Rancho Los Amigos Post-Polio Support Group

Newsletter - April 2010

Ask a Post-Polio Specialist #2

With Vance C. Eberly, M.D.
Rancho Los Amigos National Rehabilitation Center
Downey, California

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At our December 2009 meeting with Vance Eberly M.D., the orthopedist in the Rancho Los Amigos Post-Polio Clinic, he answered questions that were submitted in advance. The topics included in this report are Exercise, Hip Pain, Knee Pain, Incontinence, Anesthesia, Wheelchairs, Stiff Neck, Decreased Strength, Human Growth Hormone, Post-Polio at What Age, Preserving Leg Function, and Tracheostomy Information.

Dr. Eberly thought there seemed to be a common denominator in many of these questions:

- not a full understanding of the process that is involved when you get polio
- the recovery mechanism
- a reversal of that recovery mechanism when you later develop post-polio syndrome

Dr. Eberly believes that if you fully understand the processes listed above, you can answer almost any question regarding post-polio syndrome.

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Understanding Post-Polio Syndrome

At the initial polio infection, the virus infects the anterior horn cells in the spinal cord. Those are the nerve cells that go to the muscles and activate them. As a result, some of the nerve cells are killed, some are damaged, and some are not affected.

The skeletal muscles are the ones affected by the polio virus - those you can move yourself: legs, arms, back, chest, and neck. The polio virus doesn't affect the smooth muscles - gastro-intestinal tract, bladder, heart. "It does not affect sensation either. So if you are complaining about numbness or tingling it's not polio, it's something else," he said. When a condition develops that is not related to a skeletal muscle, it is not post-polio syndrome.

Many of the body's cells regenerate but nerve cells are one of the few tissues that do not. Perhaps stem cell research will eventually develop a way for damaged nerves to grow. In the more distant future, nerve transplants might even become available.

Exercise?

I have been hearing about new exercise standards for people with PPS. It's no longer conserve, but exercise and stop before being fatigued. Dr. Perry warned me that my muscles were too weak for exercise. Where does that leave me? Asking most doctors or physical therapists hasn't helped.

You have started to transition into the area of polio where the nerves that go to the muscle are starting to wear out. Exercise will depend upon the existing strength of the muscle. If that muscle has a nerve going to it that is working at 20% of its normal function, and it is not used, it will get weaker from disuse.

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We never say don't do anything. If you are interested in some exercise you need to have a manual muscle test that assesses the strength in your upper extremities, your lower extremities, and your back. If your muscles are a grade 3 or weaker those are antigravity muscles - the level of muscle strength we use for activities of daily living. So an active day would be exercise for those muscles. Exercise for muscles at that low level is not recommended. In effect, that exercise can make a person weaker. We are not saying don't do anything, but activities of daily living are exercise for those people.

If your muscle grades are 3+ or 4 then you can do some light exercise. Just stop before being fatigued. You want exercise to be submaximal, do it three times a week (not every day). You should be fully recovered after 15 minutes of exercise. If exercise makes you fully exhausted and the next day you are totally wiped out, exercise is not for you. If you persist in that exercise, you are going to make yourself weaker, instead of stronger.

Pool exercise is a lighter form of exercise. You can do it if you meet all the criteria above.

Over-exercise?

How can you tell if you over-exercise?

You get tired and it lasts longer than a normal tiredness would last. The next day you would be fatigued as well. You need activity, not exercise. You don't want to be inactive.

Hip Pain?

I have a great deal of pain in my right hip, the side most affected by polio. My doctor thinks a hip replacement might help. But, I'm very concerned about recovery time and losing more strength. I know we are all different, but what is

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your experience with your polio patients?

Hip pain is a very nebulous thing. I see three or four orthopedic patients in my private practice every day complaining about hip pain. But it is not hip pain; it is referred low back pain.

For this person I recommend you make sure the pain is coming from the hip joint. If that is the case and you have hip arthritis that causes pain, it interferes with your ability to do activities of daily living, you are taking pain medication, it is really affecting your life, then it is time to get a joint replacement.

However you have to be careful with joint replacement for someone who has weakness. The muscle on the outside of your hip, the gluteus medius or abductor, is the muscle that pulls on the thigh bone and pushes the ball into the socket. It needs to have grade 3 muscle strength or better. If that muscle strength is weaker, it will lead to recurrent dislocations. A chronically dislocating artificial hip is much more of a problem than an arthritic hip.

If you are thinking about a hip replacement make sure that:
- *you are a candidate for it, and*
- *you have sufficient strength in your hip muscles to tolerate it.*

Knee Pain?

