

FROM THE EDITOR

Hi Fellow PPS Managers.

In the Sept/Oct newsletter I asked for ideas on how you handle the winter cold. Since no one responded I must assume that either you *can* handle the winter cold, or you can't but don't have a clue what to do about it.

I do three things: Dress warmly (I found the best darn long johns at LLBean.com), migrate south for the winter, and/or use my spa daily.

The recommendation of PPS doctors is exercise in a warm swimming pool. Warming, stretching, and (if you can handle it) aerobic exercise do a lot for our overall health and well being.

If you don't have a heated swimming pool or don't care to go to the gym, a portable home spa could be the answer.

I've been hearing quite a lot from PPS Managers who have, or about to get, a home spa, sometimes called a Jacuzzi or hot tub. Since I've had one for several years I thought it was about time to do a full on article about it.

You may have noticed that, generally, the e-mails shared in this newsletter contain glowing praise with "Keep up the good work" as a common phrase. Frankly, I'm not sure I could have kept this thing going for almost four years without your encouragement. On the other hand, you may think that only the good comments are printed, but the fact is, there have been no constructive criticisms received. Do you have something to say? Could *your* newsletter be better? Let everyone know how you feel. Drop me a line. I'll take it with a :-) and maybe even do something about it.

Have fun....Rick

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IN THIS ISSUE:

**PRESIDENT BUSH FAINTS
LIKE A POLIO SURVIVOR**

...OWNING A HOME SPA

Letters and more

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Pray, not for God to cure you but to help you help yourself.

Kirk Douglas

ENGLEWOOD HOSPITAL AND MEDICAL CENTER

PRESIDENT BUSH FAINTS JUST LIKE A POLIO SURVIVOR.

From *The Post-Polio Institute* and International Centre for Post-Polio Education and Research

January 13, 2002. Engelwood, NJ. While watching a football game, President George W. Bush swallows a pretzel that irritates his esophagus. The irritation causes his pulse and blood pressure to plummet and he faints.

An unheard of experience? Not for some of the world's 20 million polio survivors with Post-Polio Sequelae. PPS are the unexpected and often disabling symptoms -- overwhelming fatigue, muscle weakness, muscle and joint pain, sleep disorders, heightened sensitivity to anesthesia, cold and pain, as well as difficulty swallowing and breathing -- that occur about 35 years after the poliovirus attack in 75% of paralytic and 40% of "non-paralytic" polio survivors.

"It's called vaso-BAGEL-syncope, a play on the name vaso-vagal syncope," says Dr. Richard L. Bruno, Chairperson of the International Post-Polio Task Force and Director of *The Post-Polio Institute* and International Centre for Post-Polio Education and Research at New Jersey's Englewood Hospital and Medical Center. "This is a problem that we have been studying in polio survivors for years."

The President's problem likely had to do with the vagus nerve," Bruno explains. "The vagus is the main highway for nerve traffic to your esophagus -- the swallowing tube -- your stomach and intestines." The vagus carries commands from brain stem neurons to activate the muscles in your throat, esophagus, stomach and intestines that make swallowing, digestion and elimination possible. The vagus also sends commands that tell your heart muscle to slow down and your blood vessels to open up.

"Vagus nerve stimulation, causing a drop in heart rate and blood pressure and blood vessels opening up, is responsible for the common kind of faint, called vaso-vagal syncope," says Bruno.

"But the vagus nerve is a two-way street," explains Bruno, a clinical psychophysiological who trained as the autonomic nervous system fellow at the Columbia University's College of Physicians and Surgeons. "The vagus both sends commands to your heart and gut and listens to the results of those commands." The vagus also carries information about how much food is inside your throat, esophagus, stomach and intestines back to those same brain stem neurons.

"Anything that irritates the esophagus -- like swallowing a large piece of bagel or even a pretzel -- can stimulate the vagus enough to slow the heart and drop blood pressure, which may be what happened to the President," says Bruno. "I assume he will have the same tests that we give polio survivors: a video-fluoroscopic study to make sure his swallowing muscle are working while his heart is being monitored, to make sure the vagus isn't overactive and electrical impulses are being conducted properly through the heart."

Did President Bush Have Polio? Why do polio survivors have more problems with the vagus nerve, heart rate and blood pressure than do those who didn't have polio? "The poliovirus damaged brain stem neurons that control the vagus nerve, and possibly the nerve itself," says Bruno. "Vagus damage disrupting the normal functioning of the gut may explain our 1985 Post-Polio Survey findings that swallowing difficulty, diarrhea, colitis, ulcers and constipation are as much as six times more common in polio survivors than in those who didn't have polio."

