Our Mission:
To Be in Service Providing Information to Polio Survivors, Post Polio Support Groups, Survivor’s Families and their Caregivers.

Post-Polio Fatigue and Sleep (or lack thereof).
Once again, we will be covering a topic that comes up on a regular basis with Polio Survivors and their caregivers. We are entering the beautiful month of September starting our series that will provide information about the very important topics of Sleep and PPS Fatigue. In this issue we are featuring articles by the International Centre for Polio Education, Post-Polio Health International and Dr. William DeMayo, MD.

We are happy to be able to share the video interview that accompanied the outstanding newspaper article(s) “Polio: Pain and Progress” published by Calkins Media this past June. The interview is with Polio Survivor Nick Hovemeyer and John Nanni (Polio Survivor and Rotarian) talking about life with PPS and the status of Rotary International’s drive to “End Polio Now”.

You can see the interview and read the article(s) here: http://www.papolionetwork.org/new-stories-of-interest.html

Check out all the articles written by Dr. William DeMayo, MD., the latest Facebook posts from Post-Polio Health International and the entire collection of “Bruno Bytes” on our website in our “What’s New” Section. http://www.papolionetwork.org/whats-new.html

Our newsletters are available in full color print, delivered by US Mail. Details are available: http://www.papolionetwork.org/contact.html

How to Manage Fatigue?
The Post-Polio Task Force
Post-Polio Syndrome: Questions & Answers

One way to manage PPS-related fatigue is through the use of energy conservation techniques. For example, daily activities that are not considered "critical," such as (Continued . . .)
How to Manage Fatigue (continued . . .)

making a bed, can be discontinued. Or, household items and supplies can be relocated to make them more accessible. Some people may consider certain lifestyle changes, such as working only part-time or taking a job that is less physically demanding. In addition, it helps to learn to pace daily activities, which means taking regular breaks during long periods of physical activity. Regular rest periods or daytime naps, especially in the early afternoon, can be beneficial for managing fatigue. (People with PPS who work should also consider this type of rest schedule.) Finally, it is important to get a good night's sleep; doctors can provide advice on how to improve the quantity and quality of sleep. (It should be noted that breathing disorders such as sleep apnea may interfere with sleep and contribute to fatigue.)

http://www.post-polio.org/edu/hpros/task/ques1.html#man

Insomnia (the Lack of Restful Sleep)

The First of A Multipart Series by William DeMayo, MD.

http://www.papolionetwork.org/demayo-q--a-clinic.html

The term Insomnia can be used in many ways. Most people would associate the term with difficulty falling asleep or difficulty staying asleep. It should also be used to describe non-restorative sleep. Many individuals understand that there are stages of sleep yet don’t think about the fact that their quality of sleep (amount of deep sleep) is as important as their total duration of sleep. Deep sleep is essential for healing in many ways and can be seriously affected by stress/anxiety, medications, and underlying sleep disorders, such as Sleep Apnea or Periodic Leg Movement Disorder (a common variant of Restless Leg Syndrome). We will discuss these and other conditions that impair quality and quantity of sleep in future articles.

While this article will focus on the general problem of insomnia in our society, the issue is even more important for polio survivors or anyone dealing with chronic pain. Fatigue, generalized exhaustion, and pain are frequent symptoms in polio survivors, leading to suspicion of Post-Polio Syndrome (PPS) but these symptoms are also seen in chronic sleep deprivation. In fact it is essential to rule out underlying sleep problems prior to assigning a diagnosis of PPS. Most people are fully aware how pain can lead to lack of sleep, but are not aware that lack of sleep will lead to pain. Lack of adequate deep sleep leads to muscle tightness/spasm during the day, changes in our immune system’s inflammatory response, and our nervous system’s ability to regulate pain perception. Behavioral changes and medications can further exacerbate the insomnia-pain-insomnia cycle. The process of healing from minor musculoskeletal injuries is impaired without quality sleep and, over time, these unresolved “minor injuries” can become a major problem.  

