

## Learning to Drive Again: One Hand at a Time

Joan Langhi, St. Louis, Missouri, jlanghi@sbcglobal.net

I had polio in 1949 at the age of one. My legs were affected, and after a lot of corrective surgery, I was able to walk with crutches and braces. By fourth grade, I no longer needed the braces and just used the crutches.

I graduated from college and taught in elementary schools in St. Louis and Mexico City and now work for *Yellow Pages* in downtown St. Louis. I am an avid swimmer and lead an active life. I live independently, so I am mindful of safety in all of my activities.

About five years ago, the strength in my arms began to rapidly deteriorate from overuse. After a shoulder replacement three years ago, I started using a walker. Last year, my doctor said that I needed a brace on my right leg to protect my knee, so I started wearing one, and I loved it – it was doing the job it was intended to do.



Joan Langhi, ready to drive with one hand on the spinner knob and one on the brake and accelerator control. "My van came with automatic door openers, which really helps when I stow my walker in the back seat."

What was not intended was the weight of the brace being just heavy enough that I could not safely use my right leg to operate the accelerator and brake pedals in my car. I'd been driving for years and had a wonderful little station wagon. Although it had been suggested when I had the shoulder replacement that I look into vehicle modification, I ultimately didn't want to do it – at least not until the leg brace.

I was grappling with emotions – the brace was helping me, but wearing it felt like a setback. I couldn't imagine giving up driving a car. Luckily, a wonderful associate pastor at my church

who had a spinal cord injury encouraged me to contact United Access, the company that modified his van.

United Access referred me to an occupational therapist who is a Certified Driving Rehabilitation Specialist for an assessment of driving skills, alertness and strength. I had three sessions learning to drive with hand controls (which felt like being told to be left-handed after being right-handed all my life). With my left hand, I push forward on a lever to operate the brake and push down to operate the gas. The occupational therapist also found that there was significant absence of strength in my right arm, and recommended reduced-effort steering with a spinner knob.

A salesman at Bommarito Nissan found a used van that was well suited. Then, Stephen Kinstler at United Access put me in touch with a Missouri state agency that offers low interest loans for vehicle access modifications. The process took several weeks, but the vehicle, of course, needed to work for me and fit my budget.

I was particularly concerned about my ability to parallel park using the hand devices. With a little practice, I've been able to accomplish this too. I can drive with confidence. I am a blest woman!

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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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## **Worthy of Note**

PHI's mission is to assist the survivors of polio, and we purposefully have not utilized our limited resources to eradicate the poliovirus. However, we constantly monitor the progress of the eradication effort and look forward to the day the job is finished.

PHI is asking you to thank Rotary International for their commitment to end polio and at the same time educate them about the accomplishments and needs of polio survivors. Help us educate them about PHI's mission. (See back page and the "Advocacy" section of [www.post-polio.org](http://www.post-polio.org).)

### **From the eradication front:**

Rotary International has raised \$136 million of \$200 million to meet the Gates Foundation challenge of \$355 million that will make a total of \$555 million to help "End Polio Now."

Facing new cases of polio in under-vaccinated countries, such as Tajikistan, which reported 334 polio cases as of June 29, the Global Polio Eradication Initiative unveiled its new Strategic Plan 2010-2012 ([www.polioeradication.org/content/publications/StratPlan.2010-12.asp](http://www.polioeradication.org/content/publications/StratPlan.2010-12.asp))

Progress is evident in Nigeria, where case numbers have plummeted – from 312 cases at this time last year, to three in 2010. In India, the remaining endemic states of Bihar and Uttar Pradesh have not reported any wild poliovirus type 1 cases concurrently for more than six months.

Michael Brady, MD, FAAP, chair of the American Academy of Pediatrics Committee on Infectious Diseases, in the July 15th issue of *AAP News*, warns that U.S. polio immunization rates are lower than 90 percent in many areas due to a lack of concern because there has been no recent experience in the United States, concerns about vaccine safety, religious objections to immunization and anti-vaccine activities. He advises that his colleagues, "need to ensure that their patients are fully vaccinated against polio. They also should report any case of flaccid paralysis to their local health departments."

