

The Polio Perspective

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Cholesterol-Lowering Medications and Muscle Pain in Polio Survivors

by Dr. Richard L. Bruno

I've written two articles about cholesterol-lowering drugs potentially causing unique problems in polio survivors. The first was published five years ago. The buzz in the post-polio community then was that rhabdomyolysis -- a very serious condition where kidney and muscle tissues breakdown -- occurred more frequently in polio survivors who take statins, the then newish cholesterol-lowering drugs. There have been no specific studies of cholesterol-lowering drugs in polio survivors, but there seemed to be no reason polio survivors would be more prone to rhabdomyolysis. Only about one-half of 1% of anyone who takes a statin, such as Lipitor, develops rhabdomyolysis, which can indeed cause muscle pain (usually in the calves), muscle weakness and possibly even kidney failure. With rhabdomyolysis, the enzyme creatine phosphokinase (CK, also called CPK) is released as muscle breaks down, CK sometimes increasing to more than ten times the normal limit.

You should be aware that polio survivors can have an elevated CK without taking a statin. Two studies have found that 40% of polio survivors had abnormally elevated CK, with men having significantly higher CK than did women. In one study, CK increased with the number of steps polio survivors walked in a day. In 50 Post-Polio Institute patients who were not taking statins, 21% had an abnormally elevated CK of about 225, which is one-third higher than normal, but not ten times higher. Still, an elevated CK may mean that polio survivors are making their muscles work too hard and causing the fibers to break down, but isn't evidence of rhabdomyolysis.

Regardless, your CK was normal and you had arm muscle pain -- not calf pain -- that went away when you stopped the statin. Drug companies are now reporting that statins can cause muscle pain anywhere in the body, not just in the calves, without causing muscle breakdown or elevating CK. An exception is Zocor, which, although it can cause rhabdomyolysis, is reported by its manufacturer to cause muscle pain no more frequently than in those taking placebo.

Newer cholesterol-lowering drugs, the fibrates (Tricor and Lopid), also can cause rhabdomyolysis, elevated CK and "diffuse muscle pain, tenderness and weakness." Even one of the oldest cholesterol-lowering drugs, the bile-acid sequestrant Welcol, is reported to cause muscle pain in 2% of patients versus none of those on placebo. What's more, the cholesterol lowering B vitamin, Niacin, has also been reported to cause "pain," although no more frequently than in those taking a placebo.

The good news is that a newer cholesterol-lowering drug, Zetia, is said to produce "no

excess” rhabdomyolysis or increase in CK, and produced only slightly more (0.04%) muscle pain than did placebo. However, a January 2008 study found cholesterol plaque in arteries grew faster in patients taking Vytorin (Zetia plus Zocor) than in patients taking Zocor alone.

Whatever drug you chose with your doctor, remember that and muscle pain are more likely if you’re taking a combination of cholesterol-lowering drugs, calcium channel blockers, immune system inhibitors, certain antibiotics or antifungal drugs, have kidney disease, diabetes, a slow thyroid or drink more than a quart of grapefruit juice a day. If you’re taking a cholesterol-lowering drug and feel muscle pain, even if you’ve been on the medication for a while, stop the drug immediately and call your doctor.

Also, remember that there is more to managing cholesterol than taking a pill. Reducing saturated fat and eating foods high in soluble fiber -- such as cereal grains, beans, peas, legumes, fruits and vegetables -- can help lower triglycerides and the "bad" low-density cholesterol (LDL) while raising the "good" high-density (HDL) cholesterol. It is also recommended that you lose weight, decrease stress, treat high blood pressure, stop smoking and have a five-ounce glass of wine with dinner.

By following these suggestions and The Post-Polio Institute “Diet” (that recommends eating more protein, especially at breakfast) and reducing carbs and portion size -- you can lose weight, fuel your neurons to feel less fatigue and muscle weakness, while keeping your plumbing clear of cholesterol.

Aging Well with Post-Polio Syndrome: Addressing Habits that Cause Sleep Problems

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Getting a better night’s sleep may not always happen, but if your sleep problems are due to medical issues, there are ways you can manage them. Many medical problems can disrupt sleep in people with post-polio syndrome, such as breathing problems, so treating them is a first step in addressing sleep concerns.

