



PA Polio Survivors Network

Information and Inspiration for Polio Survivors and
Their Families

From the Keystone State and Beyond

www.polionetwork.org

July 2017

Our Mission:

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

Inside this Issue:

Limb Swelling and Polio Survivors

Dr. DeMayo is always happy when one of you send him a question that he is able to turn into an article that will benefit many others. It seems that swollen limbs and the difficult symptoms that come with it is one of those topics. He'll explain just what to do when we are troubled by one of the three most significant factors:

Sitting, **S**edentary lifestyle and **S**alt.

[William M. DeMayo, MD.](#) will be joining [Daniel J. Wilson, PhD.](#) as the featured speakers at our August 26, 2017 Conference. Details are on page 7.

Prescription Drug Prices What can we do?

[Richard L. Bruno, HD, PhD.](#) brings us interesting information each month.



This month's "Bruno Byte" from the University of Michigan is particularly informative on the topic of managing the cost of medications. The link in "Bruno Bytes" will take you to an outstanding video. Not online? We understand. We've brought the fascinating graphics from the report of their Healthy Aging Poll to you. There are additional "Bruno Bytes" (Tips and Tidbits from

the Post-Polio Coffee House) in this month's issue as well.

Summer's Here . . .

How do I know when the heat is *really* a problem?

Typically, most of us become cold so easily.

How is that heat can be such a significant issue?

Seniors are one of the four most easily affected on these warm summer days.

Thanks to the CDC we have some answers.



And . . . What about my getting so cold with Air Conditioning?

This [Bruno Byte](#) Tip may have an answer for you.*

Question: I'm having spasms throughout my back - from shoulders to waist. It's worse on my right (polio) side. - and getting worse by the day. The muscles feel cold and are getting weaker. I'm constantly having to go lie down. Is this a PPS symptom?

Dr. Bruno's Response: Has anything changed in terms of activities that may be causing the spasms? What about your exposure to air-conditioning? Always be cautious of drafts.

Response: Both a ceiling AC vent and a ceiling fan are causing drafts on me all night. I wear a neck scarf to bed but I guess it wasn't enough.

*Editor's note: It certainly did for me !



Bruno Bytes

Q&A's from [Richard L. Bruno, HD, PhD](#)
Director, International Centre for Polio Education

On the topic of how to exercise on our own (5/16/2017)

Original Post: I have recently had a number of falls and with help from physiotherapists, realize my left hip has gotten really weak. I found a Nintendo Wii with balance exercises – can I use one of these for rehab?

Dr. Bruno's Response: Don't start exercise on your own. Talk to your doctor about going to a physical therapist who can spot you so you don't fall.

On the topic of Physical Therapy (6/13/2017)

Original Post: I am 45 years old. Polio affected mainly both my legs and my left arm (I use braces and a manual wheelchair).

There is a short story in the Polio Paradox book about a young blacksmith who used his right arm almost exclusively to work and live. His arm began to feel really heavy, and seemed to be losing function. DR's originally attributed this to overuse of one extremity.

That seems to be my story right now. The past years I have been waking up feeling like my right arm has been working out all night long while I was sleeping. It started off slow, and tolerable. Today it is a cause of much pain, anxiety, and fatigue for me.

The doctor sent me to a physical therapist. The therapist has me on a "light" workout of my right arm on a daily basis (3 times a day). The "light" workout is just making things worse. I was feeling some guilt for not forcing the workouts the physical therapists suggested. It's really hard for me to break that mindset that Pain equals Gain.

Additional Post: I have a night time 'heavy arm' and the pain is usually worse at night and first thing in the morning. Sometimes I cannot get out of bed.

Dr. Bruno's Response: A night-time painful "heavy arm" needs its cause to be determined. When pain is worse at night it could very well be a pinched nerve in the neck. Some physical and occupational therapy for bed positioning could be helpful. You're still using a manual wheelchair – it may be time to "power up" !

Find a Rehabilitation Physician. PPS is *always* a diagnosis of exclusion.

