

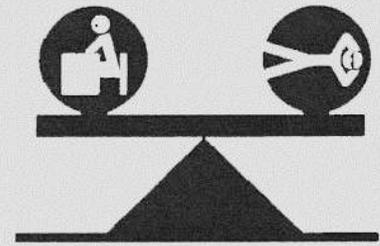
# POST POLIO PACER

Conserving Strength and Energy through Pacing

April 2017 — Madison, Wisconsin

Madison Area Post Polio Support Group Newsletter

MAPPSG formed in 1985 — This Is Our 32nd Year!



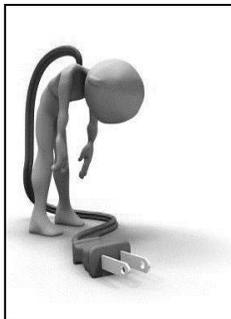
## Flu, Fatigue and Post-Polio Syndrome

Dr. William DeMayo, MD

DeMayo's Q & A Clinic

<http://www.papolionetwork.org/demayos-q-a-clinic.html>

**Question:** I was diagnosed with the flu in early February. I had extreme fatigue for a full month. Yesterday, I spent a full day in the E.R.. Nothing except dehydration showed up on tests. Could this be post-polio syndrome fatigue, along with fatigue from flu and a secondary infection? How long will I have to deal with this ?



**Answer:** To provide a specific clinical answer to the above, much further information would be needed, including information regarding age, prior diagnosis of post-polio syndrome, level of disability, medications, sleep patterns, and other diagnoses. The question does, however, provide the opportunity to talk about the issue of *fatigue and post-polio syndrome*.

First, it is important once again to remember that the *diagnosis of post-polio syndrome is a diagnosis of exclusion*. Therefore, all other causes of symptoms such as fatigue, would need to be excluded before concluding the cause is post-polio syndrome. It is interesting that many patients and clinicians jump to the conclusion that post-polio syndrome is the cause of fatigue, when in fact this is one of the few causes of fatigue that has no specific

treatment. As a rehabilitation physician, I am always focused on issues that we can do something about and pay less attention to the things that are not under our control. Therefore, I will use this opportunity to focus on some of the many causes of fatigue that are treatable.

Secondly, the word "fatigue" can be used in a variety of contexts. One can complain of physical fatigue, including a sense of exhaustion or feeling physically drained. Additionally, emotional fatigue can occur over time due to a variety of stressors and contribute to a feeling of being weary/worn out. Some individuals can also experience cognitive fatigue as the brain simply does not process information as efficiently over time. For purposes of this article we will lump these together, but when reporting symptoms to a clinician, it is sometimes important to be very specific.

Here is a partial list of some of the most common causes of fatigue:

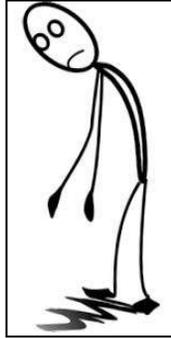
- **Insomnia** (lack of restorative sleep). Lack of appropriate duration OR quality of sleep can lead to somnolence (an intense feeling of sleepiness). Chronic lack of restorative sleep can be a major contribution to physical, emotional and cognitive fatigue. Poor sleep habits, sleep apnea, restless leg syndrome, medications, pain, and other factors can compound this problem.



- Depression/anxiety/stress. These common causes of fatigue are often overlooked or un-addressed.

- Medications. Always check with your pharmacist regarding side effects of medications you are taking.

- Over activity or "Overdoing it". Does this sound like anyone you know? This is certainly not an uncommon issue in the polio population.



- Under activity and deconditioning. This is a problem that is not unusual for individuals who adhere strongly to the "conserve to preserve" mentality. At the same time, it is also a problem for many individuals who regularly "overdo it" causing so much pain that they then need to "rest" for prolonged periods of time.