### **Looking ahead:**

The post-eradication era will include the eventual cessation of oral polio vaccine (OPV) use in routine immunization. Because of the increased cost of the inactivated polio vaccine (IPV) which includes the cost of vaccine, syringe and trained personnel, versus the OPV, which is currently 8 cents a dose for public programs, good news resulted from a recent trial. Data indicate that in Oman, fractional doses of IPV injected just under the skin at two, four and six months, as compared with full doses of IPV given intramuscularly in the same schedule, achieved similar antibody development, although at lower levels.

*Joan L. Headley, Executive Director, PHI*

# When Do You Need a Power Chair?

Lawrence (Larry) C. Becker, PhD, Roanoke, Virginia, lbecker@bookwork.net

Saul Morse, JD, Springfield, Illinois, SaulMorse@sbcglobal.net

*Larry Becker and Saul Morse, both polio survivors and members of PHI's board of directors, recently took delivery of new power wheelchairs – both, coincidentally, are Permobil chairs made in Sweden. PHI asked Larry and Saul to share their experiences and decision-making processes with readers who may be contemplating a power chair purchase.*

**PHI:** When did you have polio, and what assistive devices have you used in the past?

**Larry:** I contracted polio in 1952 at age 13. It affected my hands and arms, but not my legs and feet – what we called “upside-down” polio. Through college and graduate school and then 20 years of teaching, I used a chair occasionally and had a golf cart to get around campus. I rented a chair in the mid-1980s and finally bought the first of three scooters, which had to be modified with foot controls.

**Saul:** I had polio in 1949 when I was 21 months old. The next two years are a blur. I was separated from my family and isolated in an iron lung. I came home with a manual wheelchair. I have no recollection of a time when I didn't use one. After graduating from high school, I entered the University of Illinois, which had started a program for disabled veterans following World War II. You had to be able to push yourself, and we had to push a mile-and-a-half before breakfast to get in shape. Power chairs were not allowed, and there were no ADA laws on the books. I used a manual chair exclusively until the early 1980s when I traded my van in for another and also got a scooter.

**PHI:** When and why did you first purchase a power wheelchair?

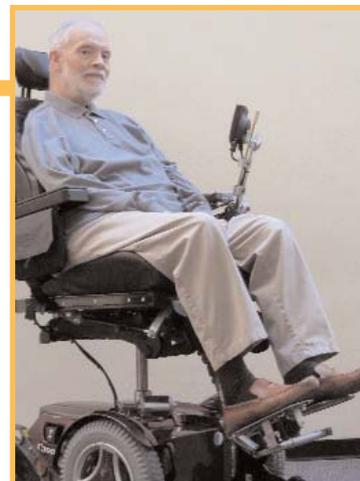
**Larry:** I got my former power chair, which was something like a personal assault vehicle – with foot controls – in 2001. I was having trouble with

transfers at the office, and it was increasingly difficult to transfer at home. I have read all about the late effects of polio, but I have always had a tussle acknowledging new problems as developing problems that might get worse. So I just bought the first power chair off the rack, without any modification other than the foot control, and without getting a thorough evaluation.

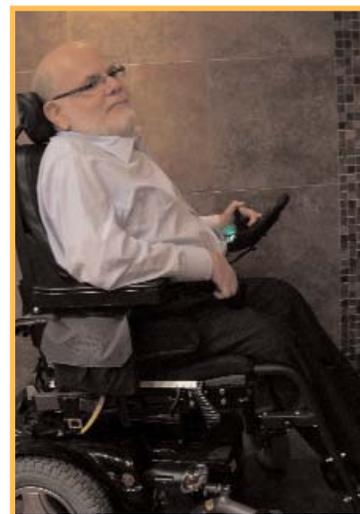
**Saul:** In the late 1980s, I represented an equipment supplier and received two manual wheelchairs as an initial fee and, later, a power chair because I didn't think I would be paid otherwise. At the time, my son was three, and I found that I was able to chase him better in the power chair and could also take him for rides. And I discovered that I was not as exhausted at the end of the day. By the early 1990s, I was using a power chair 80 to 90 percent of the time and, finally, all the time, except for transferring out of bed in the morning (and briefly when I had a mid-life crisis convertible and had to use a manual chair).

