

# March 2006 Issue

## FROM THE EDITOR

After having shortness of breath, particularly when eating, my doctor recommended that I have a sleep study done. I was a little perturbed when the therapist doing the sleep study said she had never heard of Post-Polio Syndrome. The study showed that I had 70 muscle twitches per hour, some of them strong enough to keep me from getting deep sleep that is needed to feel rested. I was on a bi-pap for the study and the recommendation was that I start using one for night. The worst part of the study was being awakened at five in the morning and told I could go home. Fortunately the study was done at our local hospital so I only had a few blocks to drive. I am still adjusting to the bi-cap but it has helped ease my daytime breathing problems.

## FACING AND FIGHTING FATIGUE

*By Kristeen Muldoon, PT and Julie K. Silver, MD*

Will Brown\* has Post-Polio Syndrome and assumed that his all consuming exhaustion was simply due to this condition. At first, Will could manage his symptoms and still do the things he had always done as a lawyer who lives with his wife and two teenaged children. However when his lack of energy started becoming unmanageable, Will got scared. Initially he went to a doctor who specializes in fatigue – a problem that faces as many as 70 million Americans, regardless of whether they have underlying medical problems. Unfortunately, the specialist could not find any reason for Will's fatigue other than the Post-Polio Syndrome and recommended that he reduce his workload and take frequent naps. This was devastating news for Will who is a partner in a law firm that he started 20 years ago.

Seeking a second opinion, Will came to our center and underwent more tests including a sleep study. This test, which is often neglected but probably provides the most accurate and important information about what occurs during rest showed that Will had sleep apnea – a condition characterized by periods of time where he stops breathing. Will was surprised because both he and his wife denied that he snored or was a restless sleeper (these are often clues to a problem with sleep). Will is now using a Continuous Positive Airway Pressure (CPAP) machine at night to improve the quality of his sleep.

Fatigue is a common complaint, and you don't have to have any history of medical problems to suffer from a lack of energy. However, people who walk around exhausted deserve to have a better quality of life, and Will's case emphasizes the importance of seeking the advice of your doctor and in some cases getting a second opinion. Many people may brush off feelings of excessive tiredness, low concentration, mood swings, and pain as something "that everyone has." Although it is true that fatigue is a common symptom, the good news is that it is often highly treatable.

The first step in addressing fatigue is to look at your lifestyle and sleep hygiene. Sleep hygiene refers to the way that you prepare for going to bed at night. In terms of your lifestyle, do you have a high-stress job? Are you traveling for your job four days a week? Are you working a 40-hour (or more) job, driving kids to after school activities, coordinating the neighborhood social functions and acting as a pillar of strength for your extended family? If so, then you may consider changing some of

these things so that your life becomes more manageable. Making adjustments to your lifestyle may be enough to decrease your symptoms.

If you make adjustments but are still tired your doctor may order tests, because the symptoms you are experiencing might be caused by an underlying medical condition. Conditions like hypothyroidism, anemia and chronic infections can all have fatigue as a side effect. If there is an underlying problem, no amount of sleep or sleeping aids will help you get a refreshing night's rest. Of note is that these conditions can often be detected by simple blood tests.

If all of these tests are negative, your physician may next order a sleep study. A sleep study requires an overnight stay at a sleep lab where they monitor your body movements, sleep cycles, and breathing patterns. Often a hidden sleep disorder is revealed such as sleep apnea or restless leg syndrome (also called periodic limb movement disorder.)

There are many treatment options for someone who has a sleep disorder and can include medications, specialized equipment to help with breathing and in some cases even surgery. As with most medical problems, if you are suffering from fatigue that is limiting your ability to function in the most basic of daily activities, see your physician.

\* Name and identifying characteristics have been changed to protect patient's identity.

