

PHI's mission is supported by its Membership.

## Margaret Pfrommer Endowed Memorial Lecture in Home-Based Mechanical Ventilation

Post-Polio Health International (PHI) and International Ventilator Users Network (IVUN) announces that it has contributed \$67,000 to The CHEST Foundation, the philanthropic arm of the American Academy of Chest Physicians (ACCP), to fully endow the Margaret Pfrommer Endowed Memorial Lecture in Home-Based Mechanical Ventilation.

The purpose of the endowment is to honor an individual who possesses superior knowledge of home mechanical ventilation (HMV) and who promotes the health professional/patient partnership.

Each year an individual deemed expert in home mechanical ventilation is honored for their work and is asked to lecture at the annual meeting of the ACCP.

PHI Board President William G. Stothers, San Diego, California, comments, "As an HMV user, I am keenly aware of the importance of educating medical providers so that I and many others continue to live independently in our own homes. We can breathe a bit easier thanks to this effort to provide long-term funding for the Pfrommer Lecture."

PHI's gift assures that home mechanical ventilation will always be a topic at the annual meeting and assures that younger physicians will be exposed to the philosophy, skills and techniques of providing care for adults and children with neuromuscular disease who live at home on mechanical ventilation.

During the discussions, it was decided to slightly revise the criteria for selecting the recipient of the award. Consideration for the award shall be given to a researcher, clinician or ventilator-assisted individual or parent of a ventilator-assisted child from any country (translator will be provided for non-English speaking individuals), and previous recipients if they have contributed new knowledge to HMV.

The Steering Committee of the Home-Based Mechanical Ventilation and Neuromuscular Disease NetWork of the ACCP will be instrumental in nominating an individual to receive the honor. The final decision will be made by the Scientific Presentations and Awards Committee of the ACCP.

Nominations for the award can also be made through IVUN, typically each December.

Established in 1999 by Dr. Allen Goldberg and Dr. Eveline Faure, the lecture honors polio survivor and advocate Margaret Pfrommer from Chicago, Illinois. Pfrommer, a quadriplegic from polio, spent part of her life in a nursing home after her mother's death. This experience compelled her to become an advocate for herself and for all those with significant disabilities.

She was one of the first to pilot a motorized wheelchair with a "sip-and-puff" mechanism. Her consultation and feedback were instrumental in developing the prototype and other technologies that allowed Margaret and many others with significant disabilities to live independently.

Drs. Goldberg and Faure issued a \$10,000 matching challenge to their colleagues at the ACCP to assist in fully funding the lecture. Thanks to generous donations from them and other supporters of HMV, the goal was met.

Daniel J. Wilson, PhD, Allentown, Pennsylvania, Chair of PHI's Research Committee adds, "This award, supported by PHI, honors the memory of Margaret Pfrommer and the many other polio survivors who pushed the medical profession to help us live full and independent lives." ■

*"To announce that there must be no criticism of the President, or that we are to stand by the President, right or wrong, is not only unpatriotic and servile, but is morally treasonable to the American public." –Theodore Roosevelt, The Kansas City Star, 18 May 1918*

## What to do?

The above was sent to me privately on Facebook after I was chastised for sharing an article that said that the then President-elect Trump had made fun of the reporter Serge Kovalski. "Do your homework. He did not."

Another was upset because the article stated that Trump would be an ableist president, and they do not think he is "able." (Ableism, aka, ablism, disablism, disability discrimination, is discrimination and social prejudice against people with disabilities.)

My point in sharing the article was the discussion on possible cuts to Medicaid and Medicare. I was surprised that many didn't think that polio survivors would be on Medicaid. They are. (Thanks to the individuals listed on page 11, we mail this newsletter complementary to many who are on Medicaid or in developing countries.)

When reading the less-than-polite comments, I had a flashback to a dinner in Washington, DC, (1988) with our founder Gini Laurie and Mary Jane Owen, then with the National Catholic Office for People with Disabilities. The discussion centered around the importance of words and the belief that language and practices which could offend – as in matters of sex or race or disability – should be eliminated. In some circles, that common sense politeness has been discounted and even ridiculed, as seen daily on social media.

