



Neuropathy and PPS

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Question: I had “bulbar” polio in 1952 when I was 7. Except for some difficulty swallowing, I recovered. (To this day, I must turn my neck slightly when I eat). I became a runner in my 30s but in my 50s started having a lot of muscle problems and huge fatigue. I was diagnosed with having the “late effects of polio” and I have been doing my best to manage the symptoms.

For the last 2 years I have been suffering constantly with burning pain in my limbs, that is worse towards the end of the day and particularly during the night. This is having a terrible affect on my sleeping. Is this common for polio survivors? My doctors know very little about polio and cannot find out what is wrong. The burning pain episodes seem like it is nerve pain. Is this something that other polio survivors experience?

Dr. DeMayo’s Response: First and foremost, you are not alone! There certainly are a good number of polio survivors with similar symptoms and many people in the general public with this issue.

You are right in that this type of pain is typically associated with the nervous system serving as a pain generator. This does not necessarily mean that PPS is the cause. This type of symptom is also very common in peripheral neuropathies in the general population.

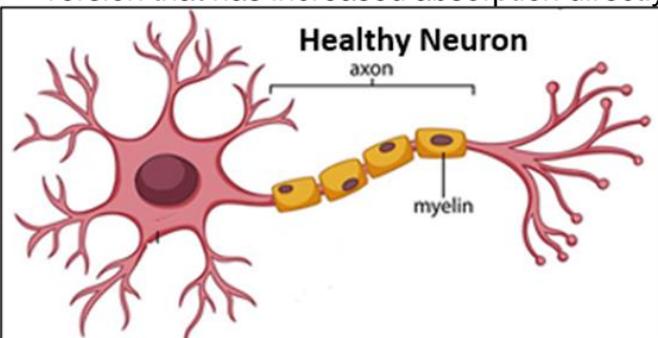
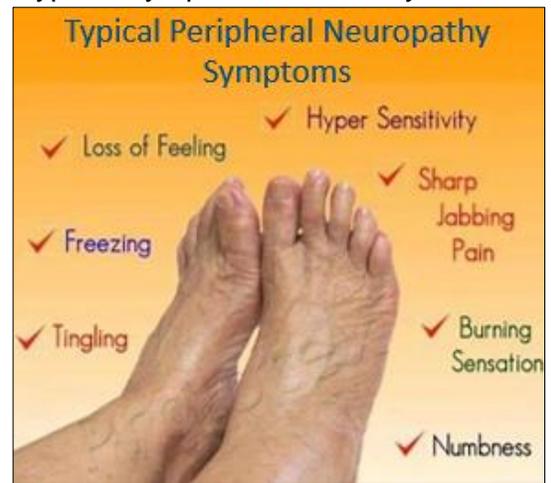
Two main thoughts arose in my head as I read your question:

- Is anything being missed that could be causing or contributing to this pain?
- What can be done to minimize the pain moving forward?

With regard to the first question, there are many factors that could play a significant role. Of course, these may or may not apply to you but are worth considering and possibly discussing with your primary care doctor. It should be noted that NONE of these require any specific knowledge of PPS and it is important to not minimize the role of your primary care physician.

All causes for neuropathy should be considered as they could be having effects that add to the symptoms you experience as a result of possibly having PPS.

- Diabetes is by far the most common cause of neuropathy. Even though it is typically a late symptom, sometimes neuropathy comes quite early in the progression of symptoms. A specific test called a hemoglobin A1c is an excellent screen for diabetes as it gives you a type of "average" of what glucose levels in the blood have been overextended time.
- B12 deficiency is certainly also another possibility. B12 levels can easily be checked, at the same time "low normal" levels may still be a problem since metabolism of B12 is very complex. Primary care physicians are very capable at evaluating and treating this. B12 can be taken orally or intramuscularly, however some patients simply do not absorb B12 properly. There is a sublingual (under the tongue) version that has increased absorption directly into the bloodstream.

