



POLIO NSW

formerly Post-Polio Network (NSW)

NETWORK NEWS

Incorporating – Polio Oz News

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Editor's Report:

The warmer weather has arrived and spring has sprung in our gardens and bushland. Polio NSW Board has been busy finding volunteers with the skills we need to assist those who run our webinars and support groups programs. Secretary, Merle Thompson has done the bulk of the work and has found two suitable people to provide the help that we need. What would we do without Merle.

Gail Hassall's webinar report from 26.6.23, "Living with Post-Polio – Maintaining a Satisfying Life" was presented by Senior Occupational Therapist, Linda Walters. It has practical advice and is very informative with some great examples of helpful gadgets to make activities of daily living easier and safer. The online webinars continue to be well supported. There is an opportunity to ask questions after each presentation.

In this issue of Network News there is a new Anaesthesia Alert Card and information sheet from Pennsylvania's Polio Network. In Polio Australia's Polio OZ you will also find a new Medical Alert card for your wallet. Remember that there are many useful fact sheets on Polio Australia's website as well as Polio Health www.poliohealth.org.au.

An extensive article titled 'What is Polio?' comes from the Christopher Reeve foundation and is a very detailed look at polio, its symptoms and the complications of Post-Polio Syndrome, see page 5.

A collection of Q and A from Bruno Bytes include topics on numbness in arms and hands, muscles 'shaking' and heat intolerance, see page 13.

On a lighter note, I always enjoy reading the personal and thought provoking articles written by Polio Perspectives editor, Millie Malone Lill. I agree with Millie's thoughts on spending time with little children in her article titled 'The Lipstick Theory'. I couldn't help adding two of her articles to this issue. (It is no wonder her articles are so clever, I discovered that Millie is an author of several novels including 'Semi Crazy: or Granny Goes Gypsy'.)

Members' stories have been included in many past issues of Network News and I would love to see more of your stories to share with our readers in a future issue of Network News.

Enjoy this lovely spring weather and I hope you find this issue helpful and informative.

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Vale - Moya June Adams

By Susan Ellis



Moya passed away on 25th June 2023 after a long and tough struggle with her health dealing with the complications of post-polio.

Moya contracted polio in 1954 after finishing her teaching degree. She had begun teaching kindergarten but was unable to continue. Moya was cared for at home having physiotherapy to build up her strength and learning to walk again with the aid of callipers. In 1955 Moya commenced a Bachelor of Arts degree at the University of Sydney studying English, History and Psychology. It was here that Moya met her husband Robert Adams who thought she was remarkable. They married in 1962 and moved to their home of 60 years in Turramurra. Moya and Rob had three children, Stephen, Prue and Rachel.

Once the children were at school Moya returned to study a Research Masters with Honours in Education at Macquarie University, exploring the impact of drama on social development for high school students. This led Moya to become a senior lecturer where she created and taught a ground-breaking course designed to improve the teaching standards of the university's lecturers. This work was internationally recognised. Moya retired after a long and successful career in 2001 aged 66.

Once Moya settled into retirement she was able to return to painting, researching her family history and enjoying time with her four grandchildren. Moya had many passions including playing the piano and she loved it when her family gathered around the piano for a sing-along, it gave her great pleasure throughout much of Moya's life, it was a love that she passed onto her children and grandchildren.

Moya became a member of Polio NSW and in 2010 attended the first Polio Australia 4 day retreat with her husband Rob. It was at this retreat that I first met Moya and found that she and I lived close to each other. At the end of the Retreat we both decided that we should join a local Polio NSW Support Group.

Moya took over from Elizabeth Wood as convenor of the Hills District Support Group in 2013. Little did we know how capable and experienced Moya was at chairing meetings with the experience she had gained over her career. The group meets monthly and we share with each other our stories on how we each live with the Late Effects of Polio. There were many laughs, funny and serious stories, that we shared at our meetings and afterwards as we shared lunch together. I will always remember Moya's infectious smile and her quiet lady-like demeanour. Moya served as convenor of the Hills District Support Group for the next 7 years until driving and health issues became too difficult to manage.



WEBINAR REPORT

By Gail Hassall

Living with Post-Polio – Maintaining a Satisfying Life

The Webinar was presented on 26 June 2023 by Linda Walters, a Senior Occupational Therapist. Linda offered a clear picture of how an Occupational Therapist works and how we can use their services for a wide range of situations.

What is Human Occupation? The What, When, How and Why of Living

It is all the things we do every day of our lives.

- o Identify the barriers to achievement, safety, independence, and quality of life.
- o Focus on strengths, build on success.
- o Find practical strategies and solutions.

Key Occupational Therapy Interventions

Person/Task/Activity Focus

- Rehabilitate: maximise and/or maintain function
- Modify, adapt, or simplify
- Falls Prevention
- Back, joint and muscle care (looking after your joints, muscles, and posture)
- Energy conservation using **The 3 Ps** (see below)

Home Modifications

- Major or minor

Equipment (tools, gadgets, gizmos, and gear)

- Mobility, self-care, positioning and pressure care, daily living, driving, travel.

