

Calcium, Vitamin D and Bisphosphonates. Oh My!

Joan L. Headley, Post-Polio Health International, Executive Director, St. Louis, Missouri,
director@post-polio.org

John Fan, MD, Hutchinson Clinic, Hutchinson, Kansas, reminded polio survivors at PHI's 10th International Conference (June 2009) that there was research justification for "taking a holiday" from bisphosphonates. His message was heard, and polio people started asking more questions. Using research data and in consultation with Frederick M. Maynard, MD, I offer the following answers to frequently asked questions.

Question 1: *When I had my DEXA (Dual Energy X-ray Absorptiometry) scan, they scanned my spine and my good hip assuming that my polio hip would be worse. My friend's experience was the opposite – her polio hip was scanned because the technician thought it was important to know how bad it was, so "the physician will know what to do." Which is the most logical thinking?*

One recent study found a significant relationship between bone density of the hip and muscle strength of the affected leg of polio survivors. Participants with osteoporosis of the hip had weaker leg muscles than other patients in the study. The weaker a patient's leg muscles were, the more likely they were to have osteoporosis of that hip.

This retrospective clinical study also reported that about 19 percent of polio survivors (n=164) who had bone density scans had them performed only on their stronger hip. If they only had osteoporosis in their weaker hip this would not have been apparent in their bone scans, and they would be assessed as not having osteoporosis.

The researchers directly answer your question. They recommend that all post-polio patients be evaluated for osteoporosis at both hips (or less preferably at the hip of the weaker lower extremity) and at the lumbar spine. (Osteoporosis in a post-polio clinic population, Haziza M, Kremer R, Benedetti A, Trojan DA, Archives of Physical Medicine and Rehabilitation, 2007; 88:1030-1035.)

Dr. Maynard cautions polio survivors and health professionals about the pitfalls of interpreting scan scores. "Remember that for polio people who were left with significant lower limb weakness during childhood, a 'normal' maximum bone density was never attained by early adulthood. A low bone-density DEXA score for one's age when done at age 50 to 60 does indicate an increased risk of fracture prevalence for the tested bone compared to peers of the same age, but it does not mean a person has an accelerated rate of bone mineral loss compared to able-bodied peers of the same age."

continued, page 3

PHI's mission is to enhance the lives and independence of polio survivors and home mechanical ventilator users through education, advocacy, research and networking.

Post-Polio Health

Summer 2011, Vol. 27, No. 3

ISSN 1066-5331

Editor: Gayla Hoffman
editor@post-polio.org

Designer: Sheryl R. Rudy
webmaster@post-polio.org

©2011 Post-Polio Health International (PHI)
Permission to reprint must be obtained from
Post-Polio Health International (PHI).

How to contact PHI

Executive Director: Joan L. Headley, MS
director@post-polio.org

4207 Lindell Blvd., #110
Saint Louis, MO 63108-2930 USA

Phone: 314-534-0475
Fax: 314-534-5070
info@post-polio.org
www.post-polio.org

PHI sends *PHI Membership Memos* via email. Be sure to set your spam filter to receive emails from info@post-polio.org.

Moving? Change of address?

Notify PHI before you move by calling 314-534-0475 or email info@post-polio.org, and tell us your old and new addresses.

Away Temporarily? Send us your "second" address and dates you will be there, and we'll do our best to send your newsletter.

**WE'RE
STILL
HERE!**
October 9-15, 2011
www.post-polio.org

October will be here soon.

Have you reviewed the accessibility features of places of worship in your community using the checklist in the last *Post-Polio Health*? (www.post-polio.org/edu/pphnews/PPH27-2sp11p2-5.pdf) I drove around my neighborhood and snapped a few photos. The results were mixed.

Help make your place of worship more convenient for people with disabilities and those who are aging.



Need assistance? Many faith-based groups have excellent websites. The list is featured at www.post-polio.org/werestillhere/wsh-2011main.html#fai. Call us, if you don't have access to the internet.

Remember to send photos of your success.

Joan L. Headley, Executive Director, PHI

Like Us



**Post-Polio Health
International (PHI)**

on Facebook

Enjoy the photographs!

Calcium, Vitamin D and Bisphosphonates. Oh My!

continued from page 1

"Only serial DEXA scans can show that new loss is occurring and how fast. This is an important distinction because new treatments for osteoporosis have only been shown to be effective among people who have *accelerated bone mineral loss* by slowing down the rate of loss. They rarely actually increase bone density in a specific bone."

Dr. Maynard concludes, "To me, there is value in scanning both hips. The hip DEXA score of the weaker leg will indicate how easily that hip may fracture due to localized osteoporosis of that hip bone. The DEXA score of the stronger leg will be a better indicator of the generalized diagnosis of osteoporosis and the possible value of systemic treatments."