*Reprinted from International Rehabilitation Center for Polio at Spaulding Rehabilitation Hospital Newsletter*

## **ROLLING RIGHT ALONG**

*By Dorothea Nudelman*

A friend of mine who is perfectly able-bodied has turned napping into a high art form. When she visits for an extended time, she often takes several naps in the course of a day. She laughs about it, but I find when she's here I nap more and enjoy myself more too! At such times, I never think of napping as a PPS issue—deep fatigue. It's just something I do that energizes me for hours afterwards. I'm beginning to learn that as more polio losses come I have to continue this massive exercise called "taking care of myself!" in body, mind, and spirit.

The practical aspects of adjusting to the post-polio losses of strength and mobility are in themselves awesome. For some of us it means using a wheelchair for the first time or being fitted for a brace. For others, it means substantial loss of endurance, increased pain, and chronic fatigue. Many experience a combination of the above. No matter how much we try to anticipate our own needs, I think it's natural to feel surprised and even discouraged when loss actually happens. From my perspective, having suffered depression, it is essential that we address the emotional aspects of these changes as we experience them. Moving beyond discouragement or depression frees us to fully enjoy the lives we have.

As many of you know from my book *Healing the Blues*, I was initially resistant to dealing with the onset of new polio losses in middle age. Now, in my mid-sixties, after yet another new home and new community, I have had to cope with more severe losses. After walking with crutches and braces since age ten, I have recently joined the ranks of the "vertically challenged." This has been a major and challenging change as many of you understand. But continuous work on my attitude and feelings

has helped me to "spit back" at anyone who looks at me as an object of pity. For me, pity is a death knell signaling the loss of hope, humor, and belief in myself.

Nevertheless, the world looks different from here. Always having to look up to make eye contact can feel diminishing; and for the person who is standing, it is often easier to dismiss, patronize, or ignore the person sitting. "If she needs to use a bathroom, there's an accessible one just outside Gallery 5." Hearing oneself addressed in the third person is very strange indeed!

For years I had wondered if I would ever have to use a wheelchair except for trips to the bathroom during the night. Further, I'd wondered how I'd make the decision to do so since a tiny part of me always hung onto the conviction that sitting down was "giving in." Hard to believe I still wanted to hang onto the hope that this would never happen, that I'd be spared "the chair." You'd think I was being sentenced to the "electric chair." So the practical aspects of confronting and evaluating whether I'd have to use a chair were deeply tied to my attitude towards doing so.

Twenty years ago when my husband and I built our first house, I didn't have a clue about how new physical losses would affect my mobility. When we moved recently to our present northern Sierra foothill location, I was still walking but had come to rely heavily on my electric scooter to get around outdoors and to manage the hilly terrain of the streets in town and on our country property. With growing awareness, we built our new home with all of the practicality needed to accommodate me in a wheelchair.

Building wide hallways, and doorways in a single level living area were obvious. We installed grab bars in every bathroom and a "drive-in" shower with transfer seat in the master bath. We lowered the mirrors and built a wheelchair friendly cutout in the vanity counter as well. In the kitchen, we designed an island with clearance on all sides for my chair. There is also a lowered butcher-block tabletop at one end of the island that I use as a meal prep area. I installed a wall oven at a lower than traditional level so I could function independently while cooking. In the laundry room we raised the front-loading washer and dryer so they would be accessible whether standing or sitting. Almost everywhere in the house there are lower level built-ins instead of overhead cabinets so there is plenty of convenient access.

At the front door are a roof overhang and a front porch so that the gently sloped (stair free) entryway is navigable in a wheelchair, protected in inclement weather, and gives easy access to guests. Repeatedly, it strikes me how appropriate the phrase "universal access" is since so much of what is necessary for persons with disabilities is convenient and appealing to others.

When we finally moved in, last November, I was thoroughly exhausted. Walking the length of the house felt like hiking to the moon. Even though I'd tried to pace myself through the move, it took so much time to recover! I joked that this would be our last move, (the next one will be out the front door, feet first!). By January my legs still ached and my blood pressure soared. I'd had a couple of close calls when I nearly fell because my good knee, the one without the brace, buckled for no apparent reason. My common sense told me it was wake-up time.

