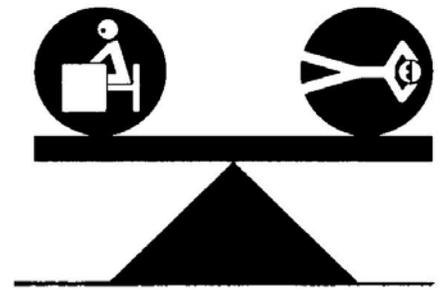


POST POLIO PACER



Conserving Strength and Energy through Pacing
January 2010 — Madison, Wisconsin
Madison Area Post Polio Support Group Newsletter
MAPPSG formed in 1985

How to Have a Successful Physical Therapy Experience

By Leslie Drawdy, P.T.
Physical Therapist and Polio Epic
Medical Advisory Board Member

I've worked with a lot of patients with Post Polio Syndrome who have come to me after having a bad experience with Physical Therapy, often in worse shape than before they started therapy. Finding the right therapist can be quite a challenge, especially in communities where practitioners are not familiar with Post Polio Syndrome (PPS). But don't lose heart! Finding the right therapist can actually be easier than finding the right physician. Here are some basic guidelines:

THINGS TO LOOK FOR IN A PHYSICAL THERAPIST: (Assuming that you can't find a therapist who has knowledge and experience in treating PPS)

1. You need a therapist that is familiar with neurological and/or neuromuscular disorders, preferably with experience treating Multiple Sclerosis (MS) patients. Start by asking others that you know with PPS who have had physical therapy. This is the best way to start looking for any health care professional. If the therapist has a good understanding of MS, then they already know the basic treatment principles for Post Polio Syndrome, whether they are aware of it or not!! Although at times, you may be able to find this type of therapist at an outpatient orthopedic clinic, *most of the time you won't*. In fact, many of my clients first received their Physical Therapy treatment at an outpatient orthopedic clinic, and ended up in worse shape!

You're most likely to find a qualified therapist in a hospital based outpatient therapy clinic, so that's a good place to start.

Your doctor may be helpful with recommendations, but don't count on it!

Often times doctors refer patients to therapists that have done a great job for them in the past, but this may not apply to PPS. Just because a therapist is great at treating knee or back problems does not mean they are going to be able to help a person with PPS! You need to do your own investigation.

If your function has declined to the point that leaving your home for an appointment completely wears you out and you are avoiding activities outside your home, you may qualify for home health therapy services. Most home health therapists are competent to treat patients with PPS, as they see a wide variety of complicated diagnoses and situations. This would be an excellent place to start if you are finding that you need increased help with your activities of daily living and general mobility in your home.

2. Keep in mind that PPS affects everything! If you had polio, you are at risk for PPS. Even if you are getting PT treatment for something other than PPS (i.e., a shoulder injury), PPS will influence your treatment plan and affect your recovery, so be sure to disclose all PPS related information to your therapist.

This can make finding the right therapist a little more difficult. Let's say you have a history of PPS, but you suffered a back injury. This would mean that your primary diagnosis for physical therapy is the back injury and related back pain, so you need someone who will treat your back injury appropriately ...

within the limits of your PPS! Again, the best place to start looking is at a hospital-based outpatient therapy clinic. Usually the therapists at these clinics are more general in their practice, treating a wide variety of clients, often with complex medical histories and multiple diagnoses.

Preparing for Your Physical Therapy Evaluation and Treatment Program:

1. If you are able to, prepare your medical history. (This is a good thing to do anyway.) Many PPS clients have thick notebooks full of information, and while this can be helpful to the therapist, it can be TOO much information! Here are the highlights of what you need:

General medical history: Diagnoses, with dates of onset; Allergies; Previous Surgeries, with dates, Date/age of original polio onset; Original effects of polio; Any devices/braces used during initial recovery; Level of function after initial polio recovery, History of PPS; Approximate date of symptom onset; Formal medical evaluation & diagnosis; Previous treatments for PPS symptoms and Medication list. Many of my clients have typed up a list which can be easily photocopied at the time of their therapy evaluation. I've always found this to be very helpful!

2. Avoid telling your whole life story at the initial visit. It is tempting to tell your life story to your therapist. There is nothing wrong with this impulse, but try to avoid doing this on your initial therapy visit. Remember, you've hired the therapist to help you regain the function that you've lost. In order to do that, the therapist will need to conduct a focused interview and a thorough physical evaluation. This will include specific questions regarding functional mobility status and/or changes, assessing range of motion and strength in all of your extremities and trunk, balance, coordination, transfers (i.e., moving from lying down to sitting up, sitting to standing, etc) and walking. If all of your time is spent on talking, the therapist won't be able to look at everything YOU NEED them to look at. Remember, there will be plenty of time to get to

know your therapist and share your story. You will likely be seeing them several times per week for approximately one hour per session.