**PHI:** What factors did you consider in your recent purchase of a power wheelchair?

**Larry:** I think the crucial considerations in my case were first, what uses I could now make of the chair that would be helpful, and second, what my needs are likely to be for the foreseeable future. Some of the features on the old power chair were not



*Larry Becker with his new chair elevated “to the max.” “The seat puts me on the same vertical plane as the center of gravity so it is very stable, and I am on an eye level with anyone under 5 foot 8 inches or so.”*



*Saul Morse operates his chair with a left-hand joystick. “The controller screen shows me the ‘drive profile’ of the chair, and has a speedometer, odometer, an indication of the charge level of the battery and a clock.”*

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## When Do You Need a Power Chair?

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*Detail of Larry's foot control. In drive mode, pushing the toe down produces forward motion, heel down is backward motion, and toes outward or inward turn the chair. "There is a very secure neutral position, so I can actually safely rest my foot in the position shown. Getting back into drive mode just takes a quick rightward flick of my foot."*

always the best ergonomically, and it was not only getting old and unreliable, but also hard to use.

I have full muscle control in my feet and require a foot-controlled chair. In the old chair, the control was mounted on top of the foot pedal, causing me to shift weight onto my left hip. It was also very touchy. I couldn't safely let my right foot fully rest on it, even while I was driving. I talked to a rehabilitation engineer and to an occupational therapist (OT) and an adaptive technology engineer, who observed me in my office to assess my needs. They agreed I needed a new chair, but they insisted that it be a custom chair and that I go through a full evaluation.

**Saul:** I've now had several power chairs. It used to be that insurance companies considered the useful life of a chair to be five years, but not any more. My old chair is a Permobil that is six-plus years old and has been used 14 to 18 hours a day every day of the year. I wanted a new Permobil that was identical because I drive my van in the chair – it rolls in and locks into place. Permobil is reputed to be the world's best mass-marketed chair, perhaps because manufacturers in Europe are required to pay for any repairs during the first five years, so they are built to last.

**Permobil** has been committed to enhancing the lives of people with disabilities for more than 40 years. As a world's leader in developing and manufacturing powered wheelchairs, Permobil is a global company whose products can be found in more than 30 countries on four continents. Its world headquarters office is Timrå, Sweden. Its North American headquarters is in Lebanon, Tennessee. Permobil's products include power wheelchairs, seating operations, accessories and operating systems. For more information, visit [www.permobil.com](http://www.permobil.com)

**PHI:** What was the administrative process you went through to get and fund the new chair?

**Larry:** The first step was to meet with my doctor who wrote an order – in my case to Medicare – saying that I needed a power chair. I made several trips to the Woodrow Wilson Rehabilitation Center, which provides comprehensive medical, assistive technology and vocational rehabilitation services to Virginia citizens with disabilities. I tried out lots of chairs on a variety of terrains. A durable medical equipment supplier (DME), who certifies to the insurance company that a power chair is needed, sent specialists to do a home evaluation. Meshing schedules with all these people meant that this full assessment took about six months with a lost paperwork glitch adding several weeks. Because mine is a customized chair, elaborate specifications were necessary for the factory fabrication. The chair was delivered to the rehab center and various features adjusted for my use. I can't use a hand-controlled joystick, and a foot-controlled joystick is not typical, so a factory representative was involved in getting that installed under the foot rest.

**Saul:** I had a face-to-face meeting with the doctor, who wrote the order. I had an OT evaluation and a DME home inspection. My insurance is through the state of Illinois, as a retired employee, and initially they wanted me to buy a cheaper model. After some negotiation, we reached an agreed price, and the power chair was ordered. People who need a high-end custom chair have to work for it! When the chair was delivered, the OT reviewed my needs and made some adjustments. ▷

## Learning to Drive: One Hand at a Time

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**PHI:** Tell us about your new chair.

**Larry:** It's an astounding chair! The foot control is wonderful – a joystick turned on its side and mounted under the foot rest. The chair has an elevating seat, which helps with transfers, and I can now carry on a conversation eye-to-eye with most people. Getting enough ground clearance for the foot control required putting a slight tilt in the seat, and although I don't need it now, the seat also reclines. The chair also has "attendant control," a joystick usable by someone else. The foot control is equipped with Bluetooth® capability for wireless operation of my computer mouse. An on-board screen that I can operate with either the foot control or a mouthstick indicates seat position, drive speed and battery level. It's a front-wheel drive and weighs 260 pounds. The top speed is 5 miles per hour. The technology is so good now – I think it's the only chair I'll ever need.

