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PHI Awards \$100,000 for New Research in 2016-2017

Joan L. Headley, Executive Director, PHI

The decision was a difficult one for the review panel of Post-Polio Health International's Research Fund, but ultimately they recommended a two-year study involving the CoughAssist to the PHI Board of Directors.

The CoughAssist (Philips Respironics) is a device that helps to clear secretions from the lungs. It was developed in the early 1990s by the J.H. Emerson Company as the In-Exsufflator. The device was reminiscent of the Cof-flator made in the late 1950s and early 1960s and used by polio survivors. Currently, there are several companies that make similar devices worldwide.

Submitted by Louise Rose, RN, MN, PhD, Associate Professor, Lawrence S. Bloomberg Faculty of Nursing, University of Toronto, Ontario, Canada, the project title is "CoughAssist: use education needs, health service utilization and outcomes." Rose also holds the TD (TD Bank Group) Nursing Professor in Critical Care Research at Sunnybrook Health Sciences Centre, Toronto.

Her co-lead researcher is Mika Nonoyama, RRT, PhD, Assistant Professor at the University of Ontario Institute of Technology and a lecturer in the Department of Physical Therapy at the University of Toronto. Nonoyama also holds a project investigator position at SickKids, Toronto.

In 2014, the publicly-funded Provincial (Ontario) CoughAssist Program was established. The program makes available the device and associated equipment free of charge to ventilator-assisted individuals living at home. A pulmonary specialist's evaluation is required to determine that the device is beneficial for that individual.

These individuals, and those new to the program, will be involved in the research, as well as caregivers.

The research questions include: What education, both initial and ongoing, is needed to assure use of the device? What effect has the availability of

the device had on emergency room visits, hospital admissions, family physician, clinic and specialists visits, e.g., health service utilization, and associated costs? What effect has it had on health-related quality of life and the individual's symptoms, e.g., shortness of breath, fatigue, etc. How does the actual use of the device compare to its prescribed use?

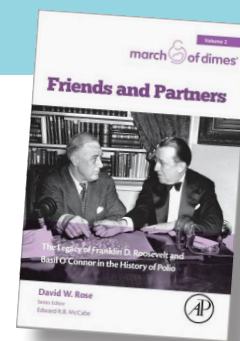
Rose and Nonoyama have lined up an impressive list of experts in noninvasive ventilation and cough augmentation, in both the adult and pediatric populations. In addition, the researchers have assembled experts in knowledge translation; health services and outcomes; qualitative methods of research that include participant observation and interview analysis.

The researchers project that the results will generate a new understanding of the educational needs of users of the CoughAssist, so improvements can be made in service delivery. They also anticipate that the results will validate the use of the device and will offer justification for similar programs around the world, providing greater access to the device, as well as improved symptom relief and quality of life for more ventilator users living at home.

Chair of PHI's Research Committee, Daniel Wilson, PhD, states, "The reviewers felt that even though the device has been used by patients with neuromuscular respiratory conditions for many years, evidence about efficacy is largely anecdotal. There is also little information about obstacles to its use." ■

The award of \$100,000 will be for activities completed in 2016 and 2017. The next request for proposals will be issued in early 2017 for 2018.

Friends and Partners: The Legacy of Franklin D. Roosevelt and Basil O'Connor in the History of Polio (1st Edition) is a new book by David Rose, March of Dimes Archivist. The book presents the story of two men, one the President of the United States, the other an ambitious attorney, who became the “architects of the fight against polio.” With unfettered access to the March of Dimes Archives, this book explores the friendship and partnership that ensured the end of polio in the US, with exclusive pictures and documentation.



The book describes the founding and history of Franklin D. Roosevelt’s (FDR) polio colony in Warm Springs, Georgia, and the early years of the March of Dimes as established by FDR in 1938 as the National Foundation for Infantile Paralysis. Other little-known aspects of the partnership are also included, such as O’Connor’s participation in FDR’s “Brain Trust,” the President’s birthday ball fundraisers during the Great Depression, the March of Dimes during World War II, and O’Connor’s simultaneous leadership of the American Red Cross.