Bruno has been following a growing number of post-polio patients from around the country who come to *The Post-Polio Institute*. These polio survivors don't usually faint but do feel exhausted after eating meal. Bruno has found that, when these polio survivors' stomachs fill with food, the vagus nerve is apparently over stimulated and triggers a drop in blood pressure, causing feelings of fatigue.

"Polio survivors also report another problem: food sticking in the upper esophagus," said Bruno. "We think this is due to the vagus not stimulating esophagus

muscles to move the food downward. When food gets stuck, irritation triggers a painful esophagus muscle spasm that also stimulates the vagus nerve, causing blood pressure to drop and the heart to change, what apparently happened to the President."

The relationship between fatigue, brain stem damage and low blood pressure links polio survivors to another group: those with chronic fatigue syndrome. About one quarter of CFS patients have fatigue that is associated with low blood pressure or changes in heart rate. Some CFS patients report fatigue when a hot shower or hot room causes blood pressure to drop, as do about one third of polio survivors. "Other CFS patients have blue feet," says Bruno, "just like our PPS patients' 'polio feet,' suggesting that blood pooling in the legs contributes to low blood pressure.

Did President Bush have a mild case of polio, damaging his brain stem and causing a "vaso-bagel" faint? "We have evidence that more than 150,000 American had a mild and undiagnosed case of polio and could be at risk for *all* PPS, not just 'vaso-bagel' problems," says Bruno. Bruno's 2001 International CFS Study found that 20% of baby-boomers, like the President, who are diagnosed with CFS today had a childhood illness that looked like a mild case of "non-paralytic" polio. "So at least those 20% of baby-boomers may have PPS today, not CFS," explained Bruno.

"But the President doesn't have chronic fatigue," said Bruno. "You don't need to diagnose him as a hidden polio survivor to explain his faint. Although rare, 'vaso-bagel' syncope does happen to those who didn't have polio."

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Everything You Ever Wanted to Know About Owning a Home Spa

(Okay. Everything I know about it)

by Rick VanDerLinden

As with many polio survivors, PPS was ushered in with a run-down feeling -- the feeling of "getting old before my time." My first reaction was that I must be getting lazy in my old age, so I started a rigorous exercise program. It wasn't long before I had aching muscles. I recognized the need for massage therapy, but it was too expensive and not available on demand. Besides, I was too shy to even try it. Solution -- a home spa.

My first spa cost \$250.00. I moved it myself (with a lot of help from my friends), spent about \$125.00 for a concrete foundation, \$100.00 for the electrical connection, and \$650.00 to replace the pump/heater package. I didn't mind the repairs and other expenses because it had an acrylic tub which will last many years. (Later I traded a bass guitar for a privacy fence.)

I then proceeded to discover the joy of owning a spa. After a long bike ride the spa would melt away the muscle ache in peace and solitude. Stretching was easier in the spa, and was seldom skipped. On a cold winter evening I could watch the snow fall through the mist rising from the hot bubbling water. On a hot summer day the water, set to a lower temperature, was refreshing.

At first the spa was a wonderful luxury, but as time went by and PPS reared its ugly head in full force weakening muscles became

more sore with less effort and the spa became a necessary part of my management program.

You probably know how difficult it is to shop for equipment and set up new procedures when you're fatigued. Fortunately, the months spent learning spa care and maintenance, and massage and stretching procedure were out of the way before I really needed them. With this in mind I share with you all I have learned about spas.

Advantages of having a home spa

- PPS related cold intolerance is washed away.
- We weigh about 90% less when we are suspended in water -- what a relief.
- Even though we may do very little exercise, we still work hard to perform our daily minimum activities and lactic acid still builds up in our overworked muscles. The jets massage away the burning acid.
- Stretching improves range of motion and reduces stress on joints. It is much safer when the muscles are warm and relaxed.
- Stretched muscles help prevent skeletal injury in the case of a fall.
- Kicking your legs and waving your hands through the water can provide a little bit of aerobic exercise with less overall stress.
- It's very relaxing. Less mental stress = less physical stress = less pain and fatigue.
- Your spa is available any time you need it.