Question 2: After a blood test, my physician advised 50,000 units of vitamin D a week for a month. Have you ever heard of that? It seemed like a lot. I now take 600 IU (International Units) of Vitamin D and 600 mg of calcium each day. I consume orange juice and yogurt each day that has been fortified with calcium.

Yes, I have heard of it and, in fact, have taken 50,000 units of vitamin D a week for a month as prescribed by my primary care physician. Research has shown that calcium and vitamin D are important for strong bones and most people (including polio survivors) don't take in enough of either on a daily basis. The current recommendation for adults over 50 is to take in 1,200 mg per day of calcium.

Experts recommend a daily intake of 600 IU of vitamin D. (Recent

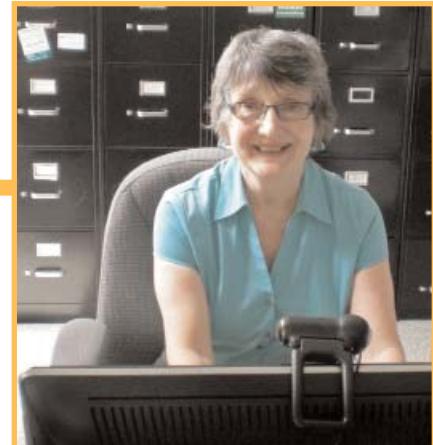
guidelines from The Endocrine Society state, "People older than 70 years should get a minimum of 800 IU of vitamin D a day.") Sources include sunlight, supplements or vitamin D-rich foods such as egg yolks, saltwater fish, liver and fortified milk. The Institute of Medicine recommends no more than 4,000 IU of vitamin D as a regular daily intake.

Your blood test must have been to measure the 25-hydroxy vitamin D level. It is the most practical method to assess how much vitamin D is in your body. It requires a blood draw. The normal range is 30.0 to 74.0 nanograms per milliliter (ng/mL), with 40-50 as optimal. Physicians may prescribe higher doses, such as 50,000 IU, to increase levels quickly to the normal range. (MedlinePlus)

Dr. Maynard reminds polio survivors that symptoms of low levels of vitamin D are similar to PPS symptoms – fatigue and muscle pain. "I would discourage survivors from taking doses of vitamin D above 4,000 IUs daily for time periods greater than one month without monitoring of blood levels and physician oversight."

Question 3: In years past, we were encouraged to take hormone replacement therapy (HRT) because it helped "prevent osteoporosis." Why don't we hear about that anymore?

Menopause is the time in a woman's life when her menstrual periods stop. It is a normal part of aging. In the years before and during menopause, the levels of



Joan L. Headley

female hormones can go up and down. This can cause symptoms such as hot flashes and vaginal dryness. Some women take HRT to relieve these symptoms. HRT may also protect against osteoporosis by preventing a sudden decline in estrogen levels, which is known to be associated with increased loss of bone mineral and can often occur during menopause, especially during an abrupt or relatively young-age onset of menopause.

The reason you hear less about HRT for osteoporosis prevention is that researchers have found that HRT also has risks. It can increase your risk of breast cancer, heart disease and stroke. Certain types of HRT have a higher risk, and each woman's own risks can vary depending upon her health history and lifestyle. Another reason you hear less is because additional, and possibly more effective, drug treatment options have become available in addition to HRT.

PHI's Research Fund supported work by a team from the University of Michigan, and in 2003, they concluded that "HRT did not confer substantial benefits in these postmenopausal polio survivors to warrant their

continued, page 4

Calcium, Vitamin D and Bisphosphonates. Oh My!

continued from page 3

using HRT at a higher rate than their non-disabled peers.”
(Hormone replacement therapy and health behavior in postmenopausal polio survivors, Kalpakjian CZ, Riley BB, Quint EH, Tate DG, Maturitas, *The European Menopause Journal*, Elsevier Ireland, Ltd., 2003;1:13.)

You and your health care provider need to discuss the risks and benefits for you. If you do decide to take HRT, lower doses for shorter time periods are safer. Taking hormones should be re-evaluated every six months.

(MedlinePlus.NIH: National Heart, Lung, and Blood Institute)

Question 4: *My family physician is pressuring me to take Fosamax®. I have read about the side effect of jaw necrosis (deterioration and cell death). But I have fallen in the past, so shouldn't I take bisphosphonates to be sure I don't break anything? I am not sure what to do. HELP!*

Before I share some of the research findings, Dr. Maynard wisely points out that, “first of all polio survivors should address the causes of the falls and learn all they can about falls prevention strategies. Fosamax® may decrease the risk of a fracture from occurring; it does not prevent fractures.” (See first question.)

