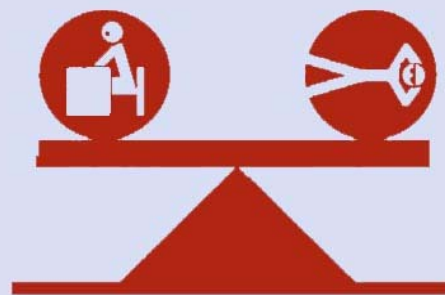


POST POLIO PACER

Conserving Strength and Energy through Pacing
July 2010 — Madison, Wisconsin
Madison Area Post Polio Support Group Newsletter
MAPPSG formed in 1985 - Our 25th Year



Living Well...With Chronic Conditions

The July 10 program is one you won't want to miss! Our presenters, Beth Kowall and Harvey Padek, Master Trainers, are from the Milwaukee Post-Polio Support Group, and received their training at Stanford University in 2006. They have made over 20 similar presentations in the Milwaukee area and one for the Janesville PP Group. They are funded through Columbia St. Mary's Hospital in Milwaukee and do this as volunteers.

Living Well...With Chronic Conditions is a program designed to improve the self-management skills of people living with a chronic health issue. This program teaches new strategies to provide confidence, motivation and skills needed to manage the challenges of living with a chronic health condition such as diabetes, asthma, arthritis, stroke, cancer, heart problems (and/or post-polio syndrome).

We look forward to seeing you at noon on July 10 at the Monona Garden Family Restaurant, 6501 Bridge Rd., Monona.

Energy Conservation Suggestions

by Eileen Donovan, PT

Reprinted from & with permission of the Dystonia Medical Research Foundation – Dystonia Dialogue, Vol. 32, No. 3*

Editor's Note: Although written for people with dystonia, many of the suggestions also apply to those with PPS. Check off the items

you do to evaluate your energy conservation.

Energy conservation is not just for environmentalists. Adjusting to live with dystonia often means learning to manage fatigue and/or pain. It may be necessary to find new ways to do everyday tasks. Below are suggestions from several sources for conserving energy when it's at a premium.

General

- Plan activities for the day/week to allow energy 'budgeting'.
- Keep a fatigue diary for two weeks.
- Identify what makes the fatigue better or worse.
- Select activities most important to you.
- Adhere to an exercise program tailored for you.
- Eliminate unnecessary work.
- Combine, change the sequence of, or simplify tasks.
- Work in a well-ventilated & lighted room.
- Use both hands whenever possible.
- Plan rest periods, properly spaced.
- Rest eyes periodically.
- Maintain moderate pace, use slower pace if hot or humid.
- Maintain rhythm; saves energy.
- Use music as relaxation or stimulation.
- Change body position and motions.
- Sit to work instead of standing.
- Arrange environment to minimize bending or reaching.

Bathing

- Wash hair in shower, not over sink.
- Sit to dry off; use a terry robe instead of towels.
- Use shower organizer to avoid leaning and

reaching.

- Use a shower bench or lawn chair to sit while showering.
- Use a hand-held shower while sitting.
- Use a long-handled sponge/brush to reach feet and back.
- Wrap things that are hard to hold, such as toothbrushes, eating and writing utensils, in a sponge or foam rubber pad to make them easier to use.

Grooming/Hygiene

- Don't lean forward unsupported.
- Rest elbows on counter or dressing table.
- Use long-handled brushes/combs to avoid holding arms overhead.
- Use elevated commode seat.
- Soap on a rope enables you to use it with one hand, and keeps it from falling. A liquid soap dispenser may be even easier.
- Install grab bars in your bath or shower to prevent falls.
- Electric toothbrushes make brushing easier.

Dressing

- Organize early so you won't have to rush.
- Lay out clothes to avoid extra steps.
- Bring foot to opposite knee to apply shoes/socks to avoid leaning over.
- Wear slip-on shoes.
- Use long-handled shoe horn and sock aid.
- Fasten bra in front, then turn it around (*or purchase front-closing bras*).
- Wear button-front shirts rather than pull-overs (for hand problems, it can be the reverse).

Mobility

- Wear low-heeled shoes with shock-absorbent sole/insole.
- Use wheelchair for long trips (i.e., shopping).
- Get a rolling walker with a built-in seat and a basket for carrying stuff.
- Install ramps.
- Move around the house in circles, not back and forth.
- Lead with your strong leg when going up-stairs. Lead with your weaker leg when going down.

