

Dr. Neil Cashman Answers Polio Quebec Members' Questions

POLIO QUEBEC AGM - September 1997

1. Have you ever considered what the chiropractor can do to help the pains and the general condition of the spinal cord?

A. I now feel that chiropractic manipulation may be good for some especially if they have acute lower back pain. A chiropractor may even give quicker relief than a traditional doctor in certain cases. But I am very worried when people get their necks manipulated. I've seen too many accidents in this context nerve roots being pinched or torn - actual damage to the spinal cord or brain stem. I still cringe when there is talk about neck manipulation.

2. (a) When do you decide to prescribe Mestinon to a patient?

A. We think that Mestinon helps with severe generalized fatigue and also with muscle fatigability. Exert yourself, walk the length of a mall, and you may have increased weakness and have to sit down to recover your strength. These kind of symptoms seem to be helped by Mestinon. We think Mestinon improves the communication between the nerve and the muscle. First of all we advise non-medical ways of treating fatigue: activity planning, changes in life-style. If those don't work, we consider trying Mestinon. Even if we prescribe Mestinon, we find only about 60% respond to it well, so we don't have a predictive test as to whether a person will respond well or not. When we have exhausted non-medical ways of treating fatigue, we try Mestinon.

2. (b) Is general fatigue a criteria for the use of Mestinon, or is it more for weaknesses to legs, arms or for pain?

A. There's no physiological explanation for it to be effective for pain. Mestinon might have other uses than just for fatigue, but at present, we're not smart enough to know how it works, or whether it can work for pain.

3. Has there been any research/invest into alternative medicine techniques either using herbal remedies or other healing techniques (Qi-gong)?

A. The use of alternative medicines is a matter of choice for the individual. Although we can't cure postpolio syndrome, we believe we can treat some of the symptoms. Be sure you have good advice before taking them so that you avoid hurting yourself physically or financially. Remember that nobody has the cure for post-polio syndrome.

4. Do you recommend taking extra Calcium or Vitamin E for PPS?

A. The trouble in the muscle is inside the muscle. It's not due to not enough calcium. It's due to the muscle cell physiology, so extra calcium wouldn't help there. However, there are reasons to take extra

calcium, i.e., for osteoporosis and health in general, but not for post-polio syndrome specifically. As for Vitamin E., it is a different story. It is a very potent anti-oxidant, and there is apparently no toxic dose of this vitamin. So it is safe to take several hundred units a few times a day. It won't hurt you. Perhaps it will help. At least there won't be a side-effect.

5. Should a PPS person do conditioning exercises, sub maximal exercises or maximal fatiguing exercises, or all three?

A. The role of exercise in PPS is hotly debated at present and is being researched actively. We used to say that any exercise to the point of pain, muscle cramps or weakness in the muscle was too much and that it might actually accelerate weakness in PPS. At this point there are people under carefully controlled research conditions (e.g. Dr. Agre in Wisconsin) who have been able to show that even fatiguing exercise can result in an increase in strength with time. The conventional wisdom is "don't push, it may make things worse." But there are some cracks beginning to appear in the conventional wisdom. As for specific advice, do NOT exercise to the point of cramps or pain or weakness unless you are under some carefully controlled research environment. There has to be a happy medium between some form of activity and over-exertion. And for the time being, I think it is best to stay in that happy medium. Don't just sit and do nothing!

6. What are your thoughts about CPAP?

A. This is a non-invasive machine to assist breathing, especially at night. It can be used if there is a profound weakness of the respiratory muscles or if the patient has sleep apnea.

7. Elaborate on the role of free radicals in PPS?

A. Tough question which would take pages to explain and my answer is based more on an idea than on very specific knowledge. Motor neurons appear to be very sensitive to the effects of free radicals. A free radical is a molecule that can oxidize things in the cell, e.g., lipids, DNA and proteins and make them not function properly. We found that the motor neuron generates a pulse of free radicals when it is about to die. If one can block the action of free radicals then you can prevent or slow down motor neuron cell death. I have wondered whether there is a similar effect at the nerve terminal which is where we think the action is in PPS. What we think is happening in PPS is that the hugely enlarged nerve "tree" with 10 times more branches than it was supposed to have undergoes a loss - a sort of breakdown or PPS pruning. This loss of terminal axons over time after polio, and why these degenerate is not known at present. A possible mechanism for degeneration. involves free radicals that they be oxidizing the lipids and proteins in the nerve terminal. It opens the possibility that some anti-oxidant medicines may prevent or slow down the loss of terminal axons in PPS. Something as simple as Vitamin E, for instance, might slow down the loss of nerve terminals in PPS and other related diseases. More work needs to be done.

8. Does the [Canadian] government recognize PPS? Has any progress been made towards getting compensation for PPS?

A. Yes. We have been able to have people declared disabled with post-polio syndrome. But applications for compensation seem to be automatically rejected, requiring the appellant to go to appeal. If you decide to opt for disability with your doctor, expect a battle of between 6 - 12 months, if indeed you succeed.

9. Given that weight control is a problem when mobility is reduced, what advice would you give given that weight loss is a twofold formula of fewer calories combined with increased physical activity?

- **A.** The Polio Clinic, through Dr. Trojan at the Montreal Neurological Institute and Hospital, can refer you to a dietician, a physiotherapist and an occupational therapist. Together they can recommend an appropriate diet and exercise program.
- **10.** Is there anything new to relieve the feeling of coldness due to polio?
- **A.** Just as there are many reasons for post-polio fatigue, there are dozens of reasons why people who have polio may experience cold in their extremities, e.g., poor circulation, loss of muscle mass in a leg. Some reasons may be related to polio, but not necessarily so. I have been doing some work which is not yet published showing that when one gets nervous or tired or something similar, there can be prominent constriction of the blood vessels which causes a sensation of cold.
- 11. Are tendonitis and bursitis a sign of PPS? Are there short-term or long-term remedies? Is exercising recommended to regain strength?
- **A.** These conditions are often the result of people overexerting for a long period of time. If arms are bearing weight or being used to get around in a wheelchair, they begin to complain.
- **12.** What impact will Mestinon have on the heart?
- **A.** Mestinon increases acetylcholine everywhere in the body; part of the rhythm control of the heart is due to levels of acetylcholine at a synapse of the heart. Too much acetylcholine in the heart causes a slowing down of the heart. This isn't dangerous; in fact it is barely noticeable. But people who have had heart disease, either myocardial infarction or a rhythm a abnormality should consult their doctor before embarking upon Mestinon therapy.
- **13.** How old is your youngest post-polio patient?
- **A.** Fourteen years old.

Audio Cassette (English Only) and Video Tape (English Only) of the above which includes Dr. Cashman's Annual Report and his resumé of the Grand Rounds on the three possible causes of Post Polio Fatigue are available by calling Canada <u>514 932 6092</u>. In UK contact the <u>Lincolnshire Post-Polio Network</u>. Cost of audio-cassette - \$; cost of video-cassette (thanks to Mansour Jabbari) - \$ are unknown at the date of going to press. If you would like a copy of the Annual Report, please contact <u>the Association</u>. Sally Aitken <u>aitken@accent.net</u>.



The Lincolnshire Post-Polio Network

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