

### PA Polio Survivors Network

Information and Inspiration for Polio Survivors and Their Families

From the Keystone State and Beyond

www.polionetwork.org

May 2017

#### Our Mission:

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

#### Shoulder pain - it's a common Post-Polio issue.

In February, DeMayo's Q & A Clinic featured the article

"Shoulder Problems in Polio Survivors". This month, William M. DeMayo, MD. follows up with a second article, that can help ease shoulder issues with self management. This article has a clear explanation as to how our shoulders actually "work" along with great advice as to what to expect from our professional caregivers when we have shoulder pain.

With help from Post-Polio Health International (PHI) we have another article that can help with this issue. "Strategies for Management of Arms and Shoulders" offers additional strategies geared to Polio survivors, to ease shoulder overuse and pain.



Unfortunately, we hear lots of reports about "Scams" and the older population. Rarely, are we given outstanding details about them and strategies as to how to manage these issues.

<u>Richard L. Bruno, HD, PhD.</u> has written a "Bruno Byte" Tidbit regarding scams in the area of home delivery of power mobility devices (PMD). Be very, VERY careful how you respond to

anyone who asks for banking information. If you didn't read our featured article from April about purchasing PMD's now may be the time.

Dr. Bruno also shared "tidbits" about energy loss and braces & crutches.

The Social Security Administration and the Office of the Inspector General (OIG) have issued a "warning" about phone calls from Impostors.

Thank you PHI for bringing this to our attention.

Going to a more cheerful note – It's Spring!



Enjoy the warmth and sunshine.





## Concepts of Shoulder Self Management for the Polio Survivor

William M. DeMayo, MD. DeMayo's Q & A Clinic

In February of this year, we published an article titled "Shoulder Problems in Polio Survivors", which talked about common shoulder diagnoses. This article will focus on some key approaches to self-management. Clearly any shoulder rehabilitation program needs to start with a specific diagnosis (reviewing an individualized exercise program is far beyond the scope of this article). I hope to explain some basic approaches that may encourage polio survivors to understand that relief of shoulder pain is possible.

Any persistent shoulder pain should be evaluated by an appropriate healthcare provider and I would highly suggest requesting a specific home exercise program to supplement any other treatment.

I will review some basic physiology concepts regarding the shoulder, which your health care provider will take into account when determining your specific exercises.

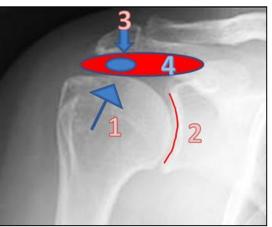
- The shoulder is inherently unstable with the "ball" (#1in graphic on the next page) of the humerous (upper arm bone) fitting into a very shallow "cup" (#2) of the shoulder blade (scapula). It is the muscles, tendons, and ligaments that keep the shoulder in place.

  Supraspinatus
- Muscle weakness can cause excess motion
   within the shoulder joint, leading to increased
   pain and long-term problems such as tendinitis and arthritis.
- Strengthening muscles that bring the humerus (#1) down in the shoulder joint during movement can be essential part of rehabilitation. Your physician or therapist may mention the "Supraspinatus", "Infraspinatus", or "Teres Minor" (together called the "external rotator" muscles) whe
  - (together called the "external rotator" muscles) when discussing this. Another rotator cuff muscle (the Subscapularis) is in the underside of the shoulder blade. Together these muscles are the key to shoulder stability.
- Muscle tightness can also alter the normal motion of the humerus within the shoulder joint.
- Heat and cold both have therapeutic benefit.
  - Moist heat is often helpful prior to stretching or activity in order to loosen tissues.
  - A cold pack can be very helpful after activity, to relieve muscle spasm, or to reduce inflammation. One only has to watch a professional pitcher in the dugout after he pitches to understand that ice can prevent inflammation and pain after activity. A pitcher routinely uses a bag of ice on the shoulder for this purpose to require less recovery time prior to his next game. I often say, "if it is good enough for a million-dollar pitcher, it should be good enough for all of us".
- Nonsteroidal anti-inflammatories can also be helpful if taken <u>regularly</u> for 7 to 10 days. They should always be taken with food and discontinued if there is G.I. upset. Individuals with kidney disease or other medical problems should only take these under the direction of a physician. While many people are hesitant to take medications, a reduction in the inflammation of the shoulder and restoring normal function can actually prevent further damage and have benefit far after the medication is discontinued. This is very different than taking medications such as "painkillers".

