

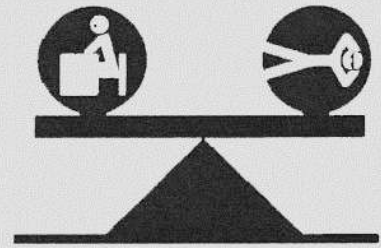
POST POLIO PACER

Conserving Strength and Energy through Pacing

January 2018 — Madison, Wisconsin

Madison Area Post Polio Support Group Newsletter

MAPPSG formed in 1985 — This Is Our 33rd Year!



What Did You Miss on Nov. 11, 2017?

Traci Miller, RPh, a pharmacist at a Racine hospital provided an informative session on "All you need to know about medications" including a lively Q & A time. Plus, a bonus—to be described later...

She emphasized the importance of the patient participating in their care and knowing what the difference is between prescriptions and OTC (over the counter) items. Over the counter items—vitamins, minerals, herbs are NOT evaluated by the Food and Drug Administration. Read the drug facts and ask your primary care physician or pharmacist about the interactions with prescription medication.

Side effects vs. reactions: side effects include upset stomach, headache; allergic reactions, hives, tongue swelling, etc., check with your physician.

Medicines used for years may keep you from getting well, so check with your physician about need for the medicine, increasing or decreasing dosage, or prescribing a similar medicine.

Drug interactions: Alcohol causes drowsiness but should be avoided at bedtime. Use of many different pharmacies and physicians may cause drug interactions, especially if you do not share your list of medications, vitamins, herbals, etc. with

each physician you visit.

You should know what each medicine is used for, and if it is a brand name or generic. Understand the specific instructions—how much is each dose, how often/time of day to take, with or without food or water and what to do if you miss a dose.

Most physicians or pharmacies can print out a list of your medications which you can keep in your purse or wallet.

And now the bonus: Traci Miller, a member of Mercy Ships, talked about her experiences with Mercy Ships illustrated by a power point presentation. The ship is huge



and provides free lifesaving surgeries for people where medical care is nearly non-existent. The African Mercy has meeting and work spaces as well as berths for an average crew of 400. Surgeries include: facial tumors, cleft lips, blindness, club feet and more. Volunteers donate their time and pay their own way.

EXERCISE GUIDELINES FOR POLIO SURVIVORS

Dr. Carol Vandennaker
University of California – Davis
Post-Polio Clinic

Exercise is defined as planned, structured, and repetitive body movement. Physical activity is movement occurring during daily activities. A therapeutic exercise program is designed for health benefit—generally to reduce pain, increase strength, increase endurance and increase the ability to do daily activities. Not all polio weakness is due to overuse, often lack of exercise and physical activity leads to muscle wasting and cardiovascular deconditioning. Research supports a carefully designed therapeutic exercise program for most polio survivors to enhance optimal health and function. The program should be individualized and modified if problems arise.

Important principles to follow are:

1. Start very slowly. Often 3-5 minutes is all that can be tolerated initially if muscles have not been exercised for a period of time.
2. Interval exercise, short bouts of exercise alternating with rest periods, can be very effective.
3. Progression should be slow, especially in polio-affected muscles.
4. Intensity should be low to moderate.
5. The plan should include a rotation of different types of exercise such as stretching, cardiovascular (aerobic) conditioning, strengthening, and range of motion exercises.
6. Pacing should be incorporated into the program with at least one day of rest be-

tween strengthening exercise sessions.

7. Aquatic exercise is often ideal as the buoyancy of the water helps to support weak muscles and joints while providing mild resistance to muscles. Remember it is easy to overdo in the pool because it is so much easier to move!!

8. Be aware that signs of overuse can occur 24-48 hours after too strenuous exercise or an overly active day. Symptoms of overuse indicate a need to decrease the amount of exercise or decrease the frequency of activity. The symptoms to watch for are: muscle cramps and spasms, muscle twitching, muscle pain and extreme fatigue.

REMEMBER THAT YOU CAN EXERCISE SAFELY AND IMPROVE YOUR CONDITION IF YOU APPROACH IT WITH PATIENCE AND CONSISTENCY!

Reprinted from Polio Epic, Inc., Arizona Post-Polio Support Group. Dec. 17-Jan. 18

Muscle Spasms

A Bruno Byte “Update” from the original 2017 article from Richard L. Bruno, PhD. (Rev. 1/2018)

<http://www.papolionetwork.org/bruno-bytes.html>

Original Post: When I wake up at night or in the morning with my neck, legs & back muscles in painful spasm, before I can get out of bed I have to stretch two or three times to make my arms and legs less rigid before I can function properly. I then have to shower to try to turn off the spasms in my neck and back. What’s happening?

Dr. Bruno's Response: Painful muscle spasms develop during sleep, the pain usually waking you just before you get up when your brain had been in REM (dream) sleep. During REM your brain actually paralyzes your muscles so you don't "run" when you're being chased in a dream. This sounds like another polio paradox, muscles spasm during sleep *after* being paralyzed. But the clue as to why muscles go into spasm while you sleep lies in the brain's ability to control your motor neurons and your muscles.

