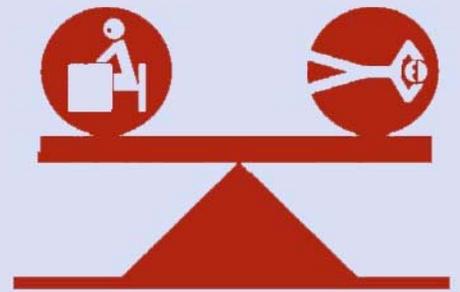


POST POLIO PACER

Conserving Strength and Energy through Pacing
April 2013— Madison, Wisconsin
Madison Area Post Polio Support Group Newsletter
MAPPSG formed in 1985 — This Is Our 28th Year!



Navigating the Seating and Mobility World with Post-Polio

Sara Kraft, PT, DPT, NCS, ATP, Asst. Professor, Medical University of South Carolina, Division of Physical Therapy. College of Health Professions, kraftsv@musc.edu

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.

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.

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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 top-most 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 Duo-Derm® that I changed every two days and the second was 3M TEGaderm, a thin cellophane-like 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.

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Happy and Healthy with Hobbies By Kathleen Blair, Columnist

We enjoyed a delightful discussion of hobbies at our March 9th meeting at Monona Garden Family Restaurant with 11 people in attendance. It was fun hearing about how we aging Pacers keep our minds sharp and our hands busy:

- making scrapbooks;
- baking and decorating 3D cakes for special occasions;
- belonging to several card clubs;
 - playing board games;
 - writing newsletters;
- preserving family memories with photos and journals, and
- having good conversations with friends and family.

All of these are hobbies of Pacers in wheel-chairs, on crutches, canes and walkers – proof that we know how to keep our lives meaningful.

Sheryl Shaffer’s hobby of making scrapbooks fascinated me. Sheryl told us she loves working with paper – different textures and colors – to create her own unique scrapbooks.



Cover of Sheryl's Scrapbook

She loves music and combines lyrics of favorite songs with photos to create special memoirs for her children and loved ones.



Graduation - "I'll have tears as you take off, but I'll cheer as you fly."

Find Your Wings is the song she used for her daughter’s special scrapbook. Captions under the photos of inside pages show the lyrics of the song for that page.

What a treasure this must be for Sheryl’s daughter!

I’ll tell you about some of the other interesting hobbies in our next issue of Pacer.

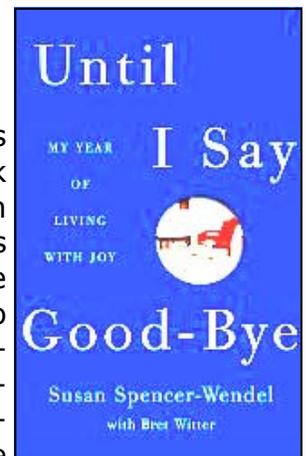
The Book Shelf

Until I Say Good-Bye. My Year of Living with Joy

by Susan Spencer-Wendel

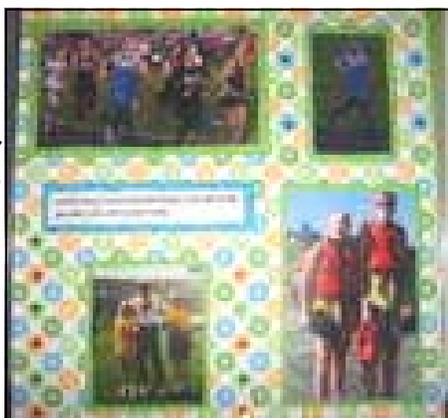
Book Review by Mary Parks

The author of this thought-provoking book was diagnosed with ALS in her middle 40s. Doctors indicated she would have about a year to be able to function “normally” – whatever that is. Spencer-Wendel was an award-winning reporter for the Palm Beach News for 20 years. Following the diagnosis she discovered she had a one million dollar life insurance policy that could be cashed and used prior to death, an option she decided to elect. After quitting her position, she established a bucket list, so to speak, of



Baby – "It's only for a moment you are mine to hold; the plans that heaven has for you will all too soon unfold."

Sports – "May conviction keep you strong, guide you on your way."



things she wanted to do and places she wanted to see while still able. High on her list was doing something with each of her three children to create memories for them after she was gone, such as taking her 14 year old daughter to New York City and among several activities, taking her to a bridal salon to try on wedding dresses, knowing she would never see her marry or have children.