Sleep apnea, or episodes where people stop breathing during sleep, is a very important problem to discuss with your doctor if you have this symptom. Pain, which can also disrupt sleep, is a major topic that will be addressed in a future column. Here are some physical factors that can disrupt sleep and tips on eliminating them.

Caffeine ... Caffeine often plays a role in sleep problems, because it is a stimulant that affects the central nervous system. It temporarily increases alertness and wards off drowsiness, which are also the reasons it can cause sleep problems. People who drink caffeine are less likely to sleep well than those who do not. If you have sleep difficulties, it is a good idea to avoid caffeine or limit it only to the morning. Caffeine is present not only in coffee and black tea, but also in many sodas. Check labels. Decaffeinated coffee and tea are good substitutes.

Alcohol ... Alcohol is a sedative. Although it may seem like it helps with sleep problems, it can actually cause them. For example, alcohol can help you to fall asleep, but it also disrupts the sleep cycle and the quality of sleep. The sleep you get after drinking alcohol is not restful, because it interferes with the ability to achieve and stay in the deep (so-called “Stage 3” and “Stage 4”) sleep cycles. It is a good idea to avoid alcohol altogether if you have sleep problems; at a minimum, you should limit drinking it to earlier in the evening rather than right before going to bed.

Sleeping pills ... Even though they are often prescribed to help people fall asleep, sleeping pills can actually worsen sleep problems over time. They also can depress breathing. However, like alcohol, most sleeping medications disrupt the sleeping cycle by interfering with our ability to achieve deep and restful sleep. Almost all sleeping medications, if they are sedatives, are recommended to be prescribed for a very short time (two weeks at most) to help someone sleep during a stressful time. Many sleep medications are addictive, and your body builds a tolerance to them. This is especially true of the benzodiazapines such as Xanax®, Librium®, Valium® and Ativan®. If you are taking a strong sedative for sleep, you should talk to your doctor about tapering off. Getting off these drugs must be done gradually and with medical supervision. Stopping abruptly can be dangerous.

Nicotine ... Nicotine, whether smoked or chewed, is a stimulant like caffeine. It causes temporary alertness or jitteriness, and raises your metabolism. These physical changes can in turn keep you from falling asleep or disturb your sleep once you’ve fallen asleep.

Yoga and Post Polio

by Melissa Gatlin

What is Yoga?

Yoga basically means Yoking of Mind and Body and is one of the oldest recorded practices that mapped all the movements a body is capable of and designed movements, called asanas that take your body through all of the movements it can do. We also link these movements to our breath, encouraging the full use of our lungs and can turn the physical movements into a movement based meditation. Yoga itself is over 5000 yrs old, older than any religion that adopted its use, so while some religions (Buddhism and Hinduism in particular) do use yoga, yoga itself is not a religion. And its not something you have never seen as a lot of exercises you have used in gym classes or PT are based off of yoga Asanas.

Examples:

Lunge (Warrior)

Painless Posture (Mountain Pose)

So why use yoga for Post Polio?

Well yoga is both a muscle stretching and a muscle strength building activity. Unlike weight lifting which just builds muscle through contraction, yoga also lengthens muscles so it helps keep that balance needed in our muscular structure.

It is also a bone building activity while still being low impact. When we stretch a muscle it causes a pull on the bones which encourages the bones to grow. And of course we all know weight bearing also helps our bones and yoga is a weight bearing exercise.

Yoga is also beneficial in stimulating, revitalizing and balancing the digestive system .. most of the yoga postures compresses and releases the abdomen where the digestive organs are located. With each posture, these organs automatically get a deep massage. Each time we compress a digestive organ and release it, old blood, bile and lymph fluid is released and fresh blood flows in. If you hold a posture for at least 20 seconds while doing slow, deep breathing, the up and down movement of the diaphragm also massages the digestive organs from the top, creating a constant pumping that stimulates and rejuvenates all the digestive organs. Which is also why you will hear gas passed or belching in most classes.

- Yoga reduces blood pressure.
- Yoga reduces anxiety, depression and is even helpful for post traumatic stress.
- Yoga can be modified to meet the needs of people of all ages and physical conditions while still providing all the benefits.

Multiple studies have been done on yoga and post polio and they have all shown positive effects.

HOW TO FIND A YOGA CLASS:

There are yoga class out there but here are some that you can look for even in areas that do not have a lot of studios and are usually appropriate for those with PPS .. you will often find these offered at Physical Therapy Clinics, YMCA's, Churches, Community Centers, Hospitals,etc.