Remember: If something you do hurts, either don't do it or do a lot less of it.

Here's an article from an experienced, PPS Physical Therapist who was with our Clinic treating Polio Survivors for more than ten years.

[Physical Therapy and PPS](#) by Shanti (Chacko) Molayal

On the topic of Questioning Prescription Drug Prices (6/30/2017)

Dr. Bruno's Original Post: Another reminder for Polio Survivors to be their own accountants and question medication prices ! This is an outstanding video from the University of Michigan

"Poll Finds - Older Americans Don't Get – or Seek – Enough Help
From Doctors & Pharmacists on Drug Costs."

"HALF the people with a drug cost burden have not talked with their doctor about the price of their drugs". www.healthyagingpoll.org

Bruno Bytes

As of this date, we have 2 ½ years of

[Richard L Bruno, HD, PhD](#) Q & A's accumulated in one place.

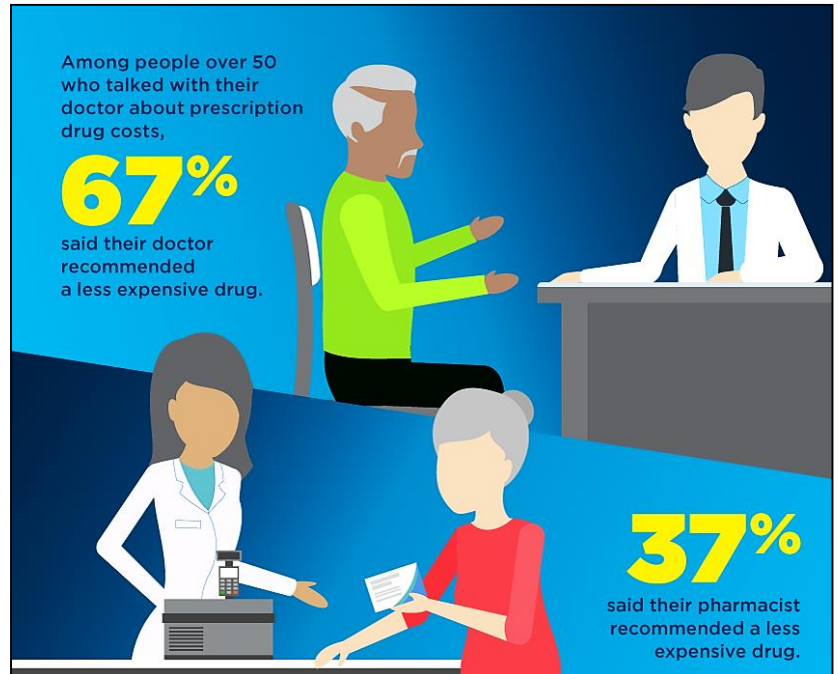
Looking for a specific topic? With Dr. Bruno's help, we have created an "Index" by [Subject](#).

Doctors and Pharmacists: An Underused Resource to Manage Drug Costs for Older Adults

M NATIONAL POLL ON HEALTHY AGING
UNIVERSITY OF MICHIGAN

PATIENT TIP

“If your prescription drugs are too expensive, mention it to your doctor at your next appointment, or talk with a pharmacist about possible alternatives”.