(Continued . . .)
In my practice, sleep evaluation and management is a primary focus for any patient with chronic pain, especially polio survivors. The Centers for Disease Control (CDC) reports that school-age children require at least 10 hours of sleep, teens need 9-10 hour sleep, and adults need 7-8 hours. These recommendations are similar to the national sleep foundation (see chart). Yet nearly 30% of adults reported average of less < six hours of sleep per day, and only 31% of high school students reported getting at least eight hours of sleep on the average school night. It is recognized that individual needs will vary, but the problem is most people believe that they are the exception. I thought about using an analogy with debt. I changed my mind when I saw an article about a report from the Pew Charitable Trust indicating that 80% of Americans are in debt with the median debt load being $67,900. (I mention this because it seems to be an indication that our society tends to focus on the here and now rather than the future). Instead, I will use an analogy between sleep and oil in our cars. If an individual purchases a new vehicle, there is usually an owner’s manual in the glove compartment which states the recommended number of quarts of oil to be used. If you can, imagine a friend purchasing a car and saying, “my car only needs half that amount of oil” and with the first oil change they use only half the quantity recommended. With modern engineering, the engine may start and sound as if it is working well, but anyone knows that at some point there will be a problem and the engine will either wear out early or seize up. Similarly, many people define the amount of sleep they need as being just over the amount of sleep that leads to dysfunction the next day.

[SLEEP DURATION RECOMMENDATIONS]
Insomnia (continued . . .

Most people seldom look at the long-term effect of sleep deprivation and how it can lead to “early wear” of our neurologic, cardiovascular, musculoskeletal, and immune systems. The following statistics can be reviewed with an easy search of insomnia on WebMD.

Sleep deprivation has been shown to be associated with:
• Risk of accidents (100,000 auto crashes/year, 3 mile Island, Exxon Valdez oil spill, and Chernobyl have all been linked to sleep deprivation).
• Impaired cognition (including decreased attention, alertness, concentration, reasoning, and problem solving).
• Increased risk of serious health problems such as heart disease, heart attack, heart failure, irregular heartbeat, high blood pressure, stroke and diabetes.
• Decreased libido.
• Depression and anxiety.
• Early aging of skin (yes, you do need your “beauty sleep”).
• Memory impairments.
• Weight gain. (Voluntary restriction of one hour sleep was recently correlated with a 20 pound increase in weight).
• Increased risk of death.
• Impairment in judgment, especially about the need for sleep. Most people think they “adapt” to the lack of sleep despite the fact that their performance on objective tests continue to decline with less sleep.

Adding to this problem, most people (including myself) are very poor at accurately reporting the quantity and quality of sleep they have experienced. As a personal example, I had a sleep study in which I remember turning over multiple times during what I thought was a three or four hour period prior to falling asleep. The actual data showed that my “Sleep Latency” was only six minutes. This was the time between when the computer showed the lights were turned out and my EEG indicated I was in stage one sleep. I only later learned that people can be quite aware of their environment when in stage one sleep. The point here is that your estimate of your sleep may be way off due to a combination of simply not paying attention and the possibility of misperception. For anyone in doubt, I would suggest a sleep diary be completed. These can be downloaded from The National Sleep Foundation: https://sleepfoundation.org/sleep-diary/SleepDiaryv6.pdf (or other sources) and can provide insight about your sleep habits. Additionally, Fitbit and other activity monitors can produce computer printouts that log your sleep as well as document periods of restlessness that could indicate underlying sleep disorders. (These topics will be covered in a future article).

The focus of this first article in the series, is the old adage:
“The first step in solving a problem is realizing there is one”

Dr. William DeMayo, MD.
September, 2016
Do you have a question for Dr. DeMayo?
Email us at: papoliolnetwork@gmail.com (or)
You can call us: 215-858-4643

Dr. DeMayo has nearly 30 years of clinical experience in the field of Physical Medicine & Rehabilitation. He has served as Medical Director for several comprehensive inpatient rehabilitation units and has also maintained an active outpatient practice.

For multiple pages of information about Post-Polio Syndrome:
Check out this section of our website:

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Two outstanding articles from the series that helps explain PPS to our caregivers and friends.
Published by Post-Polio Health International
http://www.post-polio.org/edu/healthcare/pt4managetreat.html

Foreword:
Fatigue: For a presentation at the Polio Australasia-Pacific Post-Polio Conference entitled "Polio – Life Stage Matters," PHI surveyed health professionals with experience in post-polio care. One of the questions asked them to rank classic complaints in order of the most commonly reported.

