PA Polio Survivors Network

Information and Inspiration for Polio Survivors and Their Families
From the Keystone State and Beyond

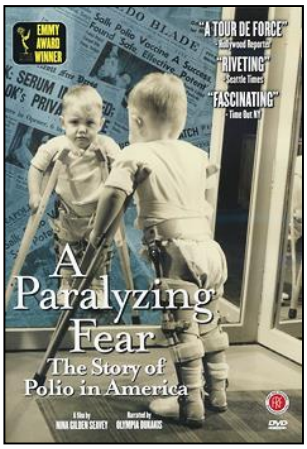
www.polionetwork.org

March 2017

Our Mission:

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

"A Paralyzing Fear"
The Story of Polio in America



Thanks to the generosity of Director Nina Gilden Seavey, we are happy to be able to offer the outstanding documentary film *A Paralyzing Fear* , in DVD format, to all of you. Nina Gilden Seavey is an Emmy Award-winning documentary filmmaker and Research Professor of History and Media and Public Affairs at George Washington University. She is currently the Director of The Documentary Center, which she founded.

When we spoke to Professor Seavey, we were particularly moved not just by her spirit of generosity, but by her compassion towards the complex issues faced by Polio survivors.

"Flu, Fatigue and Post-Polio Syndrome"

William M. DeMayo, MD. is always happy when he's asked a question by a polio survivor that he can turn into an article that can benefit us all. This month, at the tail-end of Flu season he has had that opportunity once again.

Polio Australia
Improving health outcomes for Australia's polio survivors

The Late Effects of Polio – Do you know the signs?

"Acute poliomyelitis (polio, also known as 'infantile paralysis')
is a viral infection affecting the nervous system".
This sentence begins an outstanding article that was shared with us by Polio Australia. This is a great article that contains clear graphics.

What's So Bad About Sugar?

Each month, our friends at Post-Polio Health International publish interesting articles on their Facebook page. We know that many of you are not on Facebook and as a result, we bring their posts to you. This February "post" caught our eye. After all, who DOESN'T like sugar ? (You can see numerous interesting posts from the last two years on our website).

Check out this month's Bruno Bytes.

Published regularly in a collaboration between our network and Richard L. Bruno, HD, PhD since 2014, they are *all* available along with an Index by *subject.*

Polio Australia
Improving health outcomes for Australia's polio survivors

The Late Effects of Polio: Do you know the signs?

Pathophysiology of the Late Effects of Polio (LEoP)

Acute poliomyelitis (polio, also known as 'infantile paralysis') is a viral infection affecting the nervous system. It can infect both the central and the peripheral nervous system, but the most common infection is in the anterior motor horn cells, resulting in flaccid paresis of the muscles. This can present as a widely variable distribution of weakness in skeletal and bulbar musculature, with residual impairment and paralysis ranging from minor muscle weakness to total paralysis requiring intervention such as ventilation.

After motor-neuron destruction during the acute polio phase, surviving motor units sprout axons to reinnervate the denervated or 'orphaned' muscle fibres. This process of denervation and reinnervation is ongoing over the muscle lifespan. As a consequence, polio-affected muscles have oversized motor units and increased muscle-fibre density. It is thought that these large motor units result in increased weakness as they 'drop out' due to ageing and/or overuse. Due to this process, people with LEoP may have experienced a prolonged period of stability of physical symptoms such as weakness and pain, often lasting several decades, before presenting to their primary care provider with what can feel like a resurgence of polio-like symptoms.

LEoP can present as a unique cluster of biomechanical and/or neurologic features in each individual, which can be moderated if properly assessed and managed. The LEoP are essentially a 'diagnosis of exclusion', but should be considered for clients/patients who are known to have had polio themselves — or other members of their family (which may indicate undiagnosed sub-clinical damage). The LEoP refer to any of the following features.

Musculoskeletal features

- Decreased muscle endurance and muscle fatigue
- Overuse of compensatory muscle groups
- Muscle pain and/or spasms
- Joint pain and/or degeneration such as arthritis
- Biomechanical deformity such as kypho-scoliosis
- Muscle contracture
- Osteopenia or osteoporosis

Neurological features

- New muscle weakness
- Muscle atrophy
- Preservation of sensation irrespective of muscle loss
- Muscle twitching/fasciculation
- Compression neuropathy

Respiratory features

- Shortness of breath due to chest deformities
- Respiratory insufficiency due to sleep apnoea
- Weakening respiratory muscles
- Hypoventilation due to early damage to the respiratory control centre

Bulbar features

- Impaired thermoregulation
- Dysphagia/swallowing problems
- Dysphonia/vocal dysfunction
- Dysarthria/unclear speech
- Chronic fatigue, headaches, poor concentration