3. It is important to work WITH your therapist. Give your therapist an honest report about your body's response to changes in activities or exercises. There may be times when a therapeutic intervention doesn't work the way you and the therapist hoped it would! Maybe it caused you to be too fatigued, or caused a significant increase in muscle soreness. In order to adjust the treatment appropriately, the therapist needs to know. Be as specific as you can! Physical Therapy can be tricky in the beginning, as each person responds to physical interventions differently. Medicine is more of an art than a science, and sometimes a little "trial and error" must occur in order to find just the right thing. Ever tried a new medication that didn't work and have to get a prescription for a different one? The same thing can occur with therapy. However, if your therapist is not listening to your feedback and not adjusting your treatment program (just pushing you to do the same thing regardless of your response), you need to find a new therapist!

Worst Case Scenario:

Sometimes, no matter what we do (or don't do), a client with PPS will continue to have functional decline. This may be in spite of 100% appropriate participation in treatment. In this case, therapy interventions must shift focus to adapting to the new level of disability with appropriate equipment and/or assistance, in order to maximize independence. Like many other chronic conditions, PPS ranges from very mild to very severe. Those who develop very severe PPS will likely continue to decline whether they participate in therapy or not. The problem is that there is no way to tell if this will be the outcome or not, until it happens. In the hands of the right therapist, a well designed and highly individualized treatment program won't harm you, and may help you.

Best Case Scenario:

Some individuals actually experience resolution of their PPS symptoms with successful completion of their therapy program. They regain the functional independence for which they were hoping. This is ideal! However, it is important to keep in mind the principles of energy conservation and activity pacing. You want to avoid exacerbation/recurrence of PPS symptoms. Don't start over doing it because you feel great! One patient of mine just recently had an exacerbation, after years of no PPS symptoms, because he started to "ignore the rules" and overwork himself at the gym. PPS is a life changing condition. If you have been able to resolve your symptoms, you need to continue with whatever program or modifications to your lifestyle that helped you achieve these results!

WHAT NO ONE WILL TELL YOU:

Some of this may be hard to hear, but I believe every PPS patient should know there is a widely held perception in the therapy community that PPS patients are "high-maintenance", needy, emotionally draining, and never satisfied. In fact, many of the therapists I have worked with and educated about PPS treatment actually dread seeing that diagnosis come across their desks. Some have even refused to treat PPS patients. How could this be? Generally speaking, polio survivors have overcome huge obstacles in their lives, and are very educated, knowledgeable people. They should be an exciting group of people to work with, right?

Well, there is a trend in the complaints I've heard from therapists. Basically, their clients become argumentative and noncompliant. They are not willing to try following the therapist's recommendations, and don't want to take any responsibility for the therapy "not working." For example, let's say that a gentleman with PPS has started Physical Therapy. He is having increased loss of balance and has had a few falls, all of his transfers are more difficult, and he

doesn't have the energy to go to his weekly investment group anymore. His therapist tries using a walker with him, and this greatly improves his balance and stability with movement. She recommends that he use his walker at this time to help safely increase his mobility. He, however, is very resistant to the idea, and refuses.

The therapist and patient then have lengthy discussion about the seriousness of potential injury related to falling, and the likely continued decline of function related to overuse and inappropriate activity pacing. She suggests the idea of utilizing the walker as a tool to safely increase his mobility and independence, while continuing therapy to see if he can regain enough endurance, strength and balance to resume his normal activities without a walker. Despite the safety concerns and benefit that the therapist outlines, the patient continues to refuse. Could this be related to the stigmas associated with disability and assistive devices from the time of the polio epidemic? Is it from this gentleman's denial regarding his current functional status? Is it just because the situation he now finds himself in is completely, inarguably unfair?

This gentleman needs to step back and take a hard look at the situation. Arguing with the therapist's recommendations, just because he doesn't like what he is hearing, is not helping him. Yes, it is unfair that after having overcome polio once in his life, he is forced to deal with its ongoing effects. It should be obvious to the reader, however, that the therapist has made an honest professional recommendation for the patient's safety, consistent with his goals of increasing activity and independence. Think of it this way: You hire a lawyer to evaluate a legal situation and give you sound advice on the matter. You're paying the lawyer for his expertise. Once he provides you with the information and recommendations, it is your choice to follow his advice or not. Would you sit and have a debate with him because you don't like what he has to say? Would you go and do the exact opposite of what he recommends, and then argue

that his legal advice was no good?

