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Exercise Guidelines for Polio Survivors

Carol Vandenakker Albanese, MD, University of California, Davis, Department of Physical Medicine & Rehabilitation



Carol Vandenakker
Albanese, MD

I'm sure most of you have heard that exercise can be dangerous to a polio survivor. You've heard things like "use it or lose it," that muscle strengthening contributes to overuse, that if you are feeling muscle pain, then you're burning out motor neurons, or that you can't do strenuous exercise. And some of that is true. There are reasons those things were perpetuated, but they're not exactly true. The

truth is that there are just as many or more dangers of not exercising as of exercising. Let's explore some different types of exercise and how to determine what's right for you.

Dangers of Inactivity

Let's start with some of the dangers of not doing exercise, or inactivity. For everybody, polio survivor or not, if you are not engaging in much activity, are immobilized for some reason, or are stuck in bed for an illness or injury, deconditioning occurs. That means muscles atrophy and get weaker. It's most pronounced in muscles that are our primary postural muscles—the spinous, paraspinals and lower limbs. Those are the muscles we normally use to work against gravity. For somebody on strict bed rest, studies have shown that muscles lose 10 to 15 percent of their original strength per week of bed rest. Over five weeks, that can add up to 50 percent. Of course, strict bed rest isn't often used anymore.

For most medical conditions, we try to keep people as mobile as possible, so the amount of weakening that happens when you have limited activity is a lower percentage of what we see with strict bed rest. When people aren't moving, they can also get connective

tissue or soft tissue contractures where joints stop moving as well and may lose bone strength or bone density.

Health Benefits of Exercise

A major health benefit of exercise is, of course, improved cardiovascular health. Inactivity is a major risk factor for the development of cardiovascular disease, and it works in secondary prevention as far as reducing mortality for people with cardiac disease. If you go through cardiac rehabilitation programs, you can reduce the impact of whatever disease is present. Exercise helps to decrease blood pressure, decrease triglycerides and bad cholesterol, increase good cholesterol, and reduce the risk of blood clots, which can lead to other medical issues.

How much exercise do you need?

The answer to this very much depends on the individual, and, especially for someone who's had polio, there are a lot of factors to consider. Before starting an exercise program, I recommend getting a medical evaluation. If you're over the age of 35, the rule of thumb is that you should be exercising about 30 minutes per day. Now, this is not necessarily true for polio survivors because exercise is really just on the gradient of activity—normal daily activities versus what is done for exercise. Depending on what your day-to-day activity looks like, you may or may not need to do a lot of additional exercise. This is especially true in a polio survivor who is still ambulatory and who may have a fair amount of deficits, so that actually just walking in your day-to-day life is basically the energy equivalent of exercise for somebody who doesn't have physical impairments. Sometimes exercise is really just increasing the activity you do in a day.

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The benefits are dose-related up to a point. That means that there is a ceiling effect, and at some point, more exercise is not better. Exercise is also dependent on long-term compliance, meaning doing exercise today won't necessarily benefit a person next year. It has to be part of a lifestyle balance and having energy for exercise or day-to-day activity versus just maintaining your life and a level of function.

EXERCISE COMPONENTS

Below we'll examine four main components of exercise:

- Aerobic Conditioning
- Strengthening
- Flexibility
- Coordination

Aerobic Conditioning

Aerobic conditioning is what you may think of as cardiovascular exercise. It is a lower-intensity long-duration type of activity—an activity you can continue to do over a period of time, not a sprint that you can only do for a very short period. When you're conditioned, it's a type of exercise you can do that won't overly fatigue you or produce a lot of painful byproducts in your system and can be maintained for long periods of time.

When we talk about prescribing aerobic conditioning, we talk about activities that are more than a resting effort but of submaximal intensity, can be done repetitively, and incorporate as many muscles

as possible. The perceived exertion should be in the range somewhere between fairly light to moderate. The general recommendation is that aerobic conditioning is done for at least 20 minutes, at least three times per week, but this may be different for a polio survivor.

When you're thinking about doing aerobic exercise, you should use your strongest muscle groups as much as possible. Those are the ones that should be used for any repetitive activity. You also must be careful that whatever exercise you choose to do does not increase stress on weak muscles or overstressed or unstable joints.