**Saul:** My chair has a left-hand joystick. It has a seat elevator, which is great for restaurants, talking to people at eye level and transferring to high beds in hotels. I also got a seat recliner that I use more than I had imagined. It's a rear-wheel drive and weighs 280 pounds. Top speed is 7 to 8 miles per hour. I like speed! ▲

**Stephen Kinstler**, United Access Mobility Specialist, St. Louis, Missouri, [skinstler@unitedaccess.com](mailto:skinstler@unitedaccess.com)

More than half of the modifications we do are non-driver modifications – wheelchair and scooter ramps and lifts, van door and roof extensions, etc., that have to do with mobility issues.

Because Joan needed driver modifications, she had to be assessed by a Certified Driving Rehabilitation Specialist, an occupational therapist who gives us an independent, impartial evaluation of what is needed. The therapist provides on-the-road driver training on hand controls and may be able to develop exercises to strengthen driving muscles. The therapist also observed that, in Joan's case, reduced-effort steering was needed. This reduces the amount of strength required to turn the wheel by half or more and can even to go zero.

Joan recognized that she needed help and she got it. Mobility changes for people who have had polio are often gradual, and they sometimes feel they are giving up something when they get help. I had a spinal cord injury, so, for me, change was instant, but I understand the reluctance to give something up. I say, don't be afraid to need a little help – it's out there if you just look. ▲



Stephen Kinstler

**UNITED ACCESS** is an industry-leading provider of wheelchair accessible vehicles, driving systems, mobility seats, handicap lifts, and other vehicle modifications serving customers in Missouri, Illinois, Kansas, Tennessee, Arkansas, Indiana, Oklahoma and Mississippi. [www.unitedaccess.com](http://www.unitedaccess.com)

**ABLEDATA Informed Consumer Guide** – A comprehensive website that lists a broad range of potential state-specific sources of funding and funding information for assistive technology and provides lists of specific organizations and programs from which funding and funding information are available. [www.abledata.com/abledata\\_docs/funding.htm](http://www.abledata.com/abledata_docs/funding.htm)

# Swallowing Difficulty and the Late Effects of Polio

Barbara C. Sonies, PhD, CCC, BRS-S, College Park, Maryland, bsonies@hesp.umd.edu



**Barbara C. Sonies, PhD, CCC, BRS-S**, is a Board Recognized Specialist in Swallowing and Swallowing Disorders and Professor, Department of Hearing and Speech Disorders, at the University of Maryland in College Park.

**A** major polio epidemic in the mid-20th century left many survivors with a wide variety of physical limitations including problems swallowing foods. Many persons with swallowing problems also had original bulbar signs of polio including difficulty breathing, clearing the throat, speaking and singing.

Some persons however, had no overt signs of swallowing difficulty and seemed to recover many of their original physical abilities. Twenty to 30-plus years after the original polio episode, many people began to experience new signs of muscle weakness with difficulty walking or breathing and new problems with swallowing. Many polio survivors are now beginning to complain of difficulty swallowing and food getting stuck in their throats.

In a series of studies completed at the National Institutes of Health in 1991-1996 by Dr. Barbara Sonies and Dr. Marinos Dalakas, and in other studies, it has been substantiated that new swallowing complaints begin to emerge decades after the initial polio onset. Many people are only mildly aware of any change, and others who deny swallowing problems actually do have symptoms. An informal survey taken in 2003 of 23 persons diagnosed with post-polio syndrome (PPS) indicated that more than half had both new complaints of swallowing difficulty.

## **What are the possible causes of changes in swallowing?**

Current thinking is that muscle overuse is responsible for swallowing problems that are emerging as new symptoms or reappearing in persons who recovered from swallowing problems years ago. The assumption is that the remaining fewer healthy nerve fibers and muscles they innervate (motor units) become overused. This overuse

appears to cause a slow deterioration of the function of the head and neck bulbar muscles needed to swallow. Once-healthy muscles of the face, palate, tongue, throat, lips and larynx become weakened. Because many of the muscles and nerves that control swallowing also control speech and voice, changes making swallowing more difficult may also make speaking more difficult.