When asked, "What are we going to do?" in response to the predicated attacks on health care and disability rights, I had another flashback.

In 1987, I actively advocated for the Americans with Disabilities Act. After it passed in 1990, I was elated. I proudly told a long-time advocate about the letters I sent, articles I wrote, and all the postcards I had people sign and mailed to Washington, DC. He responded, in a patronizing voice, "Those didn't really matter. It all happened because Evan Kemp, a lawyer with a disability, became close friends of C. Boyden Gray, a lawyer, who was close to George H.W. Bush."

I went from elated to deflated ... temporarily.

For 30 years, I have marched. I have written letters. I have signed petitions. My emails receive a canned response but are counted, and I learn my legislators' positions which aren't always as expected.

I have called my legislators, which "insiders" say is the best thing to do, and on some days lately, I have found the phones are overwhelmed.

By the way, the switchboard operator in Washington, DC, is 202-224-3121. When calling, I ask for my Senator or Representative and then the staff in charge of my concern – healthcare, Medicare, disability rights/access, environment, etc. (Check out How to Contact Your Elected Officials at [www.usa.gov/elected-officials](http://www.usa.gov/elected-officials).)

Don't forget your state officials. Their decisions affect you, too.

I am committed to *doing something* on a regular basis.

I hope you will join me.

–Joan L. Headley, Executive Director

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*PHI's mission is to enhance the lives and independence of polio survivors and home mechanical ventilator users through education, advocacy, research and networking.*

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**PHI sends PHI Membership Memos via email.  
Be sure to set your spam filter to receive emails  
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### Moving? Change of address?

Notify PHI before you move by calling 314-534-0475 or email [info@post-polio.org](mailto:info@post-polio.org), and tell us your old and new addresses.

### Away temporarily?

Send us your second address and dates you will be there and we'll do our best to send your newsletter.

# More on the Mayo Clinic Study

Joan L. Headley, Executive Director, Post-Polio Health International

PHI published an article by anesthesiologist and polio survivor Selma H. Calmes, MD, in *Post-Polio Health* (Vol. 32, No. 3). Dr. Calmes is retired from Olive View/UCLA Medical Center, Sylmar, California, and has written extensively about anesthesiology and has generously advised health professionals and polio survivors over the last decades.

The article, “Important New Paper Published on Anesthesia and Polio” reported on the first scientific study of polio patients having anesthesia for major surgery. The study was done at the Mayo Clinic and compared each post-polio (PP) patient to two control patients of the same age with the same severity of preoperative illnesses and having similar surgery.<sup>1</sup> (If you misplaced it, Dr. Calmes’ article in *Post-Polio Health* is online at [www.post-polio.org/edu/pphnews/.](http://www.post-polio.org/edu/pphnews/))

PHI received a few comments from polio survivors asking about the article essentially saying that it was much more positive than they expected; a few people found the article confusing.

It is true that the results of the study regarding anesthesia and the polio survivors in the study found no difference between the post-polio survivors and controls.

Consequently, we asked Dr. Calmes to write another article to address the major concern of those contacting us – *fear of over-sedation*. The article, “More on the Mayo Clinic Study of Anesthesia in Post-Polio Patients,” is posted online at [www.polioplace.org/living-with-polio/more-mayo-clinic-study](http://www.polioplace.org/living-with-polio/more-mayo-clinic-study).

In the article, she discusses the evidence to see if the fear of over-sedation is justified and the need for peer-reviewed research vs anecdotes, i.e., individual polio survivor stories. (I vividly remember the well-known Jacquelin Perry, MD, saying at an early conference, “Our study showed 75% of polio survivors were experiencing pain.” There was a groan from the audience. She noticed and followed with, “BUT remember 25% were not.”)

Calmes mentions other things that can affect a person’s reaction to anesthesia. These include age, how much they weigh, other drugs that patients might take (some post-polio patients take narcotic drugs for pain and these add to the effects of anesthesia drugs), how well their liver works (many anesthesia drugs are broken down in the liver) and genetics.