Often, you should consider doing a non-weight-bearing mode of exercise. My recommendation is that you start well below the suggested intensity. You can increase the amount of time spent exercising by using rest intervals or pacing. Any progression in exercise should be very gradual to prevent injuries or excessive muscle soreness, and you should always monitor for symptoms of overuse.

Strengthening

Strengthening exercises increase the strength of not just muscles but ligaments, tendons, connective tissue and bones by providing stress to and increasing demand on those structures. It increases the strength of the tissue but does so by causing some breakdown of tissue which then remodels and regrows stronger. It is very easy with strengthening exercises to overdo and overstress. If you overwork and those tissues are not able to regenerate, reform and become stronger, it will result in deterioration, weakening and injuries.

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Editor: Brian Tiburzi, MA
info@post-polio.org

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Post-Polio Health International's mission is to collect, preserve and make available research and knowledge to promote the well-being and independence of polio survivors, home ventilator users, their caregivers and families, and to support the health professionals who treat them.

How to contact PHI

50 Crestwood Executive Center #440
Saint Louis, MO 63126 USA
Phone: 314-534-0475
Fax: 314-534-5070
info@post-polio.org
www.post-polio.org
www.polioplace.org

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This type of exercise carries more risk than your basic cardiovascular exercise, so it should be individualized. But if you're going to do a strengthening program, how do you know which muscles you should be targeting? For all of us as we get older, and especially for a polio survivor, you want to pay the most attention to muscles that are functionally important. This is where a physical therapist may be helpful in helping you decide what you need to work on. As always, you should start with less than the recommended amount and be very careful about how much you increase that amount.

Polio survivors should set very specific goals for functional gains. You're not working on strengthening the muscle just because it's weak. If a muscle is so weak that it's not helping you functionally and doesn't have the potential to become functional, then you don't need to work on strengthening it.

You really want to be aware of which muscles are at risk of overuse and which joints are at risk of too much stress lest you exacerbate degeneration in the joint. Polio-affected muscles are going to require longer rest periods to recover between strengthening sessions. Again, you need to be very diligent about monitoring for overuse and making sure you adjust those rest periods if you do see symptoms of overuse.

Flexibility

This type of exercise is concerned with the pliability or elasticity of muscles, connective tissues, tendons and ligaments. To maximize a muscle's function, we want an ideal range of flexibility. We don't want the muscle to be too stiff, but we also don't want it too lax. When people are put on stretching or flexibility

programs, the goal is to restore or maintain the full range of motion of a joint. Identifying restrictions in motion that may function or stress other tissues is important in determining how much stretching you need. If connective tissue isn't regularly stretched, it will gradually shorten, especially as you get older.

Genetics, gender, age and temperature can all affect flexibility. Excess flexibility is not necessarily beneficial and can actually put joints at risk. Flexibility is especially important for polio survivors, who have muscle function around a joint where one group of muscles that move the joint is stronger than another. Often when you see this muscle imbalance around a joint, the stronger side will tend to shorten or tighten up because it's not adequately opposed by the opposite action.

For polio survivors with stretching, we don't worry about muscle overuse, but we do worry about muscle damage. Static stretching is the safest method for polio survivors. You typically want to warm up a muscle before stretching to get the best results. If it's a muscle that's hard to warm up, warm water or a warm bath can help. Bear in mind, especially for those of you who had surgeries, bony changes, joint changes, or fusion of joints may be contributing to loss of motion. So, if something just isn't moving, don't force it because that could result in a fracture. If you have a very relaxed joint, you don't want to stretch around that joint because you can do more damage to the joint.

Coordination and Balance

This is exercise geared toward improving proprioception or awareness of the position and movement of body parts. In general, polio survivors have very good proprioception and may be more aware of body movements than the average person. However, the body's response can change as one gets older and develops arthritis, loses range of motion, or develops neuropathies that involve losing some sensation, which makes maintaining coordination and balance a lot harder.

There are certain exercises geared toward improving balance which focus on the postural muscles, which contribute to maintaining balance. Sometimes using external stimuli for proprioceptive feedback can be helpful when engaging in this type of exercise.