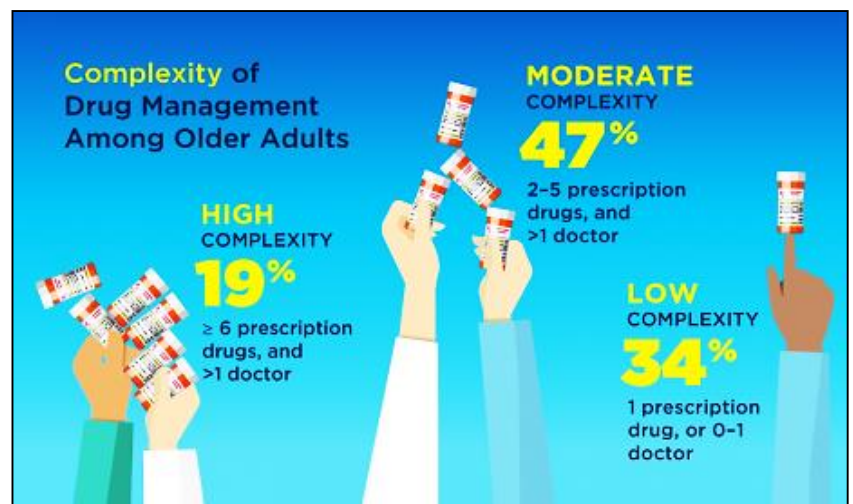


Source: www.healthyagingpoll.org

“By tapping into the perspectives of adults, older adults, and caregivers from throughout the United States, we are bringing the public’s voice to matters that affect the health and well-being of older adults and their families.”

Dr. Preeti Malani

Univ. of Michigan Professor of Internal Medicine and Director of the National Poll on Healthy Aging



Swelling and Polio Survivors

Why we need to take it seriously.
[William M. DeMayo, MD.](#)
DeMayo's Q&A Clinic



Question: Dr. DeMayo - My right leg has always been very thin. It's now terribly swollen from the knee down, and feels extremely heavy (I'm having trouble transferring into the shower). The doctor did an ultra sound to rule out blood clots. It was negative. I've been using a power chair for 18 years. What should I do?

Response: This is a great question that pertains to many polio survivors. Before addressing the issue of swelling itself, I want to acknowledge and endorse the evaluation of unilateral swelling with ultrasound to rule out blood clots (Deep Venous Thrombosis-also known as DVT). Given that a DVT in the leg can break off and travel through the heart to the lungs, it is a potentially life-threatening condition that is easily diagnosed using this technology that involves soundwaves (like sonar). Venous clots are most common in someone who has recently become sedentary or has had an injury followed by unilateral swelling. Although they are less common in the chronic setting, it is a diagnosis that should never be missed. This reinforces the general concept in healthcare management to be sure and rules out the most serious causes, especially if diagnosis is easy. It is also important to rule out other common causes of swelling such as congestive heart failure or kidney failure but these typically present with swelling in both legs. Unilateral swelling can also infrequently be caused by issues such as tumor obstruction to blood flow. In any case, it is always important to discuss swelling with your physician before concluding it is benign.

With the above said, the most common cause of swelling in polio survivors is “dependent edema”. Swelling in the feet and lower legs accumulates due to gravity. The heart pumps fluid to the feet, but physical activity needs to pump the fluid back. Contracting muscles literally squeeze the blood in veins towards the heart and valves prevent the blood from moving back.

Any immobility, paralysis, or sedentary behavior will limit this pumping action. Fluid from the accumulating blood seeps into surrounding tissues leading to edema. The extent of edema in the tissue is assessed by pressing for several seconds and evaluating if “pitting” of the tissue occurs where fluid is pressed out of the area. The more pitting there is, the more severe the problem.



Treating lower extremity edema centers around minimizing the effect of the three biggest factors that exacerbate swelling: **S**itting, **S**edentary lifestyle and **S**alt.

- **S**itting

Gravity makes it more difficult to return fluid to the heart and increases the chances that edema will accumulate in the legs. The lower the feet are relative to the heart the greater the hydrostatic pressure that needs to be overcome and returning blood to the heart. Furthermore, resistance at the knees and hips in a bent sitting posture can make this return of blood even more difficult. Unfortunately, the opposite is also true if the feet are at the level of or above the level of the heart then it is easy for fluid to return. Most people wake up with less edema in the morning. Elevating the feet above the heart as much as possible will result in further reduction in swelling. **If** there are no heart problems or other contraindications, a brick under the foot of the bed, can result in fluid slowly moving out of the feet into the general circulation over the course of the night so it can be excreted by the kidneys. This effect of this small elevation can be illustrated if one thinks of water on a flat surface; it doesn't take much elevation of one side to get the fluid to flow to the other side. The slight elevation is compounded over the long duration we are typically in bed at night.