Additional considerations

- Biomechanical problems
- Bladder dysfunction
- Weight gain due to decreased mobility
- Oedema
- Psychosocial concerns due to increasing disability
- Pre and post-planning for surgical procedures

Comorbidities

- Cardiovascular disease
- Endocrine and metabolic diseases
- Chronic pulmonary disease
- Hip and limb fractures due to falls

Supporting factors

- Actual or suspected history of poliomyelitis
- A period of partial or complete functional recovery after acute infection, followed by an interval of stable neurologic function
- Symptoms persist for at least a year
- Exclusion of other neurologic, medical and orthopaedic problems

Factors NOT supportive of the LEoP condition

- Resting tremour of limbs or head
- Worsening peripheral neuropathy
- Dizziness or vertigo
- Numbness
- Problems with sensory organs
- Primary altered sensation

LEoP Health Team

- General Practitioner
- Rehabilitation Specialist
- Neurologist
- Physiotherapist / Occupational Therapist
- Orthotist / Podiatrist
- Respiratory / Sleep Specialist
- Speech Pathologist
- Dietitian / Nutritionist
- Osteopath / Massage Therapist
- Psychologist / Social Worker

More information

Polio Australia's www.poliohealth.org.au website contains resources for health professionals including clinical practice publications, post-polio research papers, and the Health Professionals Register for referral or further consultation.

Contact Polio Australia:
PO Box 500, Kew East, Victoria, 3102
Email: office@polioaustralia.org.au
Phone: 03 9016 7678

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It is easily available for printing and sharing in PDF on our website.

And more from our friends in Australia.
Polio Oz is an outstanding PPS Resource. . . .

Do You or does your Family Member or Patient have breathing muscle weakness for any reason?

If you have generalized muscle weakness, decreased breathing capacity, and a weak cough, now is the time to ASK YOUR DOCTOR about how to prevent respiratory failure and avoid invasive tubes. And if your doctor does not know about the benefits of non-invasive respiratory care, then today is the day to SHARE THIS INFORMATION with your physician. Non-invasive ventilatory support (NVS) and mechanical insufflation-exsufflation (MIE) may help you to avoid episodes of serious breathing problems (e.g. respiratory failure), avoid the need for invasive airway tubes passed down the throat (e.g. endotracheal tubes), and avoid the need to resort to invasive airway tubes passed through the neck and into the windpipe (e.g. tracheostomy tubes), which cause increased morbidity and mortality.

www.breatheNVS.com / www.breatheBB.com

John R. Bach, MD, is a professor of Physical Medicine & Rehabilitation, professor of Neurosciences, the director of the New Jersey Medical School Muscular Dystrophy Association Clinic, and medical director of the Center for Ventilator Management Alternatives.

Note: We are grateful to the work of Dr. John R. Bach, MD. His article "Breathing Outcomes for PPS" is one of the articles on the direct link from our updated Anesthesia Warning Cards.

Flu, Fatigue and Post-Polio Syndrome

William M. DeMayo, MD.
DeMayo's Q & A Clinic

Question:

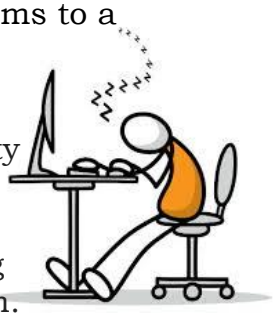
I was diagnosed with the flu in early February. I had extreme fatigue for a full month. Yesterday, I spent a full day in the E.R.. Nothing except dehydration showed up on tests. Could this be post-polio syndrome fatigue, along with fatigue from flu and a secondary infection? How long will I have to deal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

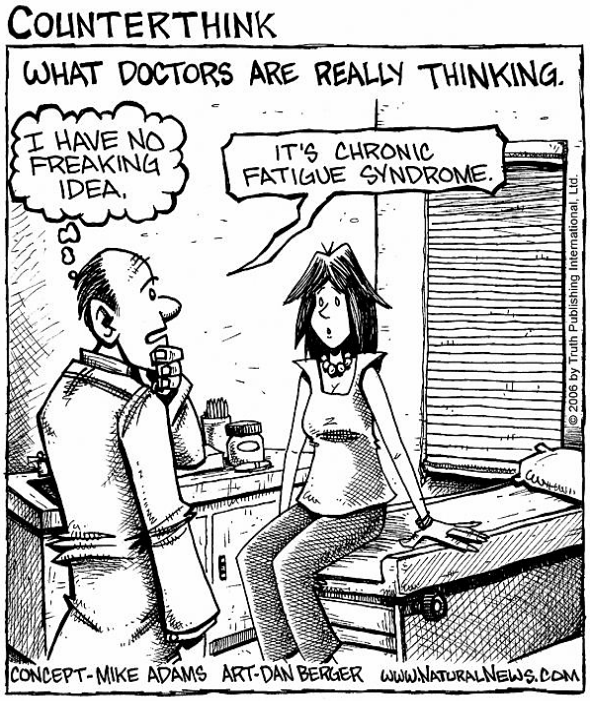


Here is a partial list of some of the most common causes of fatigue:

- 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 unaddressed.
- 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.