Spinal cord motor neurons are like misbehaving, stubborn children. They want to make muscles contract all the time. It's what motor neurons do! But, to prevent the "kids" from doing what they want, their "parent," the brain, sends signals to the spinal cord telling the kids when and how much they should turn muscles on and, just as important, turn muscles off. If something interferes with the signal to turn muscles off -- like a sleeping, poliovirus-damaged brain -- the kids indeed do what they want. They turn muscles on! And when turned on for too long you get rigid muscles and painful spasms.

You can see the result of this brain/spinal cord disconnection in a condition that polio survivors know well: leg movements during sleep. Poliovirus-damage to brain muscle control neurons prevents the sleeping brain from automatically sending a "turn off" signal to the spinal cord and allows motor neurons to do what they want: Contract!

Our studies of sleep in polio survivors found that these contractions don't just happen in leg muscles but can happen in muscles anywhere -- arms, abdomen, chest and, maybe most painfully, the back and neck.

How do you prevent sleep spasms? Since alcohol turns brain "stop" signals down, you shouldn't drink in the evening. Overusing your muscles during the day "irritates" poliovirus-damaged motor neurons and makes them more likely to cause muscles to contract and spasm at night. Stretching and *painless posture* during the day, stretching and a hot bath before bed and keeping the muscles that spasm warm while you sleep (using a heating pad with an **automatic** shut off or a little dab of Capzasin) can also help.

See the POLIO SURVIVORS HANDBOOK in the Post-Polio Library at:
<www.postpolioinfo.com> for chapters on preventing cramps and spasms.

Richard Bruno **SLEEP NECK PAIN/HEADACHE SURVEY**

Does this describe you?

"When I wake up in the morning, and sometimes even after a nap, the muscles in the back and/or sides of my neck are in painful spasm or cause a significant headache that can last for several days.

The spasm and pain are much worse and last longer if I've done something to my neck, like being in an awkward position, or typing or knitting for hours without moving, and if I feel even mild pain before I go to sleep. The pain can cause me to wake up and not be able to get back to sleep."

If YES please PRINT BOTH PAGES of the PAIN SURVEY, fill it out, and e-mail to postpolioinfo@aol.com by the following:

SCANNING or TAKING a PICTURE of each with your PHONE (you can tape survey pages to the refrigerator to get a flat and readable picture)

OR FAX to 201-342-6777.

MANY THANKS FOR YOUR HELP!

Dr. Bruno

You can find the survey forms at <https://www.facebook.com/groups/PostPolioCoffeeHouse/> If you do not have a computer you can request the survey forms by:

Phone—608-249-2233 or send a letter (*with a stamped, return address envelope*) to: Marcia C. Holman, 3629 Alpine Rd., Madison, WI 53704 requesting the survey forms.



As people age, it can become harder for the body to fight off illness and fully recover. The immune system weakens and other conditions can complicate a cold or the flu. Taking steps to stay healthy and protect against illness (as much as possible) is essential for all of us, especially seniors. From eating right and staying active to avoiding certain situations, there are many ways seniors can be proactive.

Get Vaccinated.

If you and your loved ones haven't already had a flu vaccination, now is the time. Adults age 65 and older can get a "high dose vaccine" to provide even more immune support and protection. Remember that it takes about two weeks for the vaccination to become fully effective, so still take care around individuals who may be sick. While getting a flu shot won't guarantee that you won't get sick – it only protects against certain strains of the flu, it can help reduce your risk.

Rest Up.

Give your body plenty of time to rest and recover, especially if you are feeling worn down. Pushing too hard can stress your body and weaken your immune system making you more susceptible to illness. Sleep allows your body to heal and recharge, fighting off germs. Avoid individuals who are sick. As much as you want to see your grandchildren or visit with friends, if someone is ill, try to stay away until they are feeling better. Limiting your exposure to germs can help you stay healthier. In the meantime, consider using FaceTime, Skype, or another digital platform to stay in touch without sharing germs.

Wash Your Hands.

This is an effective way to reduce the spread of illness if you are vigilant about it. After you've been out in public, touched common items, or spent time around a lot of people, it's a good idea to wash your hands and even change your clothes. If you can't get to a sink, keep some hand sanitizer in your bag or car. Try to avoid touching your face as much as possible because the eyes and mouth are prime entryways for germs.

Eat Right.

Make sure you are eating a well-balanced diet that includes plenty of fresh fruits and vegetables and lean protein. This can help boost your immune system. If you can't find fresh produce, frozen is okay too.

Stay Active.

Regular exercise (based on your personal limitations) can help to stimulate your immune system, sweat out toxins, and keep illness at bay. It also supports stress management – too much stress can weaken your immune system. It's great to go outside and get fresh air, but make sure to bundle up.

