



PA Polio Survivors Network

Information and Inspiration for Polio Survivors and
Their Families

From the Keystone State and Beyond

www.polionetwork.org

February 2017

Our Mission:

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

How many of us have Shoulder Pain?

We were grateful to a member of our Polio Network who asked [William M. DeMayo, MD.](#) an outstanding question about her chronic shoulder issues. Dr. DeMayo always tries to turn an individual's question into one that he can answer for the majority of us. This month, he explained just what makes our shoulders "work" (or "hurt"). Thank you Dr. DeMayo.

"Polio-Like Illness". What IS it?

Many of us have read about the "polio like" illness affecting so many children. We were happy to find an article that explained this heartbreaking virus in a language we could understand. Thank you Dr. Eve Glazier, M.D for giving us permission to share your article.

"Bruno Bytes" Index – By Topic

"Bruno Bytes" are published regularly, through a combined effort between [Richard L Bruno, HD, PhD](#) and the PA Polio Survivor's Network. They are answers to questions posted in the "Post-Polio Coffee House" (on Facebook). This partnership began in November, 2014.

From 1988 to 2010, Dr. Bruno was the Director of an outstanding research and comprehensive treatment center for Post-Polio Sequelae. His multidisciplinary program included patients being seen by Dr. Bruno for behavioral psychotherapy, evaluation and treatment by a physiatrist (a rehabilitation physician), a registered dietitian, occupational and physical therapists. Dr. Bruno is now the Director of the non-profit [International Centre for Polio Education](#) advocating for and teaching polio survivors and medical professionals around the world about the cause and treatment of PPS.

The goal of "Bruno Bytes" is to help to teach polio survivors, spouses, caregivers and health care professionals about the many and varied topics related to the physical and emotional issues associated with having had polio and managing PPS. Please remember that "Bruno Bytes" are for education only and that any personal treatment must be determined in association with a PPS knowledgeable health care professional. Thank you Dr. Bruno.

"Going Forward . . . She Does Not Yield"

Polio Survivors are "famous" for our strength and determination. Survivor Nancy Moffett tells a story this month that reflects her very own "true grit" Thank you Nancy.

Winter Travel Can be Difficult.

We've brought you some cold weather safety tips from the CDC winter weather prevention checklist.



Contact us: info@polionetwork.org (or) 215-858-4643
We are a Registered 501C3 organization

Shoulder Problems in Polio Survivors

[William M. DeMayo, MD.](#)

DeMayo's Q & A Clinic

Question:

I am now 86 and contracted polio when I was three. The polio left me with paralysis in my left arm, the muscles of my stomach and I have a slight curvature of the spine. Over the years I have been doing fine and even bore 5 children.

About two years ago I developed horrible pain in the upper part of my right arm. I am allergic to NSAIDs so I use Tylenol which gives me occasional partial relief. I also use creams such as Blue Emu and have had therapy. Also, occasionally I use Icy hot electrodes. The pain is with me daily however it does not interfere with my sleep. I am able to be fully responsible in my daily requirements but with pain. I am truly blessed that I am not dealing with worse.

