POLIO NSW *formerly Post-Polio Network (NSW)*

NETWORK NEWS

Incorporating – **Polio Oz News**

Editor: Susan Ellis
Email: editor@polionsw.org.au
Website: www.polionsw.org.au

PO Box 2799, North Parramatta
NSW AUSTRALIA 1750
Phone No: 02 9890 0946

Patrons: **Michael Lynch** AO CBE **Professor Emeritus Sir Gustav Nossal** AC CBE FAA FRS

Editor's Report:

Winter has passed and it is a joy to appreciate the coming of spring and the warmer weather. I also hope that you enjoy this issue of Network News.

Gail Hassall's webinar report about dementia appears on Page 2. The webinar was held on 17th September, 2024. The presentation given by Donna Ward from Group Homes Australia, explained dementia in simple terms and included her 18 year experience of supporting her mother who lived with dementia. Gail's report is extensive and gives those that could not attend an clear insight into dementia.

There are a number of articles relate to brain function in this issue – psychologist Hal Goldberg article titled "How Polio and PPS Impact our Character, Personality and Emotional Experiences", Dr Bruno talks about 'brain fog' and Millie Malone's article, "Is This PTSD?" (post traumatic syndrome disorder). A second article by Millie is "The Last Straw".

The latest edition of Bruno Bytes covers "New" muscle weakness, Tremors/Shaking, Statins (cholesterol medication) and Vitamins.

Therapist and Counsellor, William Montgomery discusses how to approach family who are non-vaccers in his article, "My Grandchildren May Not be Vaccinated".

A topic of interest to many polio survivors is fatigue. An article by Dr Marney on fatigue – "Fatigue – WHY am I so tired? - covers this topic in depth.

Dr DeMayo's article "Exercise and Weight Loss for the Polio Survivor" answers all our questions on how to balance these two issues.

I have one more issue of Network News to produce in November when I will hand over the baton as editor. I have enjoyed and honoured to have produced 40 newsletter under the guidance of Gillian Thomas and with the assistance of Nola Buck since 2012.

I hope this issue of Network News is of help to you as it has for me researching these articles from near and far.

Polio NSW Webinar Report - Demystifying Dementia

By Gail Hassall, Webinar Co-ordinator

Presented by Donna Ward, from Group Homes Australia - 17th September, 2024

Donna Ward started the presentation by introducing herself and talking about her mother who lived with dementia for 18 years before she died.

The presentation included -

Learning how to reduce risk factors -
- Learn practical tips and strategies to support your loved ones and others in the community to live well with dementia

Understanding Dementia –
- Delve into the various types of dementia, their symptoms and risk factors and how the GHA strengths-based approach helps you think about dementia differently

Communicating and Connecting –
- Understand the complexities of communication challenges, including language and memory loss, plus exploring methods to foster meaningful connections

Human Needs –
- Understand each other's basic human needs and how they can be impacted by dementia

Unmet Needs –
- Recognise and tackle challenges related to unmet needs for people living with dementia and offer practical ways to fulfill these unmet needs

Ambiguous Loss –
- Understand and manage the ongoing brain changes and transitions that people living with dementia will experience

Donna had worked in advertising but decided she could better help others with dementia following her experience with her mother. Donna provided a clear outline of the types of dementia, the risks factors for dementia, understanding the complex needs of people living with dementia and managing brain changes.

These notes are from my note-taking only and not official information from Donna or GHA.

Dementia is an 'umbrella' term encompassing a group of symptoms and a group of diseases. Each dementia will present differently and respond to different strategies. The most common symptom that is known about dementia is memory loss. However, dementia can impact many different areas of brain function. For example, emotions, the ability to calculate numbers and manage finances, orientation of time and place, word searching, and many other symptoms.

The most common types of dementia are:
- Alzheimer's - 60%-70% of all dementias
- Vascular Dementia – 16%-25% of all dementias
- Fronto-temporal Dementia – 2%-4% of dementias
- Lewy Body Dementia – 2%-20%

Other types of dementias include:
- Parkinson's Disease

- Chronic Traumatic Encephalopathy (CTE)
- Huntington’s Disease
- Head Trauma
- Alcohol related
- Creutzfeldt-Jakob Disease (CJD)
- Younger Onset Dementia

Risk Factors for dementia – **non- modifiable**
- Family history – you cannot change your family history
- Genetics – even if you have the gene for Alzheimer’s, it doesn’t mean you will develop it
- Age – dementia is not a natural part of ageing but the longer we live the more chance there is of developing dementia

Unmet needs may cause odd behaviour, for example, imagine that someone turns up at your door and says they are there to shower you. You don’t know the person, don’t understand why they are there and this might result in you behaving oddly, too.