Continued . . . .

- Medical issues.
  - Infection - either bacterial or viral
  - Dehydration
  - Endocrine problems.
    - Thyroid disease.
    - Adrenal disease.
    - Diabetes.
    - Other
  - 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
  - Other
- 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 and 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.

HOW OPTIMISM WORKS

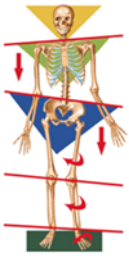
A pessimist might see the interrelationship of multiple causes of fatigue as being problematic. At the same time optimists, including myself, will focus on the fact that any of the above interventions will have a "spillover effect" into other areas.

(continued . . . .)

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?"

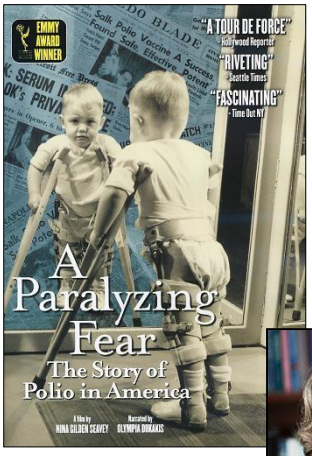
William M. DeMayo, MD.
March, 2017



*Check out Dr. DeMayo's article in our December, 2016 Newsletter:
"Conserve to Preserve – What does it Mean?"

Do you have a question for Dr. DeMayo?
Feel free to contact us: info@polionetwork.org (or) 215-858-4643

A Paralyzing Fear – The Story of Polio in America



This Emmy Award Winning Documentary was
Directed and Produced by Nina Gilden Seavey and
Narrated by Olympia Dukakis

Seldom has society come full circle in the cycle of a disease - from illness, to epidemic, to cure. Polio is the 20th century's most notable exception.

Every baby boomer remembers collecting dimes in their dime cards, hearing the success of the Salk shot, and lining up for oral vaccines taken in a sugar cube. But few know the story of how polio came to America in grew into the frightening epidemics of the 1940's and 50's when the disease crippled tens of thousands of children every summer.

Led by President Roosevelt who was crippled by the virus himself, the battle against polio was the first, and perhaps the most successful, fight against a disease.

This fascinating story is told here using thousands of photographs and films along with interviews with polio survivors, their families, nurses, doctors, and community leaders, bringing to life an America that was both brave and innocent - when people believed in scientists, government, and the power of every person in the fight to protect the children.

We are happy to announce that through the generosity of Professor Seavey, we have library copies of *A Paralyzing Fear* to share.

This series is outstanding for all Polio Survivors, Post-Polio Support Groups as programming, and anyone interested in the history of the Polio epidemic(s) and the need for vaccination.

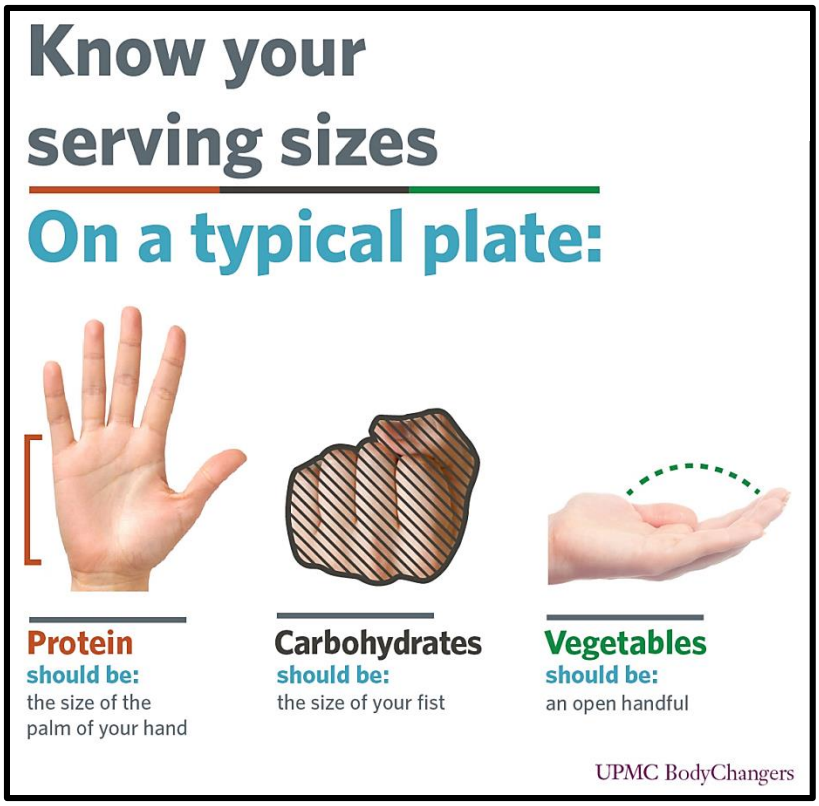
We have been given permission to put this wonderful film in it's entirety on our website.