A recent study conducted in Ireland of 50 post-polio patients (30 women, 20 men) reported that, based on bone mineral density data, 28 (56%) were diagnosed with osteoporosis and 20 (40%) had osteopenia, but only eight (16%) received antiresorptive therapy. Of the 19 patients who had a fracture, 14 (74%) had osteoporosis and five (26%) had

osteopenia, of whom only six (32%) received antiresorptive therapy. Fractures of the hip were more common in the weak leg.
(High incidence of osteoporosis and fractures in an aging post-polio population, Mohammad AF, Khan KA, Galvin L, Hardiman O, O'Connell PG. Department of Rheumatology, Beaumont Hospital, Dublin, Ireland. *European Neurology*, 2009; 62(6):369-74.)

In a study reported in the *Journal of the American Medical Association*, healthy women (not those who had polio) who discontinued alendronate (a bisphosphonate) after five years showed a moderate decline in bone mineral density (BMD). In the study that measured total hip BMD and at other sites, the cumulative risk of a non-vertebral fractures, after five years, was not significantly different for those continuing or discontinuing alendronate.

(Effects of Continuing or Stopping Alendronate after 5 years of Treatment: The Fracture Intervention Trial Long-term Extension (FLEX): A Randomized Trial, Black D, et.al. *JAMA*, December 27, 2006, 296 (24):2927-37.)

In an editorial in the same issue, the authors find it reasonable to conclude that women who are at high risk of vertebral fracture because of previous vertebral fractures might be considered for continued therapy. They further state and their answer to your question is, “Decisions about additional treatment should consider the individual fall risk, individual fracture risk, response to previous therapies and remaining life expectancies.”

(Ten vs Five Years of Bisphosphonate Treatment for Postmenopausal Osteo-

porosis; Enough of a Good Thing, Colón-Emeric, C. *JAMA*, December 27, 2006, 296(24):2968-69.)

The FRAX® tool has been developed by the World Health Organization (WHO) to evaluate fracture risk of patients. It is based on individual patient models that integrate the risks associated with clinical risk factors as well as bone mineral density at the femoral neck. It can be accessed at www.shef.ac.uk/FRAX. The FRAX® models have been developed from studying population-based cohorts from Europe, North America, Asia and Australia.

Dr. Maynard points out that there have not been any studies that show that bisphosphonates actually help polio survivors, “and there are side effects that should not be ignored, such as the ones mentioned in the question.”

Question 5: *I read that drinking tomato or papaya juice is beneficial in reducing the risk of osteoporosis. Is this true?*

A small study (n=23) of post-menopausal women (presumably none were polio survivors) aged between 50 and 60 were asked to stick to a diet free of lycopene for one month. For four months, one group took two 15 mg lycopene supplements daily; another group drank two glasses of regular tomato juice (enough for a daily intake of 30 mg of lycopene); a third group drank a special Japanese tomato juice high in lycopene (70 mg daily); and a control group took placebo capsules. The researchers compared the effects on chemical signs of bone loss in

GLOSSARY

Alendronate, a bone resorption inhibitor (resorption is the process of calcium from the bone being reabsorbed into the blood), is a nonhormonal medication for the treatment of osteoporosis that builds bone, restoring some of the bone loss.

Antiresorptive therapy is one of two primary types of drug therapy for osteoporosis. Antiresorptive drugs, such as calcium and vitamin D supplements, reduce bone loss as do antiresorptive therapies such as bisphosphonates and estrogen.

Bisphosphonates are a class of drugs that prevent the loss of bone mass, used to treat osteoporosis and similar diseases.

DEXA stands for dual energy X-ray absorptiometry. It is an imaging test that measures bone mineral density by passing X-rays with two different energy levels through the bone and is used to diagnose osteoporosis.

FRAX® is a web-based calculation that assesses the 10-year risk of osteoporosis fracture based on an individual's risk factors and femoral neck bone mineral density if available. The values are entered into the website tool, followed by clinical risk factors. The FRAX® tool then provides a figure indicating a 10-year fracture probability as a percentage, which, together with a clinical assessment, provides guidance for determining access to treatment in health-care systems. As of July 2010, the tool was available for 26 country models and in 11 languages.

International Units (IU) and **milligrams (mg)** are not equivalents. IUs are a measure based on the biological activity of a substance in the body. They are set by a research committee commissioned by the World Health Organization and provide a measure of the effect on the body a substance will have regardless of its mass. Milligrams are a measure of mass or weight.

Lycopene is an antioxidant compound that gives tomatoes and certain other fruits and vegetables, such as watermelons and papayas, their color.

Osteoporosis is a disease, most common in postmenopausal women, in which bones are less dense and more fragile and thus at greater risk for fracture. This disease often affects bones in the hip, spine and wrist.

Osteopenia is the term used for bones that have become somewhat less dense than normal, but not as severe as in osteoporosis. Not everyone who has osteopenia progresses to osteoporosis.

the women. Women taking lycopene from either juice or pills had lower levels of the chemical by-product associated with osteoporosis.

(Dietary restriction of lycopene for a period of one month resulted in significantly increased biomarkers of oxidative stress and bone resorption in postmenopausal women, Mackinnon, ES, Rao AV, Rao LG. Department of Medicine, Division of Endocrinology and Metabolism Sr. Michael's Hospital, Toronto, Ontario, Canada. *Journal of Nutrition Health and Aging*, 2011, Feb; 15(2):133-8.)