Risk Factors for dementia - **Modifiable**
- Physical activity - 3 in every 4 (75%) adults do not meet the Australian physical activity guidelines. (Australian Heart Foundation)
- Manage hypertension - Around 1 in 4 adults living in Australia have high blood pressure (23%). (Australian Heart Foundation)
- Quality of sleep – chronic sleep deprivation has been linked to an increased risk of anxiety and depression as well as other chronic mental health conditions
- Smoking
- Alcohol intake in moderation – no more than 4 standard drinks on any one day although current advice is no alcohol
- Cognitive training – start a new activity, try a craft, read more, word puzzles
- Socially active - conversations and social activities with others can help stimulate cognitive function.
- Oral hygiene – there is a link between Gingivitis and dementia
- Healthy diet – Sugar is like a bullet to the brain. Mediterranean Diet is recommended. What is good for your heart is good for your brain
- Hearing –mental decline seems to increase when hearing problems become worse
- Manage diabetes – higher risk of dementia if diabetes is not managed

Symptoms of dementia
- Poor or decreased judgement
- Change in personality
- Frequent memory loss that affects daily activities
- Problems with language – forgetting words or using different words
- Loss of initiative
- Difficulty performing daily tasks
- Problems with abstract thinking
- Changes in mood or behavior
- Disorientation with time and place
- Misplacing things or putting them in different places

Brain changes
May have an impact on:
- Planning

- Speech and language
- Way finding
- Judgement
- Memory sequencing
- Initiating

Group Homes Australia

Group Homes Australia think about dementia differently.

What needs to change in order to live well with dementia? Well-meaning people take away the human needs.

Group Homes Australia is unique. They specialise in supporting those with dementia who have high care needs to live purposeful and meaningful lives. Smaller care environments have been proven to improve quality of life, reduce rates of depression and reduce hospitalisation for people living with dementia. Currently Group Homes Australia has 23 homes in Sydney and Central Coast. Each group home accommodates 6-10 people with 24/7 dedicated care.

An initial assessment with the Social Workers and Registered Nurse from Group Homes Australia team happens within a Resident's own home where possible. The purpose of the assessment is to build a relationship, learn about the Resident and their families life and what makes them unique, as well as an understanding of their care needs.

You– who is this person? What is their life story? An in-depth look at who they are, what work did they do, what kind of life did they have, relationships etc.

Environment – Friendly
Familiar
Functional
Forgiving

Brain changes

- Sensitivity – person may no longer like to be touched; a shower may feel like pins and needles
- Hearing changes
- Peripheral vision can be affected
- Loss of sense of smell – may smell burning
- Taste buds change – may taste very salty or very sweet

Community
“Social participation and social support are strongly connected to good health and well-being throughout life.” (World Health Organisation)

Time
Allowing people the time to settle into their environment, not forcing or rushing them

Purpose and Meaning
Find out what people love and what is meaningful to them, how they would like to contribute, and what activities they would like to participate in, based on their interests, preferences and experiences

How Polio and PPS Impact our Character, Personality and Emotional Experiences

The PA Polio Network www.polionetwork.org June, 2024

As a part of the Polio Health International's 2024 Educational Series and presented June 3, 2024.

“Hal Goldberg has worked in Colorado as a psychologist for over 40 years and as a private practitioner since 1988. For the past 15 years his practice has focused on supporting people with chronic or life threatening health issues. He also works with a geriatric population around issues for aging, isolation, loss, and transition. He is currently facilitating groups for polio survivors and those experiencing life challenges related to post-polio syndrome.”

This is the latest in the outstanding series published by PHI. These videos are easily available on the Living With Post-Polio Syndrome page of our website. Look in the Index under the topics of Post-Polio Health International (or) Videos.

https://www.youtube.com/watch?v=1y2E6Be5JCU

The PA Polio Network www.polionetwork.org

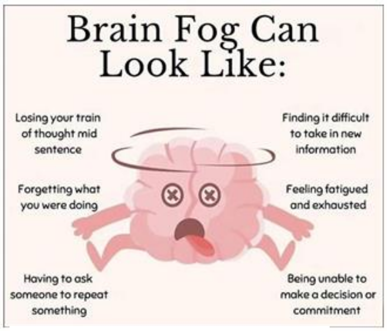
"Brain Fog" and Mental Status Exams

by Dr. Richard L. Bruno, HD,PhD International Centre for Polio Education

The PA Polio Network www.polionetwork.org July, 2024

Question: I did a book review for my book club. It was a challenging book and I was well prepared. This used to be easy for me but I talked cautiously and felt brain “foggy” at times. I just couldn’t think very fast. I generally feel my mind is good but I guess the stress of doing the presentation was too much.

