



Rancho Los Amigos

Post-Polio

Support Group

Newsletter - May 2006

Ask Dr. Perry - Revised

With Jacquelin Perry, M.D.

Reported by Mary Clarke Atwood

Rancho Los Amigos Post-Polio Support Group Newsletter

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Our thanks to Dr. Perry for so graciously taking the time to review and update these responses. Since retiring after 40 years of dedicated, full time county service, polio specialist Dr. Jacquelin Perry continues her work at Rancho but in a new capacity -- as a volunteer consultant.

The Rancho Los Amigos Post-Polio clinic continues to be a source of excellent care each Friday afternoon due to the commitment of two other excellent physicians. Dr. Sophia Chun is the current chief of the clinic; her medical training includes both internal medicine and rehabilitation. Dr. Vance Eberly is an orthopaedic surgeon. Both attend the clinic regularly and Dr. Perry is there frequently. Dr. Perry also volunteers as a medical consultant to the Rancho Los Amigos Pathokinesiology Laboratory. She no longer gives lectures.

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Question 1. What is the natural progression of post-polio syndrome? Will a person return to the same degree of paralysis that was experienced at onset?

Answer: When focusing on the natural progression of PPS it is important to understand that muscle function depends on three systems:

1. Control from the brain
2. Sensation from the periphery
3. The lower motor system from the spinal nerve cell (anterior horn cell) down to the muscle.

The third system is the most important for people with PPS because if you lose the nerve, you lose the muscle. We talk about muscle weakness, but polio is actually a nerve disease that damaged or killed anterior horn cells. This makes a lot of difference in terms of exercise, etc.

Acute: During the acute phase of polio some spinal nerve cells died while others were injured but later recovered. Some people had paralysis but others did not. The effects were like spatter paint. If you had a lot of "paint" you had a lot of damage, while others were just touched lightly. But all survivors were left with a damaged neuro-muscular system.

Recovery: Recovery from polio entailed all three methods of recovering function:

- Neuro recovery
Between 12% - 91% of the nerve cells that were injured by the poliovirus recovered.
- Axon sprouting
New branches of the remaining nerve cells were sent out to adopt the orphaned muscle fibers. The result was that each nerve was then doing 50% more work, or even up to four times as much as normal.
- Hypertrophy
The muscles enlarged themselves up to about 40% so they could increase function.

It is not known how much a survivor's recovery was due to spontaneous nerve generation, nor how much could be credited to patching by the axon sprouting, nor what amount was due to hypertrophy. Upon recovery polio survivors had a

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random disability in regard to the amount of paralysis. The amount of muscle weakness a person had was pure chance; it depended upon the amount of poliovirus a person had and where it went. Some survivors remained paralyzed, while others looked or felt normal although they were not.

Research: During the 1940s Bodian traced the poliovirus in the motor nerve cells of monkeys. He found that polio, a systemic disease, affected 95% of these cells by either injuring or destroying them. Research confirms that there is some obvious weakness as a result of polio:

- Agre found that polio survivors with no current symptoms had only 80% of normal muscle strength. Symptomatic survivors had 60% or less muscle strength compared to the normal group.
- Following a four-year study Grimby reported a normal 2% - 5% loss of muscle strength in asymptomatic polio survivors, but for symptomatic survivors this loss may be as high as 13%.
- A study by Grimby confirms that weaker muscles work longer and twice as hard.
- An electromyographic study by Dr. Perry also confirmed that weaker muscles work longer and twice as hard.

This research says that it is necessary to protect an overused muscle system. The muscles that are grades 3, 3+, and some 4s are getting all the exercise they can tolerate. In order to maintain this function these muscles must be protected from overuse. Dr. Perry added, “New damage is prevented or curtailed by being active, but avoid getting tired. When fatigue begins, STOP and rest. Two 20-minute rest periods a day preserves one’s endurance.”

Now: For many, many years polio survivors have been working with a damaged neuro-muscular system that keeps working harder than ever to meet their normal demands. We need to appreciate the fact that each anterior horn cell innervates several hundred muscle fibers and the surviving horn cells have been doing 50% more work than normal. Plus it appears they don't like being overworked!