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Symptoms of Overuse

What are some signs of overuse you should be looking for? Any fatigue that lasts more than a few hours after the activity likely signals you're doing too much. If you're doing an exercise program, you should be able to go home, rest, and a few hours later feel back to normal and not feel wiped out for the rest of the day. If you feel weaker after the activity or if you can do less later that day or the next day, that's a bad sign. If the muscles are painful, that's oversteering and breaking down tissue. If you have a sensation of muscles cramping, twitching or crawling, that's another sign of overuse. Sometimes these overuse symptoms don't come on the same day.

If you are starting out on an exercise program, it may be a good idea to journal your activities as well as their symptoms to look for patterns, as sometimes, when the result of an activity doesn't show up until several days later, you may not remember what you did that may have overstressed a certain muscle group.

Additional Advice for Polio Survivors

In general, low-impact, gentle exercise is best tolerated. This is true for most people as they get older. This is why we often talk about using aquatic exercise, Tai Chi or adapted yoga—exercise that really doesn't have a lot of impact involved. You understand your body better than anybody else, so when you're working with a therapist or a trainer or talking to your PCP, don't be afraid to speak up and say, "Hey, I just can't do that" or "That hurts to do that." Give feedback and don't let anybody bully you into doing something you know you shouldn't do.

Developing an exercise program will almost always require trial and error. It's a matter of trying something, seeing how your body responds, and going from there. That's why we talk about starting slow and progressing slowly because you don't want to make big errors.

Your exercise needs and tolerance are going to change over time. Things in your body change. What you're able to do mobility-wise changes. What you

need to do exercise-wise will change. A good example of that is if you go from being ambulatory a majority of the time to using a wheelchair or a scooter. All of a sudden, you're walking a lot less and may actually need to add some exercise to your daily routine.

You understand your body better than anybody else, so when you're working with a therapist or a trainer or talking to your PCP, don't be afraid to speak up and say, "Hey, I just can't do that" or "That hurts to do that."

Summary

Exercise is not the enemy. It shouldn't hurt, but on the other hand, it's not necessarily easy, either. We want gentle exercise programs, but it is going to be a little bit of work. It has to be very individualized. One of the most unique things about polio is that there's no standard recommendation for a polio survivor because everybody's different.

Getting a medical assessment before starting is important, particularly to make sure your heart and lungs are fine to stress. As far as finding somebody who really knows the ins and outs of polio and what you can and can't do, that can be difficult. It is hard to find somebody with experience, but there are some resources available through PHI (including the *Post-Polio Directory* which is continuously updated). There are therapists that are always willing to talk to a therapist you're working with or your physician.

Most importantly, you know your body and you know its signals. Pay attention to that. Exercise performed with the right prescription, instruction and technique can be beneficial and improve function and well-being. ■

FINDING OPPORTUNITIES

Paulette Bergounous

This past June I attended the Chicago's Abilities Expo at the Renaissance Schaumburg Convention Center. It was the first Abilities Expo that I have ever attended. Although registration is required, there is no fee to attend.

Before attending, I was able to print out an exhibitor list and was quite surprised to see more than 100 exhibitors committed to attending the Expo. I also was able to print out a floor plan of where the exhibitors would be located, which is really beneficial when you're looking for specific items.

There were several hands-on exhibitors. I saw wheelchairs, wheelchair accessories, scooters and even vans. There were multiple agencies that assist people with disabilities on-hand. They not only covered education, but sports and recreation, as well.

I was pleased to find two separate businesses catering to the needs of individuals with upper body paralysis. I had the opportunity to meet the owners of these two businesses and learn about their motivation for creating their products.

As someone who has had upper right quadrant issues for many years, I was delighted to see an interest in supporting the needs of single-handed individuals. Over the years I've had to come up with my own accommodations with some limitations in design and materials. Now I see the interest in making affordable adaptive aids for those with upper body paralysis.

The first product I want to share with you is a bra. The company, Springrose, was started by Nicole Cuervo. Nicole watched her grandmother struggle trying to put on a bra and decided that she was going to spend time developing one that was easier to put on. The result was an adaptive bra, with a cushioned back closer and wide shoulder straps that adjust in the front, making them easier to reach. It has an optional O ring that allows you to put on your bra even with

limited dexterity. No pinching, gripping or grabbing required. It has front closure and an innovative design that lets you put on the bra with one hand. The Velcro hook and loop closure makes it easy to put on and take off. Whether you are lying down, sitting up or standing, there are multiple ways to slip into this bra. For more details, go to their website at www.springrose.com.