There are things we can do to have a more satisfying life.

Energy conservation – the three Ps

- **PERSPECTIVE** (our attitudes, assumptions, and expectations)
 - o “Cruise it or lose it”, versus “use it or lose it”.
 - o Work smarter, not harder.
- **PRIORITISE**
 - o Take stock, what is important to you NOW?
 - o Essential versus Optional, balance responsibilities and leisure
 - o Can you delegate?
- **PLAN**
 - o Pace/pause, slow down, be strategic and REST!
 - o Tactics: work to your strength and fatigue levels, keep 20% in reserve to protect capacity
 - o Position: change body, task, or object

Change the environment. - Do a home safety audit

Check for repairs:

- pathways, floor surfaces
- hoses, gardens
- mats and rugs – ask yourself is this essential? Is it safe?
- lighting, indoor, sensor lighting outdoors
- steps and stairs
- bed covers, ensure they don't reach the floor and cause a trip hazard.

Change the task or activity: Use the KISS principle, Keep It Simple Solutions

- adapt, simplify, or modify
- try new techniques or habits
- be resourceful
- be creative
- be open-minded
- be proactive

Examples

- sit to shower or dress
- walk a different route
- sleep semi-reclined
- carry smaller loads
- try new dressing techniques

Take care of your body

- orthotics, braces, body position
- ergonomics – fit, form and function of tools or implements

Tools, gadgets, gizmos, and gear

- mobility – hiking sticks, walkers, scooters, wheelchairs, hoists, and stair lifts
- seating, positioning, and pressure care – height adjustable chairs, recliner lift chairs, adjustable beds, mattresses, cushions
- self-care – long-handled aids, shower stools, bidet
- daily living gadgets – kitchen aids, cutlery, garden tools, digital services, software, machines
- driving – seating supports, modified driver controls
- car access – swivel seat pads, wheelchair, or scooter lifts (hoist)
- portable ramps

The Occupational Therapist can work with you to identify barriers, build on strengths, or find solutions tailored to your individual needs. They can provide advice and expertise and can teach strategies for managing impaired function or pain and fatigue. Ongoing reviews and planning for changes are part of their service. The OT can also help with advice and assistance for accessing funding where appropriate.

You don't need a referral to consult an Occupational Therapist you can contact an OT for information or advice. If you think you may like to have ongoing support from an OT, you can discuss an Enhanced Primary Care Plan (EPC) with your Doctor.

If you have a support package through My Aged Care or NDIS, you can speak to your provider who could organise for you to see an OT.

Never be afraid to ask questions, it may make a big difference to your having a more satisfying life.

Some of the products mentioned at Polio NSW Webinar by Linda Walters, OT. Priced at local Port Macquarie independent living stores, prices could vary across NSW.



Tipping Kettle: Price \$110.00



Soft swivel car seat cushion \$38.00



Shower stool \$130.00 price range up to \$600.00 for different styles of chairs and stools



The Jar Key \$6 to \$8 each



New TRUST Lightweight walkers range from \$699.00 to \$899.00 weighs 6.5 Kgs



ACRE Carbon Fibre Rollator Walker Price range \$1195 to \$1295 weighs 6.7kg

What is Post-Polio Syndrome?

Taken from the Polio Network newsletter www.polionetwork.org June 2023

Source:

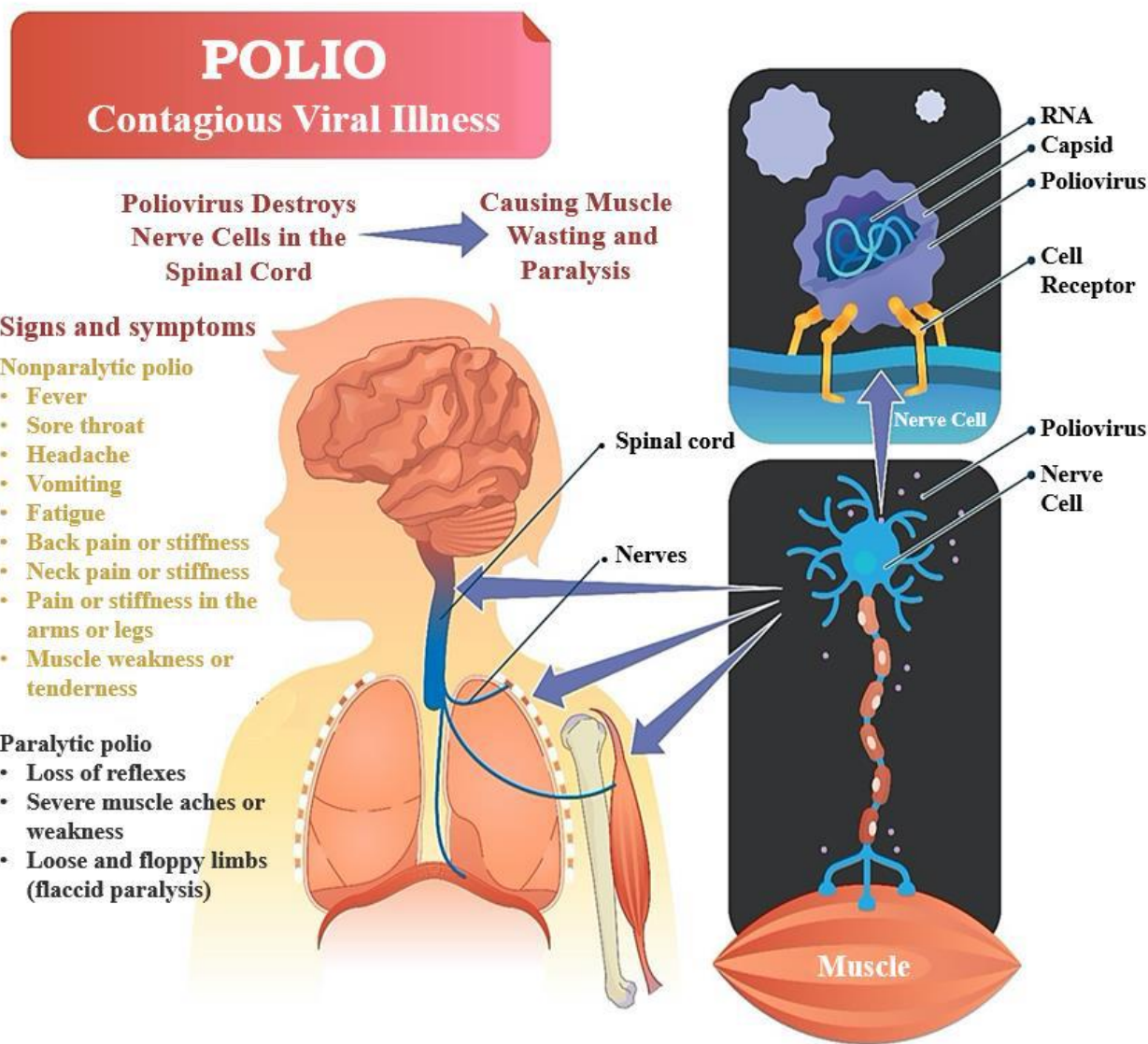
www.christopherreeve.org/living-with-paralysis/health/causes-of-paralysis/post-polio-syndrome-poliomyelitis.

“Polio was an epidemic in the United States in the 1940s and 1950s. People in the United States do not often contract polio because of the development of a polio vaccine which was developed in 1955 by Jonas Salk and an oral vaccine in 1962 by Albert Sabin. Vaccinated individuals cannot host a virus which makes it unable to replicate and spread. The polio virus is still active in some areas of the world. Improved sanitation measures have also helped to control it.

Poliomyelitis or polio is a contagious virus that enters the body. It is spread in respiratory droplets and through solid body waste. Most individuals who have polio will have flu-like symptoms. Rarely, polio affects the motor nerves (nerves that control movement) of the body especially in the spinal cord. This can be a sensation of tingling (paresthesia), an infection in the covering of brain and spinal cord (meningitis), or weakness in the muscles of the body (paralysis). Motor nerves are affected by polio which can lead to paralysis

anywhere in the body with decreased movement seen in the arms and legs and most notably in the muscles that control breathing.

Some individuals survived the polio epidemic. Those with motor nerve damage may have some residual movement deficits. To accommodate the loss of movement, affected nerve fibers develop new nerve-end terminals (dendrites) that will connect with other nearby muscle fibers. The result is functional movement recovery. This process is a representation of neuroplasticity or the ability of the nervous system to recover by developing nerve buds to improve the strength of the polio affected nerve fibers and muscles. After the initial polio episode, the individual can have partial to what appears to be a full recovery.”



“Over time, some individuals with a history of polio which affected the motor nerves may develop new muscle pain, weakness, or paralysis 10 to 40 years after the original polio episode. This is post-polio syndrome (PPS). Years later, the overused motor nerves become unable to keep up with movement demands which results in their slow deterioration. There may be some improvement a second time, but eventually, the nerve terminals slowly malfunction without further recovery. Progressive weakness and paralysis can occur.”

“Post-polio syndrome is not contagious. It is not a re-activation of the virus but rather an effect of deterioration of the replacement or supplemental nerves.”

Symptoms and Risk Factors of Post-Polio Syndrome

“Post-polio syndrome tends to develop slowly with alternating periods of stability followed by increasing symptoms. The development of PPS occurs over time.

PPS occurs in individuals with a history of polio that included motor nerve involvement. It is typically not life-threatening unless breathing is affected and untreated. Individuals differ in the amount of affected function. Some will have mild cases of PPS with minor adaptations while others will have more significant issues requiring changes in lifestyle.”