## **What should I expect from a swallowing diagnostic examination?**

To evaluate and make an appropriate treatment plan for someone with a swallowing disorder, a clinical swallowing assessment should be conducted. In this examination, the strength and coordination of the various muscles used to swallow will be assessed during a series of activities. If weakness or incoordination of the muscles of the mouth and throat are found, strategies for treatment will be suggested.

Swallowing safety will be observed during eating a meal or with liquids and soft foods in a clinical setting. A thorough history of medical/surgical diagnoses, medications, allergies and family and caregiver observations will be included along with a history of the polio progression. Oral hygiene and condition of the teeth will also be evaluated.

If the swallowing problem is such that the person is at risk for aspiration, where food enters the airway, an instrumental swallowing examination

### What are some signs of swallowing difficulty?

A wide but consistent range of complaints is noted including food sticking in the throat, trouble swallowing pills, coughing during eating, food backing up from the throat, eating a meal takes longer and unintentional weight loss. A self-assessment questionnaire for dysphagia (swallowing disorders) listed below can help determine if you need further attention (adapted from Sonies, BC, Parent LJ, Morrish K, Baum, BJ, *Dysphagia* 1:178-186, 1987).

If you answer YES to more than three of the following questions, seek consultation from a physician and speech-language pathologist.

If you have many of these symptoms, contact a speech-language pathologist at a hospital or rehabilitation center who specializes in dysphagia. (Go to [www.swallowingdisorders.org](http://www.swallowingdisorders.org) to see a listing of specialists in your state.)

- Do you have difficulty swallowing?
- Do you have difficulty chewing hard foods?
- Do you have an overly dry mouth?
- Do you have excessive saliva or drooling?
- Do you cough or choke during or after swallowing?
- Do you have a feeling that food catches or remains in your throat?
- Do you have continual mucous dripping into the throat?
- Does your voice become hoarse or gurgly after you swallow?
- Do you have food particles backing up into your throat or mouth?
- Do you have heartburn or indigestion?
- Do you have difficulty swallowing liquids?
- Do you have difficulty swallowing solids?
- Do you have difficulty swallowing pills?
- Do liquids sometimes come out of your nose?
- Does it take you longer than everyone else to eat a meal?
- Have you had episodes of airway obstruction during eating?
- Have you had frequent pneumonia or aspiration pneumonia?

will be conducted. The two primary techniques are the *modified barium swallow* and a *fiberoptic swallowing examination* of the throat. These procedures will help to determine if the problem is in the oral, pharyngeal or esophageal phases of the swallow. Both of these techniques are objective and can assist in determining the severity of a problem and allow the clinician to suggest proper treatment.

### What can I expect from swallowing treatment?

Most of the swallowing problems experienced by persons with PPS can be treated. For example, if one side of the body is weaker, specific strategies can be used that can help swallowing be more efficient. There are other strategies that can help to develop better oral sensation, move food from

the mouth through the throat, alter foods so that they can be swallowed safely and reduce risk of aspiration. Postures and positions can be used to help food enter the throat and esophagus without sticking. Some treatments use food, and others focus on muscle strengthening, biofeedback and rehabilitation without food until the strategy is safe to use while eating. Depending on what was found in the clinical and instrumental examination, treatment will be individualized to suit the findings and provide optimal help for each person.

Although PPS may be progressive in some cases, the strategies to improve swallowing can assist in stabilizing the swallow to maximize safety and provide adequate nutrition.

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### Modified Barium Swallow:

A radiologic examination, performed while the patient swallows barium-coated substances, that assesses quality of the swallowing mechanisms of the mouth, pharynx and esophagus.

### Fiberoptic Swallowing

**Examination:** A procedure to diagnose swallowing disorders by inserting a flexible fiberoptic endoscope through the nasal passage into the hypopharynx, allowing direct observation of the pharyngeal and laryngeal structures during swallowing.

### Suggested Readings and Websites:

- BC Sonies, Speech and Swallowing in Postpolio Syndrome (2004) in (Eds.) Silver JK & Gawne AC, *Postpolio Syndrome*, Hanley and Belfus, Philadelphia.
- BC Sonies, Long-term Effects of Post-Polio on Oral-Motor and Swallowing Function. (1995). In (Eds) Halstead LS & Grimby G. *Post-Polio Syndrome*. Hanley & Belfus, Philadelphia.
- Board Recognized Specialists in Swallowing and Swallowing Disorders website: [www.swallowingdisorders.org](http://www.swallowingdisorders.org)
- American Speech Language Hearing Association, Special Interest Division on Swallowing. Rockville MD, [www.asha.org](http://www.asha.org)

# Promoting Positive Solutions



Rhoda Olkin, PhD

**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:** If I am told, “I never think of you as disabled,” should I be complimented or insulted?