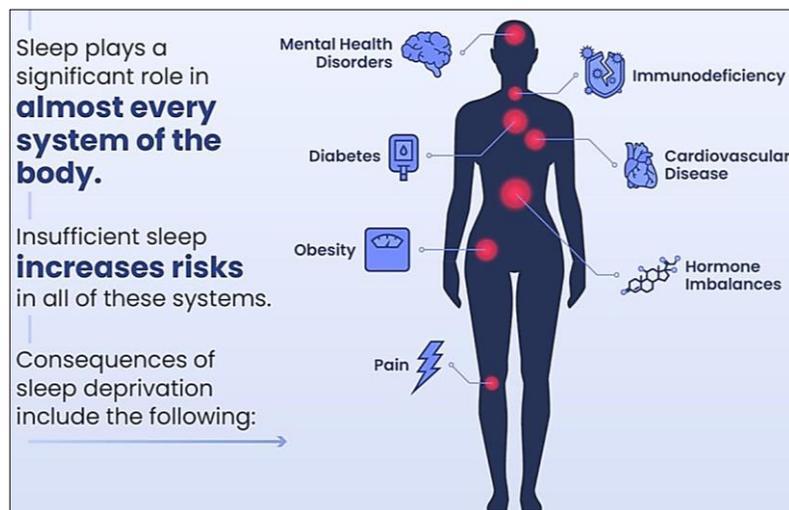


Ask your primary care physician for a screening of the causes of neuropathy. Depending upon your history, the workup could include thyroid tests and possibly folate level, ANA, serum protein electrophoresis or other lab investigations. Most of the common causes of neuropathy can be screened for by a primary care doctor. A neurologist would likely screen for even wider set of potential causes including heavy metal exposure, Lyme disease and other uncommon causes. If the initial screening does not result in

a common cause of neuropathy, then a referral can be made for EMG/NCS (Electromyography and Nerve Conduction Studies). This is a test that involves placing thin needles in the muscle to look for changes. In continued . . .

addition, it will stimulate nerves electrically and watching how quickly they conduct the current. This cannot only definitively diagnose a peripheral neuropathy but also define if it is a problem with the axon (the nerve cell itself) or the myelin (the insulation around the axonal).

These are typically done by both neurologists and rehabilitation physicians.



Contributing factors such as stress, anxiety, and sleep problems should also be considered. For example, lack of deep sleep alone can be like "gasoline on the fire" for any chronic pain but especially pain of neurologic origin.

It is very common for patients to say that they are not sleeping because of nerve pain. As true as this is, it is also true that they may be having severe nerve pain because they are *not* sleeping. Diagnosis and management of underlying sleep or stress related issues can be a significant factor.

Regardless of the actual source of the pain you describe, there are several approaches that can be

helpful in neuropathic pain.

- Managing stress, anxiety and sleep can have a profound impact on this type of pain and is often underestimated. Since the pain is coming from within our nervous system, other factors within this system can "dial it up or down". Yoga, relaxation techniques, counseling, improved sleep hygiene and medical management (if needed) are potential options to investigate.
Note: Caution should be exercised with medical management as most medicines that address these issues can actually decrease the amount of deep sleep, even if they increase the amount of total sleep. Deep sleep is what everyone needs.
- TENS (Transcutaneous Electrical Nerve Stimulation) can be helpful in some situations. Typically, this is obtained through physical therapists.
- Medication certainly has a role, especially if the pain is severe.
 - It is Important to Note: Prescription and dosage adjustments should always be coordinated with a physician experienced with these medications - *never* adjust dosages on your own.
 - Amitriptyline (Elavil) is an old medication which can be very effective in both decreasing pain as well as improving sleep (without the loss of deep sleep). Dosing can be highly individualized and physicians who are not comfortable in using it may prescribe a simple flat dose with a "pass/fail" approach. In my experience, it is much better to start at a low dose increase each evening until there are side effects in the morning (typically a "hangover type feeling") and then back off immediately to be sure that the patient is within the "therapeutic window". This is the dose that gives us the maximum benefit with no side effects.
 - Neuroleptic medications: These include Gabapentin (Neurontin) or Pregabalin (Lyrica). Most primary care physicians are familiar with these. At the same time many are not used to the higher doses that are sometimes needed. Both can be quite effective however pregabalin tends to work more quickly and dosing is much easier. Gabapentin needs to be increased slowly and can take several weeks to reach the maximum dose of 1200 mg 3 times per day. Typically, the primary side effect is sedation. If sleep is a problem, then taking a higher dose in the evening and lower dose during the day can help with both pain and sleep.
 - Medications that treat underlying issues of neuropathy, that may be contributing to the pain, should always be considered. As mentioned previously, these may include thyroid medications or B12.

This is an overview that I hope helps provide a foundation for understanding neuropathy and neuropathy pain. The basic message is to work with your primary care physician on all factors that might be contributing to your symptoms, and then look for the approaches or medical management that can help you.