



# Polio Survivors Serving Others

Information & Inspiration  
For All Polio Survivors and their Families

The PA Polio Network

[www.papolionetwork.org](http://www.papolionetwork.org)

March, 2023

## Our Mission:

*To Be in Service Providing Information to Polio Survivors, Post Polio Support Groups, Survivor's Families and their Caregivers.*

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## Inside this Issue:

**Chronic Pain: What can I do?** Many survivors live with this problem. With help from the Cleveland Clinic, we have some suggestions.

**Polio Survivor and Disabilities Advocate Judy Heumann:** Her life had meaning. "Disability only becomes a tragedy when society fails to provide the things we need to lead our lives – job opportunities or barrier-free buildings, for example," she said. "It is not a tragedy to me that I'm living in a wheelchair." With all her passion and determination, we loved discovering her beautiful sense of humor. Maya Angelou's words at the end of this newsletter reminded us of Judy. She had a beautiful song to sing and did it well.

**What is Neuropathy?** Can polio survivors get it? This type of pain is typically associated with the nervous system serving as a pain generator but, that does not necessarily mean PPS is the cause. We are happy to welcome back rehabilitative physician William M. DeMayo, MD with an outstanding article on this topic. Dr. DeMayo has had an exciting few years working at a rehabilitative hospital in Abu Dhabi in the UAE. He has written an extensive library of articles, all of which are available on our website: [DeMayo's Q&A Clinic](#)

**Nonparalytic or Asymptomatic Polio. It's a reason to vaccinate.** To quote Richard L. Bruno, HD, PhD: "The poliovirus is tricky." It doesn't always cause paralysis. Most people are unaware that there are hundreds of asymptomatic poliovirus infections for each paralytic case. But, just because someone had no symptoms or minor flu like symptoms, showing no obvious weakness or paralysis; doesn't mean that the poliovirus didn't do damage to neurons in the brain and spinal cord. Just as a case of polio with unrecognized or mild symptoms" can turn up decades later as PPS, we aren't surprised with the sad reality that a mild case of COVID can result in "long COVID". We *know* that a virus can result in lifelong disability.

As we write this, there are 37 countries on the Polio Outbreak list. What's happening proves that as a result of global travel, the spread of polio and many other vaccine preventable diseases is easier than ever before.



## **Neuropathy and PPS**

[William M. DeMayo, MD](#)

**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.

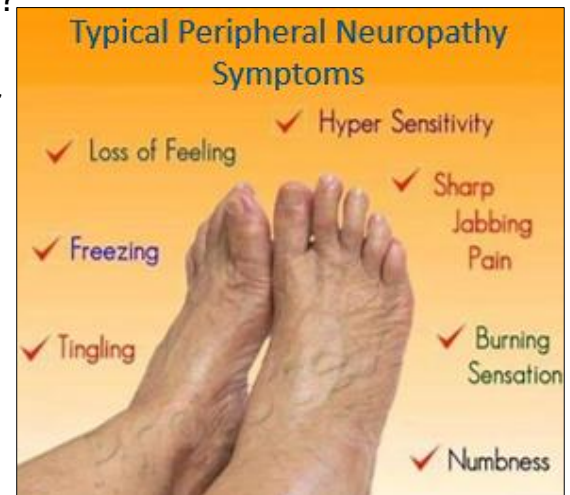
Two main thoughts arose in my head as I read your question:

- 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.

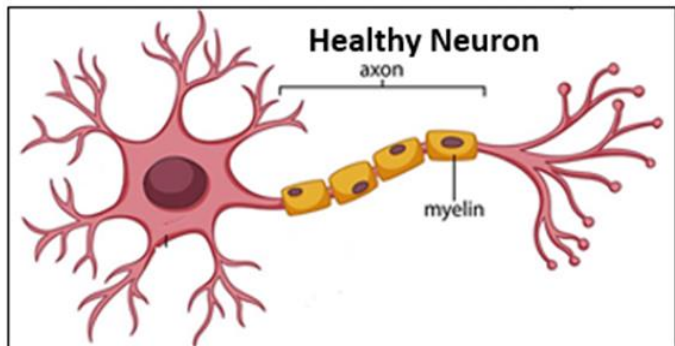
All causes for neuropathy should be considered as they could be having effects that add to the symptoms you experience as a result of possibly having PPS.