- Medical issues

- Infection - either bacterial or viral
- Dehydration
- Endocrine problems
  - Thyroid disease
  - Adrenal disease
  - Diabetes
- Anemia
  - Due to chronic blood loss/iron deficiency
  - B12 deficiency, kidney disease and other causes
- Cardiac disease and congestive heart failure
- Pulmonary diseases
- Chronic Fatigue Syndrome
- Neurologic disease and autonomic dysfunction

- Poor nutrition

- Chronic pain

Management of fatigue often requires more than one approach since the above contributing factors rarely occur in isolation. For example, chronic pain can contribute to sleep problems and depression as well as poor nutrition. Subsequently these can worsen fatigue. Some of the interventions most helpful for fatigue, that I would recommend for you to talk to your physician about include the following:

- Appropriate testing and management of underlying medical conditions
- Appropriate goalsetting and pacing
- Use of adaptive equipment, braces, mobility aids, or wheelchairs/scooters (when appropriate)
- Behavioral management and counseling
- Physical Therapy & Occupational Therapy
- Energy conservation techniques
- Appropriate home exercise program
- Aerobic
- Strengthening
- Flexibility
- Yoga or Tai Chi (preferably with an instructor familiar with disabilities)
- Meditation or scripture
- Medication changes
- To remove medications that might be causing fatigue
- Consider talking with your physician about any medication or supplements that might reduce fatigue

A pessimist might see the interrelationship of multiple causes of fatigue as being problematic. At the same time optimists, including myself, will focus on the fact that any of the above interventions will have a "spillover effect" into other areas.

Addressing medical problems can significantly increase exercise tolerance and both lead to less fatigue over time. Physical exercise (as appropriate for your limitations), professional counsel and meditation can all have a profound effect on mood and emotional fatigue.

As one factor improves there is a “snowball effect” on other areas.

In summary, I greatly appreciate the above question as a lead-in to even better questions - “What would be causing fatigue other than post-polio syndrome?” and “Where can we intervene to eventually improve your disability?”

Dr. William DeMayo, MD.  
March, 2017

Reprinted from the PA Polio Network  
Check their website  
[www.papolionetwork.org](http://www.papolionetwork.org)

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## Let Your Light Shine

**By Kathleen Blair**

Light has been on my mind a lot lately as I endure the cloudy, windy days, and I rejoice whenever I see the sun break through. On those gloomy days I find I can spice up my day by making the effort to see friends and family whenever possible.

Wednesdays during Lent have been wonderful. On those afternoons I meet with five “salt of the earth-type people” at a home nearby. We discuss what we have learned from a Matthew Kelly book that encourages and challenges us to rediscover the beautiful possibilities God places before us daily. I enjoy the heart to heart sharing and support we receive from each other. It’s refreshing and I always limp back to my car feeling that I received more than I gave. They were salt and light to me, and I hope that I gave some back.



I read a great article recently about this same subject. Recognizing that most of us aren’t equipped to do the really great things that bring salt and light to the world, the author highlighted the value of the small gesture, the kind word and the gentle touch.

The Bible tells us, “*You are the salt of the earth*” . . . and . . . “*You are the light of the world.*” This may seem like a big, bold claim, but it really isn’t. We can be salt and light from our recliners, walkers and wheelchairs. Welcome a newcomer, call someone who may be lonely, pray for a person who is hurting. Those small gestures can and often do make a difference in another person’s day. Add a smile and you light up the room and possibly dispel some darkness in another’s heart.

At every Post-Polio Support Group meeting I attend and every Pacer that I read I learn more about the volunteer activities and contributions our members have made and continue to make. Kudos to all of you.

Keep smiling and **let your light shine.**

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## Have you read any of these books?

**By Marcia Holman**

If you would like to read any of these books donated recently by Dorothy Schlimm-Sand, come to the Madison Area Post-Polio Support Group luncheon meeting on May 13 to make your choice and *then return it on July 8*. The books will be available at each meeting.

“A Summer Plague, Polio & its Survivors”, by Tony Gould. ©1995.

“In the Shadow of Polio—A Personal & Social History” by Kathryn Black. ©1996.

“Managing Post-Polio--A Guide to Living Well with Post-Polio Syndrome”, by Lauro S. Halstead, M.D., Editor. ©1998.

tor would be most appreciated as well as encouraging others to read.

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## May 13th Program

### "Managing Your Weight through Small Diet Changes"

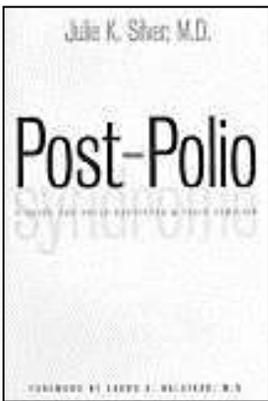
If this sounds like a topic you would like to hear more about, come to the May 13<sup>th</sup> luncheon meeting at Monona Garden Family Restaurant and meet Sara Shaffer, Registered Dietitian.