As usual, further and larger studies need to be done, but until it is proven without a doubt, there isn't any harm in drinking tomato juice or eating foods that contain lycopene, e.g., tomato products, watermelon, pink grapefruit, guava, papaya and rose hips.

Question 6: *I got the impression from Dr. Fan at the conference that he is not too keen on our taking the bone building medications for years and years. Did I get the right impression? Why is he hesitant?*

Dr. Fan explains his reluctance this way. Bone is a living tissue. Bisphosphonates work by "forcing" calcium into the bone. This is analogous to filling the bone with concrete. It makes the bone solid and brittle, not flexible and living. When it is damaged in a fall, it may crack or crumble. Dr. Maynard, too, has reservation about the quality of bone that results from use of these medications, especially when used for long periods of time. A more recent study, cited below, suggests this to be true.

(Bisphosphonate Use and the Risk of Subtrochanteric or Femoral Shaft

Fractures in Older Women, Laura Y. Park-Wyllie, PharmD, MSc; Muhammad M. Mamdani, PharmD, MA, MPH; David N. Juurlink, MD, PhD; Gillian A. Hawker, MD, MSc; Nadia Gunraj, MPH; Peter C. Austin, PhD; Daniel B. Whelan, MD, MSc; Peter J. Weiler, MD, MASc, P Eng; Andreas Laupacis, MD, MSc. *JAMA*, February 23, 2011, 305(8):783-789.)

Conclusion: I wrote this article because the topic is personal. I have had scans every few years for the last 15 years and have osteopenia-type scores. I have taken Evista® and Fosamax®, but am currently on my "holiday." Articles say that "Decisions about additional treatment should consider the individual fall risk, indi-

vidual fracture risk, response to previous therapies and remaining life expectancies."

Well, I have fallen twice in the last year. One was a legitimate accident. The other might have been from new left leg weakness. I cracked my sacrum in the legitimate fall. My scan scores maintained and improved slightly with Fosamax® use. My parents lived to the ages of 88 and 92, so I presumably have genes for a longer life, and I am in otherwise very good health. For now, I take my calcium, vitamin D, eat yogurt with calcium, drink orange juice

continued, page 9



Rhoda Olkin, PhD

Promoting Positive Solutions

QUESTION: As a group leader I sometimes feel I come across as too “pushy” when suggesting a polio survivor try out an assistive device. How can I get someone who obviously needs to use a new device to try it without appearing to be too pushy?

Dr. Rhoda Olkin is a Distinguished Professor of Clinical Psychology at the California School of Professional Psychology in San Francisco, as well as the Executive Director of the Institute on Disability and Health Psychology. She is a polio survivor and single mother of two grown children.

Response from Rhoda Olkin, PhD:

Sometimes it is easier for someone else to see what a person needs than it is for that person him/herself. But what do you do with that knowledge? Let me tell you how I first went from being a crutch user to a scooter user as a way of introducing how hard this transition can be. I was teaching at a university, and one day I arrived at work to find a scooter parked outside my office. I was told, “Oh, the Dean thought you could use this on campus to get around.”

Well, it seemed churlish to refuse, so I started using the scooter. And lo and behold, I found I went places I hadn’t gone before because they were too far, and I conserved energy. But at first I limited my scooter use to on campus, that is, I was okay with being a “scooter user” in my professional life.

Then I got a scooter for home and began to use it with friends. Suddenly I could go to big box stores, museums, the park – the scooter expanded my world. The last place I used the scooter was with family. That was the harder transition – both for me and for my parents – bringing up lots of feelings in all of us. Our identity shifts when we go from being upright to a seated position; I get that, it’s hard.

But you know the moral of the story. It’s the one every new scooter or wheelchair user can recite: You don’t realize how much you have limited your world until you get wheels and expand it again. Then you feel a sense of freedom that you couldn’t have predicted, and you would never go

back again to not having wheels. But how do you impart this moral to someone who is not there yet? I have a few suggestions.

Have a questionnaire for people to fill out and discuss with each other. Ask questions like: Are there stores you don’t go to because they are too big? How long can you stand in line? How active do you envision yourself being in the next five years? Have you fallen in the past six months?

Plan an outing at a place that is easy to get to by scooter, but difficult on foot. Make scooters available for those who don’t usually need them.

Have small group discussions about self-image as a person with a disability and what it means to be a crutch user, or scooter or wheelchair user.

Have timed treasure hunts in the facility where you meet. Have clues spread out in the facility so that walkies have to go all over. Offer scooters for use as needed.

Put wheelies on one side of the room and walkies on the other and have them talk about what is easy and hard about their mode of transportation.

Remember, you can lead the horse to water, but only the horse can make itself drink.