Dr. Bruno's Response : A polio survivor with "Brain Fog?" You're not alone! Here in the U.S., Medicare pays for a MMSE (Mini-Mental State Examination) at primary care checkups for everyone over 65. These tests ask questions like day & month, counting backwards and repeating simple words/phrases. Those results could in fact be skewed by PPS fatigue. Here are two articles from the Encyclopedia of Polio and PPS that you can share with your primary care physician:



Source: Brainbodydoc

CAUTION: False Positives in Polio Survivors with Post-Polio Sequelae Given Mental Status Examinations and Post-Polio Brain Fatigue – Little Spots Mean A Lot

These two articles and more are easily available in the Index of the Encyclopedia of Polio and PPS under the topic: "Fatigue".

* * *

Https://polionetwork.org/anesthesia-card

ANESTHESIA WARNING!

I am a Polio Survivor

- **Easily Sedated**, and can be difficult to wake
- Can have difficulty **breathing** and **swallowing** with anesthsia
- **Hypersensitive** to **pain** and **cold**

May need heated blanket and increased pain medication post-op

www.polionetwork.org/anesthesia-card

"My Grandchildren May Not Be Vaccinated"

by William Montgomery, Licensed Marriage and Family Therapist

The PA Polio Network www.polionetwork.org August, 2024

Counselling Corner with William Montgomery, MFT

Question: "My children don't want to vaccinate my granddaughter. My son has never known a mother who wasn't disabled from polio. My husband had the measles as an early teen - it was awful. His mother always talked about how sick he was. I don't know if I'm heartbroken or furious. How do I address this with them?"

Dear Reader, A child . . . any loved one . . . not being vaccinated can be scary and upsetting. It can, certainly, lead to arguments.....which are usually to no avail. The person deciding against a vaccination does not, as you know, change their mind because someone argued with them. So, what to do?

First, be aware that this is an emotional issue for both people. The one that refuses has some fear, probably, that harm can eventually occur due to something they do not trust if the vaccine is given. (Note here that Fear and Mistrust are both emotions), and the person insisting has a fear, most likely, of harm happening if the vaccine is not given. In fact, neither person can know if they are correct. There can be science pointing one way or the other, but for any one person, no one knows for sure. Probabilities, yes, but not certainty. So, this is not a certainty-based argument. It is emotionally-based, as are most arguments.

So, the first step is to be **Aware**. Aware of your own emotions around this situation. If the vaccine is not planned for the child, then most likely you are experiencing concern (or even fear), and a feeling of being dismissed or unheard. Perhaps more. And, of course, you would likely be feeling frustrated or angry. The frustration and anger are actually the result of the fear and feeling dismissed . . . they drive the frustration/anger. These are all understandable emotions for you to have.

The next step is to **Ask** to hear their concerns. Be curious. Hear their fears without judging them. Seek to understand before being understood. The underlying key concept here is to seek to deeply understand . . and thereby validate . . . their emotional mind-set that is driving their frustrations and fears. Validating their emotions is not the same as agreeing with their view of the science of vaccines, but rather validation is letting them know that you understand that they have fears . . . as you do.

After hearing them, and expressing that you understand, ask to be heard. Speak from inside of yourself, expressing your emotions around this and expressing your own experience. You can't know that you are absolutely right . . . even though science is on your side . . . that your daughter or son should or must have their child immunized. Because you can't tell exactly what is going to happen. You have your fears and you do have your experience. You can start sentences with ' I ' or 'me' or 'my' and not with 'you’ . . . as in 'You should . . . '. Express, for example, that you are afraid for your granddaughter and it scares you if they are not vaccinated, and you're not telling them what to do but you're confused because you don't see any evidence of a problem with vaccines but you see lots of evidence of problems when there are not vaccines . . . so you're confused but it does not mean they are wrong.

In other words, the beginning of a productive discussion begins with each party feeling that their concerns are accepted as legitimate to them. That each person feels heard and understood. Not about right or wrong, but about each person feeling validated in having fears and concerns and confusion. This can be difficult for people to practice at first.