- 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



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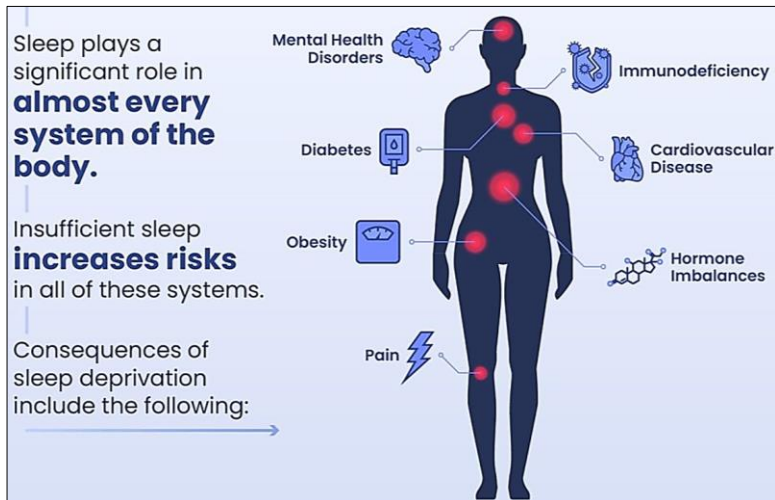
can be taken orally or intramuscularly, however some patients simply do not absorb B12 properly. There is a sublingual (under the tongue) version that has increased absorption directly into the bloodstream.



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 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.



*Thank You*

THANK you for your kind words, generous donations and active participation.

Your [donations](#) help our work continue.

Your active participation brings forward the questions that many, MANY polio survivors are wanting to ask.

## "It is not a tragedy to me that I'm living in a wheelchair." Polio Survivor and Civil Rights Advocate Judy Heumann



Judy Heumann was a major American civil rights activist who remained little-known until a flurry of attention in the last three years of her life. Joseph Shapiro/NPR

"Judy Heumann was the first person I called when, in 1987, I reported my first story on disability rights. Judy, who contracted polio when she was 18 months old, gave me the quote that perfectly summed up that little-known [civil rights movement](#).

"Disability only becomes a tragedy when society fails to provide the things we need to lead our lives – job opportunities or barrier-free buildings, for example," she said. "It is not a tragedy to me that I'm living in a wheelchair."

That idea seemed so unexpected and strange that my editors at a newsmagazine decided not to publish my story.

It was still a radical claim that disabled people didn't see themselves, or their conditions, as

something to be pitied. Or that they insisted what held them back wasn't their health condition but society's exclusion - maybe attitudes that they were less capable to do a job, go to college or find romance; or a physical barrier, like a sidewalk without a curb cut.

That reimagining of what it means to be disabled did gain traction over the years - [the passage of the Americans with Disabilities Act](#) just three years later in 1990 was a milestone - thanks to leaders like Heumann, who died suddenly (on March 4, 2023) at age 75 at a hospital in Washington, D.C. She'd been hospitalized the previous weekend with breathing problems."

[Joseph Shapiro](#) for NPR



"I don't think I felt, really, shame about my disability.  
What I felt more was exclusion."

Source: 11 Memorable Quotes from Crip camp

"You don't just advocate for human rights, and rights for people with disabilities, but you FIGHT for them and you fight for them with a passion."

[Trevor Noah on the Daily Show](#)

March 10, 2020

[www.youtube.com/watch?v=ybcQbpSVo3c&feature=shares](http://www.youtube.com/watch?v=ybcQbpSVo3c&feature=shares)





"What's been incredibly important for me is to be part of an ever-growing Disability Rights movement. That to me is really one of the most seminal moments, seeing younger, disabled people saying they're part of the ADA generation and recognizing that they have the law, but it isn't going to get implemented effectively without all of our voices."

Source: ADA National Network



**Polio has been around since ancient times.**

This ancient Egyptian tomb painting shows a man with a withered leg unable to bear weight without use of a walking stick.

This means that most muscle fibers are replaced with scarring (muscle-wasting) that is permanent.

If someone had polio as a child or young adult but had kept or recovered some or all movement of weakened arms or legs, even to the point of being athletic afterward, they can become weaker in late adulthood.

That is post-polio syndrome (PPS), a condition that can affect polio survivors' decades after they recover from their initial poliovirus infection.

Some PPS patients become wheelchair dependent when they had not been before.

[www.cdc.gov/polio/what-is-polio/index.htm](http://www.cdc.gov/polio/what-is-polio/index.htm)



**Noninvasive Ventilation**

Featuring Norma MT Braun, MD, FACP, FCCP

Post-Polio Health International held the 2nd in their series of 2023 Town Hall Meetings. For those survivors with any breathing issues, Dr. Braun offers an enormous amount of information that can help you as you go forward.

[www.youtube.com/watch?v=5GNJbKvCLUA](http://www.youtube.com/watch?v=5GNJbKvCLUA)

**LECTURE SERIES**

February 21, 2023  
at 1 pm CST

**Noninvasive Ventilation**

Presented By:  
Norma MT Braun, MD, FACP, FCCP  
&

**POST-POLIO HEALTH INTERNATIONAL**  
INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK



1. Take deep breaths. The average adult takes 8 to 16 breaths a minute. Slowing that down to 5 or 6 deep breaths that really fill your lungs will help you relax, which can lessen your discomfort.