Symptoms include some or all of these factors:

- progressive weakness in muscles and joints
- pain in muscles and joints
- body/mind fatigue and exhaustion with minimal activity
- loss of appetite
- Fever
- muscle atrophy (wasting)
- bone distortions such as scoliosis (curving of the spine)
- breathing issues
- sleep disorders, insomnia, sleep apnea
- swallowing issues
- cold temperature intolerance, occasionally intolerance to heat

Risk Factors for Post-Polio Syndrome

Risk factors for PPS include a higher incidence in those individuals who had a severe initial course of polio with motor nerve involvement. If recovery of function was good or excellent from the initial polio event, more stress is placed on the supplementing nerves which can lead to post-polio syndrome motor nerve failure. Development of polio later in life as a teen or adult can relate to a higher risk of PPS because the sprouting nerve terminals are slower to develop as individuals age. Over exercising to the point of muscle fatigue can be a trigger for PPS if you have a history of polio with motor nerve involvement.

Complications of Post-Polio Syndrome

Issues that result from PPS depend on location of injury to the nerve such as in the spinal cord, in the body or both. Complications arise as weakness progresses. These are some of the key issues.

1. Falls: muscle weakness can lead to balance problems, slipping or getting your toe caught under a rug or stair step. Falls can have profound consequences such as pulled muscles, bruising, and broken bones.
2. Difficulty swallowing: individuals with PPS that affects oral motor activity such as chewing and swallowing can lead to nutritional issues and dehydration. Poor oral motor control can lead to pneumonia if food is misdirected into the lungs.
3. Breathing: issues arise due to weak chest and abdominal muscles. This can reduce the ability to produce a strong cough to clear airway passages which can lead to pneumonia. Muscular changes can lead to breathing issues such as sleep apnea or chronic respiratory failure.
4. Muscle and skeletal structure: changes from strong muscles pulling the body against weaker muscles can result in structural bone changes leading difficulty in body positioning, discomfort, pain, contractures, difficulty in hygiene. Muscular changes can lead to breathing issues such as sleep apnea or chronic respiratory failure as well as pressure injury.

Scoliosis, a change in the structural positioning of the spine affects the body's ability to inhale deeply and effectively.

5. Neurogenic bowel and bladder: nerve miscommunications change your ability to toilet. Bowel and bladder programs can be established to keep your body healthy. These programs reduce complications and maintain continence if elimination is challenged.

6. Bone mineral density: reductions from skeletal changes or inactivity can create osteopenia (low bone mass) or osteoporosis (extremely low bone mass).

7. Assistive device: issues such as braces and splints rubbing on the skin or use of crutches can lead to pressure injury and joint pain.

Diagnosing Post-Polio Syndrome

Your healthcare provider will perform a complete physical examination and health history. They will be differentiating your symptoms from other neurological issues. Clues to PPS include a history of polio specifically affecting the motor nerves followed by partial or complete recovery for a period of 10 years or more.

The history of PPS includes a new onset of slowly progressive muscle weakness, decreased endurance, muscle atrophy, muscle and/or joint pain and fatigue. Typically, later developing symptoms include breathing or swallowing issues. Onset of PPS is gradual but inactivity from trauma or surgery can make the symptoms appear suddenly. Even though you see your healthcare provider early, a diagnosis of PPS is typically not made until symptoms have been in process for a minimum of a year.

Questions about other health concerns that could be similar to PPS symptoms will be asked. These include issues with depression which affect activity levels or functional issues such as joint pain from use of braces or crutches. Some of the symptoms of PPS are stand-alone medical conditions, such as breathing dysfunction or scoliosis, and are therefore not conclusive symptoms for PPS.

Included in your healthcare professional's physical examination is manual muscle testing (MMT) where the strength of each of your major muscle groups is assessed and rated. This is done by the provider in their office at a usual visit. You are asked to push or pull muscle groups against the resistance of the examiner.

Some instruments may be used for more precise measurements.

- An electromyography (EMG) test is done to establish motor neuron loss. This is performed on any muscle of the body by using a sensor or needle to assess electrical conduction to the muscle by the nerve. Nerve conduction studies (NCS) may or may not be done depending on individual circumstances.
- Imaging such as magnetic resonance imaging (MRI) and computed tomography (CT) of the spine can follow progression of PPS.
- A muscle biopsy might be done to exclude other diagnoses.
- There are no laboratory blood tests used to diagnose PPS.
- There is no test that predicts which survivor of polio with affected motor nerves is at risk for PPS."

Note: Article Abbreviated for space. Image has been enlarged for clarity. Complete article:

www.christopherreeve.org/living-with-paralysis/health/causes-of-paralysis/post-polio-syndrome-poliomyelitis



IN FAVOR OF HOBBIES

By Millie Malone Lill, Editor, Polio Perspective

Reprinted from Polio Perspectives, August 2023

Most of the polio survivors I know hate to rest. Yes, we know we need to rest. I don't know about you, but the cobwebs in the corners do not bother me at all if I'm up and active, doing fun or necessary things. However, lay me down on the couch or recliner for mandatory rest periods and I can see every web, every speck of dust, each cat toy that is out of place. Not exactly restful if I'm lying there all tense and counting down the time till I can get up and fix it all.