Once each party feels really heard and understood, the door is . . . or hopefully is . . . open for each to have a discussion of what can be done. What most often helps is that once each person feels deeply heard and understood, this can be more powerful than the subject itself. So, each party can be more open to considering options and compromises, or to talk to a doctor together . . . and many more possibilities.

These are not easy discussions, especially since we are not practiced or experienced at having discussions about our emotions . . . yet our emotions are largely in charge of all we do . . . so it is best to learn and practice these new skills.

Good Luck . . . Bill Montgomery

* * *

Fatigue - WHY am I so tired?

by Dr. Marny K. Eulberg Primary Care Perspective

The PA Polio Network www.polionetwork.org July, 2024

Just thinking about fatigue can make me tired! There are so many aspects to this issue. First, people can mean so many different things when they use the word. Are they talking about muscle fatigue that happens when they have exercised beyond the limits of their muscle(s)? Do they mean brain fog and difficulty processing information at certain times or nearly all the time? Do they mean a lack of a sense of meaning or joy from activities that used to be meaningful to them?

Definitions of Fatigue

The American Heritage Dictionary of the English Language lists 3 definitions of fatigue (the noun), which are:
1) physical or mental weariness resulting from effort or activity,
2) something, such as tiring effort or activity, that causes tiredness or weariness, and
3) the decreased capacity or complete inability of an organism, organ, or part to function normally because of excessive stimulation or prolonged exertion.

Taber's Cyclopedic Medical Dictionary defines fatigue as:
1) A feeling of tiredness or weariness resulting from continued activity or as a side effect of some psychotropic drug. This overwhelming sustained sense of exhaustion results in decreased capacity for physical and mental work.
2) The condition of an organ or tissue in which its response to stimulation is reduced or lost as a result of overactivity.
3) To bring about fatigue (when the word is a verb)
The medical definition from Taber is closer to what I think polio survivors mean when they talk about exhaustion.

Causes of Fatigue

There can also be so-o-o many causes for a feeling of fatigue - separate from, or in addition, to one's prior history of polio and whatever damage the polio might have caused. The website for the Mayo Clinic (www.mayoclinic.org) lists 27 conditions that (can) be the basis for your feeling this way! These other conditions, if present, can be the sole reason that one is fatigued or there can be more than one thing causing this feeling of exhaustion. When these conditions are added together, it can be truly tiresome.

It makes sense that if one is not getting restorative sleep, they will be tired the next day. Causes of non restorative sleep can include untreated sleep apneas, restless legs, the need for frequent trips to the bathroom during the night, depression, and difficulty getting to sleep or maintaining sleep.

Unrelated to poor sleep is an even longer list of conditions that can be responsible for fatigue including severe liver, kidney, heart or lung diseases, various causes of anemia, many cancers or the effects of chemotherapy or radiation used to treat them, auto-immune diseases such as rheumatoid arthritis or inflammatory bowel conditions, an underactive or overactive thyroid gland, uncontrolled blood sugar, a number of medications (pain meds especially opioids, some heart and blood pressure drugs, antihistamines, and meds for anxiety, depression, and other mental health issues), and miscellaneous conditions as diverse as chronic fatigue syndrome, long COVID, fibromyalgia, post-concussion syndrome, multiple sclerosis, and grief.

Treatment Options for Fatigue

It is important to rule out and/or treat conditions that could be causing or contributing to a person's feeling of being overtired. Depending upon the cause of your fatigue, the treatments can vary and will be different than the treatment recommended for fatigue due to post-polio syndrome (PPS).

Note: Your physician can treat these causes simultaneously while the individual is enacting the measures recommended for post-polio fatigue.

Several medications to treat PPS fatigue have been researched. Several had significant side effects and, to date, none have been found to be any more effective than lifestyle changes. It would be wonderful if there were medications that decreased or eliminated post-polio fatigue but two years later, as I update my original 2022 article, that is still NOT the case.

The measures that have been found to be helpful are pacing activities, taking rest breaks, and a careful assessment of one's activities and using that information to modify one's activities. Once again, I have attached an activity diary (fatigue log at the end of this article) that was developed by the International Centre for Polio Education for use in their clinic.

To cover the kind of detail that is needed to get a "full picture", this diary/log will be a multi-page exercise. (I understand that this is a tedious undertaking, but one that is, without question, worthwhile). During the period that the data is being recorded, recordings of activity should be made at least once an hour. It is easy to "forget" or negate some activities that you may just take for granted if you wait until the end of the day to write them down. After completion of a carefully done, brutally honest activity diary, some polio survivors will be able to self identify areas where they need to make changes. I imagine that the majority will benefit from going over the results with someone who can be much more objective. That person might be a trusted friend, a spouse, or a professional such as a physical or occupational therapist.