Fatigue was number one. New weakness and pain were almost tied for the second position of the most common issues reported. Functional decline was next, not many points behind. Rounding out the list were chronic longstanding weakness, breathing and swallowing. A summary of the information gained from the survey will be published at a later date in Post-Polio Health.

The survey was a companion to our Spring 2014 survey of polio survivors about their polio care from post-polio specialists and primary care providers. Post-Polio Health, Spring 2014, Vol. 30, No. 2, pages 9, 10. The results were compiled and reported in Post-Polio Health, Fall 2014, Vol. 30, No. 4, pages 3,4, 5.

Weakness
New muscle weakness is the hallmark of PPS and is associated with the effects of aging on muscles already weakened by the effects of polio. New muscle weakness is more likely to occur in muscles most affected during the acute poliomyelitis. However, occasionally "previously unaffected" muscles may also develop some

(Continued . . .)
new weakness. Polio could have affected "previously unaffected" muscles during the initial illness, but the new weakness is not apparent until aging makes it evident.

As a rule, new muscle weakness parallels a decline in a polio survivor's ability to do certain activities. For example, a decrease in strength of the quadriceps (front thigh muscle) may correspond with increased difficulty climbing stairs or walking long distances. Individuals may also experience problems with breathing and/or swallowing. The course of new weakness is variable with some individuals experiencing a slow, continuous progression while others report a stepwise course with plateaus between periods of progression.

Disuse weakness may occur if there has been a change in lifestyle and the individual has been more sedentary. For example, a change in work responsibilities or a recent hospitalization may result in this type of weakness. A trial of carefully monitored exercises may improve the strength in muscles with disuse weakness.

<table>
<thead>
<tr>
<th>New Muscle Weakness</th>
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<tbody>
<tr>
<td><strong>Problem</strong></td>
</tr>
<tr>
<td>Getting on/off toilet/couch (leg weakness)</td>
</tr>
<tr>
<td>Long distance walking</td>
</tr>
<tr>
<td>Foot drop or slap when walking (weakness in ankle muscles)</td>
</tr>
<tr>
<td>Choking, swallowing problems</td>
</tr>
</tbody>
</table>

**Pacing and Bracing**

To manage new weakness, generally it is important to stop overusing weak muscles by pacing activities and using assistive devices and/or braces. Research demonstrates that non-fatiguing exercise programs can improve the strength of mild to moderately weak muscles. However, new muscle weakness in polio survivors is frequently not due to disuse weakness. The important point in managing new weakness is to avoid frequent or continuous muscle overuse, or muscle exhaustion, and to use a non-fatiguing exercise program.

**Fatigue**

Fatigue is one of the most common symptoms expressed by polio survivors with a variety of possible causes. Fatigue is a nonspecific term that polio survivors often use to describe decreased muscle stamina and endurance. Survivors also

(Continued . . . )
describe a global or generalized exhaustion that can affect mental alertness. Many polio survivors describe a major decrease in stamina following illness, surgery or trauma, and recovery may take three to four times longer than for people without prior polio.

To treat fatigue adequately, first identify the contributing factors. For example, many medical conditions may result in fatigue. Some of the more common medical disorders associated with fatigue include anemia, diabetes, thyroid disease, fibromyalgia and depression. Dealing with disability and lost function is emotionally draining for many and can lead to depression with decreased attention, decreased ability to concentrate and increase in fatigue.

Fatigue occurring upon awakening usually reflects sleep disturbances that can be the result of a variety of conditions including musculoskeletal pain, restless leg syndrome, or respiratory abnormalities, such as sleep apneas and difficulty breathing due to spinal curvatures. Survivors may have new respiratory muscle weakness, which results in inadequate breathing and ultimately excessive fatigue.

Prescription medications such as beta-blockers and sedatives contribute to feelings of fatigue. Narcotics used for treatment of chronic pain may also disturb sleep and can contribute to a feeling of fatigue and irritability.

Chronic musculoskeletal pain can also lead to deconditioning, another contributing factor to general fatigue. While staying "in shape" or "in condition" is important, each survivor must find the balance between overworking polio muscles and appropriate conditioning exercise. A safe approach is for survivors to start a realistic supervised exercise program and slowly add additional exercises and repetitions to it.