I recommend finding a hobby. Maybe it's a series on TV that you are hooked on. For me, Heartland on Prime Video could keep me motionless for at least two episodes. I also like to knit and listen to audiobooks while I do so. I try to limit my time in the recliner and intersperse it with other things. Listen to two chapters, then unload/reload the dishwasher. Knit for an hour, then make my bed. On days following days of overdoing, which are getting less as I am getting older and maybe (doubtful) wiser, I spend a lot more time in the recliner. I find that on those days, I sometimes get ambushed by a nap. That's OK, I tell myself. I probably needed that nap.

Type A personality is a problem with many of my polio survivor friends. Some of us get quite angry when our get-up-and-go has gotten up and left. I'm guilty of that myself. I wake up from one of those naps that have kidnapped me and held me hostage for a couple of hours and think, "Damn it! I need tofill in the blank with whatever it was I slept through...Oh well, I can do it tomorrow." At my age, there are fewer and fewer tomorrows to do it in, whatever it was, but also at my age there are fewer things that I absolutely have to do.

Pick some things that you genuinely enjoy and indulge in them. I suggest that you look for more than one hobby. As PPS is progressive, we try to slow it down as much as possible, so search out hobbies that can age with you. Spectator sports are good. I love to knit, but I am very careful of my hands and don't want to burn the precious neurons that remain there, so I intersperse knitting with other things. I love to write and I have a very active online social life. Scrolling through Facebook and seeing what my polio family is up to, doing Wordle puzzles, and online crosswords keep my mind active and my body less so. I have wonderful, loving grandchildren who like to call me and tell me what's going on in their lives.

Find something that you can do that rests your body and lets you keep your brain active, but remember there is also brain fatigue so choose wisely. We don't want you balancing your check book with a very fatigued bunch of little gray cells, do we?



Pensylvania Polio Network

The PA Polio Network and its Newsletter has been a great source for information on all things relating to polio and post-polio. We have been fortunate to be able to share this information with Polio NSW member over many years. Articles by Dr Richard Bruno, Dr. William DeMayo and Dr. Marny Eulberg as well as Q & A from Dr Richard Bruno's Bruno Bites appear in their newsletters regularly. The PA Polio Network now has a new name as follows.



Polio Network

Polio Survivors Serving Others
www.polionetwork.org

Transitioning from www.papolionetwork.org to www.polionetwork.org

Here's our July Tip for using our new website.

Finding information by Subject/Topic

INDEX/CATEGORIES

The enormous number of articles, written by our generous, primary contributors now have easy access to an extensive index. When you are searching information, look for the Index/Category "Button". With one click on the button, every index item is listed alphabetically for easy access. "Click" on the topic of interest and the articles will come up.

<u>Article/Resource</u>	<u>Author</u>	<u>Index Entries</u>
Bruno Bytes	Richard L. Bruno, HD, PhD	483
DeMayo's Q&A Clinic	William M. DeMayo, MD	53
Encyclopedia of Polio and PPS	Richard L. Bruno, HD, PhD	572
Polio History –Putting the Pieces Together	Daniel J. Wilson, PhD	44
Primary Care Perspective	Marny K. Eulberg, MD	61

We have to thank our PA Polio Network volunteer, Denise, for her 8 years of dedication to keeping the Index that has been the basis for this outstanding tool. It supplements the standard "search bar" in that it brings the ability to seek very specific topics for the professionals who give so much to us all.

Anesthesia and Polio Survivor Treatment Information

Taken from the Polio Network newsletter www.polionetwork.org July 2023

Polio Survivors with Post-Polio Sequelae (PPS) often have all or some of the following symptoms:

- EASILY SEDATED and can be difficult to wake
- Can Have Difficulty BREATHING and SWALLOWING with Anesthesia
- HYPERSENSITIVE to PAIN and COLD.
- May need a heated blanket and increased pain medication post-op
- In addition, Polio Survivors with Post-Polio Sequelae also can experience:

Cold Intolerance Difficulty Swallowing Difficulty Breathing Muscle & Joint Pain
Muscle Weakness Overwhelming Fatigue Sensitivity to Anesthesia Sleep Disorders

The QR code on our newly updated Anesthesia Warning Card goes to the following information on our new website. The great advantage to this format is when new information is added (ex: Norma M. Braun, MD and Polio Denmark) the card immediately gives your physician access to the article as well as the contributor's biography.

Both the Anesthesia Warning Cards (available in both English and Spanish) and the newly updated "Polio Survivor Treatment Warnings for Medical Personnel and Caregivers" document are easily available for download.

www.polionetwork.org/anesthesia-card

Caregivers can read the following information when determining the treatment plan for any Polio Survivor.
www.polionetwork.org



Breathing Outcomes: Post-Poliomyelitis Syndrome (PPS): by John Bach, MD

Polio Patients and Surgery: from Polio Denmark

Post-Polio Syndrome and Anesthesia: For Anesthesiology Magazine:

by David A. Lambert, M.D.; Eleni Giannouli, M.D.; Brian J. Schmidt, M.D.

