



Rancho Los Amigos

Post-Polio

Support Group

Newsletter - June 2011

Ask a Post-Polio Specialist #3

With Vance C. Eberly, M.D.

Rancho Los Amigos National Rehabilitation Center
Downey, California

Reported by Mary Clarke Atwood

Editorial assistance by Richard Daggett and Vance Eberly, M.D.

At our December 11, 2010 meeting with Vance Eberly M.D., orthopedist in the Rancho Los Amigos Post-Polio Clinic, he answered questions that were submitted in advance and also from the audience. The questions and answers included in this report are:

- What are the most frequently asked questions at the polio clinic?
 - Do I have post-polio syndrome (PPS)?
 - Can you give me the medication to get rid of this problem?
- What are your thoughts on stem cell therapy for PPS?
- What are your thoughts about blood pressure and post-polio?
- How are muscles graded?
- Can I exercise?
- What are the general guidelines for hip replacement surgery?
- How can the pain of an arthritic hip be treated?
- In scoliosis, would wearing a corset prevent further curvature?
- What are your thoughts on cholesterol lowering drugs and PPS?

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What are the most frequently asked questions at the polio clinic?

Those questions are about diagnosing PPS and medications.

➤ Do I have post-polio syndrome?

Post-polio syndrome (PPS) is a clinical diagnosis based upon a person's history and functional decline over time; it is a diagnosis of exclusion. There is no blood test to confirm it. The bottom line is that you had polio (probably in your early years) and had some weakness, even sub-clinical weakness, and you recovered from it. You lived your life for 10 or more years at a certain level of function and then noticed your level of function was declining a little.

You may have noticed some of these possible changes, which are similar to a reversal of the compensatory mechanisms from acute polio.

- fatigue
- muscle weakness
- muscle pain, muscle cramps, muscle atrophy
- joint pain
- cold intolerance
- problems swallowing
- maybe you have to sit up to catch your breath
- speaking in shorter sentences and similar things

When all other conditions are ruled out as the cause, there is a clinical diagnosis of PPS.

The original polio affected the anterior horn cells in the spinal cord which go to your muscles. Those are the nerves that go out from your spinal cord to make the muscles work. Polio killed some of those cells and damaged others.

A muscle without a nerve is useless, it just sits there. That is like a motor in your car without the electrical system making it do what it normally does. If you take away that car's electrical system the motor doesn't work. Over time that motor will just rust. That is what the muscles affected by polio basically do also.

With our body being a biological system, we try to compensate for that. Some of the nerve cells were killed, so the remaining nerves try to branch out and go to

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other muscles fibers to help compensate and get them to do what they normally do. Then the neuron (nerve) is going to more muscle fibers than it normally does, it is doing more than it usually does over a lifetime, and it wears it out sooner. It will not necessarily last as long. When you have a neuron that has been damaged by polio and it tries to do more than it should be doing, those are the ones that are dropping off over time and you develop PPS.

➤ **Can you give me the medication to get rid of this problem?**

Unfortunately there is no medication to treat PPS. In reviewing the literature you can read about trials for neurotransmitters, neurotransmitter uptake blocking agents, growth factors, growth hormones, anti-inflammatories, anabolics to try to build muscles - but none of those work.

If you really look at the cause of polio, then it will make sense that none of these drugs will really work. Polio affected the motor neuron cells; it killed a certain number of them and it weakened others. So you have these damaged or lifeless nerve cells. Taking any of these medications is not going to change the weakened or lifeless nerves. There will never be a pill to solve the problem.

What are your thoughts on stem cell therapy for PPS?

The “pill” that everyone is looking toward today is stem cell therapy. Dr. Eberly believes that stem cell therapy will have limited usefulness for people with the late effects of polio.

If you were a child going through your growth years and got polio, and it affected the muscles and you have muscle weakness, then all the other tissues don't experience the normal stresses they would. Frequently there will be leg length discrepancies, hypertrophic development of the joints and of the bones. Over time there will be joint contractures.

The muscles that those nerves once innervated have been nonfunctional for many years and become fibrotic. They are replaced with scar tissue and fat. Over time, a muscle that has not been worked for many years, regardless of the cause, is not going to work anymore once you try to fire it back up.

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So if stem cells are placed in the spinal cord, and for example the nerve axon finds its way all the way down to the calf muscle, that calf muscle is not going to be working, even if it is innervated. It is a worthless muscle at this point in time. Then the joints are still going to be contracted and you are still going to have all of the problems associated with long term denervation of the muscle.

With that said, stem cell therapy will not be completely useless for the late effects of polio. Dr. Eberly thinks that polio survivors who have bulbar symptoms, where polio affected the brain stem, might have these symptoms:

- breathing difficulties
- swallowing problems
- central fatigue where they are chronically tired
- decreased concentration

In the future, people with these symptoms might benefit from stem cell therapy. Dr. Eberly does not know of any ongoing stem cell research for PPS right now. The important thing is that stem cell research is happening. Once it is optimized, stem cell therapy will probably be applied to every disease state. Researchers don't necessarily have to be looking at PPS currently, because in the future they will be able to apply what is learned to other diseases.

What are your thoughts about blood pressure and post-polio?