(continued . . .)

During the day, support socks/stockings can often help prevent fluid from accumulating when an individual is sitting. Support stockings can range from over-the-counter support socks from Walmart to custom stockings prescribed by a physician.

Donning these socks can be problematic. This is especially true if there is upper extremity weakness. A sock-aid is a plastic sleeve with a rope pull that can be quite helpful. Despite this aid, many people abandon compression socks as being impractical. I have always found Tubigrip

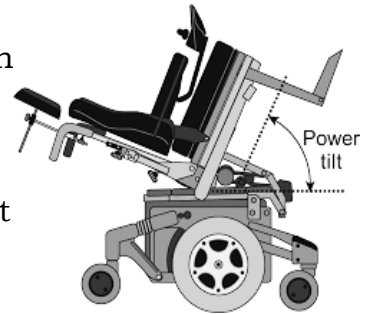


to be a helpful alternative to stockings - it is a tubular bandage that has enormous elastic qualities. A double layer from the toes to the knees is usually easy to slide on and well-tolerated. Moderately severe swelling usually requires size E. A roll can be obtained on the Internet through [Amazon](https://www.amazon.com). Some providers also sell it by the yard.



For individuals who do not respond to static compression sequential compression pumps are available by prescription (see your doctor). In some cases, these devices can be very helpful. They involve use of an inflatable "boot" with several chambers. A pump inflates the chambers in the foot, then the ankle, then the lower leg pushing fluid back towards the heart. Treatment usually takes a couple of hours a few times a week.

For those who are using a power wheelchair, lower extremity edema can be dramatically improved with a "tilt in space" option. A "tilt in space" option requires specific medical documentation to be provided to the insurance company. As the head and upper body move down, the feet are raised and the hips and knees are maintained at 90°. This is very different than reclining (when the feet stay at floor level). Tilting periodically throughout the day can drain fluid from the feet and dramatically prevent accumulation.



- **S**edentary Lifestyle

Many polio survivors have significant impairments in mobility. For those who are able to walk, even short walks multiple times per day can be of significant benefit in preventing swelling. While walking is clearly the best activity to facilitate muscles pumping fluid back to the heart, any contraction of these muscles will help. "Ankle pumps" are



exercises that are often taught to all patients on rehabilitation units to prevent swelling and clots. They can be done in bed or wheelchair and simply involve forceful contraction of the calf muscles while pointing the toes down followed by pulling the toes up towards the body and repeating multiple times

throughout the day. It is helpful to think of this like pumping the handle on a well to move fluid. Many polio survivors with severe atrophy in the lower leg may simply not have the muscle mass to "pump" the fluid. If atrophy is only in one leg, it is typical to see swelling mostly on that side.

- **S**alt

Kidney failure leads to swelling because salt is not excreted in the urine. To keep the concentration of salt normal in the body, we then retain more fluid to dilute the salt. Most of us, especially as we get older, can see this impact even without kidney failure. Eating salty chips, soup, or other foods high in sodium can dramatically affect edema for many individuals. Evaluating sodium intake is the first step in preventing this. Talk to your doctor if the swelling continues. Physicians may recommend a "Water Pill" (Lasix, hydrochlorothiazide, or others). If one is prescribed, it is best taken the morning to avoid interfering with sleep.

Leg swelling is more than a cosmetic issue or inconvenience and donning shoes and socks.

(continued . . .)