The second product, Fiber, is produced by a company called Hominid X. This product allows you to grip objects of different sizes. Thane Hunt, the owner of Hominid X said he is determined to create assistive devices that are reasonably priced. It is called "Fiber" because it acts like a muscle fiber. I found it lightweight and very comfortable to wear. I purchased one, and for the first time in 77 years, I was able to hold a glass in my hand. The photo (below) shows the grip I have around a plastic cup.

I would encourage you to attend an Abilities Expo near you. It is an opportunity to see the latest equipment and services available for all. Check out the cities and dates for upcoming Abilities Expos at www.abilities.com. ■



Paulette Bergounous



Fiber allows me to do things like hold a glass in my hand.

In August, PHI was joined by author and travel blogger Candy Harrington, for a discussion on accessible travel. Below is a list of travel resources for those traveling with a disability that she shared with PHI's members. The list is also accessible online at <https://emerginghorizons.com/postpolio/>. The full video of the town hall may be accessed on our website at <https://post-polio.org/education/post-polio-experts-present/> or on PHI's YouTube channel (@post-poliohealthinternational).

AIR TRAVEL RESOURCES

Air Carrier Access Act

www.ecfr.gov/current/title-14/chapter-II/subchapter-D/part-382

Timeline for Implementation of Accessible Lavatories on Single Aisle Aircraft

barrierfreetravels.com/2023/07/do-the-math-timeline-for-implementation-of-airline-accessible-lavatory-rule/

Disabled Air Travelers Bill of Rights

emerginghorizons.com/disabled-air-travelers-bill-of-rights/

DOT Accessible Travel Brochures

www.transportation.gov/individuals/aviation-consumer-protection/disability-training-materials-and-helpful-information-0

DOT Hotline for Air Travelers with a Disability

800-778-4838

DOT ACAA Complaint

airconsumer.dot.gov/escomplaint/ConsumerForm.cfm

Transportation Security Administration

Security Guidelines for People with Disabilities

www.tsa.gov/travel/special-procedures

TSA Cares

855-787-2227, www.tsa.gov/contact-center/form/cares

TSA Pre-Check

www.tsa.gov/precheck

LODGING RESOURCES

Americans with Disabilities Act (ADA)

www.ada.gov

ADA Complaint

civilrights.justice.gov/report/

CRUISES

Cruise Critic Disabled Cruise Travel Forum

boards.cruisecritic.com/forum/114-disabled-cruise-travel/

ROAD TRIPS

Mobility Roadside Assistance

www.mobilityroadsideassistance.com

National Mobility Equipment Dealers Association (NMEDA)

www.nmeda.com

National Parks for Wheelchair-Users and Slow Walkers

emerginghorizons.com/national-park-primer-for-seniors-wheelchair-users-and-slow-walkers

America the Beautiful Access Pass

www.nps.gov/planyourvisit/passes.htm

Handicapped Travel Club

handicappedtravelclub.com

www.facebook.com/groups/handicappedtravelclub

Winnebago Roam (Denver)

www.braunability.com/unitedaccess/us/en/wheelchair-accessible-vehicle-rentals/wheelchair-accessible-rv-rentals.html

FIA Parking Guide

www.disabledmotorists.eu/en/home/

ACCESSIBLE TRAVEL RESOURCES

How Much Training Does Your Travel Agent Really Have?

emerginghorizons.com/travel-agent-training-how-much-does-your-travel-agent-have

Pantou Database

www.pantou.org

Accessible Travel Club Facebook

www.facebook.com/groups/AccessibleTravelClub

CANDY HARRINGTON

Candy@EmergingHorizons.com

Facebook: www.facebook.com/candy.harrington

Twitter: www.twitter.com/cbharrington

Pinterest: www.pinterest.com/candyharrington/

Candy's Website

www.EmergingHorizons.com

Candy's Blog

www.BarrierFreeTravels.com

Candy's Books

www.EmergingHorizons.com/books

Seeking Users of Negative Pressure Ventilation for Interview

Dr. Norma Braun is seeking to interview post-polio patients and others who can describe their experiences when in negative pressure devices (iron lungs, chest cuirasses), and who might have needed ventilatory support in later years. She plans to include patients' experiences as part of a book chapter being written for the 21st century. This will be unique for a medical text. Any person so willing to be interviewed can be assured that no identifying data will be included. Your privacy will be protected.