Because of this overuse of the neuro-muscular system, new weakness is now developing. Survivors may develop new weakness not only in "polio" muscles but also in other muscles that did not seem to be involved during the acute phase.

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Although the amount of weakness a polio survivor develops in later life depends upon the original involvement; age is also a factor. Anterior horn cells do not have infinite durability -- they begin aging at about 60 years of age. So polio patients aged 70 and up have a natural weakness just from age that needs to be appreciated and put in perspective also.

Question 2. Do you know of any research on treatments for PPS?

Answers:

- **Mestinon:** There was a six-center study of the drug Mestinon (pyridostigmine) in 126 patients. Mestinon acts at the nerve-muscle junction by changing the chemistry and making the connection last longer. For many years this drug has been used for myasthenia gravis patients. Since Grimby's research has shown that polio survivors can overuse the nerve-muscle junction, the use of Mestinon for some polio survivors makes sense to Dr. Perry.

In this 1995 Mestinon study, Dr. Daria Trojan reported that there was trouble getting statistical significance, but the best correlation between Mestinon and relief versus the placebo occurred in subjects who had 25% or less normal strength, i.e. muscle grades 3+ and down. Dr. Perry believes Mestinon has a role for those who are quite weak, but for people with grade 4 muscles and up she has observed no improvement with its use.

- **Anti-inflammatory Drugs:** These medications have been Dr. Perry's mainstay because the first reaction to muscle overuse is inflammation. These drugs take away the added insult from having overdone but they are not pure pain medicines. Dr. Perry does not use pain medications per se for PPS because they only mask a person's overuse and do not help that problem. She wants patients to control their lifestyle and not overdo and thus avoid the pain of overuse.
- **Growth Hormones:** These drugs have been found to relate more to muscle function than to nerve control. They seem to parallel function rather than control function. No significant changes have been found for polio survivors.

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Question 3. Are you familiar with electro-stimulation for polio survivors?

Answer: The answer is yes and the answer is no. The easiest way to stimulate a muscle is to use one that has a nerve. Therefore, this involves the nerve-muscle junction. Electro-stimulation has been tried on a few polio survivors at Rancho with no affect; Dr. Halstead, a polio survivor affiliated with National Rehabilitation Hospital in Washington, D.C., tried it on himself with no affect; several of Dr. Perry's patients tried it at Dr. Pape's office in Canada with no affect. So electro-stimulation is not an answer. Post- polio patients' problems are with the nerves.

Exercise: Some researchers in other parts of the country favor exercise for certain polio survivors. I observed that their research has been done in parts of the country that have bad weather -- so their subjects already have about 3 months disuse due to climate. Here in Southern California we do not have disuse because of bad weather. If disuse of muscles does exist, then exercise may be needed. But if there is no disuse, such as here in Southern California, exercise is not indicated.

Question 4. Can trauma be a trigger for PPS?

Answer: The answer is yes. Following an acute injury there is a period of disuse during recovery. Up until the time of injury a person's strength has been built up very gradually. There is an old saying that says, "If you can lift a calf every day, when you become an adult you can lift a cow. But don't ever stop." This phrase is saying that if you got a very small amount of increased exercise on a regular basis (as the calf got larger) you built up yourself gradually. But don't ever change the model. As soon as you stop, there is no way you can exercise that gently anymore. It is very difficult to recover on a therapeutic basis after that. Once there has been an injury the model has been changed.

Question 5. Does spinal stenosis occur earlier for polio survivors?

Answer: Spinal stenosis is the thickening of bone around the spinal canal. It does occur in natural society but it is not very common. I have not seen any PPS patients with spinal stenosis.

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Question 6. Could you give us some tips for putting less stress on our upper extremities?