**Response from Rhoda Olkin, PhD:**

This question created an opportunity for discussion among some of us. Some people wanted to delete “or insulted” at the end of the question, after getting feedback from a few folks who couldn’t understand why someone might be insulted. But I wanted to keep the phrase there, because I really do get why someone (myself included) might be insulted by being told “I never think of you as disabled.” I’d like to try to explain why.

First, let’s examine what someone might mean if they tell you they don’t think of you as disabled. I believe the person means it as a compliment. S/he is saying that you seem very able, that you don’t pity yourself, that you engage in activities much like someone without a disability would, that you don’t use disability as an excuse and that you seem to have overcome your disability to the greatest extent possible. That’s a good thing, yes?

Yes. But there is a flip side. Though let’s be clear about the language: I am not a *disabled person*, I am a *person with a disability*. There is a difference. I also am a mother, female, Jewish, a psychologist and a person who had polio. It’s one of a list of things, not the main thing, so I relegate it to the background.

But imagine someone saying to me “I never think of you as Jewish.” What might this mean? Does it mean I think, behave and talk so much like a non-Jewish person that my Jewishness disappeared? And would I be complimented or insulted by this statement?

I think you can see why I would be insulted. “Ahhh,” you say, “but Jewishness is something to take pride in, while disability is not.” Isn’t it?

There is a certain pride in being a person with a disability. It means I have survived, have experienced suffering and become more empathic for it, have felt the cruelty of other children and grown stronger, learned a lot about myself as I faced discrimination, learned to choose my fights wisely, became expert in disability laws and rights, joined a disability community that challenged my viewpoints, juggled my pain and fatigue and still planted a beautiful garden and raised two children. Would I have done these things without a disability? Some of them, perhaps, but not the same way.

There are no answers to the questions “who are you without a disability?” or “how does having a disability change you?” I am who I am *with* my disability, not *in spite of* it. So when you tell me you don’t even notice my disability, I hear that part of me has been disavowed.

There is another reason I might feel insulted. *Disability* is not a dirty word. You don’t have to lower your voice when you say it. I am not ashamed of having had polio. (I may be annoyed, fatigued, in pain, sick of it, angry, fed up, but I am not ashamed – I did nothing wrong.) So if being a polio survivor is not shameful, why would I want someone to tell me that they don’t even see that part of who I am?

Try telling another person “I never think of you as \_\_\_\_\_” – and fill in the blank with gender, ethnicity, sexual orientation, religion or country of origin. See if s/he takes it as a compliment or an insult.

## Response from Stephanie T. Machell, PsyD:

There's no "right" way to feel about anything. How you feel is how you feel. From your question, I'm guessing that you felt confused or uncertain how you felt. Or maybe you felt more than one thing at once and had difficulty sorting it out. On a subject as complicated as your disability, it would be likely that you would have mixed feelings – maybe in this case both proud *and* insulted.

How you feel about yourself as a person with a disability most likely influences your feelings. Are you ashamed of your disability? Were you always able to "pass" as nondisabled and now PPS makes that impossible? If so, you might be proud that the other person sees you as still able to pass. Conversely, you may be proud of your identity as a person with a disability and so you might be insulted that the other person doesn't see or accept that part of you. If you are uncertain, it may be because you feel ambivalent and are struggling with how you feel about your disability.

How you might feel about someone saying he or she forgot you had a dis-

ability might also depend on the context, including how well you know him or her, what your relationship is, what you know about the person's attitudes towards disability and how relevant your disability is to the interaction the two of you are having.

For example, a close friend may not think of you as disabled because for him it is not the most important fact about you. People in close relationships where there are differences of gender, race or religion – or disability – often report forgetting about the differences until a situation that makes them relevant occurs. If your friend were to take you out to dinner to a restaurant that turns out to be inaccessible, your disability would be quite relevant to both of you.