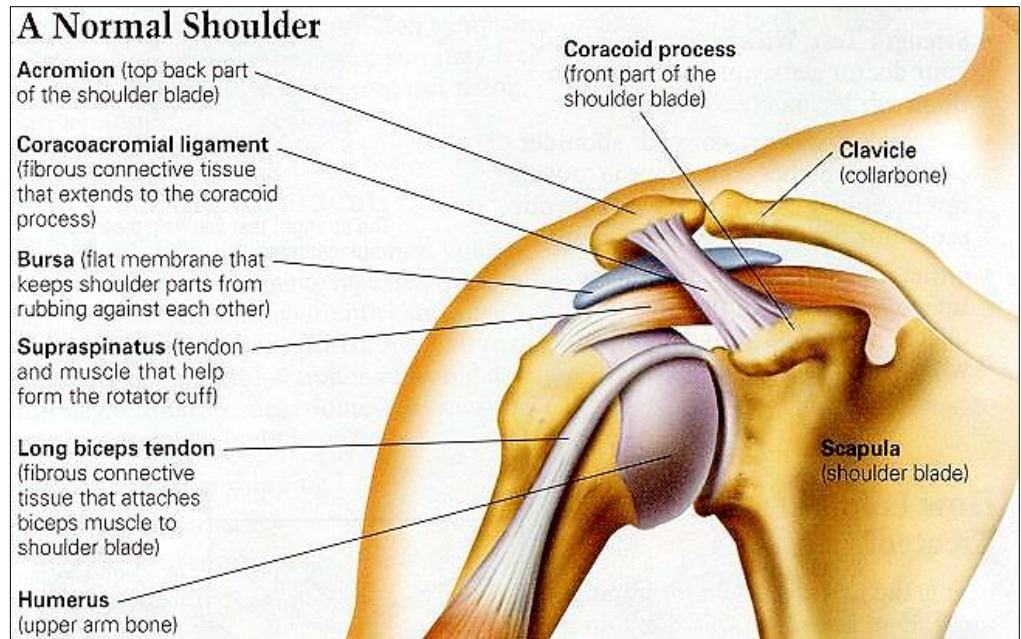
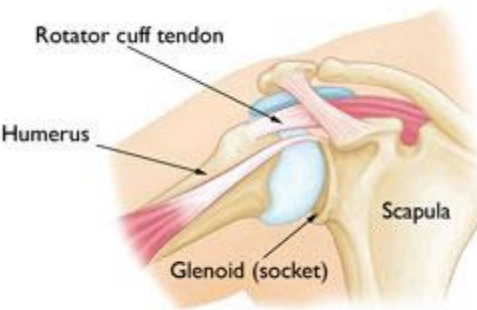
I was curious if you may have any recommendation so that I can make the pain leave. I have also been told I have arthritis in the area.

Reply:

Shoulder problems in the elderly can be very difficult to rehabilitate and this is especially true in the polio population. A comprehensive review of shoulder problems is well beyond the scope of this article, but I will share some perspectives that may be helpful.

First, it is important to remember that the shoulder joint is inherently unstable without muscular support. Polio survivors with weakness

of shoulder muscles can learn to substitute but are clearly at much higher risk for subsequent problems such as arthritis, shoulder impingement, bursitis, and tendinitis because the shoulder simply cannot function as it was originally designed. In order to understand this fully, a basic knowledge of shoulder anatomy is essential (see above). One only has to glance at the shallow "cup" (socket) of the shoulder blade which articulates with the humeral head in order to appreciate the importance that soft tissues play in stabilizing the joint during normal use.



Without normal muscle strength, the ball simply does not move normally within the socket. When the ball does not move normally within the socket, other muscles are overused, leading to possible muscle and tendon problems. Many polio survivors with leg weakness rely on their arms and shoulders to get up from a sitting position, to bear weight on crutches/walkers, or to push a wheelchair. The shoulder is simply not designed for this kind of regular weight bearing function.

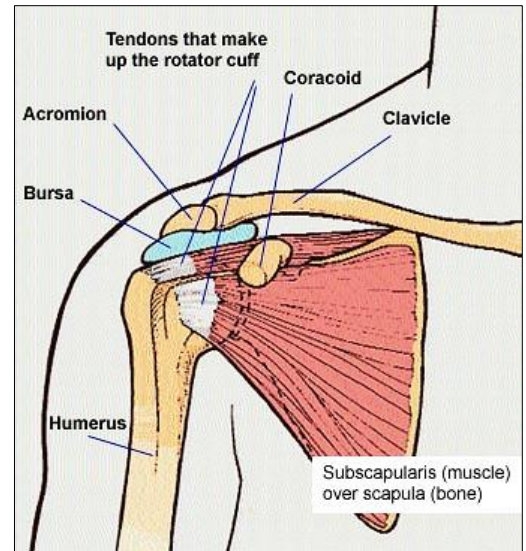
Given the history and location of your pain, arthritis of the humeral head and "cup" (a.k.a. glenoid fossa) is a likely component of the problem you described. Other possible contributing sources of pain, however, should always be evaluated. Although not likely in this case, polio

survivors should always be aware of other diagnoses to consider when you have a complaint of shoulder pain.