Since we had laid hardwood or tile on all the floors, the surfaces were perfect for wheel-chair cruising. My intelligence told me it was too risky to walk. My feelings balked. What was holding me back? I just didn't want to sit down after a lifetime of walking. Then one day in late winter a newsletter arrived from the Rancho Los Amigos PPS Support Group (March, 2004.) It contained an article on "Understanding Muscle Strengths" with Dr. Sophia Chun. The article included many useful definitions of muscle strengths and a muscle test that one could self-administer. There was also

a series of questions and answers about equipment available for those who might now need assistance walking. After I'd read the article thoroughly and took the muscle test, I understood I truly didn't have a "marketable muscle" in my good leg, not one strong enough to reliably support my walking. It was time for me to "ride."

There were other, more mundane practicalities to face. In the months of slowing down before I made the decision to give up walking, I'd gained far too much weight to be healthy and move easily. While this is a common problem in PPS and aging, I knew I'd become less than vigilant about watching my weight and I'd also begun using food for entertainment and reward for hard work. I started the Atkins diet and have lost thirty pounds in the last ten months. It wasn't easy, but doing so has made me aware that I had to change the way I ate if I were unable to raise my energy output. The weight loss and change in eating habits has renewed my confidence in my ability to make difficult changes.

Finally, this past summer I tried out the IBOT when it became available for evaluation in San Francisco. For those who haven't heard, the IBOT is a robotic power wheelchair, equipped with three computers, capable of climbing stairs and curbs. I had watched its development by Dean Kamen for years and hoped that it would be the answer to my prayers. I'd imagined it as some kind of Bat-Mobile that would overcome rough terrain and other barriers! My new community is full of hills and steps making many friends' homes off limits now.

Much to my disappointment, the IBOT proved to be too limited in the range of things it can do to merit either the cost or the risks. Can you imagine a health insurance company even cost-sharing a power chair that sells for \$29,000 plus extra for training, with only a one year warranty on parts and labor? But IBOT technology is moving in the right direction. If we can send people to the moon, we can move closer to getting disabled people beyond early barriers. This is cause for hope, I think.

While it is impossible to change the world to meet our needs, we can all make small changes that make a difference in our daily lives. We can install grab bars to make ourselves safer; get rid of carpeting and lay vinyl for not much money; create more accessible food preparation areas and find easy one-dish recipes. If we can accept and expect change, we can maximize our assets. Small changes create ways to preserve our independence, vital to maintaining self-esteem.

Maybe accepting change is where the practical physical aspects of our dilemma come together with the mental and emotional ones. What will be important to us in ten years depends much more on how we feel about ourselves, our own image of self-worth, than whether we walk with crutches or sit in a wheelchair.

We can't control what happens to us; no one can do that. For me, letting go of the will to control my life has made a difference. When I let go of the need to do things the way I always have, to do everything I always have, I am relieved. I have learned to stop a task and take a nap when I listen to my body's signals. I have learned to say NO to another activity or commitment even if I think I might enjoy it. Consequently, I have discovered a richer relationship with my family, and I am better company for myself. In creating this newer, healthier balance, I have learned to cease worrying about things. The practice of joyful surrender has made this possible. And it is worth more to me than losing thirty pounds!

This mental adjustment to change did not come easily. My bad feelings often got in the way. When I finally knew I had to give up walking and sit in a chair, I felt bummed, sad, defeated again by this old illness that makes unannounced comebacks. I wondered if everyone felt that way. But after allowing myself these

feelings, I saw the benefits of having made a sound evaluation. I knew I could trust my own intuition without waiting for a doctor to prescribe a wheelchair for me. So much of this struggle is with feeling. As a dear friend said to me after I'd made the choice, "You know, you have courage and intelligence. To walk would be foolhardy now. You'd risk a terrible accident and confinement from which you might never recover. Riding means you're taking care of yourself. It takes guts to see it and do it!"