Intermittent Fatigue

What if you don't have daily fatigue or maybe even not what you'd call "exhaustion"? Polio-related fatigue may still affect you and can lead to falls and injuries if you don't pay attention and alter your behavior.

Many of us have soldiered on and pushed through for much of our lives. We have ignored the messages coming from our bodies sometimes to the point of totally blocking those messages. Similar to telling a child or pet "just a minute", we have told our bodies "just a minute". But how often was that really only a minute (60 seconds) instead of 10-15 minutes or even more? Sometimes we could persevere without any apparent ill effects other than temporary "tiredness", but that might no longer be true.

Have you become aware that after a certain amount of activity you are much more clumsy than usual and/or are more likely to fall? Often family members or friends recognize when we are "overdoing" long before we do. Does your spouse tell you to stop and rest when you are doing some tasks, or they step in and take over? They have recognized the signs that you are getting fatigued. Pay attention to the same clues that those who care about you notice. If you can't identify those cues yourself, ask your loved ones what they see that leads them to "catch" you and then start watching for those signs yourself.

When you feel those signals, it is time to stop and make a mental note of what those signals are for you. You may not even be aware that you feel anything, but you may hear your loved one's voice in your head saying, "Don't you think you've done enough for now?" The goal is to internalize these signals and wrap things up quickly or stop and come back later. With practice you'll learn what your limits are or how to recognize that your body is telling you, “Enough”. If you are “tone-deaf” to your body, you can set a timer when starting any activity and stop when the timer goes off. It may be hard to believe but you actually can get more done by pausing to rest and then getting back to work than if you push through when fatigue has set in!

In his article ***A Message About Winter Wellness and Energy Conservation*** , Dr. DeMayo used the holidays as an example perhaps because it intensely highlights the choices we can make about activities that may be adding up to make us tired, fatigued, weary to the bone. Discovering what your triggers are will not be easy, nor quick. There may be a few “aha” moments along the way, but mostly it will be a series of small insights and steps that add up to decreasing your fatigue while still allowing you to get enjoyment out of your life.

The act of conscientiously filling out the activity diary/ fatigue log will be challenging. Simply sitting down once every hour to list the activities that you did in the last hour and how hard it was to do those activities may lessen your exhaustion by forcing you to take a physical rest break every hour.

Countless polio survivors who have completed the activity diary worksheets and then modified their lives continue having enjoyable and meaningful lives. Polio survivors are creative beings who learned to walk when doctors said they would never walk or discovered they could breathe on their own by using a technique such as “frog breathing ” that even the medical community did not know about. You can do this too!

Maybe you will even develop some tips and techniques that you can share with others to help them make their lives better too.

If you made these adjustments, were doing reasonably well and now the exhaustion has returned: It is time to have a medical re-evaluation especially checking your blood chemistries and thyroid, because you may have developed new medical problems since the last time you were checked.

Exercise and Weight Loss for the Polio Survivor

Polio Network www.polionetwork.org September, 2024

By Dr. William M. DeMayo, MD.
DeMayo’s Q & A Clinic

Question : My PCP recommends I go for pulmonary rehab 2 X each week to help with my fatigue & weight problem. I am concerned that these hour + sessions may do more damage to my leg muscles . . . I believe it would be better to have a home exercise plan developed for me by a PPS expert, that I can spread over the day. So which is best an organized rehabilitation program at a therapy clinic or a home exercise program?

Answer: Both! There is no question that some therapists or physicians may initiate a program in the therapy clinic that is too intense and therefore counter productive. It is also true that many individuals do not continuously challenge themselves and stick to a home exercise program. The best approach is to not over exercise or under exercise. We all benefit from exercise at a level just below our capacity or “limit”. From this perspective a polio survivor is no different than an athlete training for a marathon.

