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Promoting Positive Solutions for Aging with Polio: Highlights from PHI's May Town Hall

On May 15, 2023, Rhoda Olkin, PhD, and Stephanie Machell, PsyD, led a town hall, Promoting Positive Solutions for Aging with Polio, as part of PHI's 2023 Educational Series. Below are some excerpts from the event.

The full recording can be viewed at <https://post-polio.org/education/post-polio-experts-present/>.

QUESTION: I'm in my 70s. My husband and I still aren't retired. We both work in real estate. Are there services for polio survivors that are free, like exercise groups? Everything seems so expensive when it's related to post-polio.

Rhoda Olkin, PhD: That's a really excellent question. There's what I call the disability tax—things we have to pay for that nobody else has to pay for. There should be a local post-polio support group [near you] which is free. There are many in California. I don't know where you are, but try to see if you can find a local polio support group because that's the group

that tends to know about different resources in your local area. The other tip I have is if you need something like a grab bar, don't go to a medical store. Go to somewhere like CVS or Walgreens. It's cheaper than other places. As soon as something's in a medically-oriented store, it's more expensive.

QUESTION: I am almost 80; I am also still working. My husband passed away a year ago. I knew I was going downhill the last 25 or 30 years, but I didn't realize until I was completely on my own how much he did for me—simple things like carrying in the groceries or things that you don't even think about, such as dropping me at the door so I didn't have to walk. Travel was our hobby. I'm going to be traveling by train soon. I probably won't bring my own scooter with me and will just rent one at the hotels that I stay at. Does anybody have any tips on how to travel alone? I'll pack very light with a small suitcase on wheels. I can walk about 30 feet before I have to stop. Am I crazy to try to take a train trip given what I've told you so far?

Olkin: I'm considering a train trip from Vancouver to Banff, but I'm in the San Francisco area, so it's all about the logistics of getting from one place to the other. You can, in fact, take an Uber or Lyft if you're in a city that's big enough that they have accessible ones. You can request a wheelchair-accessible one. You actually could take your own scooter if you wanted. Or there are taxis that will take scooters or wheelchairs. Could you do a shorter trip to try it? That would be my suggestion, so that you feel more confident even if everything works out.

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TOWN HALL

Promoting Positive Solutions
for Aging with Polio

Presented By:
Stephanie Machell, PsyD
&
Rhoda Olkin, PhD



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My rule of thumb is one thing goes wrong every trip, and you just don't know which thing it's going to be. And I like to know that when that thing goes wrong, I'm still going to be okay. So, I have tried several things when something goes wrong. I've gotten stranded at airports, for example, but I've always managed to somehow get to where I need to go. So, it's a good thing to try it out on shorter trips.

QUESTION: What perspective can you share with us on dealing with asking for help when so much of our lives we've been toughing it out through our challenges as polio survivors? How do I transition from doing everything myself to letting others help without perceiving that as another loss?

Stephanie Machell, PsyD: It's hard sometimes to give an answer that's going to fit everybody's specifics because everybody's in a different situation, but I think what I would stress is that you're not going to go from 0 to 60. You're not going to suddenly be able to just do this with great ease. Think about what your lowest cost ask is. Who can you ask that you feel will give you a "yes" to your request, and who will it hurt least for you if they say "no." Build up your muscle a little bit with asking.

As a child of a polio survivor, we like being asked. So, you might want to ask one of your children—if you have children—as your first ask. Spouses are

more complicated. I always say that the hardest role in the polio family is the polio spouse. But think about who you can experiment with this on and then just see how it goes and build it up gradually.

Olkin: A lot of it has to do with how you think about asking for help. When you frame it as, "I can't do this, and I am dependent on someone else to do it," that's a very negative framing. But if you think about it in terms of, "I can do this with assistance," that's a less negative way to frame it. But I like that idea that Stephanie said of exercising the asking muscle. I think that's really a nice way to think about it.

QUESTION: Some friends do not understand my issue of fatigue and either question my words or want to tell me I am just fine. What's the best way to help them understand?

Olkin: When most people say the word fatigue, what they mean is, "I really need a good night's sleep, maybe two, and then I'll be fine." What we mean by fatigue is, "If I've left something in the kitchen, it's going to stay in the kitchen because I can't get from the bedroom to the kitchen." That's a very different level of fatigue, and it is hard to help other people understand what that's like.

I actually wrote a book called *Teaching Disability*, and one of the exercises in it is about how to make people without a chronic illness or disability understand

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

Designer: Sheryl Prater

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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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fatigue and the way that you have to parcel out your energy over the week. One way I have tried to explain it to people is that recovery time is measured in days, not hours. And imagine you went on a hike that was just much, much more than you are used to ever doing—like maybe you went three-and-a-half miles up a mountain and three-and-a-half miles down a mountain, and you’ve never taken a walk more than maybe a mile. You would feel a level of fatigue that would take you a day or two to recover from.

Now imagine that the recovery is compromised because you’ve overused muscles and don’t have others to spare. So, it is very hard to explain to others, but I think the main thing I’m trying to get across is that this is not just about sleep. This is about muscles being worn out and needing to rejuvenate. And because you don’t have backup muscles, when they give out, they give out, and there’s nothing left.

I’m still working and so people see me popping around work, and I look fine. They don’t know that the day after I’ll be lying in bed. Sometimes I have to tell them that this is the cost for me of doing this. This is what I have to do to be able to do this. So, it does take some self-disclosure. The other thing I was really interested in is that sometimes they want to tell me I’m just fine. I did a study on women with disabilities and the kinds of micro-aggressions they experience. And one of them was, “You look fine. How come you’re not fine?” Somehow the way you look means you’re okay. I think that happens to women more than men.

QUESTION: I’m 87 years old and suffering not only from PPS-related fatigue but also long COVID fatigue. How much should I push through? I worry about damage. My fatigue gets severe and makes me breathless. I’ve had thorough health exams, all normal. I practice all the help tips that you have spoken about and use assistive devices. Would either of you have any advice for someone in that situation

who’s dealing with either PPS-related fatigue or fatigue that’s been made worse by COVID?

Machell: I think that the things that Rhoda said earlier regarding fatigue would certainly apply to this situation, except, of course, you have a multiplier on your fatigue. What she was talking about with muscle fatigue and the need for muscles to recover, sometimes you don’t know what’s going to happen until you push yourself past something. It’s frustrating to have to take the time that you need to take to rest and recover, but what I often tell my clients is to think about the things that give your life light and color and try to prioritize those with the energy you have, especially when you’re in a recovery time with long COVID. We don’t know how long that’s going to be.

When you’re in a period where you’re going to have diminished strength, be gentler with yourself. Try to let go of the things you absolutely don’t have to do. See if you can strengthen your “asking” muscles, as it were, to get the support you need. Imagine yourself convalescing. I realize that may be problematic for some of you who had trauma with your convalescence from polio, so that might be triggering some feelings, too. The simple answer would be to see how much energy you do have and try not to push past that amount. Or as Rhoda had said earlier, build in a recovery day if you know you’re going to need it.

I’m seeing that there are a number of questions about emotional pain. Unfortunately, we can’t deal with them right now, but I would strongly encourage people to write to us, and we’ll try to take the time to answer them.

Brian Tiburzi: Thank you, Stephanie. If you have questions of that nature, you may send them in an email to info@post-polio.org, and we will pass them along to Drs. Machell and Olkin. ■