The article talks about the fact that the issue of the non-effectiveness of drugs to reverse the effect of muscle relaxants has become a big issue in anesthesia practice in the last few years. It is not just post-polio patients who may have issues.

And, based on her experiences of talking to many survivors facing surgery, and her long experience as a practicing anesthesiologist (including attending to many polio patients), she expands on how anesthesiology has changed since the operations that many had during the epidemics. Her comments are reassuring.

So, yes, the study results were “positive” as her past articles have been. However, she and I would make this very important point. Respiratory failure is the greatest known risk for post-polio patients, especially for those who had bulbar and high-spinal polio. That is a significant concern. Pre-planning and selecting the right facility is a must for them.

Are we splitting hairs? Maybe, but we are hopeful that the days of polio survivors NOT choosing surgery out of fear of over sedation for a cancerous tumor or other situations that are life-threatening are over. ■

<sup>1</sup>Van Alstine LW, Gunn PW, Schroeder DR, Hanson BS, Sorenson EJ and Martin DP. Anesthesia and poliomyelitis: A matched cohort study. *Anesthesia & Analgesia*. 2016; 122:1894-1900

Members who do not have access to the internet may call us at 314-534-0475 for a copy of Dr. Calmes’ article.

Post-Polio Health International has posted several articles and advice from Dr. Calmes on [www.post-polio.org](http://www.post-polio.org) at [www.post-polio.org/edu/majtop.html](http://www.post-polio.org/edu/majtop.html).

**Polio survivor:** Hello, thanks for taking my call. I called to tell you about my first visit to the new pulmonologist's office.

**Post-Polio Health International (PHI):** Hi, how did it go?

**Polio survivor:** OK, I guess. He asked about my machine and how often I used it. And, he assured me he would get the details from the Astral 150 through my home healthcare company.

**PHI:** Good. Yes, they can do that. And, that info is more accurate than memory. What else happened?

**Polio survivor:** We just talked. He asked me questions about my life and the jobs I had had. He didn't ask about my breathing.

**PHI:** When he was asking you questions he was watching you breathe, move, observing how long of sentences you used, etc, etc. He was checking you out! I am sure he noticed your scoliosis. That affects your breathing ability, too.

**Polio survivor:** I think you may be right. At one point he moved his chair saying, "Let me move. You can't move your head this way very well, can you?"

**PHI:** Good for him! Asking you about your life and what you did and observing that you came to his office on a snowy day in your power chair tells him a lot about you and your expectations in life.

**Polio survivor:** Do you think? We scheduled another appointment, although I am doing OK. I told him that if it is too cold or if I can't get a driver I may cancel. He seemed just fine with that.

**PHI:** Good! You know it is so important that you have a physician who knows you when you are well, so they can be your advocate when you get sick. Health professionals who don't know you and only see you in the ER or in a hospital bed don't understand. Keep him! Educate him a little more each time about you and your situation. He will come in handy, even if he isn't a "post-polio expert."

**Polio survivor:** OK. At least he didn't walk in and say, "We need to decide how much oxygen to put you on," like the last guy did.

**PHI:** Ahhh, remember. But, hooray, you kept looking ...! The polio survivors who avoid physicians who see them face-to-face and haven't befriended one in their area, can be in trouble when a crisis arises. Glad you persisted. Let's stay in touch and take it step by step. ■

**International Ventilator Users Network (IVUN) is part of Post-Polio Health International. For more information about using home mechanical ventilation part or full time, visit [www.ventnews.org](http://www.ventnews.org) and [www.facebook.com/HMVnews/](http://www.facebook.com/HMVnews/).**

The image shows a website header for the International Ventilator Users Network (IVUN). The header includes the IVUN logo, the text "INTERNATIONAL VENTILATOR USERS NETWORK", and "an affiliate of Post-Polio Health International". On the right side, there is a "CONTACT US" link. Below the header is a navigation menu with several items: "VENTILATOR-ASSISTED LIVING", "HOME VENTILATOR GUIDE", "RESOURCE DIRECTORY 2016", and "RECHARGE CHANCES". Below the navigation menu is a banner for "HOME MECHANICAL VENTILATION THE BASICS". At the bottom of the page, there is a footer with social media icons for Facebook and Twitter, and a "JOIN IVUN OR DONATE" button.

