

Mornington Peninsula Post-Polio Support Group

Next meeting: Saturday, June 9, at 11am at the Information office, Mornington, cnr Main and Elizabeth Sts, rear of the building. The next social outing is lunch on June 19. For the record: meetings are held on the second Saturday of each month, with outings - lunch or dinner - on the third Tuesday unless the meeting date is mid-month. Please contact the secretary for confirmation, venue and details, or if you need a lift.

The Fatigue edition

Following a request for back information from Fred Lodge our Phillip Island representative, this edition will focus on fatigue.

Fred had cleaned out paperwork and lost the references, including tragically, the one on the benefits of hot chocolate!

Fatigue is one of the most frustrating and least understood outcomes of late effects of polio, by us and family members who don't get why we can no longer manage walking round a supermarket; deal with large and noisy crowds; think rationally or remember what was said yesterday.

So have sorted through our library on the subject to cover causes, manifestations, and solutions.

Among the articles are short pieces around the periphery of fatigue that may offer more insights.

Back page yarn is about our friend Bill Peacock, OAM, still hard at it despite an appalling accident involving a bus and his wheelchair from the inside.

Editor and spouse have had a rough couple of weeks with a cold that went south, requiring services of Nurse on Call and the Home Doctor (who estimated he might make it by 3am but arrived just after midnight).

Both were extremely helpful, thus on P2 pls find their phone numbers if you don't already have them on the fridge.

- Ed



Summed up our May - losing grip

Secretary's notes

SUN came out after a few days of rain, bringing an active group to our May meeting.

Graeme Allum has been reading our library copy of Dr Bruno's Polio Paradox, finding it extremely useful wanted his own copy. Felt there were people with greater disability in America but was assured Australia has diversely affected polios too. On order - hard copies via Barnes and Noble, e-copies via International Centre for Polio Education, for those wanting their own too.

Members attending our meetings tend to be the relatively active ones. Bayside Polio uses its grants to pay for carers and transport for more frail members to get out and share lunch. Is this something we could do? Welcome feedback on that. Clearly such assistance is dependent on grants and we were not sure of continuing support from the State Government. However Bayside had a call from Disability Grants officer asking if they were still active. Peter assured him they were. Response was they don't have to apply again, funding would be provided. (Post script: Bruce since has had the call as well).

As our long standing/sitting Treasurer Bruce has managed our funds carefully in the event no further support was coming, due to commitments to the NDIS etc by the State Government. Once we have been contacted we can reconsider what kind of support we want and can provide for members better or differently - your call.

This subject resonated at the meeting with the potential visit from the new Community Officer attached to Polio Australia, Polio Network Victoria and Post Polio Victoria. Steph Cantrill was keen to attend one of our meetings and hear of our plans and projects. (Crikey, thought the secretary, may that not be another book for a while).

We asked around the table for ideas of what we wanted to achieve this year. Ian Bladon instantly said, 'find other polios'. Fortunately that is one of the tasks for Steph.

And what about better looking after the members we have? We discussed home visits, telephone trees for contact (we don't actually have a list of phone numbers of members owing to privacy concerns). This would be valuable of course but most of us are operating at the end of our ropes as it is. Something to discuss with Steph.

Nyorie recommended a neurological physiotherapist who understands polio: Anna Moriarty at Steps Neurological Therapy Services. Nyorie is seeing her at Hughesdale but Steps also attends Beleura. These are Anna's details:

ANNA MORIARTY- Physiotherapist, B.App.Sc.(Phys.) & M.Phys.(Neurological Physiotherapy) Anna Moriarty is a practice principal and senior physiotherapist at Steps Neurological Therapy Services. She graduated with a bachelor of applied science and physiotherapy in 2002. In 2010 Anna completed a postgraduate master's degree in neurological physiotherapy at the University of Melbourne. Anna is qualified as a titled neurological physiotherapist with the Australian physiotherapy association and has a strong clinical interest in spinal cord injury and gait rehabilitation.

Beleura Health Solutions 945 Nepean Highway, Mornington VIC 3931 Phone: 9568 5611

The meeting discussion then moved on to plumbing issues – personal and property. We have a strong male attendance so mercifully they felt free to discuss prostate and bladder issues. Several undergoing recent and similar treatments. One day we could break up into groups for male and female issues, also one for carers to share their challenges. Then maybe members facing issues with medications could share their problems and solutions. We have such diverse yet similar problems from braces, to pain, to additional disorders that those problems shared can reduce stress and offer



support and solutions. That's why we value our group so much. When individuals speak out, we find others needing to know.

For example: the property plumbing matter arose with Bill having to have his septic system dug up. Barbara Worme mentioned they had a similar need and realised they were paying for a sewerage system they weren't receiving. Contacted the water company and obtained a small amount of reimbursements. Others on outlying properties might find they too are being charged for services not provided. Barbara pointed out that water rates were charged on the amount of water allegedly going out. This was an assessment rather than metered, another cause for challenge.

We decided on lunch to continue lunches through winter and shorter daylight hours.

