’ve gleaned and questions you may have. Given the abundance and conflicting nature of information now available about supplements, it is more important than ever to partner with your healthcare team to sort the reliable information from the questionable.

Tips for talking to your health care providers about dietary supplements and other CAM use

- When completing patient history forms, be sure to include all therapies and treatments you use. Make a list in advance.
- When you talk with your health care providers, tell them about all therapies or treatments—including over-the-counter and prescription medicines, as well as dietary and herbal supplements.
- Don’t wait for your providers to ask about your CAM use. Be proactive.
- If you are considering a new CAM therapy, ask your health care providers about its effectiveness, safety, and possible interactions with other ongoing treatments or medications (both prescription and nonprescription).

Do not self-diagnose any health condition. You and your health professionals (doctors, nurses, physical and occupational therapists, audiologists, registered dietitians, pharmacists, and other caregivers) are a team working toward a common goal: to develop a personalized health plan for you. Your doctor and other members of this team can help monitor your medical condition and overall health, especially if any problems develop.

A note from VEDA

We receive an increasing number of inquiries about various products marketed with the claim that they cure vertigo, dizziness, tinnitus, or other symptoms of vestibular disorders. In chat rooms, forums, and on Facebook pages, we also see representatives of commercial businesses posing as customers who provide “personal testimonies” raving about how a product has “cured” them.

Be responsible about your health!

Before acting on any advice you find on the Internet ask your doctor about the accuracy of the information and the applicability of it to your situation.

This information was in part provided courtesy of the U.S. Food and Drug Administration (www.fda.gov) and the National Institutes of Health, National Center for Complementary and Alternative Medicine (www.nccam.nih.gov).

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This document is not intended as a substitute for professional health care.
Free Fact Sheets on Dietary Supplements

The National Institutes of Health Office of Dietary Supplements (ODS) provides information about individual vitamins, minerals, and other dietary supplements listed in the text box on this page. In addition, the ODS is developing fact sheets with a more extensive overview for many of these substances. The sheets are being produced in three versions: Consumer, Health Professional, and Quick Facts. All versions will provide the same types of information but vary in the level of detail. For example, the consumer’s fact sheet on vitamin D addresses these questions:

- What is vitamin D and what does it do?
- How much vitamin D do I need?
- What foods provide vitamin D?
- Can I get vitamin D from the sun?
- What kinds of vitamin D dietary supplements are available?
- Am I getting enough vitamin D?
- What happens if I don't get enough vitamin D?
- What are some important links between vitamin D and health?
- Can vitamin D be harmful?
- Does vitamin D interact with any medicines or dietary supplements?

Several of the new fact sheets—including those for vitamins B₁₂, C, D, and E and for zinc and calcium—are already available in all three versions. To explore information offered by the ODS, visit: http://ods.od.nih.gov/factsheets/list-all.

Please see the related story on page 1 for why it is important to consult with your physician about taking any dietary supplements.
Opportunity for Artists with Disabilities

The international organization on arts and disability, VSA, invites artists with disabilities to submit artwork for consideration in *Shift*, a June 2011 exhibit at the Terrace Gallery, John F. Kennedy Center for the Performing Arts in Washington, DC.

In the call for entries, VSA explains “Every life contains moments of change. *Shift* seeks to investigate those moments that alter the direction of a person’s path and create a new reality. Artists are invited to share a moment in time when a shift in their landscape occurred—it may be personal or professional, mental or physical, internal or external. Artists may submit a single work or a pair or series of works that illustrate this before-and-after transformation.” Eligible media include 2- and 3-dimensional art (painting, sculpture, photography, printmaking), craft (jewelry, textile, glass), digital art, installation, and time-based media (video, film).” Submissions will be accepted from artists ages 18 and older who have a physical, cognitive, or mental disability. “Disability” is defined as “an impairment that substantially limits a major life activity.” Although the artwork entered must have been completed after the onset of disability, the artist’s disability will not be disclosed during the jury process.

Further information is available by visiting www.vsarts.org/shift or by calling (800) 933-8721 or (202) 737-0645 (TTY).