Blood vessels are smooth muscles and not affected by polio or PPS. Many primary care physicians do not have much background in polio and treating PPS. Generally speaking, exercise is good for helping control hypertension. If you are in a wheelchair most of the day, your muscle strength is such that activities of daily living are probably sufficient exercise for that person.

How are muscles graded?

Muscles are graded from five to zero. A grade five muscle is normal strength. The grading then goes down 4, 3, 2, 1, 0. A muscle graded zero is flaccid paralysis.

However, this is not a linear scale. When you go down from a grade 5 muscle to a grade 4 muscle, you do not lose 20% of the strength - the loss of strength is

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actually about 50% to 60%. When you go from a grade 4 muscle strength down to grade 3 it is similar - another 50%-60% loss. At grade 3 you are basically down to about 20% to 25% of normal strength, which is what is needed for activities of daily living.

Can I Exercise?

People who had polio and whose muscle strength is globally about 25%, then activities of daily living are exercise for those people. If they go out and try to exercise, then they run the risk of developing PPS because they are making those nerves work much harder than they should. Remember, you have damaged nerves doing more than they should. If you really push them you are going to wear them out sooner and it is going to make you weaker by doing exercise rather than making you stronger. That weakness is permanent - it is not recoverable because you killed off those nerves by overworking them.

If a person is thinking about starting an exercise program, Dr. Eberly recommends that you first have a manual muscle test (MMT) done by a good physical therapist. Then look at the MMT results. If most of those muscles are grade 3 or less you should not be doing an exercise program. However, you should also avoid doing nothing, because a weak muscle group can be made weaker by disuse. So there is a fine line for those with existing muscle weakness.

People who have PPS usually know their bodies and understand what they can and cannot do. Exercise is based upon your muscle strength. Sometimes a small amount of exercise is good. It all depends upon the individual, and everyone is different.

What are the general guidelines for hip replacement surgery?

Hip replacement surgery is for someone who has hip arthritis. The hip hurts a lot, and the medications don't work.

The important aspect for someone who had polio is that you need to have adequate strength around the hip to hold that ball in the socket. If you don't have that muscle strength, and you have the replacement, the hip will dislocate. A chronically dislocating hip is much more painful than an arthritic hip.

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The muscle group on the side of the hip that lifts the leg out should be about grade 3 or 3+ or better. The patient should be able to hold his leg out against gravity for about a count of 10. If you can do that, there is no reason why you cannot have a hip replacement. If you cannot hold that leg out that long, then you should not have a hip replacement because you really run the risk of having an unstable hip. That is far more problematic than the hip arthritis itself.

How can the pain of an arthritic hip be treated?

Treatment for pain in an arthritic hip is limited. First you try the different anti-inflammatory drugs. Keep in mind that anti-inflammatories are the only class of drugs that work for some people and not for others. So you try one and if that doesn't work then you try the next one.

A hip injection can be done periodically for arthritic pain relief. That has to be done under fluoroscopy because the hip joint is so deep and so well covered by bone that you have to demonstrate that the needle is actually inside the joint before you inject steroids in it. That procedure might be done three or possibly four times a year.

When you have polio you do not have nerve pain, but you may have muscle pain and/or joint pain.

In scoliosis, would wearing a corset prevent further curvature?

It depends upon where the curve is and how big the curve is. For a severe curve the corset itself will not help. You would need to have a Thoracolumbosacral orthosis (TLSO) clamshell type thing, which is very uncomfortable to wear.

What are your thoughts on cholesterol lowering drugs and PPS?

If you have elevated cholesterol and a cholesterol lowering drug is recommended by your physician, take it. If you develop a side effect where it affects your muscles then you should stop taking it. This is the same as with the general population.

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These answers help us better understand some of the challenges facing polio survivors as they grow older. Our thanks to Dr. Eberly for so willingly providing answers to these questions. We appreciate his time, effort, and humor.

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<http://www.ranchoppsg.com/Newsletters.html>

Meeting Schedule for the Post-Polio Support Group of Orange County

Saturday, June 11, 2011 - **Van Conversions**

Saturday, July 9, 2011 - **Sharing of what has helped us live with PPS**

Saturday, August 13, 2011 - **Indoor Picnic
and continuation of sharing**

For information, please call:

Marte Fuller 562-697-0507

Marilyn Andrews 714-839-3121

Meetings are 2:00 p.m. to 4:00 p.m. in the Villa Park City Hall

Remember, your family and friends are always welcome to attend.

Meeting Schedule for the Rancho Los Amigos Post-Polio Support Group

Saturday, June 25, 2011 - **Annual Picnic**

Enter Rancho Los Amigos from Imperial Hwy. Park in front of the 601 Building. This is normally a restricted parking location, but we have permission to park here for our annual picnic.

Our annual picnic is always enjoyable. We share good food, good company, and interesting activities. Please join us.

Saturday, July 23, 2011 - **Polio Documentary: The Last Word**

This interesting documentary has never been shown in our area. It looks at the current state of polio conditions and treatment in Africa, and provides a historical look at polio in eastern Europe and other parts of the world. Over the years, we have shown many polio documentaries. This one is special. We invite you to bring your family and friends.

Contact information: Richard Daggett 562-862-4508
 On the day of the picnic only 562-688-6094
 Diane Ekonen 562-861-8128



Life is a rollercoaster

Enjoy the ride