Finally, the book explores, in detail, how O’Connor used the legacy of FDR after his death in 1945 to promote the philosophy of “freedom from disease” to achieve the goal of ending polio through the March of Dimes. ■

Thank you, Gayla

In 1976, Gayla Hoffman and her husband Arthur moved to their new home on Maryland Avenue in St. Louis, Missouri. They were greeted by their neighbors to the east, Gini and Joe Laurie, founders of the current-day Post-Polio Health International organization. Intrigued by the Lauries’ unique personalities and unbridled love for life, they became friends and were pulled into the activities of the Rehabilitation Gazette (as it was called then).

Over the years, Gayla and Art served as advisers and volunteers during conferences, providing media advice, and literally doing some heavy lifting. Gayla also served on the Board of Directors of PHI for many years.

In 2010, she became editor of *Post-Polio Health*, combining her professional journalism skills with her knowledge of disability, much of which she learned from polio survivors who met around the Laurie’s dining room table over the years.

Gayla retired from the editorship in 2015. She will be missed for her talent and faithful dedication.

For me, personally, after 28 years of conferences, board decisions, and grammatical and punctuation discussions, I will miss her intellect and her ability to be calm in all situations. I was lucky to absorb the calm.

–Joan L. Headley, Executive Director, PHI

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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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Away temporarily?

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

Creating Rewarding Lifestyle Changes

Beverly Schmittgen, retired educator, North Ridgeville, Ohio

I recuperated from polio at age 12 and was able to walk with only a slight limp for most of my adult life. However, some 55 years later, post-polio syndrome was limiting my activities more and more due to decreases in my mobility, strength and endurance. I had to use a cane when not at home and a mobility scooter for longer distances as well as taking rests during the day. I became more housebound, especially in the winter due to my fear of falling on the snow or ice, or due to my inability to climb stairs.

My new lifestyle required me to slow down and to adapt to my physical changes. I came to grips with these changes slowly after some psychological counseling and with the emotional support of friends and family.

Almost five years ago, my husband and I realized we were no longer able to maintain our large house and yard. The kitchen required 10 to 15 steps between the sink and the refrigerator or between the sink and the kitchen table. The master bedroom was five rooms and a hallway away from the laundry room.

There were steps from the garage into the house, so unloading groceries was tiring. The storage areas were down in the basement, some in crawl spaces, which was extremely difficult for both of us to manage. My husband's back problems and my difficulties with walking also interfered with our doing yard work and gardening.

Although we loved to entertain our family, some of whom live out of town, we had to admit that it was overwhelming to host large gatherings and especially to function as a "B and B."

It was time to change our residence and our lifestyle.

We discussed how we should make our own decisions about where and how to live independently PRIOR to having a health crisis that would force us into less-desirable decisions. We started looking at various types of senior living communities that included lawn care and

snow removal. It didn't take us long to find an ideal situation for our stage of life, being in our early 70s with a desire for social and intellectual stimulation.

We did not want to live in an apartment or a condominium, so we were delighted to discover that a Del Webb seniors housing development was under construction not too far away. We quickly chose a 2,200 square foot, two-bedroom ranch-style house to be built on the lot of our choice.



Our house

We planned accessibility adaptations to the model home including grab bars and raised toilets in the two bathrooms, wider doorways in the hallways and relocating the refrigerator so it would be closer to the kitchen sink.

Our monthly fee is reasonable for all we receive including yard and snow services, indoor and outdoor swimming pools and lots of social and learning activities at the community lodge. Our new home made it seem like we would be on a perpetual vacation with more time for fun and less physically-taxing work.

It didn't all happen easily, of course. Major change never does. Downsizing required us to spend several months dealing with all of our accumulated "stuff." We spent lots of time sorting, discarding, selling, reorganizing and

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planning – both emotionally and physically challenging tasks – but well worth the results. We kept our motivation up by focusing on the positive aspects of our chosen new lifestyle.

When sorting our belongings, we continually asked ourselves, “What do we want or need to take to our new house and where will we put it?” Our motto became, “When in doubt, throw it out – or donate it to a charity.” Despite all the work, difficult decisions and fatigue, we finally got settled into our new home just in time for the holidays.

The first event we attended with other people in our new community was a lovely Christmas dinner party. We were greeted warmly when we arrived and sat with friendly folks during the evening. That broke the ice. I soon decided I wanted to get more involved with activities at our community lodge. I began participating in events that would expand my horizons mentally, strengthen my body physically and bring satisfaction to me emotionally.