Preparing for Surgery for Post-Polio or Other Chronic Respiratory Disorder Patients:

by Norma M. Braun, MD

Preventing Complications in Polio Survivors Undergoing Surgery:

by Richard L. Bruno, HD, PhD

Preventing Complications in Polio Survivors Undergoing Surgery (Dental):

by Richard L. Bruno, HD, PhD

Summary of Anesthesia Issues for the Post-Polio Patient:

by Selma Calmes, MD

Polio Survivor Treatment Warnings For Medical Personnel and Caregivers

This Document was developed at the request of a survivor, who had moved into an assisted living facility. She wanted to have a single document available should she be taken to the hospital. It has a symptom checklist, QR codes to multiple resources with information regarding the late effects of Polio (PPS) and available space on the reversed side for personal notes/concerns. You can copy this easily printable document, and give it to your family and physician. Many of you have put a copy of this with your important documents.

Thank you John Bach MD, Richard Bruno PhD, Selma Calmes MD, William DeMayo MD, Marny Eulberg, MD and Richard Rosenstein DO for your advice and support in this updated project.



**Polio Survivor Treatment Warnings
For Medical Personnel And Caregivers
I am a Polio Survivor with Post-Polio Sequelae.**

I can:

Be **EASILY SEDATED**, and may be difficult to wake
Have Difficulty **BREATHING** and **SWALLOWING** with Anesthesia
Be **HYPERSENSITIVE** to **PAIN** and **COLD**.

Need a **HEATED BLANKET** and Need to have Increased Pain Medication post-op.

Name: _____ Date of Birth: _____

I have these Symptoms of Post-Polio Syndrome (PPS) - checked:

- | | |
|--|--|
| <input type="checkbox"/> Overwhelming Fatigue | <input type="checkbox"/> Muscle Weakness |
| <input type="checkbox"/> Muscle and Joint Pain | <input type="checkbox"/> Sleep Disorders |
| <input type="checkbox"/> Cold Intolerance | <input type="checkbox"/> Difficulty Swallowing |
| <input type="checkbox"/> Difficulty Breathing | <input type="checkbox"/> Sensitivity to Anesthesia |

**** Anesthesia Warning ****

Preventing Complications in Polio Survivors Undergoing Surgery

www.polionetwork.org/anesthesia-card



Breathing Outcomes for Post-Poliomvelitis Syndrome

Breathing and Ventilation Information

www.breathenvs.com



Encyclopedia of Polio and PPS

Information for all Subjects related to PPS

www.polionetwork.org/encyclopedia



Information on Multiple Subjects Related to PPS

Post-Polio Care for Families and Health Care Providers

www.polionetwork.org/living-with-post-polio-syndrome



Post-Polio Health International

www.post-polio.org



Please take this information into account, when you are creating my treatment plan.

I have added additional information, relating to my medical history, on the back side of this page. (Allergies, Current Medications, Tests Etc.)

Signature: _____ Date: _____

www.polionetwork.org 2023

BRUNO BYTES

Taken from Polio Network www.polionetwork.org



A Bruno Byte 2nd Quarter, 2023

From Dr. Richard L. Bruno, HD, PhD
Director, International Centre for Polio Education

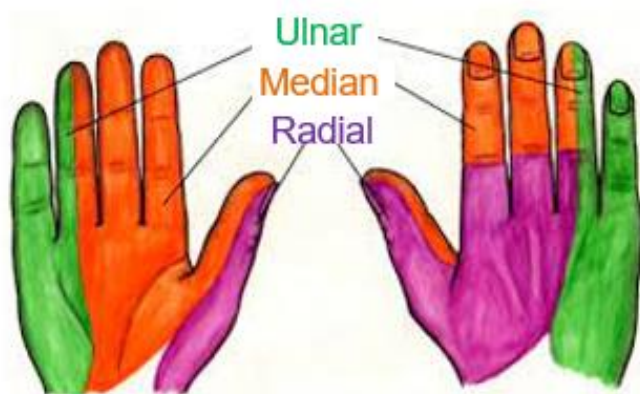
The Encyclopedia of Polio and Post-Polio Sequelae

contains all of Dr. Bruno's articles, monographs, commentaries and "Bruno Bytes"
www.polionetwork.org/encyclopedia

Abnormal Feelings or Numbness in Arms and Hands

Question: I have many symptoms of PPS and am experiencing severe pins and needles in my left hand. Sometimes in my thumb and next 2 fingers. Sometimes only in my ring and pinkie fingers. Sometimes all 5 fingers. Feelings are there all the time now, just slightly. But sometimes my entire hand is completely numb and can last up to 4 hours. When this happens, "waking" my hand up is extremely painful. My left elbow is really sore as well. Could this have to do with polio or be part of PPS. I have an appointment with a neurologist soon, thought knowing one way or the other if PPS could be involved would help.