I think sometimes patients have the attitude that Physical Therapy is like a magic pill, that the therapist is supposed to "fix" them. Unfortunately, this is not how things work. You have to actively participate in the process. If you have a bottle of pills that help control high blood pressure, but you never actually take one of the pills, your blood pressure will not change. You're probably thinking, "well, that's common sense." But many people fall into this mental trap, so to speak, of showing up to their therapy appointments and expecting some sort of magical results, without actually following any of the recommendations OUTSIDE of their therapy sessions. Unfortunately, there is no magic cure for PPS. Therapy can be helpful, but only if you really, actively choose to face the reality of your situation and give the therapy program a fair try.

**Reprinted with permission from Polio Epic,
Dec. 2009-Jan. 2010 issue.**

NEW JERSEY DISTRIBUTES POLIO WARNING CARD

Englewood, NJ (1/04/10): The New Jersey Department of Health has printed 10,000 wallet-sized cards with vital information on anesthesia dangers in polio survivors and on Post-Polio Sequelae, the disabling condition affecting New Jersey's 50,000 polio survivors. Created by Dr. Richard Bruno, Director of the International Centre for Post-Polio Education and Research at Englewood Hospital and Medical Center, the yellow, double-sided card was suggested by the Ocean County post-polio support group to comply with New Jersey Senator Loretta Weinberg's 2004 "Post-Polio Sequelae Public Awareness" bill.

"Doctors have forgotten about North America's nearly two-million survivors of the polio epidemics of the 1940s and 1950s," said Dr. Bruno, who is also chairperson of the Interna-

tional Post-Polio Task Force. "Because of damage the poliovirus did to the stem of the brain, polio survivors are easily sedated and often get too much anesthesia." Bruno has seen polio survivors end up on a ventilator in intensive care after minor surgery or even a colonoscopy.

The New Jersey DOH card features a prominent, red "ANESTHESIA WARNING!" and lists easy sedation and difficulty breathing and swallowing as problems that can be avoided by using lower doses of anesthetics in polio survivors. The card also lists increased sensitivity to cold and pain as problems in polio survivors.

"The poliovirus kills neurons in the brain and spinal cord that produce the body's own morphine," Dr. Bruno explained. Dr. Bruno's research has found that polio survivors are twice as sensitive to pain as those who didn't have polio. He recommends a general rule of thumb for treating polio survivors—"The Rule of 2": two times the usual amount of pain medication for two times as long, and the usual amount of anesthesia divided by two.

"All doses of medication must be adjusted for individual polio survivors," Dr. Bruno cautioned. "And, polio survivors should never have same-day surgery because of excessive sedation from even appropriate doses of anesthesia."

POST-POLIO SEQUELAE ALSO LISTED

The flip side of the DOH card lists the "late-effects of polio," called Post-Polio Sequelae, overwhelming fatigue, muscle weakness, muscle and joint pain, sleep disorders, cold intolerance and breathing and swallowing difficulties that can develop in mid-life.

"Doctors are also unaware of Post-Polio Sequelae, or say that they 'don't believe' in PPS," said Dr. Bruno. "PPS is very real and very treatable if polio survivors reduce the 'overuse-abuse' of their remaining, over-worked poliovirus-damaged neurons."

Side one:

ANESTHESIA WARNING!

I am a Polio Survivor...

- EASILY SEDATED, difficult to wake
- Difficulty BREATHING and SWALLOWING with anesthesia
- HYPERSENSITIVE to PAIN and COLD. Need heated blanket and increased pain medication post-op.

For more information, visit:

www.nj.gov/health/cd/postpolio/index.shtml

Side two:

I am a Polio Survivor with Post-Polio Sequelae (PPS unexpected midlife symptoms):

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

Marilyn Klotzbach ordered 50 of these cards which will be distributed at the March 13th meeting.

Update on Injured Post Polio Pacer Reporter

Carole Ann Parsons, Post Polio Pacer reporter, who suffered significant injuries in an equipment malfunction at her home in July, is now at Village at Manor Park, 3023 S. 84th St., West Allis, WI 53227-3703. Thinking of you cards, prayers, and well wishes would be appreciated.



Golden Rule of Post Polio Syndrome

"If something you do causes you fatigue, weakness or pain, you shouldn't be doing it!"

POST-POLIO SUPPORT GROUP MEETINGS

Madison Area Post Polio Support Group— the next meeting is Saturday, March 13. Dr. Daniel K. Robb will discuss Chiropractic care, techniques and treatment and how it might be able to help your spinal condition.

The Post Polio Resource Group of Southeastern WI meetings are held at the Easter Seals Kindcare Recreation Center located in Holler Park at 5151 S. 6th St., midway between Grange & Layton Ave., Milwaukee (just north of the Airport Spur). Social time from 1:00 to 1:30 pm.; meeting from 1:30 to 3:30 pm in March, April, May, September, October and November. Check their website at www.pprg.org for dates and program.