First, I decided to try one of the exercise classes at the pool. I knew I should be doing more exercise to keep from losing strength and endurance. I discussed the water aerobics class with the instructor and told her about my limitations. She encouraged me to adapt any of the exercises to my own abilities. She assured me that everyone in the class is very supportive of each other and that other participants also have physical difficulties.

I now attend this class for an hour twice a week on a regular basis. I discovered that I’m more flexible afterwards and have fewer joint pains. In the summer months, we use the outdoor pool where the sunshine and resort-like ambiance make it even more enjoyable.

Soon after getting settled into our new home, I began carefully reading the monthly newsletter for other activities in our community that seemed interesting and mentally stimulating. The book club was a “natural” for me and they welcomed me instantly as a new member. I found I got to know people easily in this small group. I’ve read books I probably wouldn’t have known about otherwise and have expanded my horizons greatly by discussing them. Attending lectures or classes on various topics has also stretched my mental abilities.

I decided to join the Glee Club. We practice every Saturday morning and give two popular performances each year as well as outreach programs at local nursing homes. Participating in a choir helps me feel energized and making music is spiritually uplifting.

Many other activities are available at the Lodge. I’m especially appreciative of how easy it is to park and enter it in the winter due to consistent removal of snow and ice. It is so much easier than attending events at public buildings with inadequate disabled parking or at private homes with stairs. I attend more



The Lodge

events now, knowing I can arrive safely and without becoming overly tired.

Being with people I enjoy has increased my inner strength. I began reaching out to new people in our community at social events and during creative activities which have kept my spirits high. For example, my husband and I have enjoyed attending the annual Memorial Day recognition of veterans at a flag-raising ceremony followed by a huge buffet breakfast.

Over time, it has been increasingly rewarding to be a “joiner” and to extend myself beyond my previous pursuits. I often attend events on my own, but there is also a social group for single people which is very popular.

All in all, moving into our active seniors’ community has been one of the best changes in lifestyle I could have made at this time of my life. At last I’m not the only person who has physical limitations. I’m finding that lots of other residents have health issues, too, which is why they moved here! No one pays attention to how differently I walk or that I use a cane.

I’ve also learned to ask for help when I need it. I’ve accepted the fact that I cannot be totally self-sufficient and strong. It is not a weakness to accept this need to change and adapt.

Change is hard, but I’ve also learned it can be so very rewarding. I love this new lifestyle of being involved with like-minded people, living in a welcoming and supportive community, and participating in activities that enhance my mental, physical and emotional well-being. It has given me a new lease on life! ■

Suggestions on How to Downsize

Beverly Schmittgen

Think positive thoughts about the future. Your upcoming move is an opportunity to create a simpler, more satisfying lifestyle. Avoid emotional attachments to “things” from the past. Remind yourself that spending time with people and activities that you enjoy is far more important than having lots of possessions.

Talk with your children/heirs about which items they would like to have now. Schedule a time for them to come and remove these items from your home ASAP! Other items that they would like in the future can be listed in your will. This is a good time to do or revise estate planning.

Schedule adequate time to plan and sort through possessions over a three-month period prior to moving. I spent lots of evenings going through a couple of boxes of “stuff,” such as old photo albums and memorabilia that I inherited from my parents. We also had toys, games, costumes, art supplies and musical instruments for our grandchildren’s entertainment that were no longer needed now that they’re grown up.

We scheduled several days during the week to go through cupboards, closets, the garage and basement to sort and discard, or donate, all of the things we no longer needed or were out-of-date. I forced myself to make quick decisions and not ponder these choices. We filled up garbage cans with lots and lots of these things for trash pick-up.

Be ruthless in discarding memorabilia you’ve saved for years! Only keep a representative sample of old photos and collections. My daughter suggested we take a photo of a keepsake and then give it or throw it away. That way I still have the memory. I suggest removing old photos from their frames, labeling them on the back and putting them in a cedar chest or similar long-term storage box. Ask yourself if your heirs will want these items or not. When in doubt, throw it out or give it away!

Plan which furniture you will take to your new home and where it will fit. This requires measuring all the rooms in the new house and your current furniture, determining where TV, phone and electric outlets are, and calculating how much space you’ll have for storage. We added extra shelves in closets, the laundry room and the garage to maximize storage in our new basement-less house. I created a schematic map of our new house and where the furniture, TV’s, computers and phones would be placed. This was extremely helpful on moving day.