Infraspinatus A

2







• The concept of "impingement" is very important in understanding the shoulder. In the above diagram the humerus (#1) can ride up in the shoulder joint and "impinge" the rotator cuff (#4) against the part of the shoulder blade: the acromion (#3). This can produce tendinitis of the rotator cuff muscle or even a tear (indicated by a blue oval). Impingement is especially problematic if the acromion (#3) does not have a flat under surface. Often a "hook" (sharp protrusion of bone pointing down) can exist causing increased damage in the tendons when the humerus rides up. Because of this phenomenon, it is essential that rotator cuff muscles function as normally as possible and prevent the humerus from elevating when the shoulder moves.

• Posture of the spine can be essential in preventing shoulder damage. The under surface of the acromion (#3) should be horizontal to the ground when we are standing or sitting. If we do not "sit tall" with a good curve in the low back then the shoulders become "rounded" and the acromion (#3) is no longer horizontal to the ground but rather tips forward narrowing the space for the rotator cuff (#4).

There is no question that issues such as weakness around the shoulder and posture are more problematic in the Polio population. I am always aware of this when determining the

need for a power vs manual wheelchair. Rather than this being a reason to "live with" shoulder pain, I see it as a reason to more aggressively seek assistance (sometimes lifelong) to optimize shoulder biomechanics and minimize the long term impact on function. Rehabilitation physicians, Physical Therapists, Orthopedists, and even many primary care physicians can have the knowledge to help.

As always, it is important to find the health care provider that will listen to your unique circumstances and "have the heart of a teacher" to share with you specific individualized approaches. This kind of care can help maintain your shoulder integrity over the years.

William M. DeMayo, MD May, 2017





#### Do You Have a Question for Dr. DeMayo?

Many of his articles are based on your questions. Feel free to contact us: info@polionetwork.org (or) 215-858-4643



POST-POLIO HEALTH INTERNATIONAL INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

## **Strategies for Management of Arms and Shoulders**

Mary Ellen Brown, PT, Danville, California, and Nancy L. Caverly, OT, Mexico, Missouri

#### **Posture & Alignment**

- •To improve function and to minimize stress and pain, keep your arms in good alignment. To keep your arms in proper alignment, good postural alignment of the entire spine and good stabilization of the shoulder girdle muscles is a requirement. In other words, SIT UP STRAIGHT with chest up and shoulders back and down.
- •To have good posture and a stable position of the spine, functional trunk strength is a requirement, so custom seating to support the back while in a seated position, and a custom brace while standing, possibly will be needed.
- •Learn RELAXATION techniques for neck, shoulders, arms, wrists and hands to avoid fatigue from tension and to prevent unnecessary muscle overuse from muscle stress. Explore a variety of relaxation techniques designed for the resting body, to find one suitable for you. Possibilities include meditation, listening to music, creative visualization and/or taking a class on stress management. Deep relaxed breathing is essential. (See "Lifestyle").
- •Do a daily stretching routine to maintain good mobility of joints and muscles. If you cannot do these exercises yourself, have someone do them with you.

#### **Lifestyle/Stress Management**

- •During rest breaks in mid-morning and mid-afternoon, make sure your arms are resting, too. Holding a book to read while relaxing the body doesn't rest the arms.
- •DELEGATE chores that are too demanding such as vacuuming, mopping, chopping, and gripping. If you have four things to do today, pace yourself to do one in the morning, one in the afternoon, one in the evening and delegate the fourth.
- •Do deep breathing exercises for relaxation and for increasing the oxygen supply to the tissues. Use ventilatory assistance, if necessary.
- •Eat a healthy well-balanced diet low in animal fat and high in vitamins and minerals from fruits, vegetables and grains. Add extra high-quality protein for neuromuscular maintenance.
- •Make sure you get plenty of sleep regularly to allow your body to repair itself from any effects of soft tissue micro-trauma.

#### **Mobility**

- •Avoid stairs! Banisters may help lower extremities (legs), but they only strain upper extremities. Use elevators or escalators, if your balance is good enough.
- •Sit in firm chairs that have sturdy armrests. Avoid "soft" couches, as you will put a great strain on your arms when getting up and down. The one exception to the rule is if you are on the floor, maneuver yourself to the nearest couch, put your arms up on the couch, and then roll yourself onto it. This procedure is usually easier and safer than trying to rise from the floor.