Edema can reduce blood flow to the skin and increase the chances of infection. Additionally, the sheer weight of the fluid can severely impaired function in individuals who already have weakness. Excess fluid in the legs can add up to 10 or 20 pounds of “deadweight” and lead to fatigue over the course of the day or inability to climb stairs, transfer into the tub, or get in a car. Think about the impact of putting 10 pound weights on one’s ankles for the entire day. Furthermore, over weeks and months this can also result in functional decline leading to a more sedentary lifestyle and a vicious circle. Conversely, removing a significant amount of edema can often improve function. A minor amount of swelling is very common and may not be problematic but moderate or severe swelling is almost always important to address with your physician. For cases that did not respond to the above suggestions, Lymphedema clinics are available. My experiences have been that many of these clinics provide short-term benefit with edema returning after treatment concludes. If, however, they can get swelling down so that compression stockings can be used then long-term management can be achieved.

I encourage Polio survivors to continue to pursue treatment of moderate or severe edema (swelling) until a customized approach is developed that meets their needs. In most cases that includes a combination of approaches with input from a treatment team including a rehabilitation physician, primary care physician, therapist, and nurses.

[William M. DeMayo, MD](#)

July, 2017



Heat and Older Adults

Why are older adults more prone to heat stress?

- Older adults do not adjust as well as young people to sudden changes in temperature.
- They are more likely to have a chronic medical condition that changes normal body responses to heat.
- They are more likely to take prescription medicines that affect the body’s ability to control its temperature or sweat.