COPING TIP:
Consider Using the Free Talking Book Service

Reading a book presents a special challenge for a person with a vestibular disorder because an impaired vestibulo-ocular reflex results in problems focusing on objects. Words on a page can seem to move or bounce. Many members solve this problem by listening to audio books. An additional advantage of this resource is that listening to a book while resting with closed eyes can help distract a person from focusing on dizziness symptoms.

The National Library Service for the Blind and Physically Handicapped administers a free library service for borrowers who are unable to read standard printed material as a result of physical limitations. The service provides audio books on tape, digital cassettes, and/or Internet downloads for personal MP3 players. Digital and tape playing equipment is provided as part of this service. Books that you select from a catalog are sent to you. When you finish a book, just return it in the postage-paid container, and the library will send you the next book on your list. You can also go online and download books.

This program is available in all states of the U.S. and to patrons who are American citizens living abroad. To find out more, visit www.loc.gov/nls/ or call (888) 657-7323.
Letter from Member About Cataracts

Dear VEDA: Sunshine and glare bother me, so I wear sunglasses a lot. I’ve also started to struggle seeing at night, especially with oncoming car headlights and lights reflecting on wet sidewalks. Everything seems darker, and lights have annoying rays that seem to move. Night driving is difficult, and I look rather drunk when walking on rainy nights. (Just ask my dog—she gives me querulous glances whenever I veer into her.)

I knew from annual ophthalmology appointments that I was developing cataracts in both eyes, but my doctor said they weren’t severe enough to justify surgery to fix them, inferring that I was complaining more than was warranted. When I asked if my vestibular disorder perhaps affected the amount of discomfort I had with the cataracts, she scoffed.

I sought a second opinion. My new doctor almost immediately volunteered that the cataracts were likely more troublesome for me because I rely so heavily on vision to balance. I thought he was just referring to the problem with lights, but he also explained that cataracts are often mustard color, so they change how you perceive colors and can make everything appear darker. Shortly after that, I had cataract surgery in one eye; surgery for the other eye is scheduled for next month.

Immediately after surgery, I noticed a huge change in light and color. Now that I see colors more accurately out of the “good” eye, I realize how dark and tinted brownish-yellow everything appears through the “bad” eye.

I’ll admit that during this period between surgeries, the difference between each eye is causing depth-perception challenges. Until the other eye is fixed, my balance is rather catawampus. But I’m forging ahead. I may need physical therapy to recalibrate things after the other surgery, but I’m really glad I started this process—especially because I didn’t know how very much I was struggling to see until I witnessed the results from the first cataract surgery. Perhaps my story will help others know what to expect if they need to consider cataract surgery.

—B.H., Spokane, WA

Editor’s note: Cloudy areas in the lens, called cataracts, are a common eye problem that comes with age. More than 22 million Americans have cataracts. By age 80, more than half of us will have had them. Some cataracts stay small and have little effect on eyesight, but others become large and interfere with vision. Symptoms include blurriness, difficulty seeing well at night, lights that seem too bright, and faded color vision. There are no specific steps to prevent cataracts, but tobacco use and exposure to sunlight raise your risk of developing them. Cataract surgery is a safe and common treatment that can restore good vision.

—NIH News in Health, January 2011
News Briefs

"Rebooting" the brain to treat tinnitus

Tinnitus, a persistent sound in the ears, is a symptom often accompanying some vestibular disorders. Current treatments generally involve masking the sound or learning to ignore it. Researchers in Texas used a new approach that, rather than masking the tinnitus, essentially resets the brain’s auditory system to tune to frequencies other than the tinnitus one. They paired electrical stimulation of the vagus nerve—a large nerve that runs from the head to the abdomen—with the playing of a tone. Vagus nerve stimulation (VNS) is known to release chemicals that encourage changes in the brain. It is already used to treat people with epilepsy or depression. The tinnitus scientists exposed rats to a high-pitched tone for 20 days, 300 times a day, during VNS. In preliminary results, the number of neurons tuned to the high frequency had jumped by 79% compared to control rats. Variations on the tests demonstrated that exposure to the tone alone wasn’t enough to initiate the change; it had to be accompanied by VNS. When the researchers tested whether VNS treatment could also reverse tinnitus in noise-exposed rats, they observed behavioral changes and neural responses in the brain’s auditory cortex indicating that the ringing had disappeared. The scientists are now planning to conduct clinical studies of VNS paired with tones in tinnitus patients.