# The Role of the Primary Care Physician in the Life of a Polio Survivor

William DeMayo, MD, Summit Medical Rehabilitation, PC, Johnstown, Pennsylvania

On each of my several trips to Post-Polio Health International conferences, as well as on my recent three-week lecture circuit in Australia, I have been amazed at the number of individuals who see my specific expertise as “the missing piece” in their future health, yet their local therapists and primary care physicians (PCP) seem to be relegated to some distant and less important role.

While I appreciate the importance of specific expertise in this sub-specialty area, I often find myself trying to bring folks back to their local resources. In my opinion, regardless of expertise, it is local therapists and PCPs that can have a much bigger role in long-term health.

The most obvious reason to conclude this is that a polio survivor’s health is not solely dictated by their history of polio. They are just as susceptible to the same medical conditions as everyone else. In fact, for some, a relatively sedentary life will make them more susceptible.

The following conditions each have an incidence of at least 10% in those over 65 and ALL ARE ON THE RISE in this age group:

- High Blood Pressure (55%)
- High Cholesterol (45%)
- Diabetes (20%)
- Cancer (>10)
- Mental Illness (>10%)
- Back Problems (>10%)

Multiple other conditions pose a significant threat of disability as we get older:

- Obesity
- Coronary Disease/ Congestive Heart Failure
- TIA/Stroke
- Arthritis
- Bladder and Bowel difficulties
- Infection
- Lung disease
- Kidney disease

Most individuals develop MULTIPLE chronic conditions as they age:

- For 65-75 year olds
  - ◆ >20% had a chronic condition
  - ◆ >50 % had two-four chronic conditions
- This trend increases after 75 years of age with >20% having more than five chronic conditions.

Primary care physicians are the “go-to person” for nearly all the above conditions yet, somehow, their role seems to be minimized by many polio survivors.



William DeMayo, MD

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**QUESTION:** I just reviewed your online booklet *Post-Polio Health Care Considerations* but didn't see a section on personality and cognitive changes. I am a mental health therapist and friend to two women who have post-polio. I am seeing changes in both their personalities and cognition. Do you have further information on these changes?

**Response from Rhoda Olkin, PhD:**

The very brief answer to whether there are personality and cognitive changes in post-polio is no. But you are observing both, so what might we make of this?

First, there is a tendency to see many aspects of a person in terms of his or her disability. This is what Beatrice Wright (1983) called the spread effect. It means that the disability spreads to other presumed characteristics of the person. An example might be talking loudly to a blind person, on the assumption that hearing is likewise impaired. Another type of example is assuming that Itzak Perlman (the world-renowned violinist, who had polio) excelled at violin because he couldn't play sports.

In your case it might mean attributing observed changes to the polio. However, any changes you observe may be due to aging, menopause, stress, child rearing, worry over the November election (which was not resolved at the time of this writing), low thyroid or any myriad other possible explanations.

'Personality changes' can co-occur with fatigue, i.e., people get grouchy or less tolerant or more self-absorbed or less flexible and accommodating when they are trying to manage symptoms. I would not describe these so much as personality changes, but mood changes, which in turn change behavior.

To an outside observer, who makes what sociologists call the fundamental attribution error, the changes are ascribed to the person rather than to the environment or circumstances or context. To support this

idea that it is the fatigue *per se* and not an actual personality change, one study found that the fatigue associated with PPS had a negative impact on psychosocial functioning (On, Oncu, Atamaz, & Durmaz, 2006).

Regarding cognitive changes, there do not seem to be changes associated with polio or post-polio syndrome. For example, one study of people with polio with and without fatigue found no evidence that fatigue or cognitive load (doing multiple tasks in a row) affected cognitive functioning (Ostlund, Borg, & Wahlin, 2005).