Choosing the right spa for you

Be careful that you don't try to save space or money by getting a one person spa. You need to be able to stretch out in all directions while fully suspended, so your best bet is a four or more person spa depending on how tall you are. It's also nice to be able to get into the lounge chair position for rest periods. The following recommendations take these factors into account.

- 1) The ideal depth at the bottom should be about the distance between your shoulder and butt when in the seated position. One lounge seat plus bench seat(s) will give you room to move around and a place to rest.

2) Dimensions should be no less than your height. I'm 6'2" and my spa is 7' X 7' inside dimension.

3) A strong pump will give a good massage. The more jets you have the stronger the pump needs to be. My old spa had 4 jets and a 1 horse motor. My new one has 22 jets and two 4 horse motors.

4) One of the biggest arguments against owning a spa is that most people forget to use it.

a) I use mine about three or four times a week in the Winter, a little less in the Summer. I consider the spa to be my second best treatment for PPS symptoms (the first is "don't over do".)

b) One professional massage treatment costs about as much as the monthly cost of electricity to run a spa.

c) You can use the "waste of money" theory to your advantage by buying a used spa. If you can't find the right one in the classified ads you might try running an ad -- "Turn your unused spa into instant cash" for example. You may find the right one for as low as a tenth of its new price.

Spa location

The closer it is to your shower and dressing area the better (more on this later). My shower has two doors. One to the master bedroom and the other to the spa. The floor of the shower is slightly raised and I have a redwood step up between shower and spa so that it's one step up and I can sit on the edge of the spa and swing my legs over into the spa. Getting out and rinsing off in the shower is just as easy. Having the spa that close to the shower means that you only have to dry off and dress one time saving a lot of energy.

If it is enclosed you are more likely to use it in the winter when you need it the most. You can put it in the room next to your shower, add a room, put it on a the porch and build a wind break/privacy screen around it, or buy a redwood enclosure.

Ventilation is important. I was overly concerned about this when I designed my spa room. I have a 4' sliding glass door (8' with both glass panels removed -- big enough to get the spa through) three windows and two sky lights. I find that the room ventilates just fine with one sky light opened a few inches above the spa and the sliding glass door opened a few inches.

If you have an indoor spa it's a good idea to keep the air separate from the rest of the house. I have a french door between the spa room and the bedroom, and a fully sealed shower door. I also have a built in heater/AC mounted on the wall. This comes in handy on the colder days. Also, it's nice to have lots of plants in the room, and they may need to be kept warm.

As you can see there are many options, but you may need to check with a contractor to be sure you meet local building codes.

Use and Maintenance

There is a direct relationship between how carefully you use your spa and the required water maintenance. If you're careful, the water should only need replacing three or four times a year, and although the chemicals are not terribly expensive, improper use could easily double or triple the cost. Since I'm fiscally conservative (cheap) my recommendations should save you some time, energy, and money.

Organic materials (dirt, body oils, etc.) and soap and other body and garment care products shorten water life and increase chemical use. Take a good, hot, soapy shower and rinse well before using the spa. If you must wear clothing in the spa, make sure it is thoroughly rinsed of laundry products before entering the spa. Don't put your head in the water -- face and hair are particularly oily and it's hard to rinse things like conditioner out of your hair in the shower.

Normally, the main chemical you use is Bromine. It comes in granulated and in tablet form (for the floating dispenser). After filling the clean spa with fresh water, use "Metal Be Gone" or some similar product to neutralize the water, then add granulated bromine as indicated by water test kit. It takes a few weeks of testing and adding

granulated bromine to get it settled down, but after that the floating dispenser (adjust opening to about 1/2") can then be used to maintain proper bromine level with normal use. If soap bubbles start to form during use, there is a liquid product available to fix it.

Clean the filter weekly.

If you get behind on your bromine and the water gets cloudy, it's too late to fix it by adding chemicals and you need to drain and clean the tub.

How to know when the water needs changing

I look for one of three things -- all involve running the jets with air input turned on and assume that water is clear and that test show bromine is at proper level.

First, bubbles may form that are dark in color and/or stay on the surface or leave a film after jets are shut off (I call this ugly bubbles). If the bubble remover solution and filter cleaning do not cure it, change the water.

Second, run the jets with air, then shut off the jets and count how many seconds it takes for the water to become clear enough to see details at the bottom of the spa. Fresh water takes virtually no time to clear. I change water if it takes more than eight seconds.

Third, look across the surface of the water while the jets with air are running. If the popping bubbles send up a little flare it's time for a change. Also, the little flares can get in your nose and cause sneezing -- another sign that it's time.