Diabetes and vestibular system damage

People with diabetes are 70% more likely to suffer from vestibular problems. According to researchers at the Johns Hopkins Center for Hearing and Balance, this is because inner-ear hair cells are likely damaged by high blood sugar levels. In addition, over time, diabetes damages the inner ear’s small blood vessels.

—Johns Hopkins Medical Letter–Health After 50 2011;22(11):6–7

Quality of vestibular testing limited by training and experience of assessors

Poor quality of vestibular test measurements and assessments may occur with inexperienced assessors. To test this, researchers in British Columbia, Canada, compared data for caloric induced nystagmus measurements produced by different techniques and systems. They used test results for 100 patients who were each analyzed with variations in equipment (electronystagmography or ENG, and videonystagmography or VNG), experience of the assessor, and the use of a computer algorithm to quantify responses. They observed similar measurements across systems, but a failure for the inexperienced assessor to recognize certain subjective but important aspects of the nature of the measurements (e.g., ENG responses which might be “sporadic” or “scant”). They concluded that “assessment of complex VNGs should be left to an experienced assessor.”


Editor’s note: The Vestibular Disorders Association (VEDA) hears from patients and professionals wanting the health care system to more readily recognize the value of- and insurance coverage for vestibular disorder testing and treatment. Such recognition will be more likely to occur if tests and assessments demonstrate efficacy. As an advocate for people with vestibular disorders and the specialists who diagnose and treat them, VEDA supports research demonstrating the importance of education, training, and experience needed to specialize in vestibular disorders.

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Dizziness is the most common side effect of a new drug called neramexane mesylate, currently being studied as a possible tinnitus treatment. The dizziness side effect of neramexane may limit its appropriateness for persons with vestibular disorders.

Scientists in Munich, Germany used a randomized, double-blind, placebo-controlled clinical trial to study 431 outpatients with moderate to severe subjective tinnitus who had been prescribed a placebo or neramexane at 25, 50, or 75 mg/day. At the end of the 16-week treatment, no significant tinnitus improvement was measured using the total score of the adapted German short version of the validated Tinnitus Handicap Inventory questionnaire (THI 12). However, four weeks after treatment ended, THI 12 scores were significantly better for subjects who had received the 50 mg/day dose. Unfortunately, dizziness was the most common side effect, increasing with increasing dosage. The scientists noted that future research will further study effective dosage levels.

—Suckfuell M et al. BMC Ear Nose Throat Disord 2011(1)

Pro Athlete Incorporates Vestibular Rehabilitation Therapy into Recovery

VEDA often receives requests like this: “Tell me about a person who got better with vestibular rehab therapy (VRT) in real life—not just about results reported in research subjects. I can’t tell if the people in those studies have the sort of difficulties I have.” Below is an extract from a story we printed awhile ago about a professional tennis player with vestibular neuritis, followed by more recent news about her.

From “On the Level,” Winter 2006: Professional tennis player Alicia Molik has stepped away from competition for 2006 in order to recover from a vestibular disorder. One year ago, she was ranked number 8 in the Women’s Tennis Association Singles tour. In March 2005, she developed an inner ear infection (vestibular neuritis) that affected her vision and balance. “I was feeling incredibly fatigued, slightly dizzy, and a little bit heavy at times,” she said. “It was an effort to tie my shoelaces. I remember not wanting to change shoes because I knew it would require an effort.” In a May 2005 Australian radio interview she explained, “Every time I do just a little bit of exercise, I’m really exhausted and my head is spinning.” By fall, the tennis star admitted that the condition had made her a recluse. “I’ve been fighting this for a long time now,” she said. “This could improve, it could stagnate, or it could remain with me for a lengthy period of time. I need to accept that, if that’s the case.”

Since then, part of Molik’s recovery involved months of VRT. Eventually, she had enough confidence to attempt a career comeback in 2007. Leg and elbow problems set her back in 2008, but she returned again in 2009 and achieved tour-level ranking in 2010. Her most recent tournament action was at the 2011 Australian Open. Although she lost in early rounds, her state of health allowed her to energetically undertake entering all three events available to her: women’s singles, women’s doubles, and mixed doubles.
New Books on Vestibular Disorders

Two recently published books on vestibular disorders may be of interest to VEDA members.

