# Navigating the Seating and Mobility World with Post-Polio

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Navigating the seating and mobility world can be daunting for many with post-polio syndrome. Issues with scoliosis, back pain and even pressure problems can be quite serious for the person living with post-polio. If using a wheelchair, the solutions can be manageable and more easily rectified by customizing seat cushions or wheelchair backrests.

For those who are still walking, the solutions may not be so clear-cut. Walking is an activity that many take for granted but is a vital component to both quality of life and health. When problems such as scoliosis, back pain or pressure problems arise many people with post-polio are left with few choices that do not involve wheeled mobility. There are, however, options for these problems which may allow people to keep walking while avoiding secondary complications.

### **Pressure Problems**

Let's start with the pressure problems. The same cushions that are used in wheelchairs can often be used in regular chairs. These cushions can more evenly distribute pressure as well as provide pelvic support. Cushions come in a variety of materials including air, gel, fluid, foam or any combination of materials and have properties that are more effective at reducing pressure or providing pelvic support. A trained seating and mobility specialist can assist with the selection of the most appropriate cushion depending on the specific needs of that individual.

#### The Backrest Dilemma

The backrest dilemma is a more difficult one to address. Upright sitting is important for many reasons ranging from social to medical. Scoliosis can lead to problems with swallowing and breathing if left unchecked. Backrests designed for wheelchairs have many options for

providing lateral trunk support to help maintain the most upright and midline posture possible. Unfortunately, unlike wheelchair cushions, fitting these backrests onto everyday chairs is not easy due to the hardware and mounting requirements. Commercial lumbar supports do not provide adequate lateral trunk support although they can be helpful to prevent or reduce low back pain, and they can be attached to any chair.

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## **Don't Ignore Pressure Sores**

Mary Ann Buckingham, Worth, Illinois, 708-448-7237

Mary Ann Buckingham had polio when she was 12 and walked using braces and crutches. Now 73, she started using a wheelchair about 20 years ago when her arms became too weak to use crutches.

As a polio support group leader for 10 years, she was well aware of the danger of pressure sores and took preventive measures to avoid them such as rotating her weight every 15 minutes and never scooting out of the chair. And, until recently, she was successful.

"I never had one," she said, "and after getting a new cushion, I noticed a tingling and self-medicated with zinc oxide, which had no healing effect." She went to her family doctor who sent her to a wound clinic where she was diagnosed with a Stage 2 wound (the topmost layers of skin are severed with some drainage).

"They prescribed two different types of medicated patches and said the sore would heal in two weeks. I couldn't believe it, but it did" she said. "The first patch was ConvaTec DuoDerm® that I changed every two days and the second was 3M TEGaderm, a thin cellophanelike patch."

Both are hydrocolloid adhesive dressings coated with substances that promote wound healing without causing softening and breaking of tissue.

Her advice: Don't delay seeing a doctor if you think a pressure sore is developing and follow guidelines for prevention and treatment. See a seating and mobility specialist for evaluation and recommendations for proper cushions.

Mary Ann has an appointment for a seating evaluation in March.

See "Pressure Sores Are Painful, but Preventable" at www.post-polio.org/edu/pphnews/PPH27-4fall11p1etc.pdf.

Entitled "Post-Poliomyelitis Syndrome Is Not Associated with Brain Atrophy," the cross-sectional study was designed to determine if post-poliomyelitis syndrome (PPS) patients have smaller brain volumes than normal control subjects.

A 1.5 T Siemens Sonata machine was used for magnetic resonance imaging (MRI) of the brain of the following participants: 49 ambulatory PPS patients, 28 normal controls, and 53 ambulatory multiple sclerosis (MS) patients.

Normalized brain volume (NBV) was assessed using the automated program SIENAx. This method does not assess the brainstem.

Technically adequate NBV's were available for 42 PPS patients (mean age 60.88  $\pm$  7.62 years, mean  $\pm$  SD), 27 normal controls (mean age 46.96  $\pm$  14.56) and 49 MS patients (mean age 46.18  $\pm$  9.45).

As previously reported, in a multi-variable regression analysis adjusted for age, NBV was significantly lower in MS patients than controls (p=0.0054). However, for PPS patients, in a multi-variable model adjusted for age, NBV was not significantly different from normal controls (p=0.28).

The authors stated that based on previous studies, acute paralytic poliomyelitis is associated with encephalitis in essentially all cases, and that it is possible that this early brain involvement can produce permanent neuronal injury with brain atrophy. Encephalitis due to other viruses (such as Herpes I and II) in children has been reported to produce permanent parenchymal abnormalities.

To date (2012), there have been no studies of brain volume in PPS patients. This study, conducted at the Montreal Neurological Institute and Hospital, McGill University, includes a relatively large number of PPS subjects as well as a control group of MS subjects who are known to have brain atrophy.

In this study, Trojan and team confirm the presence of brain atrophy in MS, but do not find a significant loss of brain volume in PPS subjects. Because the method used to assess brain volume excluded the brainstem, it is possible that brainstem atrophy was not noted in this study.

# From PHI's Medical Advisory Committee

A few studies have been published regarding the use of IVIg for treatment of post-polio problems. (See Spring 2012, *Post-Polio Health*, Vol. 28, No. 2, page 9). PHI's Medical Advisory Committee states that as clinicians they are not ready to use it, or promote its use, based on the current evidence. The group enthusiastically supports a Randomized Placebo-Controlled (RPC) U.S. clinical trial of IVIg for post-polio syndrome.

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## **Funding and Access**

Funding and access must also be considered. Unfortunately, neither cushions nor backrests are covered by insurance unless they are being ordered for a wheelchair. The average cost of cushions ranges from \$300 to \$500 and backrests from \$300 to \$600. The cost can be self-limiting depending on the person's resources.

Access, however, in the form of an evaluation by a seating and mobility specialist is covered by insurance. People who are having postural or pressure difficulties should seek the help of a seating and mobility specialist to problem solve their unique case. This may entail modifying their everyday seating systems including office chairs, home chairs, etc., or recommending customized cushions that will help with their issues.

Both physical and occupational therapists can be trained as seating and mobility specialists. The Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) tests and certifies health professionals as assistive technology professionals (ATP). Seeking such qualified and certified health professionals is an important first step in determining solutions to the seating and mobility conundrum faced by people living with post-polio.