Sara graduated from University of Wisconsin Steven's Point, has been an RD for about 5 years and currently works at Aurora St. Luke's Medical Center in Milwaukee, where she primarily covers the cancer units.

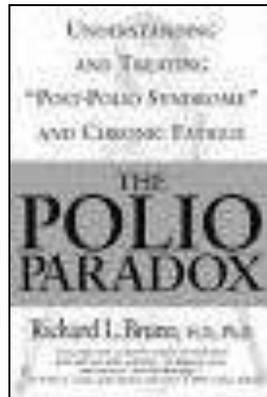
Previously she was an Outpatient RD providing nutrition counseling and education for weight management including Bariatric Surgery (weight loss surgery).

Sara will be talking about "Managing Your Weight Through Small Diet Changes" and welcomes questions on other dietary topics during the Q & A session. Bring your questions!

See "Beginner's Guide to Portion Control" on page 6 .



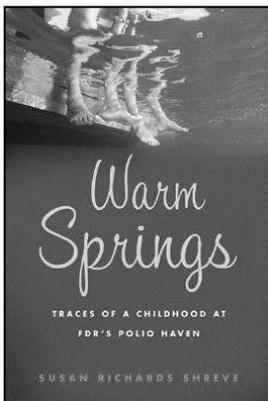
"Post-Polio Syndrome—A Guide for Polio Survivors & their Families" by Julie K. Silver. ©2001.



"The Polio Paradox—Understanding and Treating 'Post-Polio Syndrome' and Chronic Fatigue" by Richard L. Bruno, H.D., Ph.D. ©2002.

"An American Summer--a novel" by Frank Deford. ©2002

"Nemesis" (fiction) by Philip Roth. ©2010



"Warm Springs—Traces of a Childhood at FDR's Polio Haven" by Susan Richards Shreve. ©2007.

For those who live too far away to come to a meeting in Madison to borrow a book, check with your local library. If they do not have the book, the librarian may be able to request it from other libraries in the area.

And—brief reviews of the books chosen from this list, or any other book related to post-polio or post-polio syndrome, sent to the edi-

**Golden Rule of Post Polio Syndrome**  
**"If something you do causes**  
**you fatigue, weakness or pain,**  
**you shouldn't be doing it!"**



## Roosevelt Warm Springs Institute for Rehabilitation

<http://www.georgiaencyclopedia.org/articles/science-medicine-warm-springs-institute-rehabilitation>

The Roosevelt Warm Springs Institute for Rehabilitation developed around 88-degree (Fahrenheit) thermal springs that flow from the foothills of Pine Mountain in west Georgia. Tradition notes that Creek Indians brought ailing warriors to bathe in the springs to heal their wounds and spirits. The earliest known resort at Warm Springs dates to 1832, just four years after the establishment of Meriwether County. Cabins and a tavern housed as many as 200 people. Even more visitors could be accommodated after a rambling Victorian structure, the Meriwether Inn, was built in 1869.

The pools and resort attracted families from as far away as Savannah before beginning to decline in the early twentieth century. Then, in the early 1920s, a young engineer named Louis Joseph, who had relatives in west Georgia, experienced remarkable recovery from the debilitating effects of polio after exercising at the pools. George Foster Peabody, a New Yorker and native Georgian who owned part interest in the springs, invited Franklin D. Roosevelt to visit.

Roosevelt, the Democratic candidate for vice president in 1920, had contracted polio in 1921. Three years later he visited Warm Springs, which lay ten miles from the nearest paved roads and had few modern conveniences. After a few days at the pools, he felt that his legs had improved more than they had in the previous three years. He quickly grew to love the people and the countryside, which he explored by automobile. Other polio patients began to arrive in the spring of 1925, after an article appeared in the Atlanta Journal about Roosevelt "swimming his way to health."

In 1926 Roosevelt invested two-thirds of his savings in property at Warm Springs and incorporated the Georgia Warm Springs Foundation in 1927. An enclosed pool funded by automotive pioneer Henry Ford's son Edsel was added, and improvements began to be made. Physicians and physiotherapists worked with Roosevelt to develop muscle exercises. The "spirit of Warm Springs" became firmly entrenched as patients relearned to function in society and to laugh and enjoy life. Roosevelt's experiences at Warm Springs during the 1920s were dramatized in the film *Warm Springs* (2005), produced by Home Box Office and starring Kenneth Branagh as Roosevelt and Cynthia Nixon as his wife, Eleanor.