- Stairs: consider putting rails on both sides, consider a mechanical chair lift. Put a chair near the top of your stairs to rest after climbing.

Housekeeping

- Spread tasks out over the week.
- Do a little each day.
- Delegate heavy work.
- Hire help if possible.
- Use a wheeled cart or carpenter's apron to carry supplies, things to put away.
- Do whatever you can sitting (e.g., ironing, food preparation).
- Use long-handled dusters, mops, dust pan, etc.
- Get long pick-up tongs like gardeners use.
- Use long-handled sponges to avoid bending.
- A small hand vacuum cleaner may be easier than using rag or picking up by hand. Keep it on your cart.
- *A reacher is indispensable – can pick up most items from the floor or even get things off shelves.*
- *Cordless vacuum cleaners are lightweight and easily maneuverable.*

Shopping

- Organize grocery list by store aisle.
- Use grocery cart for support or power scooter if store has one.
- Request store assistance while shopping and getting to car.
- Shop with a friend at less busy times.
- Delegate shopping.

Leisure

- Wear comfortable clothing.
- Use adaptive equipment.
- Select less strenuous activities.
- Go with a friend.
- Use wheelchair or golf cart.

Meal Preparation

- Assemble all ingredients before you start.
- Use mixes or pre-packaged foods (but check nutritional info!).
- Use cookware you can serve from.
- Use smaller appliances.
- Buy ergonomically designed utensils.

- Transport items on a rolling cart.
- Store frequently used items at chest level to avoid bending.
- Let dishes soak rather than scrubbing.
- Air dry dishes.
- Use a dishwasher.
- Delegate dishwashing.
- Use a jar opener.
- Use a rubber mat or wet towel under mixing bowls to help steady while stirring/mixing.
- Don't lift heavy pans off stove. Ladle food out at the stove.
- Use placemats instead of tablecloths.
- Use lightweight utensils.
- Prepare double portions & freeze half for later.
- Obtain support from Meals on Wheels if you qualify or can afford.
- Sit down to prepare food.
- Trade meal preparation nights with a neighbor, friend, or relative.
- Have restaurant food delivered, if you can afford it and it's healthy.
- *If you use a wheelchair, a stainless steel or aluminum roaster/broiler pan works well as a tray to carry items for food preparation and cleanup.*

Laundry

- Use laundry cart on wheels.
- Use automatic washer/dryer, if possible.
- Sit to transfer clothes to dryer, if possible.
- Drain hand washables and press water out instead of wringing.
- Sit to iron. Use lightweight iron with spray attachment.
- Hang clothes on doorknob instead of top of door.
- Delegate laundry or have laundry professionally done, if possible.

Childcare (or grandchild sitting)

- Plan activities to allow sitting.
- Delegate some childcare responsibilities, if possible.
- Teach small children to climb onto lap instead of being lifted.
- Teach children to make a game of household chores (or just tell them to do them!).

Workplace

- Plan workload around your best times of day.
- Arrange workspace ergonomically.
- Take rest breaks.

**"Suggestions for Energy Conservation" was compiled by Eileen Donovan, PT, Med, a physical therapist at the University of Texas M.D. Anderson Cancer Center. Additional suggestions from a long list of practical tips in "Living a Healthy Life with Chronic Conditions" by Lorig, Holman, Sobel, Laurent, Gonzalez and Minor (Bull Publishing 1994) Even more suggestions from David Spero, RN, author of "The Art of Getting Well: A Five Step Plan for Maximizing Health When You Have a Chronic Illness" (Hunter House 2002).*

Editor's Note: A big thank you to Mary Parks for submitting the above article.

Easter Seals Campership Fund Donations

Many thanks to the following people who so generously gave to the Easter Seals Campership Fund at the May 2010 Madison Area Post Polio Support Group meeting or by mail: Kathleen Blair, Bonnie Haushalter, Marcia Holman, Fayth Kail, Gail Kempfer, Betty Leiser, Dorothy Lemon, Earl Mylrea, and Mary Parks. Our donations totaled \$362.



Actual costs at Camp Wawbeek exceed \$200 a day per camper to provide the high quality services needed. For the camper, it means an exciting vacation to renew old friendships, to make new friends, participate in challenging activities, laugh and enjoy doing fun activities they could never do at home.

For the family, it can also prove to be a much needed break. Easter Seals has never turned away a family for their inability to pay the Wawbeek camper fee.