Please send questions for Drs. Olkin and Machell to info@post-polio.org.

QUESTION: I am a caregiver of a polio survivor. At times I feel taken for granted. How can I handle this situation without hurting my partner?

**Response from
Stephanie T. Machell, PsyD:**

Caregivers, like parents and spouses and others we love and depend on, are often taken for granted. No matter how much someone appreciates your care, in the daily routine that caregiving becomes, the person may forget the importance of expressing appreciation and gratitude.

It's hard to be a caregiver, especially for a spouse or partner. It changes the relationship and can create inequalities and resentments. There is ambivalence for both partners about their new roles. The one receiving the care may be appreciative of what is given but fear becoming a burden and resent not being able to do what he or she once did. The one providing the care may be happy to help but resent the extra work and loss of freedom. Both may long for the carefree earlier days of the relationship.

It's especially hard for polio survivors to receive care. Being taken care of may bring up memories of the original polio, which may include negative experiences of caregivers who were anything but caring. Or it may bring up feelings of helplessness and dependence that can be hard to handle for someone who has always believed it was essential to be fully in charge and independent. Expressing appreciation for care, even when it's felt, might make the polio survivor feel more vulnerable.

Can you talk with your partner about how you feel? Couples often fail to discuss such sensitive issues until they come up in indirect ways or in angry and hurtful words – or until the caregiver becomes ill and unable to carry on. Such a serious and important dis-

cussion would be best held at a calm and neutral time. You might start by asking your partner how he or she feels about the way things are going in your relationship. Or you could talk first about what you value about being able to care for your partner, or ask what it's like to receive care. You could ask your partner how he or she feels about what you are doing and if there is anything he or she especially likes or dislikes.

This may be a chance for your partner to express gratitude or appreciation for all you do. If not, you can let your partner know how you feel and see how he or she responds. If talking about it doesn't work, or if your partner can't or won't do so, there may be less direct ways he or she expresses appreciation that you can observe.

For instance, he or she might look more comfortable or smile at you when you have done something helpful. You might also notice the positive effects of what you do for your partner, like having more energy.

Feeling taken for granted could also be a sign that you need a break. It's important to care for yourself so that you can care for your partner. Find a way to take time out. If no family or friends can help, there are resources available for respite care. Use them and take the time to do something that will replenish you. You will return refreshed and revived and better able to care for your partner. ▲



Stephanie T. Machell, PsyD

Dr. Stephanie T. Machell
is a psychologist in independent practice in the Greater Boston area and consultant to the International Rehabilitation Center for Polio, Spaulding-Framingham Outpatient Center, Framingham, Massachusetts. Her father was a polio survivor.

Resources:

National Alliance for Caregiving
4720 Montgomery Lane, 2nd Floor
Bethesda, MD 20814
www.caregiving.org

Family Caregiver Alliance
National Center on Caregiving
180 Montgomery Street, Suite 900
San Francisco, CA 94104
415-434-3388, 800-445-8106
info@caregiver.org
www.caregiver.org

Because We Care: A Guide for People Who Care
Administration on Aging
Washington, DC 20201
202-619-0724
www.aoa.gov

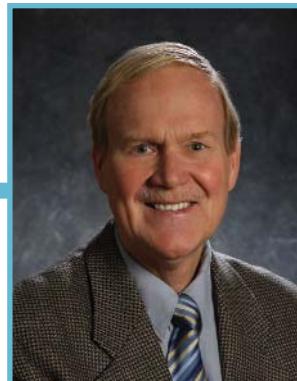
Area Agency on Aging
For caregiver support groups, respite providers, and other caregiving services.
Eldercare Locator:
800-677-1116
www.eldercare.gov

ARCH National Respite Network and Resource Center
Call to find local respite providers.
800-473-1727
<http://chtop.org/ARCH.html>

Check out

**Post-Polio Health Care Considerations
for Families & Friends**
FLOWCHART

at www.post-polio.org/edu/healthcare/



Frederick M. Maynard, MD

Question: *My physiatrist says that paraplegics have a lot more diabetes, so I started wondering how post-polio and spinal cord injury compare with regard to the disease.*

A: You are right that people with chronic spinal cord injury paralysis do develop glucose metabolism abnormalities and diabetes (by criteria) more often than their age cohorts. I attended a 90-minute course on this topic and obesity among people with spinal cord injury at a recent meeting of the American Academy of Physical Medicine and Rehabilitation. The new information reminded physicians how important muscle is to insulin utilization and, therefore, to serum glucose levels.

During the lecture, I was thinking about people who had polio, with their extensive muscle atrophy, because I expect the same issues exist for them. Not only are people with extensive muscle paralysis (paraparesis and quadriplegia, independent of causation) predisposed to obesity because they cannot move and exercise as much to burn up calories, they also are predisposed to store fat because the relative lack of muscle mass (as a proportion of the body) leaves high circulating levels of insulin which combines with serum glucose to store fat.