Sell valuable and larger items such as furniture, equipment, coins, artwork and antiques. Get help advertising and selling items on Craig’s List. Contact an antiques dealer or auctioneer who is willing to come to your house to evaluate items they might be able to sell or to auction. Be willing to negotiate reasonable prices. Remember, you are saving yourself time and effort by letting others do the selling for you.

Get ready for a huge garage sale. Sort all the useful everyday stuff you haven’t used in several years and decide what you might be able to sell at a garage sale. This especially applies to items from your kitchen, garage and basement. Keep in mind that the prices you ask will need to be very low. Advertise with yard signs, ads in the newspaper and on Craig’s List. Get help with organizing, setting up and selling on the days of your sale. Fall and spring are the best times for garage sales.

Donate, donate, donate. It is especially helpful to decide to donate a great deal of your usable items to charitable organizations that can use or sell your “stuff” to benefit people in less fortunate circumstances. Save receipts and use the donations as a tax write-off. We found churches in areas of high poverty that would pick up some of our things, or we delivered items to them and to Salvation Army drop-off centers.

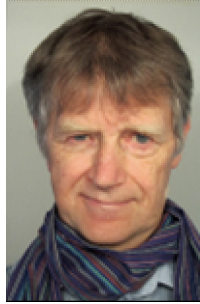
For example, I donated costumes to a local community theater. Historical items were a little more challenging. I contacted various historical societies and delivered doll collections, my father’s military items and papers from his years as a school administrator as well as my mother’s wedding dress and photo. It did take extra time and planning to arrange for appropriate donations, but it made me feel good to “do good” for others.

Focus on the future! No matter what age we are, we need to have rewarding activities to look forward to and friendly people to socialize with. The benefits of changing one’s lifestyle to make it more manageable and fun far outweigh the work involved in moving or the ease of “staying in place.” My mantras were to ask for help, keep motivated, take rests and be adaptable. ■

Speech and Swallowing Problems of Polio and Post-Polio

The German poet Christian Morgenstern said: “You are not ‘at home’ where you are resident, but where you are understood.”

I’m Thomas Lehmann, a medical doctor, who is a retired generalist with neurological knowledge. I treated polio survivors in Berne, pioneering the first center in Switzerland. I want to tell you about my polio and post-polio associated speech and swallowing problems.



In 1957, I contracted polio. Before my polio, I was a lively talkative boy, so much that in kindergarten even Santa Claus gave me adhesive tape. (Receiving that gift was quite traumatic, in fact.)

I had bulbar, and probably the encephalitic form of polio, with cranial nerve paralysis. In addition, my left arm became weaker and I am left-handed. The asymmetry of the weakness of my back muscles led to minor scoliosis.



Due to the damage caused to the cranial nerves, I had weakness and an asymmetry of my left facial muscles and eyelid. I had weakness of the phonation muscles, tongue, soft palate, which was shortened, and of the vocal cord muscles. My neck muscles were weakened, so I had difficulties holding my head upright.

I had, and still have, a hoarse sounding and low voice with functional air loss when speaking, resulting in fatigue and dizziness, and the need for more air to continue speaking. The shortening of the soft palate causes a nasal pronunciation.

As a child, communication with my family was very difficult but also very important for them to help me.

My main problem was not being able to swallow food, liquids or my own saliva. It ran out of my mouth or had to be spat into a glass. My tongue and the muscles for closing my soft palate were paralyzed or weakened, so liquid came upwards out of my nose. The muscles closing the epiglottis and the upper esophagus also did not function properly and I aspirated saliva. I nearly suffocated several times, giving me the feeling I was about to die because I was unable to call for help.

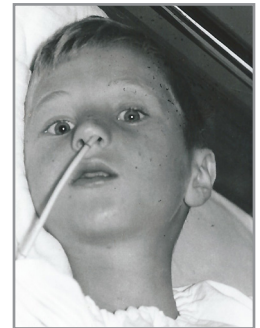
In hospital, they considered doing a tracheotomy to facilitate better clearing of my upper airways of the saliva, food or liquids that I aspirated. However, I didn’t have one and, thankfully, I did not have any infections of the respiratory tract or lungs.

For about a year, I was fed through a red rubber feeding tube, which I changed myself every 3 weeks.

After I moved to the newly built “Polio-Zentrale” near the University Hospital of Berne, I received different therapies. I don’t remember them all, but I had daily gentle massages to my dorsal and frontal neck muscles to strengthen and straighten my neck to gain better control of my head and swallowing.