Although an earlier study did find that polio fatigue is associated with attention deficits, a more recent study found "no support [for] the hypothesis of 'brain fatigue' in polio survivors, assessed by cognitive tests or event-related brain potentials" (Schanke, et al., 2002).

So ask your friends what they think. Do they notice changes in themselves? If so, to what do they ascribe these changes? Describe what you notice, then listen to their responses. ■

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**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.

**QUESTION:** *I am in my 80s and have become less and less involved in “changing the world.” I have come to terms with that decision and just want to relax and enjoy life. But at the same time it seems like everything is so difficult anymore. Errors abound at the pharmacy, at the doctor’s office, the plumber seems not to carry the basic supplies in his truck, the young cleaning lady has a different definition of clean than I have, etc. Do you have advice on how I can just relax and enjoy these later years?*

**Response from Stephanie T. Machell, PsyD:**

It sounds like those you rely on are what’s preventing you from relaxing and enjoying your life. It must be frustrating to have to deal with so many incompetent people, especially when all you want is for things to run smoothly. Unfortunately, there is no shortage of incompetence in every walk of life. And that’s not likely to change, even if you devote all your time and energy to changing it, because you cannot make the incompetent competent.

There is nothing more frustrating and stressful (or impossible) than trying to change others who have no interest or investment in changing. The best way of reducing your own stress is to stop trying to do this. Instead, fire incompetent service providers and find new ones whose work meets your standards. You have a right to high-quality services and care, and though it may take some initial time and effort, once you have your “dream team” in place life will be much more enjoyable. It might further reduce your stress levels to ask for help from a family member, friend, or even someone from your local senior center or elder service program to deal with certain categories of service providers, and/or to find ones known to work well with older people with disabilities.

If the major stresses you experience come from other people’s behavior and attitudes, it’s worth learning to change the way other people’s behavior affects

you. Think about it: Are those who affect you worth the distress they cause? Do they deserve to ruin your day? Of course they don’t.

It’s hard, but you can learn to be less reactive to others. Try imagining a scale. At one end are events that are of no importance and/or have no lasting effect on you or your life. At the far end is the very worst thing that ever happened to you. Placing the person/event you find distressing on this scale can help you (re) gain perspective. You can count to ten, or take a deep breath, or find the humor in the situation. You can even vent your frustration to a friend or your journal, as long as doing this allows you to let the frustration go.

Many people find meditation useful in becoming less reactive and more relaxed. And of course, it has other health benefits as well. No matter what your belief system is, there is a way of meditating to go along with it.

Feeling disempowered and helpless is anything but relaxing. Studies show that those who remain engaged with their communities age best. Maybe you can redefine your idea of a peaceful life to include continuing to work for change. Maybe you could volunteer at the senior center to help others find more competent providers, or with your post-polio support group to develop or disseminate educational material to local physicians or pharmacies. ■

**Dr. Stephanie T. Machell** is a psychologist in independent practice in the Greater Boston area and consultant to the International Rehabilitation Center for Polio, Spaulding-Framingham Outpatient Center, Framingham, Massachusetts.

Her father was a polio survivor.



# Update from Joyce Tepley

Author of *When to Move*, (*Post-Polio Health*, Volume 32, Number 3)

“After carefully reviewing our finances and projecting five years out, we decided to stay in our own home with paid help as long as we can. Other alternatives are just too expensive and require enormous energy to downsize and move.”



Joyce and Phil Tepley

“Not many of us are lucky enough to have vigorous health into our 90s where we can be as fully functioning as possible, then one day just die. Most of us slide toward death getting worse and worse and have to rely on people and changes of types of residences for our very functionality.

What is the tipping point? When and how do you decide how much help you need and where you will go to get it?

I was a social worker and worked with many occupational therapists (OTs). They use the term Activities of Daily Living (ADLs). A check list of these activities is used to determine how functional a person is and what help needs to be provided to remain functional. The basic ADLs have to do with hygiene, such as bathing, getting dressed, toileting, grooming and brushing teeth. Added to these are feeding yourself and walking around or moving from place to place as needed.