Avoid falls! If you do fall, it does not matter what you hurt, your upper extremities will pay the price. If you hurt a leg, your arms will be stressed by using crutches. If you hurt an arm, you will become more dependent on the other arm, or someone else. Some falls are impossible to avoid, but many can be prevented by using the proper bracing, and by treating medical problems that cause dizziness or balance difficulties. When getting new glasses or trying new medications, be very careful as perceptions and orientation to space may change. Also, avoid falls by keeping your environment safe. Eliminate clutter, stay off slippery floor surfaces, and get rid of all throw rugs. Stay inside on rainy or snowy days. If you have to go out in inclement weather, always carry a small towel to wipe off the bottom of your crutch or cane tips when you go inside.

#### **Energy Conservation for Shoulders**

- •When using upper extremities for any activity, take a break at the first sign of fatigue. Do not wait for pain. Take frequent stretch and rest breaks at least every 15 minutes with any activity.
- •When lifting anything, use both hands and hold the object close to your body to decrease stress on shoulders.
- •When reading a book, support the arms with pillows or with well-positioned armrests. Prop the book on a slanted reading rack or on a stand.

- •Use a headset for telephoning to keep neck straight and to eliminate need for using arms and hands. Get comfortable in a recliner chair or by lying down, and enjoy your chat!
- •Alternatives for heavy purses or bags are fanny packs, backpacks and jackets with large pockets. Leave your purse in your vehicle when shopping. Carry cash, checkbook or plastic in your pocket.
- •Large pockets and belt loops are good places to relax arms when standing; rest arms on a fanny pack at your waist or place arms on top of your head for a few minutes. Pillows are essential for arm support when sitting or lying down. Arms are very heavy, so get rid of their weight by supporting them on whatever is available.
- •Avoid unnecessary carrying at home by putting duplicate supplies, such as towels, sheets, and cleaning supplies, in each room where they will be needed. Also, try this strategy at work.
- •Eliminate ironing by buying permanent press clothing and by hanging garments on hangers when still partially damp from the dryer. If clothes must be ironed, rotate iron on and off of the garment without picking it up each time.
- •Use reachers for picking up light objects off floor or other places. Remember the length of the reacher increases the lever arm, so it puts more stress on the shoulder when lifting. Do not try to lift heavy objects.
- •If your legs are a little weaker, and it is getting harder to get up and down, don't strain your arms to get into an upright position. Use pillows in chairs to raise the height of the chair a little or get a chair with a hinge mechanism to lift you part way up out of the chair. (Log on to <a href="www.abledata.com">www.abledata.com</a> or write to <a href="mailto:info@post-polio.org">info@post-polio.org</a> for a listing of select brands of lift chairs and bath lift chairs.)
- •Raised toilet seats make getting up and down easier; now there are even adapters to lift up the height of the toilet itself. (<a href="https://www.lcmdistribution.com">www.lcmdistribution.com</a>)
- •Using a regular toilet in some restrooms is a real challenge; always wait for the handicapped accessible stall. The toilets are higher, there is more space for maneuvering your body, and they have grab bars. These stalls are for "walkers" as well as wheelchair users. Note: Alert the facility to any problems with accessibility in the restroom.
- •Get a bathtub seat that can be lowered and raised hydraulically. If your legs are weak, don't try to use your arms alone to get in and out of the tub. Using your arms alone is unsafe and places too much stress on your arms and shoulders. Use a sturdy seat in the shower, so you can relax and enjoy the water.

#### **Choosing Assistive Devices (Assistive Technology)**

- If you are beginning to need assistive devices for walking, think very carefully about which device you choose and seek the advice of an occupational therapist or physical therapist. The use of canes, crutches, walkers and manual wheelchairs may help your legs but will put more demands on your upper extremities. They already have a full-time job.
- •If the need for a cane begins to arise because you need extra security with balance, get a cane with an anatomically correct handle. You can get a right-handed or left-handed cane, depending on which side you need support. (The cane usually is in the hand on the stronger side.) Collapsible canes are available for those special occasions when you are feeling a little insecure. A cane with a seat allows you to sit when necessary.
- •A better choice, if you are beginning to feel weaker, would be very lightweight forearm crutches. These will be less demanding on the upper extremities than trying to take weight off the legs with a cane that is not secure. If you are having increased hip weakness, you definitely need to obtain forearm crutches, as no brace will help the hips. When standing at rest with forearm crutches, rest forearms on cuffs to relieve stress on hands.
- •Be sure you use any lower extremity bracing that may increase your stability and security, as this will decrease the need to depend so much on crutches and canes which in turn will decrease stress on the joints and muscles in the arms. Lower extremity bracing will decrease the chance of falling.
- •Walkers are a good choice for assisting weak legs by using your arms. They are usually stable and you can carry other things in baskets or bags that hang on the walker. Also available are wheeled walkers (four wheels) with a seat, tray, and shelf space. They are useful in your home, the mall, or craft fairs.
- •For longer distance mobility, you may need wheels. If your arms are really strong, a manual wheelchair may be an option, but again, great demands are placed on your upper extremities. The shoulders, elbows, wrists, and hands are working hard to propel all of you plus the weight of the wheelchair. If this choice works for you, the wheelchair needs to be very lightweight. The width of the chair needs to be narrow enough to allow your arms to be as close to your body as possible, for better mechanical advantage in propelling the chair.
- •To make life a little easier and to decrease the demands on the upper extremities, adding a motor to your wheels makes good sense. There are attachments that can be added to manual wheelchairs to convert them