I had polio at the age of three in my left leg. I am now 45, and have recently (since eight weeks) been experiencing immense pain in my good knee, making movement painful and steps a nightmare. It has been diagnosed as Late Effects of Polio, and I have been asked to use a crutch. I wear a KAFO in one leg and have been hopping on the good leg for the past 40 years. There is bursitis in the good knee as well and some fluid. How long would such a condition take to heal? I do hydrotherapy twice a week. Would exercise or massage aggravate the situation?

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Fortunately, there are no signs of osteoarthritis, but further muscle weakness in the calf and ankle/foot of the good leg.

This person is saying his good leg is getting weaker and he has knee pain. The bottom line in treating the knee is that you have to get a good diagnosis. There are many causes for knee pain: bursitis (rare), osteoarthritis (early osteoarthritis doesn't show up on an x-ray), or torn meniscal cartilage.

Treatment depends upon the diagnosis. Sometimes you can get tendinitis, which is an overuse of thigh muscles because the calf muscles get weak. Treatment for that is often a small ankle foot orthosis (AFO brace) which takes the stress off the thigh muscles and gets rid of the tendinitis.

When there is torn cartilage, the treatment is a ten minute surgical procedure.

Incontinence?

Is incontinence one of the symptoms of PPS? Can it be cured and how?

Incontinence is not a skeletal muscle so it is not a symptom of PPS. There are many causes of incontinence and treatments. The first step is to see a urologist for a workup to determine the cause and its treatment.

Anesthesia?

Is it true about the cautions involving anesthetic for PPS patients if surgery is involved?

I would answer Yes and No. The technology that is available today and the use of intraoperative monitoring of the patient while asleep, the whole question about anesthesia in polio patients is a non-issue at this point in

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time. When you have a fair amount of weakness in your body, you have a lower lean body mass; so drugs affecting it are usually decreased. This is all monitored intraoperatively. The most important thing to tell the anesthesiologist before surgery is that you had polio; many polio patients get sleep apnea so be sure to tell the anesthesiologist if you have it. That can be important in the recovery room after surgery. They will be sure you have adequate oxygenation and will be monitored more closely as you're coming out of the anesthesia.

Dr. Eberly said he has done many surgeries on polio patients and has never seen any single anesthesia problem, not any more than what is seen in the general population.

Recommend a Wheelchair?

Where would be the best place to go for a wheelchair and who should be the one to recommend what type - transport, manual, electric, scooter, etc.?

Many people who need a wheelchair go to their primary care physician and ask for a wheelchair prescription. The patient takes the prescription to a vendor who often recommends whatever will make the most profit. I have seen many spinal cord or polio patients with a $15,000 wheelchair they cannot use because it is inappropriate for them. It doesn't fit them; they can't get into it, they can't get out of it, it doesn't work in their house – and they bought it. Insurance companies, including Medicare, will not pay for another wheelchair for five years. So they are stuck in a bad situation.

For seating evaluation, even for his private practice patients, Dr. Eberly recommends Rancho's Seating Center, located in the 900 building. It is basically a therapy unit that is staffed with physical therapists who evaluate the patients. They look at your functional level, what you can and cannot do, your home living situation (upstairs, downstairs, width of the

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doors) the type of car you drive, etc. There are many factors to consider when getting a wheelchair, and vendors often don't take those things into consideration. Before buying a car and/or a wheelchair be sure they are both compatible. There is a lot of planning that goes into these decisions, beginning with a seating evaluation.

Stiff Neck?

I developed a stiff neck, suddenly, 6 months ago. An MRI showed that I have arthritis; the doctor said it is causing the stiffness and pain. How could arthritis get so bad all of a sudden when I didn't have a hint of a stiff neck before? It has been 6 months now. Could this be from PPS?

Post-polio syndrome does not cause neck stiffness, but it can cause neck muscle pain. The extensor muscles at the back of your neck hold up your neck. They are antigravity muscles and you use them all the time during the course of the day. That can cause muscle fatigue and muscle pain.

The treatment is to lie down throughout the day. If you lie down for about 15 minutes two or three times during the day you give those muscles a rest. If you sit down you are still holding your head up. Lying down takes the stress off the neck muscles.

Although the age of this person is unknown, the cause could be arthritis. As we get older the disks degenerate, especially in the neck. Over time you can lose some range of motion. Frequently that is not noticed until it gets to the point it impairs you. This is a gradual process.

Treatment for neck stiffness from arthritis is range of motion physical therapy. Range of motion exercises can help maintain the range. Strengthening exercises would depend upon the strength of the neck, but probably not.

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Anti-inflammatory medications can minimize the inflammation and give more range of motion. Inflammation can cause pain; pain can cause a little bit of muscle spasms. So you have to treat the pain, not the muscle spasms.

Decreased Strength?

Can I regain any of the strength I have lost in the past 3 years? I was symptom free for 61 years.