Georgia Hall was the first building to be constructed after Franklin D. Roosevelt purchased the property and turned the facility into a polio treatment center in 1927. The building was paid for with nickels and dimes sent by people from all over Georgia.



After his election as president of the United States in 1932, Roosevelt continued to visit, usually in the spring and again in the fall for the annual Founders' Day Dinner at Thanksgiving. He chose a secluded hillside near the

springs to build a home, which soon became known as the Little White House. Roosevelt worked closely with architect Henry Toombs, a native of Cuthbert, on many building projects, including Georgia Hall (an administrative building and cafeteria), a school, a chapel, and an infirmary. On January 30, 1934, the first of the President's Birthday Balls were held throughout the United States to raise money for polio research. They helped put the foundation on a sound financial basis and later became known as the March of Dimes.

Roosevelt died at the Little White House on April 12, 1945, three years after he had deeded most of his property at Warm Springs to the foundation. In 1954, funded largely by the National Foundation for Infantile Paralysis, Jonas Salk discovered a vaccine that began to eliminate polio.

In 1980 the facility was renamed the Roosevelt Warm Springs Institute for Rehabilitation, which is administered today by the Georgia Department of Labor. The institute encompasses 940 acres. New facilities have been added, and patients with post-polio symptoms, spinal cord injuries, strokes, and other disabilities find treatment at Warm Springs.

Camp Dream was developed in the early 1990s as a place where disability camps could be held. It includes two lodges, a fully accessible swimming pool and boat dock, and paved nature trails along the base of Pine Mountain.



On a quarter-by-quarter basis, disabled young people from all over Georgia can reside at the Vocational Rehabilitation Unit while improving their academic, job, and independent-living skills.

Aquatic exercise classes are held in the 25-meter pool, at the Center for Therapeutic Recreation.



Minchew, Kaye L. "Roosevelt Warm Springs Institute for Rehabilitation." *New Georgia Encyclopedia*. 28 August 2013. Web. 20 April 2017.

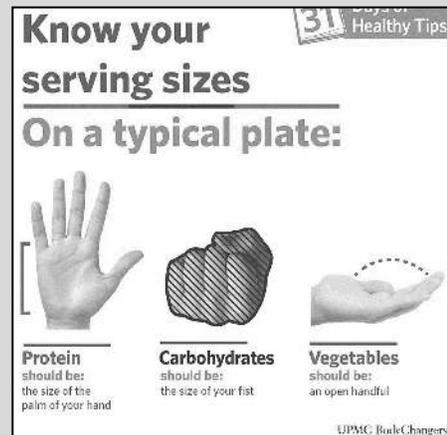
**A Beginner's Guide to Portion Control From the Magee-Women's Hospital of University of Pittsburgh Medical Center**

It's nearly impossible to out-exercise a poor diet, so healthy food choices are essential to weight loss or even weight maintenance.

Unfortunately, even healthy foods can wreck your plans, especially when they're served in the heaping portions we often see in the United States.

Portion control is a key aspect of a healthy lifestyle, so we broke down how you should be assembling your typical plate of food.

In summary, protein should be the size of the palm of your hand, carbohydrates should be the size of your fist, and vegetables should be an open handful. Even better, use this handy graphic to keep your portions in check:



Reprinted from: [www.papolionetwork.org](http://www.papolionetwork.org)

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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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**To get your Pacer in color  
on line, set your email  
program to always accept  
messages from  
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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: mchwgh@gmail.com**

**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.*

**Spring has sprung!**





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**A NEWSLETTER FROM THE MADISON-AREA POST POLIO SUPPORT GROUP**

**Mark your calendars!**

**2017 meeting dates:**

**May 13, July 8, Sept. 9 & Nov. 11**

**LOCATION:**

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

**May 13, 2017**  
**Sara Shaffer, RD, at Aurora**  
**St. Luke's Medical Center**  
**in Milwaukee will talk about**  
**"Managing Your Weight**  
**through Small Diet Changes"**

**July 9, 2017**  
**Program TBD**

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