I learned to chew better, to gulp more, and add more solid food, and to put any food I couldn’t swallow in my spittoon. I learned to eat normally, but slower than others (except for desserts), and I still had to support my head when eating.

There was decreasing coughing, no gurgling voice during or immediately after eating or drinking, and less extra effort or time was needed to chew or swallow. Less food or liquid leaked from my mouth or got stuck in the mouth.



It was not surprising that I had a weight loss problem.

My voice and pronunciation became more understandable. I attended primary school, high school, college and medical school. I joined and presided over a fraternity. I even sang in a school choir and was in the Swiss army. I married and we now have six children and five grandchildren.

In 1981, I joined Dr. Paul Walther in Berne, one of the medical pioneers of the polio epidemics of the ’50s. He assisted polio survivors in using mechanical respiration, and I became – as I promised him at my acute polio time – his successor.

Dr. Walther wrote about post-polio breathing and swallowing problems in the late ’60s. In the ’90s, I gave several lectures on aspects of post-polio syndrome throughout Switzerland, Europe and the USA.



Voice

Depending on my fatigue, which is more general than muscular, my voice gets weaker and my articulation more and more slurred. It becomes difficult to raise my voice and nearly impossible to take part in social or professional discussions when there is a noisy background.

My ideas are often not heard. It was, and still is, very frustrating. I tried speech therapy and had electrotherapy of my soft palate, but there was no real improvement.

With my difficulties of speech, people often don't understand the content of the conversation and break it off. Many lack the patience to listen. Today, I often don't seek out conversation being afraid of not being understood.

The exception – surprisingly or not – is with my patients, my family and my friends, because I can talk more quietly, more relaxed and without a noisy background.

I am very thankful to everyone who takes the time to listen to me and to eat with me, and respect the longer time I need.

Then I feel “at home.” ■

Gradually my muscles weakened, and I started having swallowing and voice difficulties as my energies and endurance decreased.

Swallowing

A near choking event resulted in an endoscopy and a videofluoroscopy of my esophagus.

Viewing the results (*below*) and understanding the situation made me more careful when chewing and eating, and when choosing my meals to avoid unpleasant complications.

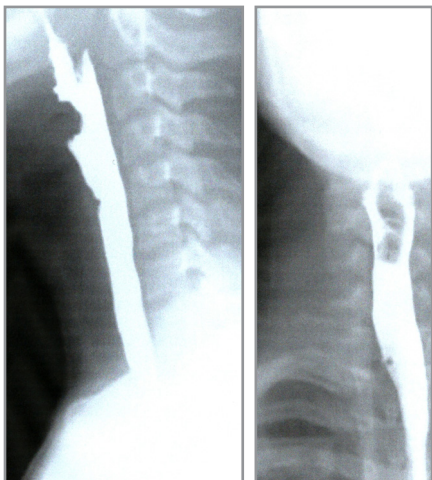
Nowadays, I sometimes can improve or enable better swallowing possibilities by lifting my hyoid bone or by turning my head to one side. Once I had a wry neck (*torticollis*) that nearly made me lose my swallowing function.

The bulbar form of poliomyelitis is not so often evident. Within every 100,000 persons infected by the poliovirus, there will be approximately 1,000 with paralysis, and of these, about 400 will have clinically-persisting paralysis/paresis and about 40 will have the bulbar form of poliomyelitis.

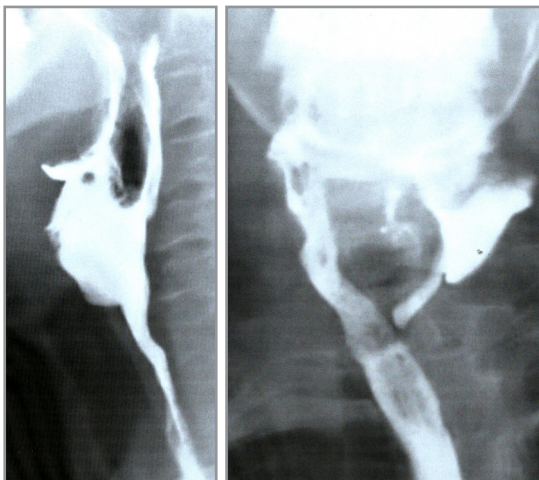
Out of my approximately 700 polio patients, there were 15 who mentioned bulbar and cranial nerve troubles in the acute phase, with about 10 still having them or experiencing new problems.