- A pinched nerve of the cervical spine (neck) can radiate pain to the shoulder.
- Myofascial pain (chronic muscular pain) can develop in the [periscapular](#) muscles around the shoulder.
- If falls have occurred then traumatic injuries such as a [humerus](#) fracture or shoulder separation (torn or partially torn ligaments between bones in the shoulder) should be considered.

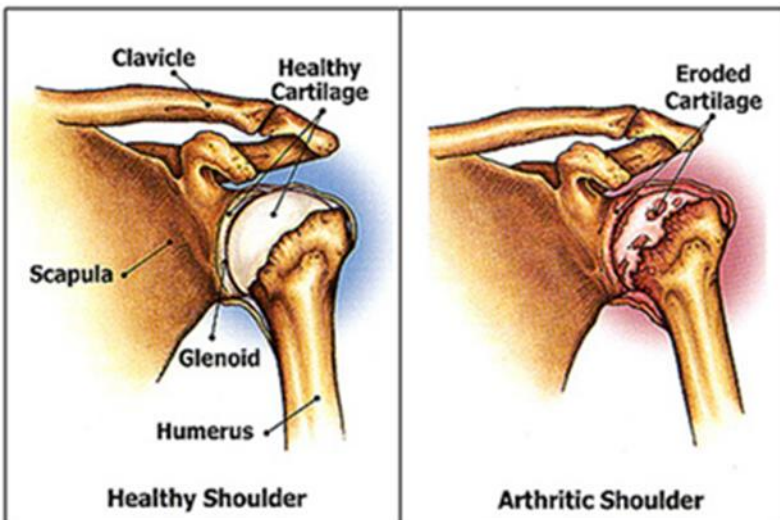
Additionally, there are multiple chronic inflammatory problems that occur frequently in the shoulders of polio survivors. These can lead to abnormal [shoulder biomechanics](#) (abnormal movement within the shoulder) that over time can contribute to arthritis. It can be important to treat these inflammatory problems early rather than simply endure the pain because problems can snowball as one gets older. Some of these inflammatory problems include:

- Bicipital Tendinitis (inflammation of the biceps tendon-see large photo previous page)-often presents with anterior shoulder pain and tenderness.
- Bursitis (inflammation of the fluid-filled sac depicted here) is often associated with other problems. It is more common in individuals with shoulder weakness or abnormal biomechanics.
- Rotator Cuff Tendinitis (inflammation of the tendon portion of the rotator cuff muscles that stabilize the shoulder joint) -left untreated this can progress to partial or complete rotator cuff tear resulting in inability to raise one's arm or rotate the arm outward. Impingement (pinching) of the rotator cuff tendon is sometimes due to a bony spur on the under service of acromion. If present, this bony spur can often be removed quite easily with arthroscopic surgery and is a good example of early minor surgical intervention that can prevent significant disability later.



Some of these inflammatory problems can be responsive to oral/topical anti-inflammatories, injected anti-inflammatories (avoid multiple) and ultrasound/physical therapy. Additionally, stretching and strengthening exercises can often help restore more normal biomechanics relieving pain and preventing further problems. Most rehabilitation physicians and physical therapists are well-versed in shoulder biomechanics and treatment.

Once severe arthritis has developed within the shoulder joint, pain can be quite difficult to treat. The choices you have made are reasonable to continue if they provide some relief. Oral



or injected steroids can also be very helpful but should not be overused. The results can be variable with improvement in pain for days, weeks or months. Although you mentioned that you are “allergic” to nonsteroidal anti-inflammatory medications (NSAIDs), it is important to distinguish this from intolerance. An allergic response typically produces a rash. Intolerance can often be avoided by protecting the stomach or using a different class of NSAID. Topical NSAIDs are also now available.