If you cannot do any of these by yourself or have to be reminded to do them, they recommend full care or supervision. I can do all of these on my own but need help with hanging wet towels for drying after I shower and getting clothes from my closet that I cannot reach. I also use a wheelchair to move around and need help putting the wheelchair in and out of the car. So I think I am 90% to 95% functional in my ADLs.

There are also Instrumental ADLs which are actions that allow someone to perform complex skills like managing finances, shopping, managing medications, using the telephone and other technology for communicating, meal preparation and clean-up and community mobility.

OTs assess your ability to perform these skills and it gives them a clearer picture of your physical and mental condition. I am mentally capable of doing all of these skills but am not physically able to do a couple of them.

This is where self-assessing gets tricky. Shopping, meal preparation and clean-up I can do, but it takes a lot of energy that I don't have in reserve. My husband used to do all the shopping and most of the cooking for us but he recently had major surgery and cannot do those tasks right now.

I've arranged to have packaged meals delivered and I reheat them. I also hired someone who grocery shops for us and helps with a variety of small household tasks and transportation thereby freeing my energy to concentrate on being my husband's caregiver.

Essentially, I have become a supervisor of others doing the work. Does that count as being functionally able in the Instrumental ADLs? As long as your brain is working, only you can decide how much help you need and if you have to move out of your present living arrangements to get it.

So far, the money my husband and I spend on hired help plus our monthly house expenses is \$1,000 less than what we would pay for an average assisted living arrangement in our home town. ■

See “What Is Occupational Therapy?” on page 10.

**Question about braces:** I got a new brace to wear and it really squeaks in my shoes. Do you know of a remedy for that?

**Answer:** Some of the ways to take away the squeak that happens when the plastic of the brace rubs against the shoe material are to wipe both the inside of the shoe and the outside of the brace with a dryer sheet or dust the surfaces with talcum powder (baby powder or after bath powder) or a light coating of cornstarch.

**Response:** The suggestion of the dryer sheets has brought me to awe as I walked the hall of my home in a quietness my wife could hardly believe. With the new addition of my second leg brace as a result of post-polio syndrome. I thought I might be forever relegated to the back pew in our church because of my new noisy brace. You have helped me in a special way ... now what do I do with the talcum powder I bought ... just kidding. Mike, San Antonio, Texas

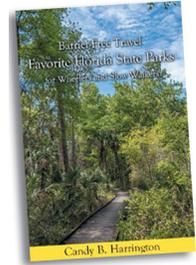
**Regarding problems with cooking:** I eat Compleats® by Hormel. They can be heated in the microwave in a minute. The Roast Beef & Gravy with Mashed Potatoes has 16 grams of protein. (This entrée contains 720 mg sodium.) Janice, New York

**What is the deadline** for the next PHI research grant application? The deadline is October 2, 2017. See [www.post-polio.org/res/rfcall.html](http://www.post-polio.org/res/rfcall.html).

### **New Florida Guidebook Highlights Wheelchair-Accessible State Parks**

*Barrier-Free Travel; Favorite Florida State Parks for Wheelers and Slow Walkers* (\$7.95, C&C Creative Concepts) explores the accessibility of some of the Sunshine State's popular state parks. Penned by accessible travel expert Candy Harrington, this new travel guide

highlights trails, attractions and lodging options for wheelchair-users and slow walkers in 12 of the author's favorite Florida State Parks. The book (\$7.95, ISBN: 978-0998510309) is available at [www.BarrierFreeFlorida.com](http://www.BarrierFreeFlorida.com).



**DePaul University researchers** invite persons with ME, CFS, MS, Lupus, Cancer, Postpolio Syndrome or HIV to participate in a voluntary research study to determine which symptoms may be commonly experienced by individuals in multiple fatiguing illness groups, and which symptoms may be unique to each illness. Participation includes completion of a confidential online questionnaire, which takes approximately 45 minutes to complete.