Dr. Bruno's Response: Many, if not most, polio survivors with leg muscle weakness have compensated for years by stressing their arms and hands using canes or crutches, pushing a wheelchair or just by using their arms to push themselves up and out of a chair. This kind of arm and hand overuse can cause pinching of sensory (feeling) nerves in the neck, arms or wrists, producing numbness, a cold sensation and pins and needles. The best known type of pinching causing hand symptoms is carpal tunnel syndrome, where tendons forming the tunnel "squeeze" the nerves as they travel across the wrist.



Abnormal feelings in your thumb and next two fingers are common with pinching the median nerve (orange color).

Abnormal feelings in your ring and pinkie fingers can result from pinching the ulnar nerve (green color) as it crosses the elbow through the tendons forming the cubital tunnel, called cubital tunnel syndrome. If your entire hand feels "completely dead" and your left elbow is sore, there also could be pinching of the median nerve across your elbow.

It may be time to talk to your rehabilitation physician or neurologist about having a nerve conduction velocity study, which uses electrical pulses to see if the nerves are being pinched.

Muscle “Shaking”

Question: My left hand and forearm shake at random times. Yesterday, I walked on a rocky area and admit I over did it. I fully understand that the pain I had was a result. What was new was a wobbly hip. I was so unstable, I barely made it back to the car. It was very scary.

I’m used to "spaghetti legs", but I have never experienced hand and arm shaking or wobbly hips. My physician did a brain scan that didn’t show any signs of other causes. Can this be due to PPS? Can my forearm crutches be causing this? What can I do when this happens?

Dr. Bruno’s Response: The forearm crutches are likely causing you to overuse your arm and hand muscles to compensate for muscle weakness in your “wobbly hips”. What you’re describing is called a "physiological tremor" and can be seen in anyone who overworks a muscle, for example competitive weight lifters. The poliovirus damage and PPS makes it easier for your muscle fibers to become overworked and cause shaking. What’s more, if you are experiencing new weakness in your hips you are likely putting more stress on your arms to walk with the crutches, which is why the shaking is showing up now.

What can you do when your muscles shake? Rest the muscles and, while you're resting, log activities that caused the arm and hand shaking and "wobbly hips" then stop those activities, pace them or do much less of them.

Inability to Manage the Heat

Question: I’m always reading about polio survivors being miserable in the cold weather. I seem to be the opposite. I feel hot, even indoors in the winter. When the temperature goes up, I sweat and soak my clothes. I feel like I'm cooking inside. Is my problem with temperature a post-polio thing?

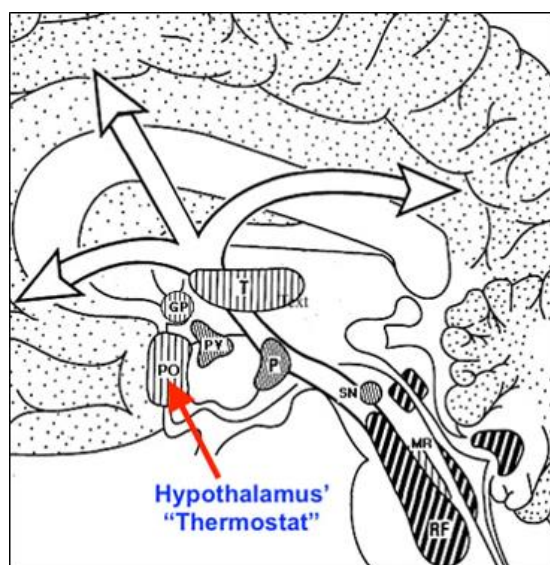
Dr. Bruno’s Response: You aren’t alone. This question is coming up more and more.

Here’s what we think is going on:

The poliovirus damaged the neurons in the brain and spinal cord that control body temperature by controlling the sympathetic nervous system. Your brain’s thermostat (in the hypothalamus) should turn on sympathetic nerves to cause skin veins and arteries to constrict when it’s cold, to keep warm blood away from the skin surface thereby preventing

loss of body heat. The reason polio survivors have cold and purple "polio feet" is that there isn’t a signal from the brain thermostat that reaches skin blood vessels to tell them to constrict. So hot blood flows to the vessels near the surface of the skin, heat in the blood radiates away from your body and your skin gets cold, which passively makes the arteries clamp down, trapping cold, purple blood in the little veins and, voilà, “polio feet.”

But if the poliovirus damaged neurons that control body temperature, shouldn't polio survivors have trouble with heat as well as cold? Over the course of decades I had not heard one polio survivor report being overcome by heat the way they were being frozen stiff by the cold. So while I studied blood flow and the effects of cold on polio



survivors, I never studied the effects of heat. But I should have. Back in 1985, in our own first Post-Polio Survey, about 1/3 of polio survivors said that they were adversely affected by the heat.