–Thomas Lehmann, MD

Normal swallowing ...



My swallowing ...



QUESTION: *My sister who had polio in 1953 at age 17 was affected from the waist down. She also struggles with bipolar disorder. Last winter she was hospitalized on a behavioral health floor for 44 days. Her crutches were taken away because they were considered weapons. She spent the days in a wheelchair and did not receive any physical therapy. Upon her release, we found she has lost what strength she had and now uses the wheelchair all of the time and is in a nursing facility. It is difficult to convince hospitals to allow the use of the usual assistive devices or equipment, and even more so, when it is a mental health facility. Do you have any advice for the family members who are advocates?*

Response from Stephanie T. Machell, PsyD:

To be an effective advocate, you need to understand the environment you're entering. Because people are admitted to psychiatric hospitals when they are a threat to themselves and/or to others the unit's focus is on safety. Because almost anything can be used in suicide attempts and/or assaults many seemingly innocuous objects are banned or allowed only with strict precautions. This means that staff may see a crutch not as an assistive device but as a weapon, or even something that can be broken down into dangerous pieces.

Psychiatric units have rules about what a patient is allowed to have. These rules are inflexible, though exceptions can be made based on human rights (which denying a person with a disability his or her assistive devices would be) provided the safety of others is not compromised.

Because hospitals are hierarchical you need to advocate with the correct staff member. For family members this is usually the unit social worker. This person, usually the only staff member trained in patient advocacy, can help you find out the unit's concerns with crutches and work with you on resolving them.

If these concerns can't be resolved on the unit, with or without the social worker's help, you can speak with the hospital's patient advocate, director of nursing, or a hospital administrator. If that doesn't provide resolution you can speak with a Department of Mental Health human

rights officer, legal services for people with disabilities, and/or the Joint Commission on the Accreditation of Hospitals (JCAHO, pronounced JAYCO).

If crutches still aren't allowed, a compromise might be. Patients should be allowed to exercise. Forbidden objects are almost always allowed under staff supervision. Perhaps your sister could be permitted daily supervised use of her crutches for exercise and/or physical therapy.

No matter who you speak with, it helps for the advocate to consider herself an ally, not an adversary. Maintaining a non-defensive tone and attitude conveys your confidence that both you and staff want the best for your sister, even when you have different perspectives.

There are some "magic" words and phrases advocates can use. "JCAHO regulations" causes hospital staff to pay close attention, especially if you have done your research and can refer to specific regulations. "You and I both know ..." privileges the person you are speaking with as someone who shares your knowledge.

Before hospitalization is needed again you might help your sister discuss her options with her providers. The best option for a person with a physical disability in need of a psychiatric hospitalization is a medical psychiatry unit, where staff may be more comfortable with assistive devices. Your sister's providers might know which units are disability-friendly. In a crisis she would have to accept whatever bed



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.

is available and later she might be able to transfer.

If you haven't already, it might be helpful to connect with advocacy groups for people with mental health issues. Family groups of the National Alliance on Mental Illness (NAMI) are full of others like you who can help you navigate the system.

Response from Rhoda Olkin, PhD:

To address this question I want to talk about the relationship between the person and her assistive devices or technology (AT). There is a range of AT from simple and common devices like compression socks, slightly more specialized equipment such as grab bars and crutches, to more sophisticated and complicated technology such as lifts and electric wheelchairs.

Adoption of any of these often carries significant psychosocial implications. For those with disabilities, AT can be an important part of daily life. Service providers often emphasize how AT can promote functional independence, but users tend to emphasize the psychological benefits.

For example, a service provider might say "this will enable you to walk a block" but to the user the benefit might be framed as "I can live at home." Service providers might say AT provides greater safety, while the user believes falling is embarrassing. These differences in language suggest that service providers and AT users see AT differently.

Several studies have demonstrated this difference. For example, hospitalized patients felt they were discouraged from exercising, that staff was not keen on having patients traipsing up and down the hall, or to have persons with dementia using electric wheelchairs. This was true even though a key to independence in

care facilities is the ability to be mobile independently.

Virtually all those who have gone from being barely mobile (with or without crutches) to use of a wheeled device talk about the new freedom they feel, and all the things they can now do that they couldn't do before. But that is after the fact, after the psychological shift that allowed the adoption of AT.