Answers:

- **Problem 1:** Shoulder pain develops in crutch users.
What does a crutch do? It supports body weight. The more weight, the more it goes on your hand, elbows, and shoulders. When the normally powerful shoulder depressors (pectoralis major, etc.) wear out, the shoulder takes the strain and the supraspinatus tendon gets impinged (pinched). This impingement cannot be prevented. Pain indicates it is time to ride -- in a wheelchair or scooter if appropriate.

- **Problem 2:** Upper arm pain when reaching overhead.
Reaching overhead uses two muscle systems. A person can avoid overhead reaching by using a reacher when necessary and by not placing things above the shoulders. Find other activities that do not involve shoulder use.

- **Problem 3:** A person's arm dropping away from the socket (usually about 1/4 - 1/2 inch).
Slings don't usually work well because they hang from your neck. I prefer to use a gunslinger apparatus to help support arm and shoulder. A gunslinger is a device that rests on the hips/pelvis area and has one or two attached pieces to support the forearm(s).
Some patients use a fannypack under the arm for support.

- **Problem 4:** Shoulder and neck pain when working at a desk.
When working at a desk, do not lean forward to do your work. Instead, try to lean back ten degrees so gravity is helping your muscles. Bring your work to you.

There are three things a person can do to relieve the strain on the upper body muscles:

1. Eliminate reaching
2. Support the arms
3. Break up activities

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Advice: Listen to your body. Feel the aches and pains. Then do something about it. **“Be an intelligent hypochondriac!”**

Question 7. When should we use cold packs or hot packs?

Answer: Cold for 5 minutes or less is good. It breaks up the edema formed by overuse. Then follow with heat for 10 minutes and REST a while.

Question 8. Are you sending any PPS patients for acupuncture?

Answer: I am not sending anyone for acupuncture although some patients are trying it and getting help. It is not going to do any harm. The reason I do not prescribe it is because I do not have any indication of whether it will help or not help. When I make a prescription I would like to know the outcome.

Question 9. Can PPS be part of a weakening heart muscle?

Answer: No, PPS cannot be part of a weakening heart muscle. The muscles and nerves to the heart are a different system so there is no direct connection to PPS.

A person can be deconditioned by not being active, but if you are not strong enough to be active your heart does not have to be that conditioned. So don't worry about it. Just don't get fat and do avoid cholesterol!

Question 10. How can a polio survivor control muscle twitching and/or cramping?

Answer: Muscle twitching is a sign of overuse. It can happen to anyone, not just people with PPS. Cramping is also a sign of overuse. A polio survivor needs to change his lifestyle to avoid overuse of muscles. [Conserve it to preserve it.]

Question 11. What are your thoughts on hip or knee replacement surgery?

Answer: For an arthritic hip, total joint replacement is just fine if you have the muscles to control it. A polio survivor needs to have about grade 3+ hip muscles

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for this surgery to be successful. Otherwise the hip will dislocate.

The knee is simpler to handle because it can be put in a brace since it is a tubular structure. But there is no brace for a hip.

Question 12. How can sleep problems be helped?

Answer: A study on sleep disorders compared people with PPS to average people. Both groups had the same problems -- restless legs, etc. I suggest that, before going to bed, people get themselves comfortable, warm, and perhaps take 2 Advil (or something like that) to get rid of the aches and pains. If a person awakens in the middle of the night, it may be helpful to get up and start again. Half the world has trouble sleeping all night. This is not unique to polio.

If a polio survivor has been diagnosed with sleep apnea it is probably related to breathing or swallowing problems from PPS.

Question 13. Is there any connection between polio and meningitis? When I was a baby my parents were told I had meningitis. Several years ago a doctor told me I never had meningitis but I had polio.

Answer: Meningitis is an inflammation of the coverings of the spinal cord and brain. Polio is an infection of the anterior horns of the spinal cord. The inflammatory reaction also involves the meninges. At one time it was called polio-encephalo-meningitis. It was actually an involvement of the whole system. The main way of identifying polio was with a spinal tap. If it got into the anterior horn cells it was called polio. There are a lot of neurological problems that are not highly defined, but can be identified by lesions revealed during autopsy.

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