2. Get a good night's sleep. Without enough rest, pain triggers may worsen. So how much sleep is enough? It varies by person, but most adults need 7 to 8 hours a night. The simple answer: however much you need to wake up rested and rejuvenated.



3. Exercise regularly\*. Stretching keeps muscles limber and tendons elongated. Strengthening core muscles in your back, pelvis, hips and abdomen aids balance and stability.

(\*Note: Know your limitations. Exercise as recommended by a PPS knowledgeable rehabilitative physician or physical therapist).



4. Tackle your tobacco habit. Smoking cigarettes or cigars decreases circulation, aggravates medical conditions, increases sensitivity to pain and may interfere with pain medication. Same goes for chewing tobacco.



5. Practice “mindfulness meditation.” This involves observing your pain rather than suppressing it. It sounds crazy, but by relaxing and accepting discomfort, you may better tolerate it. So for 20 minutes a day, sit or lie in a comfortable position in a quiet spot and just be aware, moment by moment, of your breathing, the unfolding of sensations (including pain), and your thoughts and feelings.



6. Eat a whole-food, plant-based diet. A healthy diet promotes circulation, curbs inflammation and may soothe aching muscles and joints. Base meals on whole or minimally processed foods like vegetables, 100% whole grains, legumes and fruits. Start by ditching the worst offenders: processed meats, red meats and refined carbohydrates like sugar, white bread and pasta.



7. Try yoga\*. Yoga can quiet your breathing, reduce muscle tension and energize your body and mind, all of which can ease pain. And you don't have to be a yoga master to reap rewards: Plenty of beginner poses are found online, including the warrior pose, mountain pose, child's pose and more. (\*Note: Know your limitations. Speak to your instructor. It may be a good idea to start with “gentle” yoga. “Chair” yoga has become quite common.)



8. Indulge your hobbies. Take part in activities that bring you pleasure, whether gardening, fishing, cruising garage sales or carving wood. There's a hobby for everyone that can reduce stress and take one's mind off the pain.

Continued . . .



9. Be social. People who interact with others tend to reduce anxiety and better manage chronic pain. So have lunch with co-workers, take on a special group project, cheer on your grandson at a soccer game or go to an arts festival.

\* Denotes comment specifically modified relating to Post-Polio Syndrome. Some images have been revised. Source: <https://my.clevelandclinic.org/-/scassets/files/org/anesthesiology/pain-management/infographics/pain-wellness-infographic.ashx>



## **Asymptomatic (Nonparalytic) Polio Another Reason to Vaccinate**

By Carol Ferguson

The poliovirus is tricky. It doesn't always cause paralysis. One lesson learned during the polio epidemics is that there are hundreds of asymptomatic poliovirus infections for each paralytic case, meaning that many of those infected with polio were so mildly affected that they didn't even know they'd had the virus. (1) Just because someone had no symptoms or minor flu like symptoms, showing no obvious weakness or paralysis, doesn't mean that the poliovirus didn't do damage to neurons in the brain and spinal cord.

Why is this lesson important to remember today? There are currently 37 nations on the list of polio "[Outbreak Countries](#)," those that had stopped wild poliovirus but have been re-infected either by the importation of wild or vaccine-derived poliovirus from another country, or by detection and circulation of vaccine-derived poliovirus resulting from a country's use of the oral polio vaccine.\* Four new additions to the list are Canada and the United Kingdom, both of which discovered poliovirus in wastewater, and the United States and Israel, each reporting one case of paralytic polio in 2022 and also finding poliovirus in wastewater. The CDC has identified the strains of poliovirus in these four countries as being genetically related. Poliovirus in wastewater is frightening evidence that the virus is circulating in the general population, setting the stage for more paralytic cases and an even a greater number of non-paralytic cases in those who are not vaccinated.

Since these reports, we've had an overwhelming number of questions about the danger of poliovirus circulating in under-vaccinated communities. Health departments in New York State (where the first case of paralytic polio since 1979 was reported) have been out front with their concerns about this circulating poliovirus:

“Dr Patricia Schnabel Ruppert, health commissioner for Rockland County (NY), said she was worried about polio circulating in her state undetected. ‘There isn't just one case of polio if you see a paralytic case. The incidence of paralytic polio is less than 1%,’ she said. ‘Most cases are asymptomatic or mildly symptomatic, and those symptoms are often missed. So there are hundreds, perhaps even thousands of cases that have occurred in order for us to see a paralytic case ‘ “ (2)

Continued . . .