The management of fatigue follows many of the same principles as interventions for weakness and pain. Thus, improving one symptom will often result in an improvement in others.

It is important first to identify what is contributing to the fatigue. Many health care providers use a fatigue scale to establish a baseline score or a survivor's current type and level of fatigue. They use the scale again to measure how beneficial their suggestions, such as braces, canes and breathing machines, are. With time and persistence, most people DO feel better.

You should encourage your parent or friend to make meaningful changes in their daily activities to help reduce fatigue.

***In our June newsletter, we published 3 articles from this outstanding series: Post-Polio Syndrome, New Symptoms after Stability and Aging with Polio. We will publish more of these informative articles in the months to come.***
LITTLE SPOTS MEAN A LOT

Fatigue and “brain brownout”. Difficulty focusing attention and word finding associated with fatigue are the most commonly reported, most disabling and, unfortunately, the least believed of all Post-Polio Sequelae (PPS). The biggest problem is that there is no medical test to prove that you have fatigue. Research that we began in 1993 on the post-polio brain has documented damage done by the original poliovirus infection that prevents survivors from activating their brains and thereby causes fatigue and brain brownout. There are three new studies that support our findings.

A summary of the first study begins with a sentence that warms my heart: “While individuals with post-polio syndrome do not have diminished mental function when they are well rested, their mental function declines considerably after even moderate mental fatigue.” Researchers at the US Uniformed Services University of the Health Sciences asked 65-year-old polio survivors to complete computerized neuropsychological tests of attention, thinking or memory once, and then again one hour later. The so-called “practice effect” typically improves scores the second time anyone takes neuropsychological tests. However, more than 40 percent of polio survivors had a decrease in performance on the second administration of seven of the eight computerized tests, while 50 percent did more poorly on at least three tests. Subjects didn’t make more mistakes the second time; they were just much slower performing the tests after being fatigued by taking the first set of tests. Slower performance on neuropsychological tests is exactly what our studies found, that polio survivors reporting severe daily fatigue required 23 percent to 67 percent more time to complete tasks requiring attention than did polio survivors with no or mild fatigue.

Why has our neuropsychological research and this new study found brain brownout to be related to fatigue in polio survivors? In our others studies, we used magnetic resonance imaging (MRI) to look inside the brains of polio survivors. We found small individual or multiple “white spots” (technically called hyper intense signal) in the brain activating system of 55 percent of polio survivors reporting moderate or higher daily fatigue, and no spots in those with mild or no fatigue. The more white spots, the more severe were polio survivors’ fatigue, problems with memory, thinking clearly, staying awake, mind wandering, attention and concentration.

Recently, researchers at Duke University published a study using both regular MRI, which we used, and a new, more sensitive imaging technique (called DTI) to...
look at white spots in the brains of individuals 60 and older without polio or any neurological disease. The study found that visible white spots on regular MRI may be just the tip of the iceberg, since DTI found that damage to the brain under the white spots was larger than the spots themselves. What's more, the researchers concluded that those with white spots in one part of the brain may have invisible damage in brain areas where spots have not yet become visible on regular MRI, and that this damage may be preventing brain neurons to talk to each other. This could possibly explain why 45 percent of polio survivors with significant fatigue in our study had no visible spots on regular MRI. When it comes to seeing damage on MRI in polio survivors' brain activating system, apparently little spots mean a lot.

So, there actually is physical evidence that poliovirus damage is related to brain brownout in fatigued survivors. But listen to this: Mayo Clinic researchers studied a virus in the same family as the poliovirus -- the virus that causes the common cold. They infected some mice with cold virus and not others. Both groups had their memory tested by completing a maze. Virus-infected mice made more errors and couldn’t figure out where they were going. (Sound familiar?) The mice that made the most errors had greater damage to their brains. The study concluded that even the cold virus could cause “at least some degree of neurologic deficit” in humans. If having a cold can cause brain damage, how can so many doctors still say that the poliovirus, a known killer of brain neurons, couldn’t possibly cause polio survivors to have brain brownout and fatigue? Time for doctors to read a medical journal or two and start seeing the spots.