The March 20th meeting topic is Wellness: Restoring Balance to our Lives. The speaker is Kathryn Rambo (osb oblate, MT-BC, DCM practitioner, Alverno College).

On May 15 Harvey Padek and Beth Kowall, polio survivors, will discuss Living Well with Chronic Conditions.

The **Janesville Post Polio Support Group** meets from 1-3 p.m. at the Mercy Health Mall, 1010 N. Washington St., Janesville, WI on the first Friday of May, June, August, October and Nov. Contact Art Arnold at UncleBunks@aol.com if you want information on speakers.

The Western Wisconsin Post-Polio Resource Group will meet on April 10, 2010 from 12:30 to 3:30 at the Tri-County Memorial Hospital Education Room, Whitehall, WI. For more information call Betty Marsolek at 715-985-3801 or e-mail at bmarsolek@tcc.coop

FYI

American West Center's Polio Oral Project
American West Center at University of Utah Looking for Polio Survivors This Oral History Project is Documenting Treatment, Outcomes, and Effects of Polio. If you are interested in sharing your oral history please contact: <http://www.amwest.utah.edu/?pageId=1771&newsId=1577>

Betty Leiser, who recently gave up her driver's license, has for sale her '03 Oldsmobile Silhouette GLS Extended Minivan, 36,000 miles, with all the

options and brand new tires. Presently set up and preferred sold as an accessible vehicle with a Bruno Scooter lift. A Sierra front wheel drive scooter included in the price, plus the remaining Quad seats (2), which can be easily installed when the lift is removed. Asking \$13,000.00, OBO. Call Betty at 608-222-8897, between 10-12 am or 6-8 pm if you are interested.

MEDIC ALERT BRACELETS, NECKLACES, DOG TAGS, WATCHES, ETC.

MedicAlert Foundation was founded by a physician in 1956 and remains the only nonprofit emergency medical information service with over 4 million members worldwide.

For more than 50 years, they have relayed vital medical information to emergency responders about members' medical conditions, allergies, medications and dosages, so they receive faster, safer treatment. Their 24-hour emergency response service provides family and caregiver notification so that members can be reunited with their families.

MedicAlert products are available as bracelet, dog tag, necklace, shoe tag, sports band and watch. They are available in the following materials: 10K gold filled, 14K gold, stainless steel, sterling silver and sterling silver, rhodium coated. Prices range from under \$20 to \$200+.



If you have questions call: 888-633-4298
 6 am-7 pm, Monday-Friday, 8 am-5 pm, Saturday
Pacific Time or go to their website at:
 <www.medicalert.org/?selected=Home>

Many Thanks

To the Post Polio Support Group for the lovely gift of Noni products (Tahitea, Body Souffle, Sugar Scrub and Body Butter) all in a nifty box elegantly wrapped by Marilyn Klotzbach. The box, which has a nice brass colored handle and latch, will be just right for 4" x 6" recipe cards or other "treasures".



Thank you for your thoughtfulness and caring. I appreciate all the help you have provided to make your *Pacer* a good quarterly newsletter.

Many thanks,

Marcia Holman



Come, join us around the tables.
 Listen to speakers & share your thoughts.
 Enjoy good food and fellowship.

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We **need** people to bring new ideas for speakers, topics, books to read and discuss, etc. Call or e-mail (see e-mail list) one of the people listed above to suggest program topics or speakers, volunteer to organize one meeting program, share your knowledge (or find an expert) about becoming a non-profit organization or volunteer your talents (financial, organizing, etc.) as a committee member.

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To get your Pacer on line, set your email program to always accept messages from
WGHMCH@CHORUS.NET



POST POLIO PACER is a quarterly newsletter published in January, April, July & October for polio survivors, the Madison Area Post Polio Support Group, health care professionals and interested persons to share information and to promote friendships. Articles in this newsletter are for information; medical advice is always necessary.

Please request permission from the editor to reprint articles from the Post Polio Pacer.

Disclaimer: The opinions expressed in this publication are those of the individual writers and do not imply endorsement by Easter Seals Wisconsin or the Madison Area Post Polio Support Group.



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A NEWSLETTER FROM THE MADISON-AREA POST POLIO SUPPORT GROUP

Mark your calendars!

LOCATION:

Monona Garden Family Restaurant
6501 Bridge Rd., Monona
Noon to 2:30

Saturday, March 13, 2010

Dr. Daniel K. Robb will discuss Chiropractic care, techniques and treatment and how it might be able to help your spinal condition.

Saturday, May 8, 2010

Theresa Fishler shares information about Community Alliance services.

Printing and postage is provided by:

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