The problem comes in recognizing one’s limit and communicating it with healthcare providers. Polio survivors, as a general rule, have a lifelong history of overachieving and don’t like to “complain” by reporting what they think are minor symptoms. When setting therapy goals, it is important work as a team and look at practical short-term goals by looking at current exercise capacity. Whether it be walking, lifting weights, or using a piece of exercise equipment we all have a point beyond which we will later “pay for it.” This is the place we want to avoid. By the same token, little is achieved with any exercise without challenging oneself and the expression No Pain No Gain has some truth to it. I often ask patients to be careful to distinguish “good pain” from “bad pain”. Good pain is the discomfort we feel at the time we are exerting ourselves or stretching. Bad pain is pain experienced after the activity (paying for it) and indicates injury. Sometimes bad pain is subtle and so it is important to really pay attention to our bodies while taking breaks and after exercise. In fact, the concept of bad pain may not involve “pain” at all, but rather over fatigue. If an individual has difficulty performing routine tasks the afternoon or evening after a morning therapy session, then this needs to be clearly reported to the therapist and the program modified to avoid repeating the event. This should be looked at as “micro trauma” and one’s program should be modified just the same as a marathoner would modify his schedule if he tore a hamstring muscle.

It’s interesting that you mentioned you are referred to a pulmonary rehab program. In general (but certainly not always), these programs are more attuned to watching for overexertion than more sports medicine oriented therapy programs. My advice would be to have a discussion with the professionals involved to find out more about how they run the program. At the same time, your point about a regular home exercise program is an excellent one. Far too often therapist focus on what is happening in the gym and not looking at lifestyle habits that can have a much more lasting effect. In my opinion any polio survivor receiving formal therapy should also have a formal home exercise program monitored by the therapist. I’m an advocate of home exercise logs that can be reviewed by a physical therapist or physician and updated to increase or decrease intensity as progress or symptoms arise.

Lastly, I see that you mentioned the goal of Losing weight. In my experience, fad diets and exercise programs often lose track of the fact that we only lose weight when we consume less calories than we burn. So burning calories (exercise) is only part of the equation. Perhaps this will be a topic for another article but combining a home exercise log with a nutrition log is an excellent place to start. Practical/specific weight loss goals and a specific timeline combined with an exercise and nutrition log will maximize the chance of long-term success. William M. DeMayo, MD

CONSERVE TO PRESERVE

BRUNO BYTES

Polio Network www.polionetwork.org 2nd Qtr 2024

A Bruno Byte
Dr. Richard L. Bruno, HD, PhD
Director, International Centre for Polio Education

The Encyclopedia of Polio and Post-Polio Sequelae

Dr Bruno’s Original Post: Go to the Encyclopedia of Polio and PPS (it’s easy to find at www.polionetwork.org under the heading Articles/Resources). Click on the

INDEX/CATEGORIES BAR and look for your topic of interest. This Encyclopedia is an ongoing document, easily available to everyone, that holds my entire inventory of articles (including all Bruno Bytes).

“New” Areas of Muscle Weakness

Question: When I had polio, my legs were completely paralyzed but my arms were not affected. When I recovered, I walked for many years with a very pronounced limp. I now have leg muscle weakness, use a long leg brace and a manual wheelchair. But now I am beginning to experience pain and muscle weakness in my upper arms. Could I have weakness where I had never had polio weakness? Is it true that paralysis or even muscle weakness weren’t necessary for your whole body to be affected by PPS?

Dr Bruno’s Response: Yes, that’s correct. Even if you weren't paralyzed, Dr. David Bodian showed in 1949, with 158 human autopsies of polio “non-survivors”, that if you had muscle weakness anywhere, 90% of your muscles and their motor neurons were damaged, even if not killed, by the poliovirus. Add decades of physical overuse and, wham, PPS muscle weakness! The overuse causes wearing out of remaining poliovirus-damaged neurons and produces weakness of muscles thought to be unaffected by polio.

Late onset muscle weakness can show up anywhere, regardless of the degree of initial paralysis…or none. Even "non-paralytic" polio survivors could have had wide-spread motor neuron damage but not enough in any one muscle to cause weakness initially. But those remaining, poliovirus-damaged neurons still fail with overuse abuse over time.

This article can help explain: "Non-Paralytic” Polio Causing PPS.

For more information, please look in the Index of the Encyclopedia of Polio and PPS under the topics “muscle weakness” and “motor neuron”.

“Shake It Like That”

Question: I had polio that left me severely paralyzed in all four limbs - my back, head, neck and chest. I have been wheelchair dependent ever since. My problem is this: After I’m out of bed for a bit I start shaking. I’m not cold, just shaking - head, neck, shoulders – when I'm sitting in my wheelchair. I can stop it but it starts for no reason and is increasing. My hands shake when I use them, but I interpret this as maybe age + polio weakness. But could this be the onset of Parkinson’s?

Dr Bruno’s Response: There are two broad categories of tremor. (ninds.nih.gov/health information/disorders/tremor#)

- “Resting tremor" (shaking when your muscles are at rest) as in Parkinson's disease and
- “Action tremor" (shaking when your muscles are being used).