You may be uncertain how to feel because you don't know how the person saying it meant it. She may not be a close friend, or you may not know how she views people with disabilities. Or her statement might bring up some issues or doubts for you. You could try asking this person why she said this, or (if appropriate) talking about how her answer made you feel. ▲



Stephanie T. Machell, PsyD

**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.

**Send questions for Drs. Olkin and Machell to [info@post-polio.org](mailto:info@post-polio.org).**

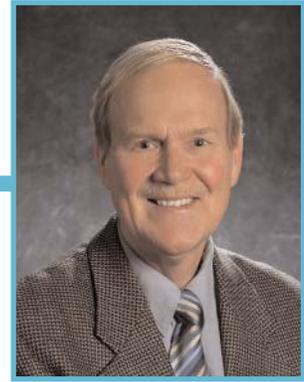
## Swallowing Difficulty and the Late Effects of Polio

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### Swallowing specifics for those with PPS

It is important that a swallowing examination be conducted periodically if any of the symptoms listed here are exhibited. Even if the problems seem minimal, swallowing should be evaluated, as people with PPS often accommodate changes that need

attention, and these can become full-fledged problems when ignored. Make sure to contact a qualified clinician for treatment. A modified barium swallow study is the most complete and reliable instrumental test to examine a swallow, so be sure to follow through if it is recommended and to follow up with additional studies if any changes in swallowing occur. Swallowing is an important human function that can be preserved in those with PPS. ▲



Frederick M. Maynard, MD

**Question:** *Can a Grade 3 concussion cause the onset of post-polio syndrome (PPS)? I developed the symptoms during recovery from a concussion and have been diagnosed as having PPS.*

**A:** Regarding your question about a Grade 3 concussion (the most serious level): After headaches and cognitive problems (poor concentration, attention and memory), fatigue is one of the most common post-concussion symptoms. Frequently, it is reported as “very low energy for doing anything” and “feeling exhausted after doing nothing.” A need to sleep 12 to 16 hours per day is common. When a polio survivor has a serious concussion, these symptoms may mimic those of PPS or aggravate mild, non-distressing fatigue present before the head injury. If an individual’s usual activity level is seriously reduced due to post-concussion fatigue and/or other symptoms for more than a few days, disuse weakness and fatigue can rapidly develop.

This type of new weakness and fatigue may, in fact, be no different than “typical PPS” new weakness and fatigue. However, it does have an other explainable cause (diagnosis) for developing, and therefore does not meet the most commonly accepted definition for PPS (*March of Dimes. Post-polio syndrome: identifying best practices in diagnosis and care, [www.marchofdimes.com/files/PPSreport.pdf](http://www.marchofdimes.com/files/PPSreport.pdf)*). Regardless of what it is called, it is especially important for a polio survivor whose PPS symptoms begin after a concussion to enter a comprehensive

rehabilitation program that includes appropriate, individually prescribed exercise. A well-designed exercise program undertaken over several months has an excellent chance of restoring function to pre-injury levels and essentially resolving PPS.

**Question:** *Are there any nutritional issues that polio survivors should pay special attention to? Are there any particular dietary needs or concerns? Any supplements that are beneficial?*

**A:** There are several important nutritional issues for people who had polio. No other issue is more important to good health than optimal nutrition, and no other is more controversial and little studied by good science.

The first issue is how to avoid excessive weight gain and obesity. Minimizing all refined sugars and grains is probably most important, particularly high fructose corn syrup which is now very widely used in processed foods and sodas. Portion control is also a central issue. Polio survivors are especially challenged to control weight and avoid developing type 2 diabetes (insulin resistance) because of their reduced muscle mass and limitations to vigorous exercise. Muscle tissue is the most important user of sugar and insulin in the body, and when there is less muscle to use, it is harder to keep blood sugar levels stable.

A second important nutritional issue is avoiding excessive sodium intake because it can increase the risk of hypertension (high blood pressure). Polio survivors have a

higher risk of hypertension, again because of decreased tolerance for aerobic exercise. Another special challenge is achieving healthy cholesterol levels and lipid profiles. It is more difficult to maintain high levels of good (HDL) cholesterol and low levels of bad (LDL) cholesterol without high levels of aerobic activity.