The interviews will be conducted by phone or Zoom. Please contact Dr. Braun via her email, norma.braun@mountsinai.org.

Question: *I often attend my local post-polio support group's in-person meetings. My partner usually requests to come along in order to show his support. I really appreciate the fact that he wants to be supportive, but sometimes I'd rather go alone. There are times when I feel I can't speak freely about certain things because he is there. I want to stress that he's a great partner, and it's not like he's demanding he be allowed to go. Am I wrong to want this space for myself? How do I go about telling him without hurting his feelings?*

Response from Rhoda Olkin, PhD:

To your first question, no, of course you are not wrong to want this space for yourself. Your feelings are your feelings, and hence, legitimate. I can understand the desire to carve out a space that is separate from your partner, and where you can speak more freely without worrying about the effect of your words on a partner.

Your partner is showing a great willingness to have the polio be a part of the partnership, that is, not just something about you, but something that you as a couple own. I applaud this, as it seems to be a key way for a successful relationship to incorporate disability. Nonetheless, as the person who had polio, your internal experiences may have some private parts that you don't wish to share with your partner. Talking to and hearing from other polio survivors can be enormously helpful.

You might approach this with your partner as an issue around space, distance and closeness. Each person in a couple comes to the relationship with differing needs for distance or closeness. Rather than saying that you don't want your partner to attend, say that you feel you need a bit more space just for you. "I appreciate how you are so supportive of me and how you take the disability as something that we both have to manage. When the meetings have a speaker, or are about something specific, I love that you come with me. And I also want to go by myself some of the time, when it's a 'sharing and caring' time."

Question: *While I feel like there are a lot of resources for polio survivors, I'm curious where spouses can turn to for help? My husband requires a lot of help around the house. I'm getting older, too, and it's becoming more physically and mentally taxing. I want to be a good caregiver, but sometimes I feel burned out.*

Response from Stephanie T. Machell, PsyD:

Part of being a good caregiver is recognizing and respecting your limits. Trying to do it all leads to neglecting self-care and ultimately to the burnout you are already beginning to experience. Yet trying to step back and delegate some of the tasks and care you



Dr. Rhoda Olkin is a Distinguished Professor of Clinical Psychology at the California School of Professional Psychology in San Francisco, as well as the Executive Director of the Institute on Disability and Health Psychology. She is a polio survivor and single mother of two grown children.

are providing may make you feel guilty, especially if your husband resists the idea of “outside” help.

Before things get worse, it’s time to reassess what you’re doing. Discuss your concerns with your husband. Though it is tempting to do so, don’t minimize how difficult things are becoming for you. If he is resistant to the need for help other than yours, remind him that your ability to provide this is contingent on your own well-being and that if something happens to you, he will end up depending exclusively on others for assistance. Pointing out that studies show that partners taking on more caregiving responsibilities interferes with romantic and sexual feelings may also help!

Together, make a list of everything you both do to maintain your household, including any personal care you provide for him. Consider the time and labor involved in each task and the level of difficulty you and/or he have completing it. Discuss your preferences for doing the task yourselves versus how much you wish someone else could take it on.

Decide what you want to delegate and to whom. Family members or friends might be able to take on some tasks, but for more major or skilled assistance you may want or need to hire professionals. If there is a medical necessity for either or both of you, services such as homemakers and home health aides may be paid for by insurance when ordered by a physician.

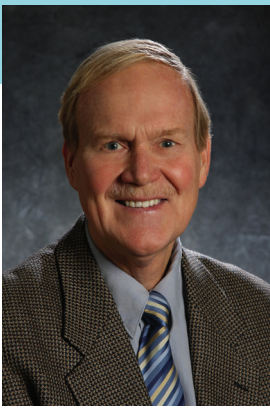
Another essential but all too often neglected part of being a good caregiver is prioritizing your own health and well-being. This means getting adequate rest, exercising as you are able, eating (mostly) healthy meals, making and keeping medical and other appointments, maintaining your social connections, and taking time to pursue your own interests.