Cleaning procedure

Shut off power to spa, drain water, clean filter, wash tub with recommended product (I use a non-abrasive foaming cleanser), rinse well. Refill, turn on power with spa set to thermostatic control (see below), add metal-be-gone, add bromine, check floating dispenser. Check bromine every other day for first week, once a week thereafter until you get the hang of it.

Timer controls

Automatic controls have two basic settings. Usually there is a switch that allows you to choose between clock only and thermostatic control functions.

The thermostatic control function is used to heat the tub after refilling. It is also the setting to choose if your spa is outdoors and may be subject to freezing.

The timer control setting allows the pump/heater to run only at specified times. I run mine twice a day for 45 minutes at a time. This keeps the water hot when I expect to use the spa and performs the necessary filtering cycle.

Recommended temperature

Based on fifteen to twenty minutes spa time: Winter - 98 to 100 degrees, Summer - 96 to 98 degrees. The hotter the water is the less time you can spend in it. If you have rubber legs or feel fatigued when you get out, either you were in it too long or it was too hot.

My routine for PPS management

Set vents and open spa before showering.

- 1) Relax in spa and let muscles warm up.
- 2) Massage. With air jets running move each muscle across convenient jets.
- 3) Stretch. Shut off jets if you want to (I like it quiet or listen to soft music). I stretch the back of my legs, quads, hips, arms, neck, back, the works. The stretches you do depend on your needs and abilities and/or the advice of your physical therapist. A good reference, however, is the exercise video from Warm Springs Georgia called "Aquatic Therapy for Polio Survivors", Part 2 of the "Wellness for the 90's" series. (800) 235-2156.
- 4) Relax. You may want to do some more massage.

Total time including shower and dressing - 1/2 hour.

Conclusion

As a PPS manager, a home spa might be one of the best things you can do for yourself. Proper use can improve mobility, reduce pain, and relieve stress better than any other treatment, professional or otherwise. I wouldn't be without mine.

Enjoy!

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From the (e-)mail bag

Advice:

My theory about stress and excitement is:

1) Anything that causes a spontaneous release of adrenaline causes muscles to tighten - immediately at a very high level, and then to a lesser degree for... I don't know... hours? The expenditure of energy is similar to working to finish a project when you know you should stop.

2) Uncontrollable situations force you to be extremely alert (and maybe frustrated) at a time when you should normally be resting and in full control of your world. You need rest - alertness is not very restful.

These two factors combine to give you a big hole in your gas tank. After all the gas has run out you have to repair the hole, and then you have to refill your tank. It could take hours, days or weeks to recover.

Be patient with your body and it will be good to you.

Hi Rick

Thank you so much for the recent newsletter - - I really enjoy your letters and find them informative and helpful. Keep up the good work!!!!!!!!!!!!!!

Dorothy

Vizenor

Conversations with Liz:

Hello Rick,

Would you please send the newsletter to my grown daughters? They have always thought of me as indestructible, probably the way most off-spring view their PPS parents...didn't we want it that way???!!! Now that has come back to bite me, perhaps the newsletter will help them understand what has happened.

Thanks, Liz

Hi Liz,

We sure did [want it that way]. And, you're right to include your family in the changes that must be made in order to manage PPS. The family wants to see you "normal" and their attempts to motivate you can

be harmful. I'm sure you have already gone through the unsuccessful self motivation phase of PPS. Mine lasted almost two years and darn near killed me.

Rick

To the daughters:

It's important for the family of a PPS person to be supportive, but it's a delicate situation. Your mother still wants to be as independent as possible, so it's best to be available to help her, but not until she asks for help.

Also, if she is like the rest of us, she needs to be encouraged to rest often, not motivated to do more. In my case I try to hide pain and weakness from my family (and myself as well). When my wife says that I look tired and should rest it is welcome advice.

Rick

How refreshing to encounter another individual who seems to have been as "pig-headed" and determined to "demolish self" as I was!! ha, ha. Our own worse enemy, true, true! Thank you for being there and now serving as a total understanding backup. It is so very hard to walk a mile in our moccasins, no one wants to, much too scary for most...tee, hee.

Thanks for the good (god) words and for sending my daughters the newsletter. Liz

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Thank you for reading the PPS Manager Newsletter. And, thanks for your help and your words of encouragement. Special thanks to Dolores M., Bill & Beverly, Virginia, Bill K,

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