A recent study of body composition among polio survivors in Taiwan found a higher proportion of fat, independent of body weight as considered from the standard of Body Mass Index (BMI). Normally a BMI (calculated from height and weight) of 25 to 27 is considered "overweight" and over 30 as "obese." Almost all polio survivors studied, even those not overweight/obese by BMI, had an

increased proportion of fat by body composition measurements, a proportion that would typically be expected only in overweight/obese individuals.

I would expect there is a correlation between glucose metabolism abnormalities and increased fat proportion of body composition.

Question: *My father-in-law is 88 years old and has post-polio syndrome. He has had trouble sleeping for the past several years, and he claims that it "takes more medication for people with post-polio syndrome." My wife is his caregiver and controls his medications so he will not overdose. What is your professional opinion?*

A: Your father-in-law is mistaken about need for higher medication doses for post-polio people. Generally, they are more sensitive to medications and require lower doses because their bodies distribute medications differently through body tissues and fluids due to reduced muscle mass. I would be very careful with sleeping medication doses, in particular, because of their potential to affect breathing during sleep (suppression) and the likelihood of creating dizziness/balance problems on awakening (leading to greater falls risk) – both greater problems among polio survivors than the general population.

Encourage him to keep talking to his doctor about what is and is not helping and to try several different types of medications or other techniques

to attain “good sleep” without just dangerously taking higher doses of prescribed sleeping pills.

Question: *I have a severe rotator cuff tear and an orthopedic surgeon has recommended a shoulder replacement because of the severity of the tear and the presence of significant arthritis. I had polio in my right leg and use my left leg to lift/stabilize myself on crutches. Apparently the increased dependency has weakened my arms and, perhaps, injured them. The surgery may help or may create complications. Can you share any knowledge to help me make an informed decision?*

A: You raise several important issues related to the pros and cons of shoulder replacement in polio survivors. First of all, if you never had any significant residual weakness in your shoulder muscles as part of your original polio, then it is unlikely that your shoulder problems are, anatomically at least, related to polio. You may have worn them out and/or injured them as you suggested, and the

shoulder problem can be surgically treated like anyone else's.

Definitely get a second opinion about whether the best treatment is arthroplasty (replacement). In addition to a second opinion from a shoulder surgeon specialist, I recommend a second opinion from a non-surgeon, such as a physical medicine and rehabilitation specialist in post-polio. That person cannot only advise about non-surgical alternatives for the shoulder problem, but also advise you on preparations for the post-operative period, if you do elect to have the shoulder replacement.

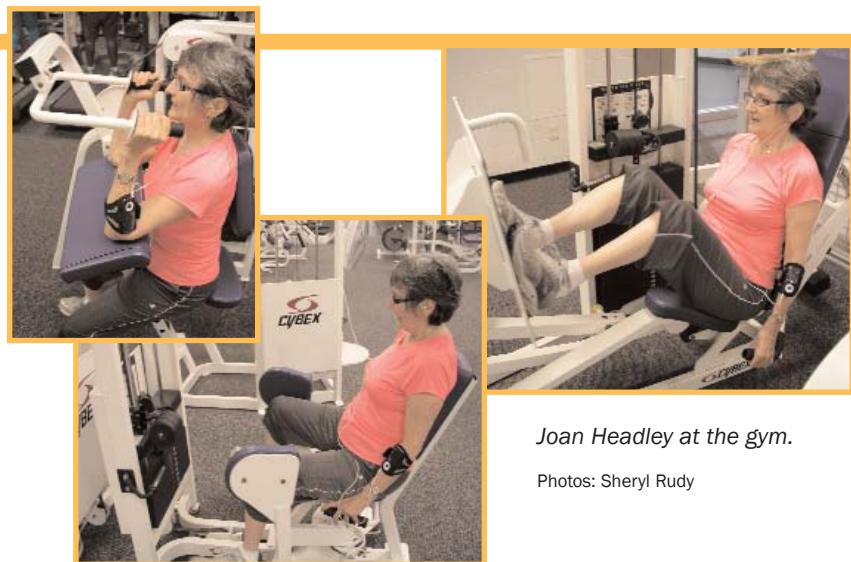
Certainly, you should at least practice transferring and walking and caring for yourself with only one arm, since you will not have much use of the arm after surgery for at least three months. You are facing a difficult and important decision. Don't make a hasty one, especially if you are not suffering severely. Take all steps possible to inform yourself about the pros and cons. ▲

SEND YOUR QUESTIONS
FOR DR. MAYNARD TO
INFO@POST-POLIO.ORG.

Calcium, Vitamin D and Bisphosphonates. Oh My!

continued from page 5

with calcium added and tomato juice. Because my polio effects are mostly in my left leg and because I can, I participate in specific targeted exercises at least three to four times a week at the gym in order to maintain my strength and therefore decrease my risk of falling, and weight-bearing exercises also help deposit calcium into bone. I will decide soon if I should end my holiday. ▲



Joan Headley at the gym.