Surgical replacement of the shoulder has

significantly improved in recent years. Polio survivors pose an extra challenge however, due to weakness of the muscles stabilizing the shoulder and osteoporotic bones. In severely arthritic shoulders, replacement surgery can provide a dramatic reduction in pain but risks need to be assessed carefully and I would always recommend more than one orthopedic opinion.

Lastly, it is important to be aware of adhesive capsulitis (frozen shoulder). With any of the above shoulder problems, reduction in shoulder range of motion over a significant period of time can lead to restriction in the shoulder capsule. This sets up an inflammatory cycle whereby more pain is produced, leading to less range of motion that leads to even further tightness and more pain. Maintaining shoulder range of motion is essential and can be achieved through relatively simple home exercises taught by most physical therapists.

I hope this information helps. I encourage you to see a shoulder specialist to discuss your particular shoulder issue. Bringing a friend or loved one can help you to be sure questions get answered. Don't hesitate to say you will think about their suggestions if you need time to consider them (especially if surgery is recommended). Don't be surprised if you feel you need to see more than one specialist to find one that you feel confident in. It will likely be worth the investment of time and energy.

[William M. DeMayo](#), MD.
February, 2017



Do you have a question for Dr. DeMayo?

Feel free to contact us: info@polionetwork.org (or) 215-858-4643



Ask the Doctors:

Reports of Children with Rare, Polio-like Illness Cause Concern

Dear Doctor: I've been reading about a new illness that's a lot like polio and is making children in parts of the country very sick. What is it, and should my family and I be worried?

Dear Reader: You're referring to acute flaccid myelitis, also known as AFM, a rare neurological disease that affects the spinal cord. The symptoms mimic those of polio, which has helped to push AFM into the headlines.

Before we get into specifics, we want to stress that AFM is quite rare. Despite the sudden spate of alarming news reports that have, quite understandably, caused you concern, the rate of infection is extremely low — one person per million. As of last November, there were 120 confirmed cases of AFM in the United States in 2016.

So what exactly is AFM?

It's a syndrome that can cause the muscles and reflexes in the body to stop working normally. Symptoms often arise quickly. What begins as a fever or respiratory illness gives way to weakness in the limbs, including a possible loss of muscle tone. In several reported cases, the first symptom in a child diagnosed with AFM was a sudden limp. Some patients have slurred speech or facial drooping. In the most serious cases, acute weakness in the muscles that control breathing has led to respiratory difficulties. At this time, the causes of AFM are not fully understood. Officials at the Centers for Disease Control and Prevention suspect a range of viruses may be involved. These include West Nile virus, enteroviruses that enter the body through the intestines, and adenoviruses, which can cause cold like symptoms, including sore throat, bronchitis, pneumonia, diarrhea and pink eye.

Research into the causes of AFM, which affects children in greater numbers than adults, is a national priority. At the CDC, scientists and public health specialists are gathering blood

samples as well as fluid specimens from the nose, respiratory tract and spinal cord of affected patients for testing. Results are collected into a database for study and analysis.

The symptoms of AFM are similar to several other conditions that are far more common. This has increased the challenge of arriving at an accurate diagnosis. However, awareness of the disease among health care providers is growing rapidly, which means diagnosis and reporting are becoming more accurate.

If you believe you or your child has symptoms that correspond with those of AFM, call your family doctor. The findings from a careful examination of the nervous system, with accurate mapping of the muscles and reflexes affected, and diagnostic tests such as an MRI and analysis of the cerebrospinal fluid, will allow a correct diagnosis.

The CDC recommends that your family is up-to-date on polio and all other recommended vaccinations, and that you protect yourself and your family from mosquito-borne viruses by using insect repellents.