“Based on earlier polio outbreaks, New Yorkers should know that for every one case of paralytic polio observed, there may be hundreds of other people infected,’ Mary Bassett, MD, the state health commissioner, said in the statement.” (3)

The concern about infections due to circulating poliovirus was underscored by Israel’s report of four asymptomatic poliovirus - infected children in March, 2023. The Health Ministry cautioned that it “demonstrated extensive spread” of the poliovirus. (4)

Why is there so much concern about the community spread of poliovirus when most cases are non-paralytic or even asymptomatic? Pediatric vaccine expert Dr. Paul Offit reminds us it’s because of the “lesson learned”:

“Think about that man in NY. He represents the tip of a much, much bigger iceberg. Most people who had polio never had symptoms. That iceberg is people who had asymptomatic infection, or maybe a mild, summer gastroenteritis that gets better, but we know you can still develop post-polio syndrome even following a mild, initial infection because that virus reproduces itself in the spinal cord and although you may not see any symptoms initially, over time, when you are using muscles to compensate that had very mild symptoms initially, so much so that you may not have even noticed them, then a fail and you now have post-polio syndrome.” (5)

The “lesson learned” needs to be taken seriously. Our network serves an untold number of survivors who had a “non-paralytic”, “asymptomatic”, “inapparent” or “mild” case of polio and now are living with Post-Polio Syndrome, the disabling “late effects” of this terrible disease. Public health experts worldwide are calling for universal polio vaccination, even in countries where polio previously had been eradicated. With the current community spread of the poliovirus, those who are unvaccinated are at risk, not only of polio paralysis, but also of “non-paralytic” polio causing hidden damage that reveals itself later as PPS.

The growing list of polio “Outbreak Countries” shows that, as a result of global travel, the spread of polio - and many other vaccine preventable diseases is easier than ever before. Polio anywhere is a threat to children everywhere. The *only* prevention is vaccination.

\*Note: Polio Eradication Dates: Israel 1988, UK 1982 and US 1979.

Sources:

- (1) [Richard L. Bruno, HD, PhD](#)
- (2) BBC News: [US doctor issues warning of many undiagnosed polio cases](#)
- (3) Medscape: [Polio in New York Linked to Potential Community Spread](#)
- (4) The Times of Israel: [Three more children diagnosed with polio virus](#) .
- (5) [Paul A. Offit, MD: Polio and COVID, Living with their Effects](#)

## Vaccines and Preventable Diseases

Unvaccinated or incompletely vaccinated adults who are at increased risk of exposure to poliovirus should receive and complete the polio vaccination series with IPV. Other adults who are unvaccinated or incompletely vaccinated should talk with their doctor to understand their risk for polio and need for polio vaccination. Adults who completed their polio vaccination but who are at increased risk of exposure to poliovirus may receive one lifetime IPV booster.

Situations that put adults at increased risk of exposure to poliovirus include:

- Travelers who are going to countries where polio is epidemic or endemic (For additional information, see [Polio: For Travelers](#)).
- Laboratory and healthcare workers who handle specimens that might contain polioviruses.
- Healthcare workers or other caregivers who have close contact with a person who could be infected with poliovirus.
- Unvaccinated or incompletely vaccinated adults whose children will be receiving oral poliovirus vaccine (for example, international adoptees or refugees).
- Unvaccinated or incompletely vaccinated adults living or working in a community where poliovirus is circulating.

Unvaccinated adults who are at increased risk of exposure to poliovirus should be given three doses of IPV at these recommended intervals:

- Two doses separated by 1 to 2 months
- A third dose 6 to 12 months after the second dose

Adults who are incompletely vaccinated (previously received one or two doses of either IPV or tOPV) and who are at increased risk of exposure to poliovirus should receive the remaining doses of IPV to complete the three-dose series at the recommended interval:

If the adult has received Dose 1, and

- It has been  $\geq 4$  weeks since Dose 1, then give Dose 2 today. Dose 3 (final) should be given at least 6 months after Dose 2.
- It has been  $< 4$  weeks since Dose 1, then wait to give Dose 2 at least 4 weeks after Dose 1.

If the adult has received Dose 2 and

- It has been  $\geq 6$  months since Dose 2, then give Final Dose 3 today. This will complete the person's primary polio vaccination series.
- It has been  $< 6$  months since Dose 2, then wait to give Final Dose 3 at least 6 months after Dose 2.

Adults who have had three or more doses of polio vaccine in the past and are at increased risk – of exposure to poliovirus may get one lifetime booster dose of IPV.

For More Information: [www.cdc.gov/vaccines/vpd/polio/hcp/recommendations](http://www.cdc.gov/vaccines/vpd/polio/hcp/recommendations)



**We have had many requests to mail our monthly, printed newsletters to Canada.**

We are happy to now be able to accommodate that request.

Please email us: [info@papolionetwork.org](mailto:info@papolionetwork.org) for more information.



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