Classes that are for Physical problems (first 10 are Hatha based)

- Silver Sneakers Sit and Stretch
- Chair Yoga
- Senior's Yoga
- Gentle Yoga
- Yoga for RA (Rheumatoid Arthritis)
- Yoga for MS (Multiple Sclerosis)
- Yoga for FM (Fibromyalgia)
- Yoga for Cancer Patients
- Pink Ribbon or Yoga for Breast Cancer
- Recuperative Yoga
- Yoga Therapy or Therapeutic Yoga (these will have teachers certified by the International Association of Yoga Therapists (IAYT))
- Iyengar Yoga (make sure they have a gentle yoga class or talk to teacher about private classes, one of the best for offering Restorative yoga)
- Viniyoga (will usually offer gentle or senior yoga)
- Restorative Yoga (best class for when you are fatigued .. all resting poses with use of props .. this is not for strengthening)

Classes to Avoid:

(Please note that I am not saying these are bad yoga ... just that they are not usually appropriate for us .. I have actually practiced several of these myself when younger and healthier)

- Ashtanga Yoga (was one of my faves when younger and stronger)
- Power Yoga (another name for Ashtanga Yoga)
- Bikram Yoga

- Hot Yoga
- Vinyasa Yoga (classes are often to fast paced with no rests between moves)
- Flow Yoga (another name for Vinyasa Yoga)
- Jivamukti (while highly meditative also physically challenging)

Can't find a Teacher

Peggy Crappy (books,videos,dvd's, You Tube .. Yoga for All of Us, etc.)

Suza Francina (book) The New Yoga for Healthy Aging

American Yoga Associations's Easy Does It Yoga (book)

You Tube: Adaptive Yoga, Easy Yoga, Wheelchair Yoga

Teacher Certification you want a minimum of a 200 RYT, has completed a 200 hr teachers training program that has been certified by the Yoga Alliance, teachers with more than this will be 500 RYT, or E-RYT's, E-RYT have more than 500 hrs training. IAYT have their own certification but teachers will have IAYT as their Certification, Iyengar Yoga as has their own certification but if they list themselves as Iyengar teachers they are certified.

Questions to ask if not sure

- Do they offer classes for Seniors or those with health problems.
- Do they know how to modify the poses for those with physical limitations.
- Do they have chairs or props available.

Shoulder Warm-Up (from Pink Ribbon Recuperative Yoga)

You can find a video of this warm-up at
http://www.youtube.com/watchv=_SEp5qOop64&w=560&h=315...

(if you have problems typing in the link go to <http://yogalp.com/> and there is a link to video there)

Studies that you might find interesting:

Researchers at Johns Hopkins University examined 152 studies on yoga, identifying 15 that assessed balance-related issues. Among these, 11 studies showed that yoga practice can enhance balance, reduce the incidence of balance-related falls and reduce fear of falling.

<http://online.liebertpub.com/doi/abs/10.1089/acm.2013.0378>

Web Corner

Amid Iraq's Political Chaos, a New Polio Vaccination Campaign Faces Challenges

<http://www.nytimes.com/2014/08/12/world/middleeast/amid-iraqs-chaos-a-new-polio-vaccination-campaign.html?ref=todayspaper&r=0>

The Myth of the 8 Hour Sleep

<http://www.bbc.com/news/magazine-16964783>

Autoimmune Research Opening Up New Options for Chronic Pain Sufferers

<http://www.prohealth.com/library/showarticle.cfm?libid=19132>

Animal therapy reduces need for pain medication after joint-replacement surgery

[http://www.sciencedaily.com/releases/2014/08/140807180314.htm?utm_source=feedburner&utm_medium=feed&utm_campaign=Feed:+sciencedaily+\(Latest+Science+News+--+ScienceDaily\)&utm_content=My+MSN](http://www.sciencedaily.com/releases/2014/08/140807180314.htm?utm_source=feedburner&utm_medium=feed&utm_campaign=Feed:+sciencedaily+(Latest+Science+News+--+ScienceDaily)&utm_content=My+MSN)

United Spinal Partners with Airshells to Provide Air Travelers with Disabilities Protective Safety Bags for Wheelchairs

http://www.bizjournals.com/prnewswire/press_releases/2014/08/07/DC84567

Study: Vaccines Safe, Problems 'Extremely Rare'