Although not a polio survivor, it is possible to identify with much of her challenges as she loses the ability to wear high heels, feed herself, take care of personal chores such as dressing herself, and needs to rely on her husband, sister or best friend. Inch by inch, her muscles were weakened and forced her to need help. It is poignant and humorous, with cute vignettes – challenges of living with a disability – contained throughout. Of interest was the fact that she questioned why there was no cure available for ALS even though it has been around what seems like forever – a question many of us also have about PPS.

Ms. Spencer-Wendel is a good writer and the book is an easy read. Her goal in writing it was to leave something tangible for her children. How many of you have written down your life stories for your family, especially as they relate to being diagnosed with polio? Because her hands were affected early in the disease, she literally used her right thumb to write it with an iPad! Pretty remarkable.

Editor's note: New and used copies of the book are available in hardcover, paperback-large print and the Kindle edition from Amazon.com. Prices are \$14.29, \$16.39 and \$12.60 respectively.



In Memoriam

Dorothy Walker Lemon, 91, of Madison, and a long time participant in the Madison Area Post Polio Support Group, passed away on Jan. 26, 2013, at Oakwood Village West from the affects of osteoporosis and polio.



Dottie's long life included Bachelor and Masters degrees from Syracuse University with a focus on education and Vocational Guidance and Counseling. She met her husband, Wallace, while in graduate school. They moved to Madison upon their marriage and have resided here since then.

During the polio epidemic she contracted polio while pregnant with their 3rd child, Mark, and spent several months in the hospital. She underwent extensive physical therapy with the assistance of the March of Dimes. She showed her strong will and spirit in exceeding the doctors' expectations for recovery several times over, and regained her ability to walk.

A wide range of volunteer activities, gardening, buying and selling antiques, as well as playing hostess to neighborhood friends kept her quite busy and involved in the Madison area. In addition to road trips to Alaska to visit their daughter, Peggy, they also traveled to Florida, Europe and Mexico and to their Arizona home in the winter.

Dorothy is survived by her husband, Wallace Lee; and her children, Margaret "Peggy" Lemon, Diane Kiabe, and Mark Lemon; her son-in-law, Hamid Kiabe; and her brother-in-law, Robert Lemon.

Our condolences to the family. She will be missed.

The information above was excerpted, with the family's permission, from the January 29, 2013 *Wisconsin State Journal*.

Have you heard? Mark your calendar!

Polio Health International's 11th International Conference will be in Saint Louis, Missouri, in 2014.

For the eleventh time since 1981, we are gathering the survivors of polio and users of home mechanical ventilation, their families, health professionals, researchers, service providers and related organizations to collectively assist polio survivors worldwide to live a better life by **Promoting Healthy Ideas**.

Health in its broadest definition includes not only the physical, but the emotional, social, psychological and spiritual. Featuring "health" in our name when we changed it in 2003 was deliberate. People who had polio are much more than their untypical body, and "to enhance life and independence" we need to pay attention to all aspects of health.

To build a program with a theme of "Promoting Healthy Ideas," we need to know specific issues you want addressed. We plan to offer sessions that are educational, interactive, exploratory and fun. You are invited to send your ideas for the program to director@post-polio.org (or via the mail at Polio Health International, 4207 Lindell Blvd., #110, St. Louis, MO 63108-2930) for consideration by the Planning Committee. We may not be able to use all of them, but we request that you help us be relevant to you as a Member.

Here is your chance to help us decide what topics are the most pertinent. Let us hear from you.

Joan L. Headley, Executive Director, PHI

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Golden Rule of Post Polio Syndrome

"If something you do causes you fatigue, weakness or pain, you shouldn't be doing it!"

Do You Need a Caregiver?

By Betty Leiser

When some of your daily living activities are difficult or unable to do, think about who might assist you. Make a list of tasks you need help with, e.g., dressing, bathing, meal preparation, housekeeping, laundry, grocery shopping, etc. Ask your family and/or friends who have caregivers for their recommendations before asking for assistance or contacting an agency.

What is a caregiver? Generally speaking, a caregiver is a responsible person who cares for others and is *usually* unpaid, i.e., family or friends. If one does not have family or friends to assist, agencies are available in most areas and have RNs, LPNs, and Certified Nursing Assistants on staff. To find out which agency would best serve your needs, interview several caregiving agencies about their services, cost, staff training, etc.

What should you expect agency caregivers, who are hourly workers, to do? Caregivers assist with dressing, bathing and hygiene according to the clients needs. Other tasks provided as necessary include meal preparation, laundry, cleaning, and grocery shopping. In addition, the caregivers provide companionship and help the client live independently with dignity, based on the client's schedule and needs.