Increased awareness of AFM is leading to an ever-larger volume of reliable data for researchers to work with. That means more information about what causes the disease and more avenues in which to seek and find a cure.

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Sample Page – [Bruno Bytes Index \(By Topic\)](#)

Bruno Bytes have been a collaboration between Richard L. Bruno, HD, PhD and the PA Polio Survivors Network since 2014.

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Going Forward . . . She Does Not Yield

By Nancy Moffett



I grew up in East Greenville, a small town in Montgomery County, Pa. In 1950, at age six, I came down with a high fever and a stiff neck. Mom called our doctor. The next thing I knew, I was alone in an ambulance bound for a hospital at the other end of the county. My memories are sketchy...weeks in isolation, where nurses and doctors wearing face masks came and went...hours with steaming hot packs on my legs. I'll never forget the smell of wet wool. I also remember the awful pain of the spinal tap that confirmed the polio diagnosis. No wonder we polio survivors are so brave and fearless.

My mom, two sisters and brother were quarantined while I was gone. No one remembers for how long. When I came home, I couldn't walk, so I scooted backwards across the floor on my bottom and learned how to do the same coming down the stairs. I was small enough that Mom could carry me up the stairs. Visits from therapists resulted in hours on the living room floor lifting my legs with weighted shoes on my feet. The fronts of the shoes were cut open so I wouldn't outgrow them, and more weights were added at each visit to increase resistance. I also spent time in a rehab pool doing more strengthening exercises. Months later, these therapies allowed me to take my first wobbly steps. We were told that I was now "back to normal." I never needed crutches or braces.

I missed 2nd grade, having to do schoolwork at home between the teacher's tutoring sessions. Instead of playing with my schoolmates, I learned to love the books that helped me forget those painful exercise sessions. After I learned to walk again, I spent many hours skating up and down the sidewalks of town, again on the advice of the therapists. As I grew, like many survivors, I put polio out of my head and felt just like any other kid. In high school, I loved to jitterbug; and my friends and I spent many hours walking to the movies and other places in town.

I married young, as many of us did in the early 1960s. During the next decade, I raised two children, scrubbed floors, painted walls and sewed curtains for my first home. If I suffered bouts of fatigue, I chalked it up to running after toddlers and doing housework. After divorcing in 1976, I worked full-time, took college classes at night and played single-parent to my daughters. On weekends I discoed and dated into the night. My legs and body carried me well through those busy years.

After buying a two-unit home in Bethlehem, Pa., where I worked as marketing assistant for a local bank, I met my second husband Jeff. Lucky me to have fallen in love with someone who had the skills needed to fix up my old house! We've been together ever since...33 years and three renovated houses later.

After the kids left for jobs and college, I had planned to finish my college degree, travel and had even begun writing a book...things I had put off while the girls were growing up. Unfortunately, that's when the first symptoms of post polio began. Leg twitches, fatigue, feeling weak and tired. An article in The Allentown Morning Call on post-polio led me to the Good Shepherd Post-Polio Clinic, where electronic probing showed muscle and nerve loss in both legs. I was told to expect anything from leg braces to eventually needing a wheelchair. "Cut back your activities." "Get more rest," the clinic doctor recommended. Another piece of advice was to start swimming, rather than walking or doing other weight-bearing exercises. As we all know, "conserve to preserve."

One of the most helpful things I did during this period was to join the Lehigh Valley Post Polio Group. By connecting with other survivors and hearing from experts, I learned to accept and adapt to PPS. I began swimming several times a week, which I continue to do to this day.

In 1992 I took time off from my career to finish my Associate's degree from Montgomery County Community College. When I was laid off from a job as Marketing Manager in 1995, Jeff and I

continued . . .



talked about my options. It was becoming impossible to get the kind of jobs I had done before without a four-year degree. So, I spent the next year at Moravian College, finally earning that Bachelor's



degree in English I started working on 20 years before. From there, I worked for six years as the Corporate Communications Editor for Rodale, Inc., Emmaus, Pa., publisher of Prevention and Men's Health magazines. However, due to PPS, it became more and more difficult to work full-time; and in 2002, I left the company to start a freelance writing business. I wrote features for The Morning Call, a builders' association magazine, and most recently, Lehigh Valley Marketplace magazine.