Finding Balance—Healing from a Decade of Vestibular Disorders, by Sue Hickey, is written for a general audience and is a personal account of the author’s experience searching for a diagnosis, undergoing years of treatment, and rebuilding a life within the confines of what her symptoms allow. The author tells the story with a compilation of personal journal entries, self-insights, and tips about what she’s learned along the way.

Prior to retiring on disability, Hickey was a high-level executive of a multi-state electric utility company. She reports, “Life fell into a pattern of surviving the work week and recovering on the weekend.” … “I wasn’t bleeding, I wasn’t throwing up, no bones were broken. Calling in sick seemed like an over reaction to something that would surely clear up soon…I ‘gutted it out.’”

She is frank about the muddle of emotions associated with work-performance stress, uncertainties and disappointments, unmet personal expectations, moments of discoveries and set-backs, and lessons learned in her arduous pursuit of diagnosis and treatment that included traditional medicine and alternative approaches. VEDA members will recognize her frustrations and struggles involved with reconciling the chasm between self-expectations and available energy reserves.

Years into the process, she admits, “I still defaulted to my ‘push through’ approach — as if I could control the symptoms. I was slowly realizing it didn’t matter how badly I wanted something or how hard I tried. This failure wasn’t about a lack of discipline or control or will. I had discipline and will to spare. What I didn’t have was balance or the patience and perspective to accept my limits.” By taking responsibility for her decisions, she illustrates that acceptance is not the same thing as giving up.

Vestibular disorders can cause overwhelming dizziness, vertigo, and other symptoms that can’t be seen, and are difficult for others—sometimes, even close friends and family members—to understand. People struggle with their profound impacts on health, relationships, family interactions, and finances. Many people struggle alone. Finding Balance gives voice to these experiences, and in the process, brings needed recognition to the personal hardships associated with having a chronic vestibular disorder. (216 pages, to be published in Spring 2011 by Demos Medical Publishing, New York)

VEDA members are receiving advance notice about the book in this newsletter. As soon as the publication date is finalized, the author will list it on her Web site: www.findingbalancebook.com. Members who wish to reserve a copy may send an e-mail to her at reserve@findingbalancebook.com.
The book *Vestibular Disorders: A Case Study Approach to Diagnosis and Treatment*, Third Edition, by Joseph Furman, MD, PhD, Stephen Cass, MD, MPH, and Susan Whitney, PT, is directed specifically toward clinicians and includes an introduction about the principles of vestibular anatomy and physiology with respect to history taking, examination, and managing dizziness. Paralleling the team approach in diagnosing and treating vestibular disorders, this book is written by team of specialists (a neurologist, an otolaryngologist, and a physical therapist) who present 61 case histories in a teaching format that summarizes history, examination, and test results, then poses a question to the reader and offers an informative answer.

Case studies address peripheral unilateral vestibular imbalance, central vestibular disorders, impaired vestibular recovery, loss of vestibular function, psychiatric dizziness, dizziness in the emergency-room setting, and conditions such as disequilibrium of old age, head injury, BPPV, migraine, anxiety disorder, Ménière’s syndrome, recurrent vertigo in children, and multiple or overlapping diagnoses. (464 pages, including illustrations; published in 2010 by Oxford University Press; New York)

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**News About VEDA**

Throughout VEDA’s history, we’ve supported our work in part through sales of our carefully written short publications. In order to better fulfill our mission to give access and empowerment to people seeking information about vestibular disorders, we’ve made much of our library of publications free and as easily available to the public as possible. We’ve just added four important documents to this free library resource:

- *Benign Paroxysmal Positional Vertigo (BPPV)*, by Timothy C. Hain, MD
- *Balance and Aging*, by Charlotte Shupert, PhD, and Fay Horak, PhD, PT
- *Ménière’s Disease*, by P. J. Haybach, MS, RN
- *Vestibular Rehabilitation—An Effective, Evidence-Based Treatment*, by Anne Shumway-Cook, PT, PhD

Check them out by visiting: www.vestibular.org/publications-membership.php

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