It's not too late to make your donation to Easter Seals Camp Wawbeek Campership Fund. Make your check payable to Easter Seals Wisconsin, indicate it is for the Campership Fund and mail it to Easter Seals Wisconsin, 101 Nob Hill Rd., Suite 301, Madison, WI 53713.

If you would like to visit Camp Wawbeek, contact Ken Saville at 608.277.8288 x 108 or ksaville@wi.easterseals.com. Learn more about the Easter Seals programs at www.EasterSealsWisconsin.com

Handicap-able Traveling

By Kathleen Blair

Traveling with our handicaps, whether with the aid of a cane, in a manual wheelchair or in a power chair, is a grand opportunity for us polio survivors to renew our focus and enjoy what's beyond our own city and state. It's healthy and therapeutic.

Since 2007 I've drained some of my budget to go on pilgrimages to shrines in both the United States and Europe with the aid of my cane and manual wheelchair with someone pushing me. My heart is always warmed by the many kind people who eagerly step up to do this. Now I use a lightweight scooter that can be checked on an airplane or carried in the luggage compartment under the bus.

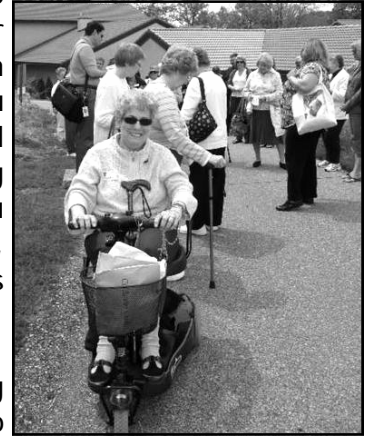
I've justified these trips by saying, "Well, I don't have that much money, but I think I have more money than time." I feel my legs getting weaker as time goes on, and in the back of my mind I tell myself that I can travel only as long as I can climb on a bus, so **I'd better go now**. As my next door neighbor has suggested, "Kathy, you don't want to be sitting here five years from now wishing you'd gone." **Right!**

My children are supportive as well. When I tell them I'm spending their inheritance –

which would be spread seven ways impacting only slightly their financial well-being – they respond, "Go for it, Mom!"

Well, I changed my mind about running out of time because of a lack of mobility after talking with Ruth Diehl about her recent train trip to New York with her husband, Bob. Ruth needs a power chair to move about.

I had been under the erroneous impression that train trips are no longer an option for me. My eldest son told me, "Mom, you need a cane to stand up in your own living room. How could you manage on a jerking, swaying train? It's just not safe for you."



Ruth proved us wrong when she related to me the adventures she shared with Bob on their journey to New York on Amtrak.

This picture was taken on a recent trip where I enjoyed the same mobility as those who could walk. And I didn't even have to breathe hard!

How did they manage this vacation? She contacted Amtrak directly and reserved handicap space in a train car where there was also a restroom with a wide door conveniently located nearby.

They traveled from Madison to Chicago on Coach USA that is equipped with a lift to get her power chair onto the bus. *She didn't have to climb onto the bus, which I've dreaded coming to an end for me too soon.*

"Each train station is different," Ruth said, "But all are comfortably accessible. Some have a portable lift; at some stations the train entrance is at ground level; and some use a ramp. But all provide safe and comfortable access to the train."

Together Ruth and Bob enjoyed the scenery as the train moved through Illinois, Indiana, Ohio, Pennsylvania and a bit of New York.

Ruth couldn't get to the dining car and, although Amtrak would have provided porter service, Bob chose to bring her food and refreshments himself.

The Diehl's adventure in New York sounded awesome. After beginning their tour of "The Big Apple" with Bob walking beside Ruth in her power chair, they learned that even the subway system is accessible. So, of course, they branched out and took in even more of New York City.

"We had a wonderful vacation," Ruth told me. "We visited the Empire State Building, saw the Statue of Liberty, attended two Broadway Shows and were even part of the audience for a couple of television shows."

Sounds like a wonderful experience to me.

Ruth and Bob Diehl are seasoned travelers having previously toured Europe, Asia, New Zealand, Australia, and parts of the Middle East and Africa using a manual wheelchair.

"Manual wheelchairs are easier to travel with," Bob told me. "Sometimes there are steps and places where a power chair just won't go."

In my own travel experience, the one or two times I encountered a place not accessible to me I accepted with no regret. I felt the trip was still worth the price, and I wouldn't have seen anything if I'd stayed home.