Additionally, a number of people, including polio survivors, cannot safely tolerate statin medications that are widely prescribed for cholesterol lowering. Many limit their intake of meat, dairy and eggs because of concerns about cholesterol, but this may leave them deficient in some essential fat-soluble vitamins only found in animal products, as well as low on essential amino acids. These amino acids and vitamins are critical to optimal muscle functioning, and polio survivors may be more sensitive to any relative deficiencies in these substances. Therefore, modest consistent intake of animal products is recommended with fish, white meats and grass-fed beef probably best.

The last issue is prevention of deficiencies in various vitamins and minerals. Vitamin D deficiency is very common today and contributes, along with low calcium intake/absorption, to the high incidence of osteoporosis in the United States. Less commonly known is that vitamin D deficiency can increase muscle and joint

## Thank you

For recognizing your friends and loved ones with contributions to support the unique mission of PHI and IVUN. PHI strives to publish an accurate list. Please contact us if we made an error.

### Contributions to PHI's educational, advocacy, and networking activities ...

#### In Memory of

Fredson Bowers	Robert Michael Mauer
Paula Brown	Theodore Mysliborski, Jr.
Dianne Marie Day	James E. Pratte
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► aches and pains, as well as lower energy levels – all common PPS symptoms. Vitamin D levels in the blood can now be readily measured and should be on survivors experiencing late effects of polio.

Adequate intake of B complex vitamins, especially vitamin B-1 (thiamine), vitamin B-6 (pyridoxine) and vitamin B-12/folic acid, are critical to nerve health and can be measured in the blood. Brewer's yeast and whole grains are excellent sources for insuring high levels of B vitamins, except B-12/folic acid, which must come from some meat intake. Fish is an excellent source of protein, the healthiest fats for a good lipid profile and a good source of vitamin D and vitamin B-12.

A high proportional intake of fresh vegetables and whole grains is recommended along with modest quantities of fruits and animal products. Organic foods should be considered since post-polio nerves may be more sensitive to the neurotoxic effects of pesticides. ▲

SEND YOUR QUESTIONS FOR  
DR. MAYNARD TO [INFO@POST-POLIO.ORG](mailto:INFO@POST-POLIO.ORG).

PHI Thanks its Members  
for their support. If you  
are not yet a Member,

## Join PHI!

Support Post-Polio Health  
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## Inside *Post-Polio Health* (Vol. 26, No. 3, Summer 2010)

Learning to Drive Again: One Hand at a Time ... p. 1 ■ When Do You Need a Power Chair? ... p. 3  
■ Swallowing Difficulty and the Late Effects of Polio ... p. 6 ■ and more.

Moving? Change of address? Please notify PHI before you move by calling 314-534-0475 or email [info@post-polio.org](mailto:info@post-polio.org).

**WE'RE  
STILL  
HERE!**  
October 10-16, 2010  
[www.post-polio.org](http://www.post-polio.org)

### PHI and Rotary International Collaborate

Post-Polio Health International and Rotary International call on Members of PHI to participate in a Rotary Club meeting the week of October 10-16, 2010.

**First, connect with your local Rotary** and ask if you may present a program about polio and post-polio. Call *now*, because many Clubs book their speakers months ahead. Use Rotary's "Club Locator" at [www.rotary.org/en/AboutUs/SiteTools/ClubLocator/Pages/ridefault.aspx](http://www.rotary.org/en/AboutUs/SiteTools/ClubLocator/Pages/ridefault.aspx)

**Second**, ask for the name of member(s) who are the most involved in polio eradication.

Contact this person and invite him/her to help you present facts about polio eradication and the late effects of polio.

**What are the facts?** Rotary has answered questions about the polio eradication effort, and PHI answered questions about the late effects of polio in "A Rotarian's Primer on Polio Eradication and Polio Survivor Support" and "Questions and Answers for a Visit to Rotary." Download both sets of Q&A from [www.post-polio.org](http://www.post-polio.org) or call 314-534-0475 for a copy.

**Third**, decide which of the questions you will ask each other, choosing ones that are the most appropriate for your town and country. Practice your part of the Q&A. Confirm how long you should speak.

**Fourth**, at the meeting, thank the Rotarians for what they have accomplished and encourage them to finish the job.

Take along some materials for the Rotarians about the late effects of polio to let them know WE'RE STILL HERE! There are several options to download from [www.post-polio.org](http://www.post-polio.org).

**Join the campaign – WE'RE STILL HERE!**