If your weakness is from post-polio syndrome and the damaged nerves have been overworked, they cannot function at that level anymore. So they are decreasing what they can do. You cannot change this.

Post-polio syndrome weakness is usually a gradual thing. It doesn't just manifest all of a sudden.

Human Growth Hormone?

Can human growth hormone be used to treat PPS?

The mechanism with post-polio syndrome is that a nerve has been overworked and it can no longer keep up. If you give it any type of medication that is going to increase its activity, that will not be good for the nerve.

Post-polio syndrome is an aging process in the neuron (nerve). Right now there is nothing to reverse the aging process, which is multi-factorial. Taking one particular drug is not going to do anything to change that nerve; it has been damaged and its functional level has been gradually decreased over time. Trying to stimulate that nerve to work harder is not a good idea. That is why electrical stimulation is not recommended for people with PPS.

In past years, many drugs have been unsuccessful in treating PPS. Some

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examples are: pyridostigmine (Mestinon), dopamine agents used in Parkinson's, serotonin mechanism drugs used to treat depression, L-Carnitine which is a muscle metabolic enhancer. (Enhancing the muscle's metabolic function is not going to help much because it is the nerve that is driving that muscle.) Strong anti-inflammatory steroids have been tried but it is not an inflammatory process. Post-polio syndrome is a difficult entity to treat. There is not a drug to treat the problem.

Post-Polio at What Age?

I am young, compared to most polio people in the U.S. I got polio as a baby in the Philippines in 1973. My whole left side is weaker, but I have always been able to live normally. Now I'm getting tired often. I'm 39 years old. Can a person only 39 years old get post-polio syndrome?

Absolutely - it could be post-polio syndrome, but age is not a factor in developing PPS. The sequence of polio is: You get acute polio, you recover to a maximum extent, you have a plateau in function, and then your function starts to drop off a little bit. One of the main manifestations of PPS is that you get a little weaker - you get tired, fatigued. You can also develop some central issues in the reticular activating system of the brainstem, such as decreased concentration or fatigue.

This inquirer needs to see his doctor for a good workup since many things could cause fatigue. If the thyroid is not functioning, there will be fatigue. If your heart isn't working as well it should be, you are going to be tired. If you have other metabolic processes such as early Type 2 diabetes for example, you will be tired. Depression can also make you tired.

The older you were when you had polio, the more involved it was, and the better recovery you had , the more likely you are to develop post-polio syndrome. The time span in developing PPS is huge; there is no magic number.

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Preserving Leg Function?

What can a 40 year old polio survivor like me do to preserve function in my right leg which has been affected for 38 years? Can I avoid or delay the development of post-polio syndrome?

Moderation is basically the bottom line. A person with this history is a perfect candidate to have a post-polio evaluation where all their muscles are tested, their range of motion evaluated, and a good history of their activity level and how they are feeling is recorded. Then a long term plan can be recommended to help prevent the onset of PPS or at least delay it.

A lot of people come back many years later and say, "I didn't listen to you at first, but after a while I realized you were right and now I'm glad I did."

Tracheostomy?

I know this is not an orthopedic question, but you might be able to give me an answer, or find the answer from someone else at the polio clinic. My question is about a tracheostomy. I have used a BiPAP machine for many years. My breathing continues to weaken, and I have a hard time coughing if I get a cold. I asked my pulmonologist about a tracheostomy and he almost yelled at me. He claims that I won't be able to talk, and I will need to enter a nursing care facility. He admits that he has no patients with tracheostomies, but he says this is because "those people" live in hospitals and die quickly. I'm frightened about my future.

Dr. Eberly said he has limited knowledge on this subject. But, if you are on a BiPAP machine and you are insufficiently oxygenated even while using it during the day, it is time for a trach (rhymes with cake). It is not just a quality of life issue. It is a function of adequate oxygenation for your entire body. You feel better; you are more alert; you are not as tired. The down side of it is the maintenance and the cost and the ability to take care of it.

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Richard Daggett has a trach and he can talk. Richard commented, "A lot of people are scared about a trach because they are told that they can't talk. Unfortunately some pulmonologists, even some pretty good ones, equate it to having a cuffed trach – a donut shaped device that is an integral part of the trach tube end. They inflate the cuff to prevent things from getting into your lungs. When that device is inflated the person cannot talk. But it can be deflated to allow speech. For polio survivors a cuffed trach tube is usually not necessary; just the trach tube is adequate."

Dr. Eberly recommended Richard Daggett for advice on a trach: richard@polioassociation.org or phone (562) 862-4508.

Our thanks to Dr. Eberly for so willingly providing an overview of polio and post-polio. That information helps us better understand this condition. We appreciate his time and effort.

This report can also be viewed at www.polioassociation.org/newsletters.html