What are the responsibilities of the client? When interviewed by an agency, be clear about your needs and usual daily schedule. You will be asked to sign a contract before service begins. If client/caregiver personalities clash, you may ask for a different caregiver.

Check your eligibility for Medicaid, state and/or federal Long Term Support Programs such as CIP/COP (Community Integration Program/Community Options Program), Care Wisconsin, Inc., Community Living Alliance, Bright Star, Comfort Care and Dream Weavers. This is not an exclusive list of agencies and may be different outside of Dane County.

Polio/Post Polio Syndrome Resources

Post-Polio Syndrome Fact Sheet: **National Institute of Neurological Diseases...**

http://www.ninds.nih.gov/disorders/post_polio/detail_post_polio.htm

Post-polio syndrome—**Mayo Clinic** - Comprehensive overview covers symptoms, causes, treatment of the late effects of polio.
<http://www.mayoclinic.com/health/post-polio-syndrome/DS00494>

Understanding Post-Polio Syndrome - **Easter Seals**

<http://www.easterseals.com/site/PageServer?pagename=ntl>

Post-Polio Health International's Official Website What is Post-Polio Syndrome?

Post Polio Syndrome Resources - Polio/PPS Information for Polio survivors and those who may have family or friend who had polio. PPSR offers support, live chat, email support, and general information <http://www.ppsr.com/>

Post-polio syndrome (PPS) is a condition that affects polio survivors years after recovery from an initial acute attack of the poliomyelitis virus.

http://www.medicinenet.com/post-polio_syndrome/article.htm

Post-Polio Syndrome Central: Search/Browse this complete, comprehensive, easy to use and up-to-date listing of internet Post Polio Syndrome Resources <http://www.skally.net/ppsc/>



F.Y.I. from Marilyn Klotzbach

Many physicians are not open to information from other specialists in the field of PPS, like Dr. Bruno. I use articles from his Library Site anytime I have a procedure done, but I **always** include this site from *Anesthesiology, The Journal of the American Society of Anesthesiologists, Inc.*

http://journals.lww.com/anesthesiology/fulltext/2005/09000/postpolio_syndrome_and_anesthesia.29.aspx

I think it is a "must use" to compliment Dr Bruno's work.

Marilyn recommends reading this article.

<http://www.poliosurvivorsnetwork.org.uk/archive/lincolnshire/library/bollenbach/biology1.html>

Two Facebook Group sites that can be trusted:

[https://www.facebook.com/groups/Postpolio/Post Polio](https://www.facebook.com/groups/Postpolio/Post%20Polio)

<https://www.facebook.com/groups/148377278537482/>
Harvest Center, Coffee House

Editor's Note:

Thanks to Marilyn for the above information and reviewing the websites on the column to the left.

Your newsletter needs your help!

Space is available for reader's comments, polio related articles (with source), topics you would like more information about, your polio story, etc.... Just think, *your* contribution could be in the next issue of *Pacer* and would make the editor very happy.

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Do you have suggestions for speakers, topics, books to read and discuss, etc.? Call or e-mail (see e-mail list) one of the people listed above to suggest program topics or speakers, volunteer to organize one meeting program, share your knowledge (or find an expert) about becoming a non-profit organization or volunteer your talents (financial, organizing, etc.) as a committee member.

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*Spring is coming...
 Spring is coming...*



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To get your Pacer in color on line, set your email program to always accept messages from wghmch@chorus.net

Names in bold are new to the list or have an address change. To add your name and/or up-date your e-mail address to this list, notify Marcia Holman at: wghmch@chorus.net

POST POLIO PACER is a quarterly newsletter published in January, April, July & October for polio survivors, the Madison Area Post Polio Support Group, health care professionals and interested persons to share information and to promote friendships. Articles in this newsletter are for information; medical advice is always necessary.

Please request permission from the editor to reprint articles from the Post Polio Pacer.

Disclaimer: The opinions expressed in this publication are those of the individual writers and do not imply endorsement by Easter Seals Wisconsin or the Madison Area Post Polio Support Group.



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A NEWSLETTER FROM THE MADISON-AREA POST POLIO SUPPORT GROUP

Mark your calendars!

LOCATION:

Monona Garden Family Restaurant
6501 Bridge Rd., Monona
Noon to 2:30

Saturday, May 11, 2013

Jason Glozier, Disability Rights Specialist and Randy Black, Physical Disabilities Commission, will discuss their programs.

Saturday, July 13, 2013

Janet Bollig, Home Health United, will describe their programs.

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