<http://www.disabilityscoop.com/2014/07/08/study-vaccines-extremely-rare/19494/>

Bachelor Contestant Raising Disability Awareness

<http://www.transfermaster.com/blog/view-post/Bachelor-Contestant-Raising-Disability-Awareness>

When Wheelchairs Are Cool

<http://www.nytimes.com/2014/08/01/opinion/when-wheelchairs-are-cool.html?ref=todayspaper>

Solar Powered Wheelchairs

<http://www.transfermaster.com/blog/view-post/Solar-Powered-Wheelchairs>

'Disabled By Polio, But Enabled By Determination': How Paralympian Anne Wafula Strike MBE Can Inspire Us All

http://www.huffingtonpost.co.uk/2014/07/30/anne-wafula-strike-mbe-post-polio_n_5633935.html

Has Anyone Seen My Dignity?

By Millie Malone

Apparently, your memory is not the first thing to go as the Golden Years stalk you relentlessly. It's your dignity. Yep, the stuff that hasn't dried up or just quit working at all leaks or creaks or starts to develop a faint odor, which may or may not remain faint. Aging still beats the alternative, but some days it is a photo finish.

I am, as you know, a “woman of a certain age,” just which age is frankly none of your business. I try to dress nicely and aim for elegance. OK, I said I aimed for it, I did not say I hit the bullseye. I can still walk, but dignity is definitely not part of that scene. Not when I tend to list heavily to port and lurch into unsuspecting door frames and unwary people. I'm much more graceful in my power chair, barring the odd toe that may get crushed when I'm in a hurry. Not my fault that my chair has such a wimpy little horn that goes *beep beep* when, to be affective, it should go **BEEP BEEP**. So there is that. Then there is the fact that my thigh muscles are pretty much useless. Not even good for decorative purposes. No, I look like I'm ready to play an invisible cello as I sit there, knees spraddled. Not elegant, not even close.

Trying to be considerate of others, I stay out of crowded places where other people may not want to become mangled as I wend my merry way through the room. I attended a meal in the building next door last Saturday. There is a woman here in town, Myong Vanteicher, who is the best cook I know. She provides a Chinese buffet once a month there and then a week later, the same thing here in my building. She charges only enough to pay for the ingredients. The problem is that while the dining area here in my building is spacious and very easy to get around in, the one next door is cramped and next to impossible to maneuver my chair between the closely spaced tables. I could skip that meal, I suppose. Are you crazy or do you just think I am?? Pass up Myong's tempura shrimp? I don't think so!

I solved the problem, I thought, by simply parking my chair in the back of the room and walking through the buffet line. It worked great, too, till I stepped on something while carrying my loaded plate back to the table. Yep, I did a little impromptu break dancing there, complete with air born shrimp, fried rice in my hair and down the front of that day's attempt at elegant attire. My skirt, which had a slit in the back originally, ended up mostly two flaps of cloth with my very inelegant lower extremities flapping in the breeze.

Everyone rushed to help me get up. I'm not sure exactly how I managed to land on what I laughingly call my Good knee, the one I always land on and that has fluid on it as a result, but of course no good

break dance would be complete without it. I managed to waddle back to my chair, red faced and minus the delicious shrimp for which I'd attended the buffet in the first place. Somehow I did get another serving of food, and I laughed about providing the entertainment for the day. One woman said she'd missed it. I told her I was not doing an encore and "You snooze, you lose."

Old age, as the saying goes, is not for sissies. Dignity, elegance, graceful mobility are all pretty much a pipe dream at this stage of my life, but do I really care? I mean, do I mind so much that I'd avoid going to that Chinese buffet? Not on your life. I really believe in the saying that if you can laugh at yourself, you will have an endless supply of entertainment. If you can't, I'll be happy to laugh at you for free. You are welcome!

A Little Bit of Humor

Here is a recipe I found that you might like if you're having a large crowd for dinner.

Elephant Stew

(for a crowd)

1 elephant

seasoned brown gravy

2 rabbits, optional

Cut elephant into bite-size pieces. This should take about 2 months.

Cover with brown gravy and cook over kerosene fire at 465° for about 4 weeks.

This will serve 3800 people.

If more are expected, add the 2 rabbits. Do this only if necessary, as most people do not like to find "hare" in their stew.