I started riding permanently almost ten months ago and the effects were noticeable immediately. No more pain in shoulders and hands from weight bearing; much reduced daily chronic fatigue; no more huge expense of energy from paying attention to each and every step I took! Confining as the chair looked and felt in some ways, sitting in it also provided a "get out of jail free" card. The anxiety that accompanies fear of falling, the tremendous focus and concentration, the endless challenge that walking everywhere had become disappeared. I felt released from a burden, no longer bound.

I still walk a little almost daily so my muscles don't forget how to do that, and my body gets stretched. It feels good. I also love getting out alone in my minivan with the electric scooter in the back, ready to travel. The world invites me with increasing "blue spots," ramps, and wide doors. I appreciate my good fortune in having a home that works for me, a decent pension from my teaching years, and a husband who is willing to help carry the burden.

Years of depression cost me a great deal of pleasure and isolated me in paralyzing fear of what was to come. Now, I trust myself to see the way. I'm having a life full of laughter, honesty, and some sadness as well. I fail to admit that, I spiral downward into fear and wear myself out. Then comes depression with its slow, dull ache. I never go to these negative places if I let myself snarl and cry every once in a while. Even wail. I heartily recommend it.

I can't predict what will happen in the future any more than any able-bodied person. Yes, if I open my heart and allow myself to feel my opportunities and blessings, I can set out each day as boldly as Huck Finn. At my age, I can ask the right questions and make increasingly discerning judgments about what is good for me and what I need to leave by the wayside as I continue this journey.

*Dorothea Nudelman and David Willingham MSW are co-authors of Healing the Blues.  
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## **EYELID REDUCTION SURGERY**

*By Elva Suderman*

What started as a routine visit to my optometrist to check the blurred vision in one eye led to a series of complex events. The blurred vision was diagnosed as a film behind a lens implanted after cataract surgery. This could easily be corrected by a laser treatment. Dr. Terria L. Winn, ophthalmologist at Grene Vision in Wichita who performed the laser treatment suggested that I would benefit from eyelid reduction surgery. She made an appointment for me with Dr. Samuel W. Amstutz, ophthalmologist and plastic surgeon also at Grene Vision.

At my appointment with the ophthalmologist he said the first thing he noticed was how I raised my eyebrows to look at him. After reviewing my test results he said that

I would benefit from eyelid reduction surgery and that he would also shorten the eyelid muscles at the same time to improve my vision. Since the surgery was for medical reasons rather than cosmetic ones Medicare covered the costs.

As time passes our facial skin and especially our eyelids often make us look older or more tired than we really feel. Drooping upper eyelids may result in diminished peripheral vision due to limitations in the upper and lateral fields.

Blepharoplasty, or eye tuck, is a frequently performed procedure to remove excessive skin and fatty tissue from the upper eyelids. It can restore a more alert appearance, widen the field of peripheral vision and in some cases, even resolve "eye strain" in those individuals using forehead muscles to help elevate their upper eyelids. Blepharoplasty is done through carefully placed incisions along the natural lines or fold of the eyelids.

I was informed before surgery that I would receive a mild sedation. In spite of cautioning the anesthesiologist that I was very sensitive to sedation the next thing I knew it was over an hour later and the surgery was almost over. I was asked to open my eyes so the surgeon could check whether both eyelids were even. There was no pain during or after surgery. I was ready to go home as soon as the surgery was completed.

The results of the surgery have all been positive. I have improved vision and less eye-strain when fatigued. It is difficult to ascertain whether the weak muscles in the eyelid were from post-polio syndrome or normal aging but it is logical this might be the case as many of our muscles have weakened. If you have droopy eyelids it would be well to have an evaluation done at a specialized eye clinic.