The cause of an average polio survivor’s tremor - and possibly yours - may be easy to explain by using your own interpretation: "age + polio weakness".

There are two possibilities for polio related shaking.

- The first and most likely is an “action tremor” caused by “age + polio weakness”, stressing muscles whose few remaining overworked, aging, poliovirus damaged motor neurons can’t sustain firing to continuously and smoothly activate muscles, for example when using your hands and sitting upright in your wheelchair.

  The loss of smooth, continuous motor neuron firing leads to the muscles turning on and off, causing shaking. Resting your hands and lying down stops the shaking as it allows the motor neurons to metabolically recover and fire smoothly again.

- The second possibility, which is rare, is a condition called "enhanced physiological tremor." EPT, also an "action tremor", occurs when brain motor neurons fire intermittently when you use your muscles, thereby causing tremor. The tremor is said to be "enhanced" because shaking occurs even when you haven't overworked your muscles. EPT also stops when you rest, for example when lying down in bed.

The simplest treatment for a post-polio "motor neuron tremor" is to monitor your activities and decrease or eliminate circumstances that cause you to stress your muscles – and your motor neurons – and trigger a tremor. EPT (see above) also decreases with a reduction in muscle activity but may require medication for there to be a significant reduction in tremor that improves your ability to function. Neurologists specializing in movement disorders should be able to make the EPT diagnosis but only if they are aware of the possibility of an underlying "age + polio weakness" tremor.

EPT (see above) also decreases with a reduction in muscle activity but may require medication for there to be a significant reduction in tremor that improves your ability to function. Neurologists specializing in movement disorders should be able to make the EPT diagnosis but only if they are aware of the possibility of an underlying "age + polio weakness" tremor.

Statins
Question: Is it a definite that statins will affect our muscles negatively? I have been on Zetia and fenofibrate but no results. The next step will be statins. Will that affect my muscles and make them weaker?

Dr Bruno's Response: That's not definite. Statins often cause calf pain and CAN cause muscle weakness. Many survivors in the Post-Polio Coffee House have been on statins for years successfully. Please go to the Encyclopedia of Polio and PPS and look in the Index for statins.

Vitamins
Question: I want to start taking multivitamins. Do you know of a vitamin with a small size capsule or pill? I cannot swallow big pills or capsules. I do not think I have a vitamin deficiency. However, I am exhausted constantly and I was hoping it would give me a little energy.
Dr Bruno's Response: There is no need to take vitamins unless you have a vitamin deficiency. Vitamins don't give you energy. It sounds as though it may be time for a visit to your primary care physician – you may find that bloodwork and a sleep study are in order!

* * *

That Last Straw

by Millie Malone Lill, Editor

Taken from Polio Perspective, May 2024

Sometimes, we people pleasing polio survivors have a hard time admitting that we can't do something. By "do something," I don't mean doing something adequately or well enough. Oh no. We have to do that something better than anyone else. Good enough is simply not good enough.

In our recovery period, most of us became used to using every motor neuron in our arsenal because that is what it took to do what our able bodied peers could do easily. This became our norm. At the time, no one realized that we did not grow entire new neurons to replace the damaged or killed ones that the polio virus took. Nope, but the damaged neurons did sprout little fingers to reach out to the muscles in an effort to mimic complete recovery. We were cured, or at least that was the popular belief.

Since we were now cured, there was no excuse not to do what everyone else did. That earlier try harder philosophy was now our mantra. You can do it, come on, you aren't even trying! Stop that limping. No, you can't be tired, look at your friend, he hasn't even broken a sweat. Keep up, lazy person. This led to many of us becoming Type A personalities. We tried so hard to be normal that we left normal behind in the dust.

Looking back, we realize that many things really were harder for us. We weren't exactly cured as we thought. Those little fingers that our hardworking neurons put forth were not complete neurons after all, just extensions of other neurons that were, themselves, somewhat damaged. After so many years of trying so hard, those little fingers finally died off. This led us back to the acute stage of polio. Some of our parts no longer worked as they had. It's kind of like patching a hydraulic hose with duct tape. It works for a while, but that tape is not a permanent fix. Under pressure, that duct tape will eventually lose its sticking power and will come off, leaving your hydraulic hose in the same condition that inspired you to put the duct tape on it in the first place. Unfortunately, duct tape isn't going to work on damaged neurons.