Photos: Sheryl Rudy

Aging Well with Post-Polio Syndrome: Don't Take Fatigue Lying Down

Rehabilitation Research and Training Center (RRTC) on Aging with a Physical Disability,
agerrtc@uw.edu

Fatigue is a major problem for many people with post-polio syndrome (PPS), one that is frustrating and hard to measure. It's a symptom that can affect your ability to work, your mobility and your quality of life. People with PPS report fatigue as their most persistent and debilitating symptom.

Although most people (with or without PPS) report increases in fatigue as they grow into middle age, interestingly, they report decreases in fatigue as they transition from middle age to retirement. Middle age is a time of great stress – work responsibility, saving for retirement and preparing children for independence.

After retirement, the decrease in daily stress helps to reduce fatigue. Unfortunately, analyses from a recently completed survey study that many of the people reading this article participated in shows that people with disabilities (including PPS) do not reap the “retirement benefit” on fatigue. Instead, for people with disabilities, fatigue stays the same or gets worse as people age into the retirement years (Cook, 2011).

In our study surveying 441 people with PPS, we found individuals with disabilities are not only at greater risk to experience fatigue than people without disabilities, but this risk increases with age. Moreover, we found that fatigue in people with PPS was the *highest* of those surveyed, which also included people with multiple sclerosis, muscular dystrophy and spinal cord injury.

A 5-year longitudinal survey of people with the late-onset of sequelae of poliomyelitis done in the Netherlands showed that fatigue was associated with perceived restrictions in physical functioning, higher levels of pain and sleep problems. A task-oriented (problem-focused) coping style correlated with higher levels of fatigue. This type of coping style may be pushing survivors beyond their physical abilities and increasing levels of fatigue (Tersteeg, 2011).

There are several non-medication ways to manage fatigue:

Assistive Device/Equipment/Technology – Protect your weakened muscles – talk with your doctor or physical therapist about the best assistive devices for you, such as braces, canes, walkers or power chairs.

Self Management is defined as methods, skills and strategies that can effectively direct activities toward the achievement of a goal or objective. For people living with a chronic condition, this translates to *“overcoming the physical and emotional problems caused by the disease. The goal is to achieve the greatest possible physical capability and pleasure from life”* (Lorig et al, 2006). This idea can be applied to fatigue. You can *manage* your activity level by planning and scheduling, prioritizing, delegating or asking for help and pacing yourself. (Ghahari, 2010)

Exercise/physical activity – Historically, people with PPS were often told to minimize exercise as a way to conserve energy. Current research has shown the benefits of a *carefully tailored and gentle* exercise program designed specifically for each person depending on how PPS is affecting the body (Davidson et al, 2009). Be sure to talk with your doctor or physical therapist about starting any new exercise program.

References:

- Cook KF, Molton IR & Jensen MP. Fatigue and Aging with a Disability. *Archives of Physical Medicine and Rehabilitation* 2011; 92:1126-33.
- Tersteeg IM, Koopman FS, Stolwijk-Swüste JM, Beelen A, Nollet F, on behalf of the CARPA Study Group. A 5-year longitudinal study of fatigue in patients with late-onset sequelae of poliomyelitis. *Archives of Physical Medicine and Rehabilitation* 2011; 92:899-904.
- Ghahari S, Leigh T, et al. Effectiveness of an online fatigue self-management programme for people with chronic neurological conditions: a randomized control trial. *Clinical Rehabilitation* 2010; 24:727-744.
- Davidson AC, Auyeung V, Luff R, Holland M, Hodgkiss A, & Weinman J. (2009). Prolonged benefit in post-polio syndrome from comprehensive rehabilitation: A pilot study. *Disability & Rehabilitation*, 31(4),309-317.
- The National Center on Physical Activity and Disability (NCPAD) To Reap the Rewards of Post-Polio Exercise - www.ncpad.org/disability/fact_sheet.php?sheet=136

Letter to the Editor

Thank you for your article, "Improving Accessibility in Places of Worship," in the Spring 2011 newsletter. I am writing to suggest that the guidelines omitted one group of polio survivors.

I had polio at age three that atrophied my right leg. At age 61, I was diagnosed with post-polio syndrome with further weakness in my right leg and additional left leg and shoulder weaknesses. I began to use a cane and depend upon my arms, shoulders, wrists and hands to rise from chairs, beds and toilet seats. Eventually, I needed a brace on my right foot and ankle and began to use a walker. And I needed a chair with arms to lift myself to a standing position.

Because I stressed my shoulders trying to get up from church pews and other seats, such as in restaurants, I needed surgery on my shoulder. I can no longer get up from a church pew, and what I need – in church and other places – is a substantial chair with arms. So far, I do not need a wheelchair, but I am in an in-between group of polio survivors.