It is important to have supportive others who understand what you are going through. Friends and family who are also caregivers can provide support and camaraderie. Though rarely specific to spouses of polio survivors, there are support groups available for caregivers through senior centers, councils on aging, many hospitals, and some churches. If your husband attends a post-polio support group, request a parallel group for spouses. And there are mental health professionals who work with caregivers.

For more information, check out the PHI website (www.post-polio.org). Under the Resources tab of the menu, you will find “Post-Polio Health Care Considerations for Family and Friends.” It provides comprehensive information on caring for a family member with polio and links to further information and resources, including relevant past newsletter articles and talks. It includes a navigation tool you can use to zero in on your specific concerns. ■

Dr. Stephanie T. Machell is a psychologist in independent practice in the Greater Boston (MA) area. She specializes in working with those affected by polio and other physical disabilities. Her father was a polio survivor.





Frederick M. Maynard, MD

Ask Dr. Maynard

Dr. Maynard is pleased to be joined in this issue by his colleague, Dr. Eulberg, who will be presenting a lecture on November 16, 2023 (see pg. 11).

Question: I am a polio survivor who contracted polio at the age of two. I am now 61 years old. I started having pain after a fall two years ago and I've been told that I needed carpal tunnel release surgery. The muscle in my right thumb is starting to atrophy. I walk with two forearm crutches and have been using them since I was two. I never had any problems prior to my fall.

I am not 100% convinced that the pain is originating in my wrist. Also, the main concern that I have is that I am worried that after the surgery I may not be able to use my crutches and will have to be confined to a wheelchair.

I've tried to look up support groups to see if anyone in my situation can offer some insight to no avail. Any help or info you can give me will be much appreciated.

Marny Eulberg, MD: Your long-term crutch use does increase your risk of developing carpal tunnel syndrome (CTS). You did not mention how the diagnosis of CTS was made. If it was by EMG (electromyogram), then it is very likely that you do have CTS. No one can absolutely guarantee that having the surgery to correct CTS will solve the problem of your hand pain, but it is concerning to me that you are developing atrophy of your thumb muscles. If this is related to CTS, unless the pressure on the nerve is relieved the damage will be permanent. The longer the nerve has been compromised the longer it will take for any recovery to occur and as time goes on the odds that recovery will happen go down and down.

As for your concern about not being able to use your crutches, it is likely that in the immediate post-operative period (10 days to up to a month) the surgeon will not want you putting any weight on that wrist/hand and during that time you may need to use a wheelchair. Some of the

Send your questions for Dr. Maynard to info@post-polio.org.

See other questions at www.post-polio.org/living-with-polio/articles-post-polio-health#AskDrMaynard

newer methods of carpal tunnel release surgery such as using a small "scope" through a small incision rather than an open approach may allow you to resume using your hand/wrist sooner than in the past.

Frederick Maynard, MD: I agree with Dr. Eulberg that you are at high risk of developing carpal tunnel syndrome because of your years of walking with forearm crutches and that electro-diagnostic testing that shows severe compromise of median nerve function at the wrist with motor axonal damage to explain your thumb muscle atrophy would confirm your diagnosis of CTS and indicate an urgent need for a surgical procedure to release and decompress your median nerve at the wrist.

My experience with post-polio people like yourself who rely on forearm crutch use walking and who develop CTS suggests that an open surgical procedure to explore and decompress the carpal tunnel may be advantageous in the long run to the newer arthroscopic methods of carpal tunnel release because, after full post-operative healing, there remains adequate decompression of the nerve in spite of returning to heavy stress on the wrist again from crutch walking. Healing time is longer with the open procedures, but most surgeons will permit the use of the operated upper limb for immediate/early walking with the use of a platform crutch which creates weight-bearing of the upper limb throughout the forearm and avoids weight-bearing through the wrist. You could obtain such a crutch pre-operatively and learn to use it in advance in order to remain independent in walking post-operatively. A physical therapist and/or physical medicine & rehabilitation physician evaluation may be helpful in accomplishing all this. ■

TOWN HALL

Join Us On
October 27, 2023
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for a discussion on
Physical Therapy

Presented By:
Carolyn Da Silva, PT, DSc
&

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LECTURE

Join Us On
November 16, 2023
at 1 pm CST
for

**The interplay between polio residuals,
aging, and common health problems
people experience as they age**

Presented By:
Marny Eulberg, MD
&

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