After Jeff retired, we finally had time to do the traveling we'd always dreamed of...the Grand Canyon, Colorado, Yellowstone, Zion, Maine...we made sure we got to see these beautiful American landscapes. Although I can still walk, that's limited to short distances. When I take my grandkids out to museums and other destinations, I use a walker; for longer walks, a cane; and I love my travel scooter, which works perfectly for airports and national parks.

After a bout with cancer in 2014, I decided to stop writing and just enjoy life. I read; cook; spend time with friends, our three daughters and five grandkids. I've learned to take each day as it comes.

I like this quote from Alfred Lord Tennyson's "Ulysses," which I think applies to us:

Though much is taken, much abides; and though
We are not now that strength which in old days
Moved earth and heaven, that which we are, we are;
One equal temper of heroic hearts,
Made weak by time and fate, but strong in will
To strive, to seek, to find, and not to yield.



That's always been my goal...to keep on going and not to yield!

**Nancy's story is in the [Survivor Story](#) section of our website.

The Winter Months Can Be Dangerous for Travelers (Especially so for those of us who are sensitive to the cold).

Not only do you sometimes contend with deteriorating road conditions because of snow and ice, but life-threatening situations can arise if you find yourself stranded on the road for a significant amount of time. Here are some tips to help you prepare and make your wintertime travels safer.

It is always helpful to have the following in your car in case of an emergency:

1. A cellphone
2. Portable charger
3. Jumper cables
4. Blankets
5. Extra layers of clothing such as hats, coats and mittens
6. A flashlight
7. Extra batteries
8. A first-aid kit
9. Water and nonperishable snacks
10. A windshield scraper
11. A shovel



In addition to your own preparations for bad weather, make sure your car is ready, too. Snow can block your vision and ice can cause slippery roads, so remember this:

- Keep a full gas tank.
- Make sure your antifreeze levels are sufficient.
- Ensure that the heater and defroster work properly.
- Check fluid levels and brake pads.

For more safety precautions, visit the federal Centers for Disease Control and Prevention's winter weather checklist and Department of Homeland Security's car safety page.

What IS Post-Polio Syndrome ?

For multiple pages of information about Post-Polio Syndrome. [Look under that topic.](#)

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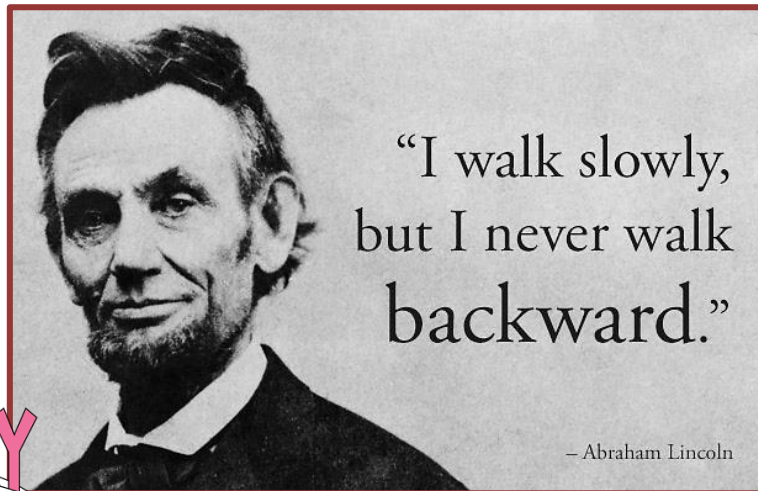
Details are [available.](#)



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Know that you are *not* alone.

[The Polio Network Team](#)



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