Before adoption, it is hard to know this in advance, or to see that the trade-off is worth it. But once AT is adopted, it rapidly becomes a part of the person, much like a body part. The body definition and boundaries now include the device. As such, someone moving or removing the AT is intrusive and presumptuous. Taking away a mobility device is like taking away people's eyeglasses – an unwelcome invasion of private body space.

The reactions of other people to someone who uses AT cannot be overemphasized, and is a big factor in resistance to adoption of AT. But it is also a factor in how the AT itself is viewed.

A crutch could be a weapon, but then so could a leg or a fist. Removing AT that reduces mobility and independence further infantilizes a mental health patient at her most vulnerable. I can see the logic if a patient is being very combative, but not out of fear that the person 'might' use it as a weapon.

When hospitalized, one takes on the role of patient, which is in many ways the opposite of independence. Convenience to staff can take precedence over patient autonomy. This may be okay for a short hospital stay, but for a longer care facility the person's access to the AT is important both physically and psychologically.

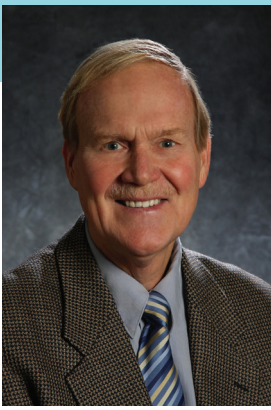
Strong advocacy will be necessary. ■

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.

PHI asked Dr. Maynard the same question. See his response in "Ask Dr. Maynard" on page 10.





Frederick M. Maynard, MD

Ask Dr. Maynard

Send your questions for Dr. Maynard to info@post-polio.org.

See other questions at www.post-polio.org/edu/askdrmay.html.

Question: My sister who had polio in 1953 at age 17 was affected from the waist down. She also struggles with bipolar disorder. Last winter she was hospitalized on a behavioral health floor for 44 days. Her crutches were taken away because they were considered weapons. She spent the days in a wheelchair and did not receive any physical therapy. Upon her release, we found she has lost what strength she had and now uses the wheelchair all of the time and is in a nursing facility. It is difficult to convince hospitals to allow the use of the usual assistive devices or equipment, and even more so, when it is a mental health facility. Do you have any advice for the family members who are advocates?

Answer: It is very important for family members or friends to become effective advocates for polio survivors when they are hospitalized for serious medical problems, including mental health problems. One of the best ways that they can do this is to read PHI's monograph titled "Post-Polio Health Care Considerations for Guidelines for Families & Friends" available at www.post-polio.org/edu/healthcare/.

They will learn that it is an important issue for a polio survivor to minimize any major decrease in their usual daily activities, especially walking and self-care related mobility. This is because a polio survivor's strength and/or flexibility can rapidly decrease with inactivity. Most health care professionals cannot be expected to know this.

One of the basic problems your sister's unfortunate experience illustrates is the difficulty our current health care system has in treating people with "double diagnoses," such as an acute mental health condition necessitating hospitalization AND a chronic medical disability condition. Significant post-polio leg weakness requires continued physical exercise to not worsen, even if a person's usual daily walking provides sufficient exercise.

Your sister should have received physical therapy services in order to ensure that her walking would continue in a manner safe in her unfamiliar environment of a psychiatric facility. An advocate might need to explain to physicians and nurses of the psychiatric facility that continued walking with crutches and performance of other self-care activities in her usual fashion are essential for her continued capability for doing them in the future. It is important for them to understand that her daily walking is as necessary as continued insulin or chemotherapy treatments for a person with diabetes or cancer who is hospitalized in a psychiatric facility.

One of the challenges for family members or other advocates who may try to ensure that a polio survivor's need for usual activity-related exercise are met is that they must "play by the rules" of confidentiality and get written permission from the patient to speak with providers, especially when a hospitalization is for mental health problems.

This can present a formidable challenge. In addition to addressing necessary assistive device use and usual activity, one of the best things for an advocate to insist on is a consultation by a physician who is familiar with the polio survivor's usual needs for maintenance mobility and independence. This could be a primary care physician or a physical medicine and rehabilitation or neurology specialist who knows them and who is willing and able to get involved.

In summary, my best advice is to "get involved" and to not rely on or trust the "system" to do the right thing relative to addressing important special needs arising from a person's polio-related impairments and adaptations. ■

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