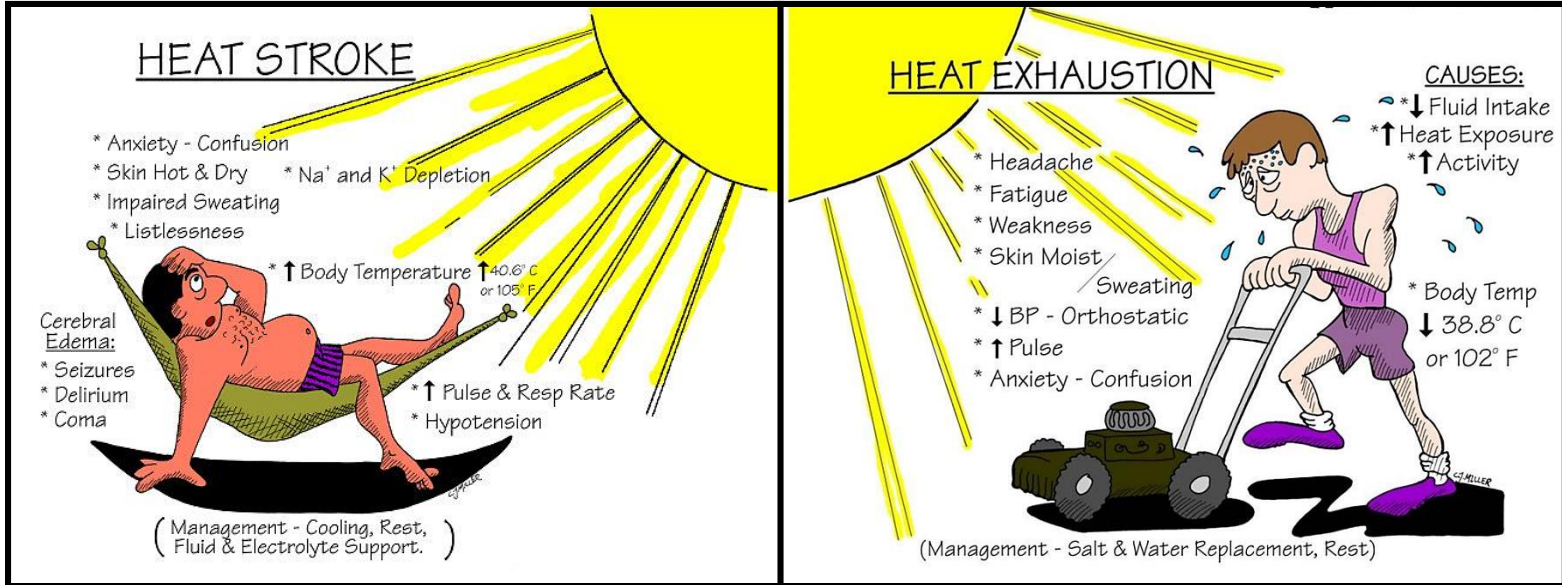
Stay cool, stay hydrated

- Stay in air-conditioned buildings as much as possible. If your home doesn’t have air conditioning, contact your local health department or locate an air-conditioned shelter in your area.
- Do not rely on a fan as your main cooling source when it’s really hot outside.
- Drink more water than usual and **don’t wait** until you’re thirsty to drink.
 - If your doctor limits the amount of fluids you drink or has you on water pills, ask them how much you should drink during hot weather.
- Don’t use the stove or oven to cook—it will make you and your house hotter.
- Wear loose, lightweight, light-colored clothing.
- Take cool showers or baths to cool down.
- Do not engage in very strenuous activities and get plenty of rest.
- Check on a friend or neighbor and have someone do the same for you.
- Follow [additional tips](#) on how to prevent heat-related illness.

Stay informed

- Check the local news for health and safety updates.

Seek medical care immediately if you have, or someone you know has, [symptoms of heat-related illness](#) like muscle cramps, headaches, nausea or vomiting.



A Summer Conference for Polio Survivors and our Caregivers



Post-Polio Care Past, Present and Future

Featured Speakers:

[William M. DeMayo, MD.](#) and [Daniel J. Wilson, PhD.](#)

August 26, 2017

Join us for an Interactive Video Conference that will take us through the history of Post-Polio care and will help Polio Survivors and Caregivers navigate the journey of effective medical care going forward.

Dr. William DeMayo, MD has nearly 30 years of clinical experience in the field of Physical Medicine & Rehabilitation. He has served as Medical Director for several comprehensive inpatient rehabilitation units and has also maintained an active outpatient practice. He currently serves on the Medical Advisory Committee of Post-Polio Health International.

Dr. Daniel Wilson, PhD is Professor of History at Muhlenberg College, Allentown, PA. He is the author of several books on the history of Polio including: "Living with Polio: The Epidemic and Its Survivors" (2005) and "Polio: Biography of a Disease" (2009). He had polio in 1955 and began developing symptoms of Post-Polio Syndrome in 1987. He currently serves on the Board of Directors of Post-Polio Health International.

This informative event will be highlighted by Polio Survivors and our Caregivers being able to experience the day in community with one another. Dr. DeMayo and Dr. Wilson will be speaking from our Doylestown location. We will be doing a live, wide-screen "feed" to Cranberry and Hanover Pa. These three Pennsylvania locations are easily accessible for Polio Survivors to join us from the surrounding states of Delaware, Maryland, New Jersey, Ohio and West Virginia.

Attendees at *all* three handicapped accessible locations will be able to participate in the questions submitted to both speakers.

Location information, multiple viewing opportunities and registration forms are available on our [website](#).

Join us for an informative, fellowship filled day.

A Note About Newsletter Article Availability

www.polionetwork.org

A lot of our readers who receive the Email version of this newsletter have been telling us that they are misplacing important articles. ALL of our newsletters are easily available in the [Newsletter Archive](#).

ALL of Dr. Bruno's Q&A's in addition to the Index by Subject are available in under "Bruno Bytes".

ALL of Dr. William DeMayo's articles are available in under "DeMayo's Q & A Clinic".

Anesthesia Warning Information (including cards for download and Symptom Checklists for printing) is available in the Post-Polio Syndrome section – under "Anesthesia Warning".

Color ink for home printers is expensive. If you would like to receive our (full color) monthly newsletter in print each month, we offer that service by US Mail. We are truly grateful to Dave Boucher, our local printer whose father was a Polio survivor, for pricing this for us so reasonably. Details to sign up are [available](#).

Thank you

We are truly grateful for your kind words of support.

Your generous [donations](#) are the key to helping our work continue.

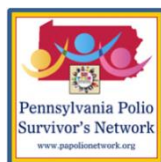


Do you have a topic you would like us to cover? Please let us know.

Always feel free to contact us.

[The Polio Network Team](#)

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