In addition, Professor Seavey has generously given us library editions of the film to share – both in DVD and VHS format.

Contact us: info@polionetwork.org (or) 215-858-4643 for borrowing information.

A Beginner's Guide to Portion Control

From the Magee-Womens Hospital of University of Pittsburgh Medical Center



It's nearly impossibly 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:

And Speaking About What We Eat . . .

What's So Bad About Sugar, Anyways?

Are you aware of how much added sugar you are consuming? There are 120 teaspoons in one pound of sugar. The average American consumes approximately 160 pounds of refined sugars each year. That's over 19,000 teaspoons of sugar! Yikes! Consistently consuming excess sugar can lead to tooth decay and cavities, obesity, type 2 diabetes, heart disease, high blood pressure, and many other detrimental health conditions. It can even contribute to nutrient deficiencies due to providing calories but limiting nutrients. In other words, added sugars are empty calories that provide little to no nutritional benefit whatsoever.

Some obvious places to find sugar are in candy bars, sodas, baked goods, and ice cream; however, it is also often hidden in food items that you would not normally consider "sugary." For instance, did you know that there are added sugars in ketchup? What about bagels, cereals, salad dressings, sauces, and yogurts? Watch out for sugar shocks and traps, as sugar is added to many foods to improve taste. This may be challenging to recognize when reading nutrition labels, since sugar can be disguised by many other names.

Consider limiting or modifying the amounts of foods or food products you enjoy if the ingredient list includes one of these disguised sugar names:

Cane Crystals - Corn Sweetener - Evaporated Cane Juice - Fruit Juice Concentrates – Fructose Glucose - High Fructose Corn Syrup - Maltose Dextrose - Molasses - Stevia - Sucrose

Still have a sweet tooth?

Consider munching on something that has natural sugar as opposed to added sugar. Fruits with natural sugars contain fiber, which makes sugar less harmful to the body. Plus, unlike empty-calorie sugary foods, fruits DO have nutritional benefits! Next time, enjoy some of nature's fresh candy before choosing a processed treat with added sugar.

You may want to watch this video from the
National Center on Health, Physical Activity and Disability: Hey Sugar !
http://www.nchpad.org/1547/6531/Sugar~Awareness

A "Bruno Byte"
From the Post-Polio Coffee House

On the topic of "Sprains, Strains and Tears" (2/27/2017)

Dr. Bruno's Original Post: I'm offering this article for information because this article explains the differences really well. If you experience any of these symptoms, please seek help from your PPS knowledgeable physician.

Credit: Texas A&M Health Science Center

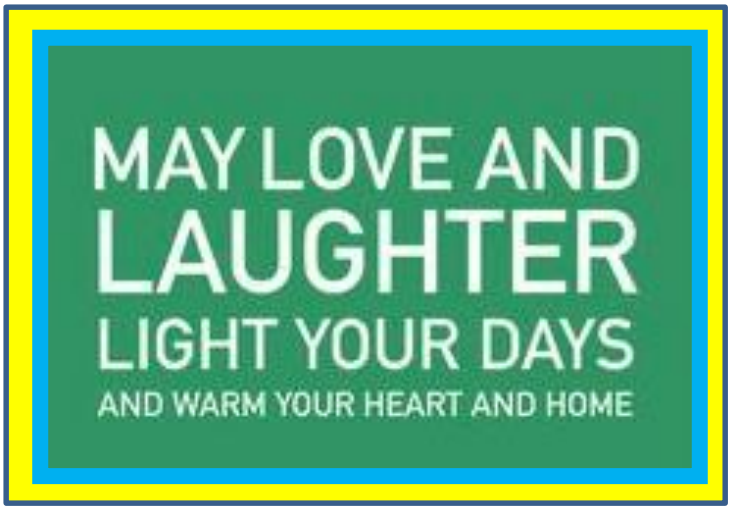
The Differences Between a Sprain, Strain and Tear

Know how they are caused, treated and prevented

TEXAS A&M UNIVERSITY

What IS Post-Polio Syndrome ?
We have multiple pages of information about Post-Polio Syndrome
Go to that topic along the top of our Home page.

We are truly grateful for your kind words of support.
Your very generous donations are the key to helping our work continue.



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Do you have a topic you would like us to cover? Please let us know.

Always feel free to contact us.
The Polio Network Team

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