After a lifetime of trying so hard, we have difficulty realizing that the duct tape is no longer doing its job. We have to slow down, we have to prioritize our activities to include things we find enjoyable and things we can't avoid, things we would like to do and things we are beginning to realize we can no longer do. We can't just stop doing. At the same time, we want to avoid that last straw, the one that limits our activities to just the bare necessities of life. Added to the overworking that damages our remaining neurons, we must realize that the aging process itself kills off a few.

Does this mean our lives must be spent just enduring rather than enjoying? Not necessarily. PPS is progressive, but it can be slowed down. Listen to your body. When it signals to you that you need to rest, rest. Divide the tasks you must do into small bites. Do a little, rest a little. It might be a plan, if you can afford it, to hire someone to do the heavy stuff. Investigate benefits your insurance plan might cover. Medicare often offers services you might qualify for. Most importantly, listen to when your body says its load of straw is complete. Time to rest. Later, once you have unloaded today's load of straw, you can pick up that last single straw so much easier tomorrow.

Is This PTSD?

by Millie Malone Lill, Editor

Taken from Polio Perspective, June 2024

You are a child, four years of age in my case. You've been very sick, painful stiff neck, inability to walk or even move some of your limbs. Your head aches and you don't understand what is going on. Mom and Dad are scared and that scares you, too. You are rushed to the hospital.

The doctor tells your parents that he thinks you have polio. The dreaded Child Killer. You have to be put in isolation till there is no chance of passing on the virus. Mom and Dad have to leave, maybe without even a goodbye hug or kiss because this virus does not only target children. People can die from it, indeed, many have.

This is so confusing, so frightening. Soon it also becomes quite painful, as a nurse places your small body in a fetal position and holds you there while the doctor does a spinal tap.

You can't have Momma hold your hand, she can't be there to comfort you, she and Daddy are in their car or in the waiting room, tearful and scared but not able to be with you.

Then you are taken to a room that you will share with other sick kids. Some of them are in iron lungs, most are in iron cribs. You have outgrown your baby crib, but the nurses don't have time to reason with you, so in you go. The sides are pulled up and locked in place. You have no idea what you have done to deserve such punishment.

During the two weeks that you are in that room, you make friends with some of the other kids. Sometimes you wake up and the bed next to you is empty. Where is your friend? What happened? The nurses don't have time to deal with your tears and bewilderment.

Time goes by. Some of the kids go to the whirlpool tub for therapy, but you are so small that you would not be able to keep your head above water without assistance and the nurses are so busy, there are so many kids for them to care for. Instead of the whirlpool, a nurse rolls in a big washing machine, one just like your Mom's, with the wringer attached. Steam is billowing out. The nurse uses a long stick to pull a steaming wet wool blanket out of the tub and runs it through the wringer. Then she wraps your little legs in it and you have to lie still till it cools. It smells like a wet dog. You wrinkle your nose but it doesn't matter. You are helpless.

Then come the exercises. Oh so painful. Your legs are pulled and manipulated and even though you have tears rolling down your face, you have to be a Big Girl and not cry. It would upset the other children and you don't want that, do you? The parallel bars are next. Because anything that touches the floor must be burned, you are told, your fear ramps up . Are you going to have your feet burned off? But the nurse fashions a pair of scuffs for your tiny feet from paper envelopes and you are helped to walk while holding the parallel bars. When you are done with this, you are exhausted and that hated crib starts to look welcoming.

At some point, you will come home but your relief is short lived because the daily exercises must continue. You are urged to try harder, to become “normal.” And you do, even though it exhausts you. You hate the heavy steel and leather brace, but it does enable you to get around. You feel as if you have a sign around your neck saying “I'm not normal. Feel free to bully me all you want because I can't really fight back.”

All of this is why most polio survivors are Type A, people pleasers, hard workers, and prone to what I absolutely believe is Post Traumatic Stress Syndrome, PTSD. The smell of pine scented cleaning products make me gag and give me a headache. That's what the hospital floors were cleaned with. Liver? NO, please, I am not anemic anymore and the sight of it brings back the steamed liver I was forced to eat a couple of times a week. Steamed, still wiggly, nasty looking. I'm a grown up now and no one can force me to eat anything I don't want to, but the sight of it still has its effect. Discovering that someone you thought was a friend has had a party and you were not invited brings back the memory of being isolated, unable to see your family, and triggers an overreaction. Perhaps the venue was simply not accessible, but you feel abandoned.

We are not soldiers, but we did fight a huge battle and sometimes the memories of what we had to go through when we were at our most vulnerable are devastating. At least understanding why you seem to overreact to certain stimuli helps a little bit.

* * *