<https://www.alwaysbestcare.com/pa/upper-buxmont/>

Reprinted from the PA Polio Network December 2017 issue, page 2. <www.papolionetwork.org>

DRUGS: If their names sound the same do they do the same thing?

Let's talk about Valium-like drugs and GABA. Neurons in the brain and spinal cord produce a chemical called GABA. GABA is the chief inhibitory or "sedative/calm you down" neurochemical. GABA is released by a neuron, floats across the gap between one neuron and several others and plugs into a GABA receptor on the neurons, like a key in lock.

However, there are at least 19 different GABA receptors! So, when you plug the GABA key into the GABA receptor locks it can have a powerful effect, a mild effect, cause you to be sleepy or calm or, if the receptors are on your motor neurons, stop muscle spasm.

The drugs that are manufactured to plug into GABA receptors are the benzodiazepines, of which Valium is the grandfather. Our research has shown that Valium (diazepam) is the best medication for treating spasm in large muscles, especially in the back and neck. We found that Klonopin (clonazepam) is effective in treating spasms of the esophagus that prevent food from going down; Valium doesn't relax the esophagus and Klonopin doesn't relax back muscles. Finally Xanax (alprazolam) is effective in turning off spinal cord motor neurons that cause your legs to twitch and jump during sleep, where neither Valium nor Klonopin are effective; however Xanax does not stop back muscle spasms or relax the esophagus.

There are a number of other oral benzodiazepines that have different effects such as decreasing anxiety (clorazepate (Tranxene), chlordiazepoxide (Librium), lorazepam (Ativan)) and promoting sleep temazepam (Restoril) and triazolam (Halcion)). The bottom line: There are different keys for different receptors that cause different effects in the body. You can't just substitute one Valium-like drug for another and expect it to have the same effect. Without even considering interactions with other medications that you may be taking, the dose of the benzodiazepine you take or how quickly your liver gets rid of the drug, just the 19 GABA receptors and the drugs we mentioned above can have 10,888,869 trillion, trillion different effects!

So, to paraphrase the old car commercial, Xanax: Accept no substitutes.

Reprinted from Bruno Bytes—November 2017

Food for Thought—from the Southern Arizona Post-Polio Support Group

At the Polio Epic meeting November 2, 2018, we enjoyed and were privileged to experience a great program with author and creative writing teacher Sam Turner, who cheerfully reminded us of who we are, what we know, what we can do, and what thrills us, among other things. He encouraged us to regularly make notes of these things, and more, as we experience our daily lives and revisit memories of days gone by. Even if you don't consider yourself a great author, these "Notes to Self" can give a foundation from which to retell your stories to loved ones and future generations who will be living in a totally different world from what you have experienced, just as our parents and

grandparents grew up in a very different age from us.

Interested in more “Sam Turner”? Go to: www.tobecontinuedbysam.com

Editor’s note: Do you have any “Notes to Self”—maybe a diary, letters that your parents saved, photos from school or camp that would help you write your polio story?

Your “polio story” would give your children and family (siblings, aunts, uncles, grandparents, etc.) a picture of how polio affected your life as a student and/or as an employee, mother/father, etc. What kind of accommodations did you need—professional ones or ones you or someone made for you? And, you can be a published author by sharing your story with the *Post Polio Pacer*.

Let us know if you need help putting your information together. Contact either Kathleen Blair or Marcia Holman. Our contact information is on page 7.

Thank you

Thank you for the gift certificates to Monona Garden Family Restaurant presented to us at the November meeting. The lovely card, the gift certificates, and mostly, all your notes are much appreciated. This “job” is a “labor of love.”

Marcia & Bill Holman

Mobile help system

Are you interested in, or curious about, mobile help systems?

Come to the March 10th luncheon meeting to see the type of mobile help system Kathleen Blair purchased recently. She will demonstrate the mobile device GPS system.



From left—fall button on necklace, base station, mobile device with charger, and at bottom—wrist band.

Help wanted

This newsletter needs more reader input!

We need more of **your** “polio stories”—however long or short, illustrated with photos if available. If you feel unable to write a story, perhaps we can provide you with typed questions to answer and/or a phone interview. Everyone has a story to tell and to share with not only the Pacer, but with your family and friends.

Suggestions for luncheon speakers, accessible vacation spots, questions you have and topics you would like to know more about, and polio related book reviews would also be appreciated.

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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
mchwgh@gmail.com**

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.





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A NEWSLETTER FROM THE MADISON-AREA POST POLIO SUPPORT GROUP

Mark your calendars!

2018 meeting dates:

**March 10, May 12, July 14,
 Sept. 8 & Nov. 10**

Printing and postage
 is provided by:

EASTER SEALS WISCONSIN

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<http://www.EasterSealsWisconsin.com>



LOCATION:

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

March 10, 2018

**Open Discussion &
 Demonstration of GPS mobile
 help system—see page 6**

