

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.

continued from page 8

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. ■

continued from page 5

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.