Fear of Alzheimer’s

Asked one polio survivor, “When I am very fatigued or stressed I will totally forget the word I was going to use. I’m frightened. Am I getting Alzheimer’s disease?” The answer? Nope.

You are experiencing word-finding difficulty, a problem for polio survivors that has nothing to do with memory loss or Alzheimer's disease. In our 1990 National Survey, 79 percent of polio survivors reported difficulty "thinking of words I want to say." Thirty-seven percent reported frequent, moderate-to-severe word-finding difficulty. In the American Journal of Physical Medicine and Rehabilitation, we describe testing polio survivors and finding that they do indeed have the "tip-of-the-tongue" experience--knowing the word you want to say but not being able to say it. Polio survivors have difficulty with naming objects and sometimes even people they know well. Our results indicated that word-finding difficulty was not associated with memory or thinking difficulty -- symptoms of Alzheimer's disease -- but was related to trouble focusing attention, a characteristic symptom of post-polio fatigue. We also found that difficulty with word finding and focusing attention were related to polio survivors' brains making less dopamine. Low dopamine is the cause of Parkinson's disease, and we found that word-finding difficulty was identical in both polio survivors and Parkinson's patients, (continued . . .)
even though polio survivors do not experience the tremor and rigidity of Parkinson’s. In 1996, we published a study in the same journal showing that bromocriptine, a dopamine-replacing drug, reduced word-finding difficulty, attention problems and fatigue in polio survivors. However, medication is not necessary to treat word-finding difficulty or any PPS symptom. Reducing physical and emotional stress decreases all PPS symptoms. So don’t worry that you have Alzheimer’s disease. If you’re having trouble thinking of a word that you want to say, try to "talk around" the word by describing what you’re trying to name. If you are forgetting your friends’ names, have some fun and just call everyone "Buddy" or "Honey."

Richard L. Bruno, PhD.
Rev. 2015

A Bruno “Byte”
(Bits and Tidbits from the Post-Polio Coffee House)

Bruno Bytes are updated monthly, and are available in their entirety through a “link” on www.postpoliinfo.com (or) directly through http://www.papolionetwork.org/bruno-bytes.html

On the topic of Low Back Pain Always Being PPS

Original Post: I was paralyzed from the waist down. Although I'm weaker all over now, my lower back is the most affected by PPS. Just a very few minutes of bending makes my lower back scream with pain, so that I have to whimper limp to couch or bed to ease it. I'm wondering just exactly what is happening to cause this pain? I know I've lost the motor neurons that make the muscles work, but is the pain coming from the last surviving neurons? I just assumed it was weak back muscles from PPS. I realize that I don't really understand how pain works.

Dr. Bruno’s Response: Don’t assume the pain is all PPS. You may need to have your lower back evaluated & probably a low back MRI. Always have significant / long term pain evaluated by a PPS knowledgeable Rehabilitative Physician (physiatrist). Once again, never assume that all symptoms are PPS.

and Always Conserve to Preserve.
Our “Collage of Gratitude”

On Friday, September 9th, we delivered our gift to Dr. Carol Pandak, Director of Polio Plus at Rotary International. We met two additional members of her team and were treated to a full tour of their headquarters.

We were thrilled with the response for this project from survivors all over the globe. For those of you who sent us your photos, we shared with her your stories. She realized that survivors and our families truly appreciate their efforts to eradicate this terrible disease.

For those of you who didn’t get your photos in? It’s not too late. As a follow up, we are creating a slideshow – one that will reflect the joyful faces of survival and the historical photos we’ve been collecting. Please send your photo to: papolionetwork@gmail.com. Not able to email photos? Call us. We’re happy to help. A full image of the collage is available for copying here:

http://www.papolionetwork.org/new-stories-of-interest.html

(Continued . . . . .)
Without question, the one thing we all share is the prayer that with worldwide vaccination; death and disability from the Polio Virus will soon be gone . . . . Forever.

We are truly grateful for your kind words of support and very generous donations.

This month’s graphic was shared with us by Polio Survivor Lynn Young.

Feel free to copy and share what you see. Please give credit to the original source. Do you have a topic you would like us to cover? Please let us know. You are not alone. We’re here to help.