#### **Eligibility Criteria:**

- Adults at least 18 years of age
- Must be able to read or speak English
- Have a diagnosis of Multiple Sclerosis, Lupus Erythematosus, Cancer, Myalgic Encephalomyelitis, Chronic Fatigue Syndrome, Post-polio Syndrome, or HIV.

If you are interested in participating, follow this link to access the survey: <https://redcap.is.depaul.edu/surveys/?s=d9gSMwkGsW>

This survey is open to any English speaking participant over the age of 18 with post-polio syndrome, regardless of location.

Our goal is to understand how the DePaul Symptom Questionnaire (DSQ; Jason et al., 2010), an instrument assessing frequency and severity of a variety of symptoms associated with Chronic Fatigue Syndrome (CFS), can be used to differentiate post-polio syndrome and CFS as chronic conditions with differing symptomatology, given that both conditions do involve fatigue. ■

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### What Is Occupational Therapy?

Occupational therapy practitioners ask, “What matters to you?” not, “What’s the matter with you?”

In its simplest terms, occupational therapists and occupational therapy assistants help people across the lifespan participate in the things they want and need to do through the therapeutic use of everyday activities (occupations). Common occupational therapy interventions include helping children with disabilities to participate fully in school and social situations, helping people recovering from injury to regain skills, and providing supports for older adults experiencing physical and cognitive changes. Occupational therapy services typically include:

- ◆ an individualized evaluation, during which the client/family and occupational therapist determine the person’s goals;
- ◆ customized intervention to improve the person’s ability to perform daily activities and reach the goals; and
- ◆ an outcomes evaluation to ensure that the goals are being met and/or make changes to the intervention plan.

Occupational therapy services may include comprehensive evaluations of the client’s home and other environments (e.g., workplace, school), recommendations for adaptive equipment and training in its use, and guidance and education for family members and caregivers. Occupational therapy practitioners have a holistic perspective, in which the focus is on adapting the environment to fit the person, and the person is an integral part of the therapy team. See [www.aota.org](http://www.aota.org). ■

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It has been my sense that this is, at least in part, due to a frequent “disconnect” that occurs when the issue of polio or post-polio related issues come up. Most PCPs willingly admit to a lack of expertise in this area and, sometimes, this creates a dynamic that their opinion on other matters is also downgraded. In fact, from my standpoint, it is unreasonable to expect that a PCP have extensive post-polio knowledge.

Rather than downgrading the PCP opinion on other matters, it is my opinion that polio survivors are better off being unusually grateful for the PCP. Since the vast majority of physicians went into medicine for good reasons, a statement like “I really need your help with ...” goes a long way. Consider comments like “I really appreciate your keeping such a close eye on my blood pressure” or “My polio slows me down enough, I’m really glad that you help me tightly control my diabetes, so I won’t have complications that worsen my disability.” These comments will increase the connection rather than allow a disconnection that may result when a PCP is not familiar with concerns that relate to adaptation to slow progress of weakness and chronic disability (aka PPS).

Having said all of the above, most of us have noticed that medicine has been changing. There may be PCPs out there that just won’t engage. In this case: find another PCP. One physician’s lack of interest should not dictate a polio survivor to poor future health.

Polio survivors, as a group, have a long history of focusing on goals and making things happen despite adversity. It is surprising that in dealing with the healthcare system, some can become passive or even fatalistic. In my opinion, the same “Can Do” attitude can be applied to assuring optimal health care by working with the healthcare system to insure that it meets their needs.

The stakes are too great not to address the issue. If developing polio is seen as a strike, and post-polio is a second strike, one more unmanaged (yet preventable) chronic condition could be the last strike leading to severe disability and loss of independent living.

In this light, one can say that the role of the PCP becomes even greater, not less, for aging polio survivors. ■

From 2004–2012, a series of conference calls was held for post-polio clinic directors. The calls were chaired by William DeMayo, MD. The PowerPoints and summaries of some of the calls are posted on Polio Place as PHI’s Post-Polio Clinic Directors Network at [www.polioplace.org/phis-post-polio-clinic-directors-network](http://www.polioplace.org/phis-post-polio-clinic-directors-network).

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