•into motorized chairs for short distances. Many brands of motorized scooters are available; choose one according to your needs. Remember, scooters put demands on your upper extremities in that you must be able to steer them. This, in most cases, would be easier than propelling a manual wheelchair. You do need to have fairly good trunk control to stay balanced in the seat of a scooter.

•If your upper extremities and your trunk and lower extremities are all feeling weaker and fatigued, a motorized wheelchair is certainly the least demanding on the upper extremities of any mobility device. Custom seating can be developed to support the spine and upper body in a more stable position allowing the upper extremities to be more functional with less fatigue. Sometimes tendinitis can develop in the thumb and fingers from operating the controls of a motorized wheelchair, so the upper extremities always have some demand unless you purchase advanced computer technology.

#### **A Final Reminder**

If you develop any pain, increased weakness, and/or excessive fatigue in the upper extremities, and reasonable amounts of accommodation and rest do not decrease the symptoms, get a medical evaluation and begin treatment as soon as possible. Many upper extremity problems can be eliminated with proper management, and the sooner the symptoms are addressed, the less risk you face of permanent decrease in upper extremity function. If your doctor does not suggest treatment, such as physical therapy and occupational therapy, INSIST ON IT. "Normal" people rarely hesitate to seek medical assistance when pain or weakness occurs in their arms and shoulders. Neither should you, who has much more to lose – your independence.

\*\*NOTE: This article was shortened from the <u>original</u> due to space

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# Inspector General Warns Public about Phone Calls from OIG "Imposters"

Posted on March 6, 2017 by Andrew Cannarsa, OIG Communications Director http://blog.socialsecurity.gov/general-warns-public-about-phone-calls-from-oig-imposters/

The Acting Inspector General of Social Security, Gale Stallworth Stone, is warning citizens about a nationwide telephone "imposter phishing" scheme. The Social Security Administration (SSA) and its Office of the Inspector General (OIG) have received several reports from citizens across the country about persons receiving phone calls from individuals posing as OIG investigators. The caller indicates an issue exists pertaining to the person's Social Security account or Social Security number (SSN) and directs the person call a non-SSA telephone number to address the issue.

The reports indicate the calls include a recording from a caller stating she is "Nancy Jones," an "officer with the Inspector General of Social Security." The recording goes on to say the person's Social Security account, SSN, and/or benefits are suspended, and that he or she should call 806-680-2373 to resolve the issue. Citizens should be aware that the scheme's details may vary; however, citizens should avoid calling the number provided, as the unknown caller might attempt to acquire personal information.

OIG investigators occasionally contact citizens by telephone for investigative purposes, but they will not request sensitive personal information from a citizen over the phone. If a person receives a similar suspicious call from someone alleging to be from the OIG, citizens may report that information to the OIG at 1-800-269-0271 or online via https://oig.ssa.gov/report.

Acting Inspector General Stone said, "This phishing scheme is targeting unsuspecting persons for the purpose of Social Security benefit theft or identity theft." She warns citizens to be cautious, and to avoid providing personal information such as your SSN or bank account numbers to unknown persons over the phone or internet unless you are certain of who is receiving it. "You must be very confident that the source is the correct business party, and that your information will be secure after you release it," Stone said.

If a person has questions about any communication—email, letter, text or phone call—that claims to be from SSA or the OIG, please contact your local Social Security office, or call Social Security's toll-free customer service number at 1-800-772-1213, 7 a.m. to 7 p.m., Monday through Friday, to verify its legitimacy.

(Those who are deaf or hard-of-hearing can call Social Security's TTY number at 1-800-325-0778)



#### "Bruno Bytes"

#### Tips and Tidbits from the Post-Polio Coffee House

Richard L. Bruno, HD, PhD.

