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.

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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.

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.