Thank you again for all the services you offer to the post-polio community.

Thomas Hutcheson

Send Letters to the Editor by email to info@post-polio.org or by mail to the Post-Polio Health International mailing address. All letters are subject to editing.

Thank you

For recognizing your friends and loved ones with contributions to support the unique mission of PHI and IVUN. PHI strives to publish an accurate list. Please contact us if we made an error.

Contributions to PHI's education, advocacy and networking activities ...

In Memory of

Phyllis Bailey
Charles Raymond Dent

Alice Mailhot
Evangeline Reisser

In Honor of

Carol Dexter
Morton Freilicher

Mary Ann E. Keenan, MD

Contributions to The Research Fund ...

In Memory of

Phyllis Bailey
Cornelius J. Cunningham

Alice Mailhot
Doris Morrissey

In Honor of

Linda Bieniek
Walter C. Bunten

Teri Held

Contributions to the Gilbert Goldenhersh Memorial Tribute Fund ...

Mr. and Mrs. Barry Worth's mother

PHI Thanks its Members for their support. If you are not yet a Member,

Join PHI!

Support Post-Polio Health International's educational, research, advocacy and networking mission.

PHI membership levels make it easy to start taking advantage of timely and important news and activities relating to the late effects of polio. Select your level below and return it with your check or credit card information. Memberships are 100 percent tax-deductible.

\$30 Subscriber

Newsletter of your choice:

Post-Polio Health (quarterly)
OR Ventilator-Assisted Living (bi-monthly)

\$55 Subscriber Plus

Both newsletters:

Post-Polio Health (quarterly)
AND Ventilator-Assisted Living (bi-monthly)

\$100 Contributor

ALL the benefits of Subscriber Plus AND
Post-Polio Directory AND
Resource Directory for Ventilator-Assisted Living;
discounts on special publications
and meetings sponsored by PHI

\$150 Sustainer

ALL the benefits of Contributor AND
One additional complimentary gift membership to:
 Person of your choice (include name and address) or
 Person who has expressed financial need to PHI

Membership at the following levels includes ALL benefits PLUS special recognition in PHI publications:

\$250 Bronze Level Sustainer

\$500 Silver Level Sustainer

\$1,000 Gold Level Sustainer

\$5,000 Platinum Level Sustainer

\$10,000 Gini Laurie Advocate

Name _____

Affiliation _____

Address _____

City _____ State/Province _____

Country _____ Zip/Postal Code _____

email _____

Phone (include area/country code) _____

Fax (include area/country code) _____

I am enclosing a check for \$_____ made payable to
"Post-Polio Health International." (USD only)

Please charge \$_____ to this credit card:

VISA MasterCard Discover

Card No. _____

Exp. Date _____

Name on Card _____

Signature _____

Send this form to: Post-Polio Health International
4207 Lindell Blvd, #110
Saint Louis, MO 63108-2930 USA
Phone: 314-534-0475
Fax: 314-534-5070



POST-POLIO HEALTH INTERNATIONAL
INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

4207 LINDELL BOULEVARD, #110
SAINT LOUIS, MO 63108-2930 USA

Non-Profit Org.
U.S. Postage
PAID
Jefferson City, MO
Permit No. 210

"I am a 33-year-old lady from Tijuana, Mexico, who had polio 'in my whole body' at 7 months. With the help of my family and Shriners, I now walk with a brace on my left leg. I am pregnant for the first time. I would like parenting hints and suggestions for devices from experienced polio survivors."

Share Your Experiences at Polio Place

PHI invites its Members to help us provide practical information and encouragement about raising children if one has paralysis or muscle weakness from prior polio. Send your comments and photographs to info@post-polio.org. Living with Polio, Medical Help, Pregnancy includes advice provided by the health professionals who participate in monthly telephone conference calls. (www.polioplace.org/living-with-polio/pregnancy)

For example, **Lise Kay, MD, (Denmark)**: "As a doctor and a polio survivor now aged 59, I can tell you that I had two pregnancies in my 20s that went well. My considerations are whether it would be a good idea to wear a corset to support the abdominal muscles to prevent them from being overstretched. Besides the size of the birth canal (which an experienced obstetrician, to some extent, can judge by palpation), lack of sufficient muscle strength in the abdominal wall may become a problem during the birth. It is important to give birth at a place where it is possible to have a caesarean section, and of course, someplace where there is knowledge of following polio patients through an operation."

Together we will expand Polio Place, making it the place that not only preserves our legacy but supports the younger and isolated survivors throughout the world. ▲

FOLLOW US ON @polioplace



Supported by
Amigo Mobility
International Inc.

Amigo Mobility International, Inc. manufactures a complete line of innovative mobility products including power operated vehicles/scooters, trunk and van lifts, and electric shopping carts. Designed to bring comfort, freedom and satisfaction to customers, Amigo's quality, made in the USA products have been *Improving Lives Through Mobility®* since 1968.