#### On the topic of Power Wheelchair (and Equipment) "Scams" (3/28/2017)

Original Post: It's so good to know I'm going to be mobile. I've been approved for a motorized chair and a company has been calling. They say they got Medicaid/Medicare approval for a chair for me. It is a portable indoor/outdoor chair called Cobra and I had no choice of other power wheelchairs. I was concerned because the salesman wanted my bank info to "secure" it. I said no, I don't want to do that. They are planning to bring it to me but I think I should maybe call Medicaid and find out just what they approved.

Dr. Bruno's Response: WARNING! Never give out your bank information!

No choices? No way!!! They're going to bring you a portable indoor/outdoor chair called a Cobra? That is either a <u>Cobra GT4</u>, a Heavy Duty Power Scooter that's far from "portable" without a crane and not intended for in-home use (as Medicare requires) or a Chinese-made power wheelchair.

This company told you they want your bank info to "secure" it. If they are asking for your bank account information, they don't have approval. You have to go through the steps for Medicare and meet requirements for Medicaid. Did your doc write the Rx and describe your wheelchair evaluation in his notes, as Medicare requires? Were you fitted by a Medicare-certified therapist for the chair as Medicare requires?

The company who called you is using high-pressure sales. Don't ever deal with anyone that forces ONLY ONE device on you, and doesn't allow you to try multiple pieces of equipment. Also, never buy a wheelchair from a company that doesn't have a vendor in your state and (hopefully) is close to you.

Additional Post: I've been going through the correct process of getting a new wheelchair, with the doctor, PT etc. I wish I had known this before. The first chair I got was through the Scooter Store and it was a horrible experience. The chair did NOT work for me! Since Medicare and my insurance helped pay for it I wasn't eligible for another chair for 5 years. I am so happy you are warning people about these scams.

#### On the topic of One Crutch or Two? (4/11/2017)

Original Post: Polio left me with an atrophied Gastrocnemius muscle on my right leg, paralyzed toes on my right foot, a foot that turned in prior to tarsal surgery as a child, and foot drop on the right leg. I wear an AFO, but have been having problems falling. Would a cane or crutch on the opposite side help to stabilize me and prevent some of the falls?

Dr. Bruno's Response: At the Post-Polio Institute, we usually always found that this formula

AFO?: Cane in opposite hand. KAFO?: Two forearm crutches. Two KAFOs: Wheelchair

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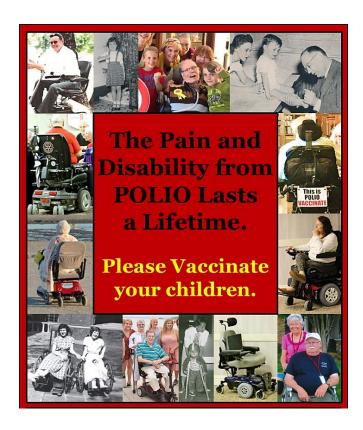
#### On the topic of Lack of Energy (3/15/2017)

worked:

Original Post: I am having a difficult time keeping my energy levels up. Is PPS responsible for this?

Dr. Bruno's Response: Always remember that PPS is a "diagnosis of exclusion". This sounds like a good time to see your physician.

All "Bruno Bytes", beginning in 2014, are available on our <u>website</u>. Looking for a specific topic? Check out the "Bruno Bytes" <u>Index</u> (by Subject).



What IS Post-Polio Syndrome? There are multiple pages of information about Post-Polio Syndrome HERE:

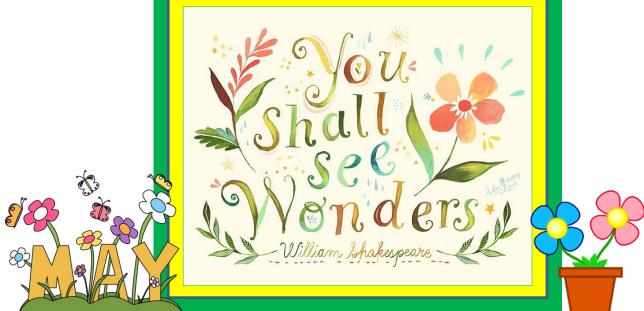
Both "Polio Revisited" and "A Paralyzing Fear" are available from Our Lending Library in DVD format.

Both of these outstanding documentaries are excellent Support Group programming.

Would you like to have our Monthly News Updates (8 pages in full color) by US Mail? Contact Us.

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The Polio Network Team



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