As Ruth and I chatted, I said, "You know, we have a choice. We can sit home in our recliners and wheelchairs and grow older; or we can let ourselves feel the excitement of planning a vacation and taking a trip to some special place with whatever assistive devices we need.

Her response – "We will only be cheating ourselves if we don't do that." **How true!**

In Memorium—Carole Ann Parsons

Carole A. Parsons, age 71, of Madison and formerly of Lake Geneva, died Monday, May 10, 2010, at The Village at Manor Park in Milwaukee.

Although she was unable to come to the Post Polio Support Group luncheon meetings, Carole was the "Post Polio Pacer Reporter" from 2000 to 2009. She used her computer to research information for *Pacer* articles. She will be sorely missed. Our condolences to her family and friends.



The following is excerpted from the obituary which appeared in the Wisconsin State Journal on May 19, 2010. "Carole Ann Parsons was born in Syracuse, N.Y., on Dec. 16, 1938, the daughter of the late Richard and Lucille (Stiles) Parsons. She was stricken with polio in 1952. Through a special home-schooling program Carole graduated from Lake Geneva High School with the class of 1957. In 1970 she earned her bachelor's degree in psychology from the University of Wisconsin. In 1972, she earned a master's degree in social work, also from the University of Wisconsin. In 2000, Carole was nominated for the Wall of Success at Badger High School.

Carole is a published poet, writing "Beyond a Tear." She wrote many articles for the Post Polio Pacer newspaper in Madison. She also was an accomplished watercolor artist. She was a member Phi Kappa Phi Sorority.

Carole is survived by a sister, Kay (David) Elliott of Delavan; two nieces, Melissa (Martin) Riniker of Franklin, and Michelle

(Paul) Lichte of Verona; and two great-nephews, Nathan and Zachary Riniker.

She was preceded in death by her parents; and a brother, Richard Parsons Jr.

A Celebration of Carole's life was held on Saturday, June 5, 2010, at 1 p.m. at CALVARY COMMUNITY CHURCH in Williams Bay."

Her sister, Kay Elliott, selected the poem below from Carole's poetry book "Beyond a Tear".

realm of remembrance

*one day
life will be
a memory
only
a thought clouded with now
yet
animated aware
intoxicatingly alive in yesterday
mesmerized reluctance overflows the heart
leaving
the secret magical realm of remembrance*

POST-POLIO SUPPORT GROUP MEETINGS



The Madison Area Post Polio Support Group meets at Monona Garden Family Restaurant. Consider supporting this restaurant when you are dining out & tell them how much you appreciate their hosting our group.

Golden Rule of Post Polio Syndrome

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

Madison Area Post Polio Support Group—On July 11, Beth Kowall and Harvey Padek will share strategies for **Living Well...With Chronic Conditions**. Our September program features Ruth Diehl discussing her participation as a UW Medical School volunteer and also her travel experiences.

The Post Polio Resource Group of Southeastern WI meetings are held at the Easter Seals Kindcare Recreation Center located in Holler Park at 5151 S. 6th St., midway between Grange & Layton Ave., Milwaukee (just north of the Airport Spur). Social time from 1:00 to 1:30 pm.; meeting from 1:30 to 3:30 pm in March, April, May, September, October and November. Check their website at <www.pprg.org> for dates and program.

The **Janesville Post Polio Support Group** meets from 1-3 p.m. at the Mercy Health Mall, 1010 N. Washington St., Janesville, WI on the first Friday of May, June, August, October and Nov. Contact Art Arnold at <UncleBunks@aol.com> if you want information on speakers.

The Western Wisconsin Post-Polio Resource Group will meet October 9th at Tri County Memorial Hospital, Whitehall, WI in the Education Room from 12:30-3:30 P.M. or later. Coffee and cookies will be provided. If you need more information, please contact Betty Marsolek, 35922 Maple Street, Independence, WI 54747. Phone: 715-985-3801 E-mail <bmarsolek@tcc.coop> Starting July 15th you have to dial the entire number even if it is a local call, so everyone dials 715-985-3801 local or long distance.

Madison P-P Support Group e-mail list:

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B

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 Karla Smith 467-7355

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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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

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

P O S T 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, July 10, 2010

Beth Kowall and Harvey Padek,
Master Trainers, will present
“Living Well...With Chronic Conditions”

Saturday, Sept. 11, 2010

Ruth Diehl, polio survivor, will cover
two topics: “(1) UW Medical School
volunteer, and (2) travel experiences.”

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