Why didn't I study heat intolerance? Truth be told, I think I was frightened by the first polio survivor I studied. He said that his polio-affected foot was always much colder than the other foot, even when he was in a room where others were comfortable. I was shocked and worried when he removed his sock to reveal a reddish-purple calf and a deep purple foot. I was afraid he had a blood clot, maybe even a clogged artery. But his veins were clear and there were bounding pulses in both feet. The real shock came when I placed an electronic thermometer on his skin. The room temperature was 75°F (24°C). I watched as the numbers on the thermometer dropped and dropped, until they stopped at 72°F (22°C). His foot was actually *colder* than the room temperature! I had to put his foot up on a stool and cover it with a hot pack for half an hour before it began to warm just slightly. And when the foot finally did heat up, the skin became as red as a lobster. It didn't take a rocket scientist to see that there was something radically wrong with blood flow in this polio survivor's leg. So that's where our research focused, on the effects of cold.

It's not that I wasn't interested in the effects of heat. The mechanism for sweating was one that I had studied fairly extensively as the autonomic nervous system fellow at Columbia-Presbyterian and before even seeing a polio survivor. The first research I presented at a national conference was on the mechanism of decreased sweating in Parkinson's patients. We knew that the brain's thermostat and sympathetic nerves not only control blood vessels but also control sweating, which cools your body by evaporation of sweat on your skin when the nerves' opening of blood vessels doesn't "dump" enough body heat via radiation. Given our finding of polio survivors' arteries not getting a signal to constrict, I would have expected poliovirus damage to the brain's thermostat and sympathetic nerves would cause polio survivors always to sweat too little. And I would have been wrong. Polio survivors have trouble with temperature regulation at both ends of the thermometer.

In a 2021 survey in the [Post-Polio Coffee House](#), six-dozen polio survivors reported difficulties with temperature, specifically heat intolerance. When asked about sweating, a minority reported "little to no sweating" associated with heat intolerance, while three times as many reported "hot flash-like" sweating, especially about the neck and face. "Comfortable" indoor or outside temperatures were reported to range from 61°F (16°C) to 72°F (22°C), while heat intolerance symptoms began from 72°F (22°C) to 85°F (29°C). The most common symptoms of heat intolerance were "nausea," "feeling faint or dizzy," being "itchy," fatigued and even anxious. Surprisingly, only three polio survivors reported that their skin became red when they felt overheated, suggesting an inability of blood vessels to open and dump enough body heat so that sweating wasn't necessary. Also surprising were polio survivors who reported having "hot flash-like" sweating from the neck up at the same time as they were experiencing painfully cold legs and feet.

With these findings, we may have come full circle. We know that polio survivors have cold legs and feet ultimately because arteries clamp down and prevent hot blood from the body's core heating the skin's surface. Perhaps the inability to get rid of excess body heat results from the same problem - surface arteries not opening - that leads to symptoms of heat intolerance and triggers sweating above the waist to try to cool the body.

So, at least for some polio survivors, cold feet cause hot heads. It seems clear that if you can't stand the heat you *may* be a polio survivor.



THE LIPSTICK THEORY

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by Millie Malone Lill, Editor Polio Perspectives

The Lipstick Theory is the idea that during economic hard times, people will still indulge but in much smaller ways. For instance, while one cannot afford to buy a new car, you can still buy an expensive lipstick. A small, more affordable indulgence.

I was wondering if this maybe applies to us polio survivors. Not in an economic way so much but as a way to use our dwindling energy in a seemingly frivolous way. A way that still gives us something that makes us feel good, but does not wear us out too thoroughly.

For instance, I can do a small amount of housework if I do it bit by bit. You know, load the dishwasher, rest for a few minutes, wipe the counters and stove top, rest a little. That is, most days I can do that much and sometimes a little bit more. Yesterday I did two loads of laundry and folded and put it all away. Then I sat and listened to an audiobook and knitted while I rested. Knitting is my tranquilizer. Maybe you would have just listened to the book and rested or even just rested. My indulgence involves the play of soft yarn and beautiful colors.

What is your favorite indulgence? I can't afford a cruise, neither in finances nor in energy. But I can get a pedicure every now and then. Soaking my feet in the scented swirling water, getting them massaged and callouses removed, maybe even pretty nail polish, it all feels very indulgent. Since I can no longer trim my own toenails, I can even consider it a medical expense, right? I knew you'd agree. The IRS maybe not so much.

I've heard people complaining because they saw someone in the grocery store using Food Stamps to buy steak. I've been on Food Stamps for a short period of time and let me tell you, sometimes it is worth it to have one really decent meal even if it means you have to eat mac and cheese for the rest of the month.

The same applies to people who, like me, have very limited energy. An evening spent with good friends or, even better, time spent with little kids uses a lot of energy for me. I know I will be worn out for the entire next day, but the laughter, the hugs, the stories are my Expensive Lipstick. So worth the exhaustion. I can replay that evening for hours as I lie in my recliner, eyes closed, feet up, with a big smile on my face.

Constant fatigue is depressing. Try to find your own Expensive Lipstick to indulge in now and then. Not all the time because it is expensive, energy-wise, but it gives you so much satisfaction to think on and enjoy over and over as you rest. Indulge in small ways that give you great pleasure. In other words, take what you want and pay for it.