May Lunch at the Westernport: good turn up to meet Bonnie Douglas, Polio Australia and Community Development officer Steph Cantrill (PA/PNV) who had the chance to chat with various members. Next outing: June 19 - should be cake - Secretary turns 75. Westernport Hotel, 12.30pm

Nurse on Call phone number – a service of the Victorian Government: **1300 6060 24**

Home doctor: 132 660

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Living in polio's shadow

BRAD CROUCH
MEDICAL REPORTER

ASK a kid today about polio and chances are you'll get a blank look – thank goodness. Australia was declared polio-free on October 29, 2000, along with the other 36 countries in the Western Pacific Region, after the last case was in 1972.

It is one of the greatest modern medical success stories, thanks to the genius of Jonas Salk, who created the life-changing polio vaccine on April 12, 1955.

However, for many Australians, the disease may be gone but not forgotten.

Years after the devastating poliomyelitis epidemics in Australia, the aftermath of the disease is now becoming evident in our ageing "polio population".

There are an estimated 400,000 people who may be experiencing the Late Effects of Polio (LEoP) or Post-Polio Syndrome (PPS), often up to 50 years after the initial infection.

Polio SA is inviting all those affected by polio to attend an information session at Tea Tree Gully, presented by clinical health educator Paul Cavendish.

The session on Saturday, May 12, will cover:

LATEST research regarding managing the late effects of polio.

EDUCATION on what makes the late effects of polio different from the ageing process.

KEY information on how to work with your health professional.

PROVEN self-management strategies.

AN opportunity to ask questions and discuss your post-polio health.

"I am keen to share the findings of the work that I have been a part of since 2005, working in allied health and multi-disciplinary clinics," Mr Cavendish says.

"With Australia's vast post-polio community, I believe it's of the utmost importance to discuss what makes the late effects of polio different from the typical ageing process, and work with health professionals to ensure this is correctly managed."

"I think it is important as a professional community we do not expect or rely on polio survivors to research and find out what to do for their condition, due to the limited support and understanding they have received for many years."

FOR INFORMATION, EMAIL WORKSHOPS@POLIOHEALTH.ORG.AU



DEDICATED CARE: The first polio patients at the Home for Crippled Children at Somerton in 1939, Pattie Guerin, 7, left, and Gilbert Munsey, 4, are attended to by Nurse Wakelin and the matron, Sister M. Hocking. Picture: ADVERTISER LIBRARY

Article from Adelaide Advertiser in April, following Polio Australia's information session there. Attended by Stephanie Cantrill, who said 80 people turned up with a high percentage of new over existing SA support group members. This was an excellent result for Polio Australia's Education program. Worked particularly well for Adelaide being a smaller city. Workshops in June will be in Geelong, Ballarat and Melbourne. Dandenong in August worth us going to.



Fatigue – what is it, how did I get it? and how to manage it

From Post Polio Health International

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 describe a global or generalised 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 anaemia, 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 de-conditioning, 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.

Fatigue (PHI's *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors*)

How to manage fatigue (The Post-Polio Task Force, 1997)

When Do You Need a Power Chair? (*Post-Polio Health*, 2010)

How to manage fatigue

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 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.)

From article on Inflammation, Marcia Falconer

In a person with PPS, when the body suffers an injury, such as physically overdoing by climbing too many stairs, walking on uneven ground, etc. the first reaction is for the cells in the affected area to release a chemical messenger. This messenger, called a proinflammatory cytokine, tells specialized cells, whose job it is to protect you from invading organisms, to come to the site of the injury.

At the same time the proinflammatory cytokines activate resident cells and cells that have migrated to the injury and all of them produce more proinflammatory cytokines setting up a cascade of events that will involve the entire body. Two proinflammatory cytokines, interleukin-1 and Tumour Necrosis Factor alpha, are especially important in triggering an acute immune response, the body's first line of defense.

The acute immune response involves developing a fever, fatigue, loss of appetite, sleepiness and other symptoms. It goes away within a few days. However, if the injury is repeated often – say if a person with PPS persists in exercising a stressed out muscle – then a chronic immune response will set in. The response to chronic stress involves the entire body including the brain and produces central fatigue, new muscle weakness, problems with short term memory and word finding, irritable bowel syndrome and other symptoms.



AIDS CAN REDUCE FATIGUE - STUDY

The extent of using mobility assistive devices can partly explain fatigue among persons with late effects of polio – a retrospective registry study in Sweden by: I. Santos Tavares Silva; K. S. Sunnerhagen; C. Willén; and I. Ottenvall Hammar

This academic article has been heavily abbreviated in order to be readable – Ed

Fatigue is reported as one of the most disabling symptoms and is common among persons living with late effects of polio. Although fatigue has been studied in the context of people living with late effects of polio, there is a lack of knowledge concerning the association of fatigue and variables of importance for participation in daily life.

Therefore, the aim of this study was to explore possible factors associated with fatigue among persons with late effects of polio in Sweden.

This retrospective registry study consisted of 89 persons with late effects of polio living in Sweden. Fatigue was measured with the Multidimensional Fatigue Inventory (MFI-20) scale, Swedish version. Pearson's correlation coefficient was used to analyse the correlation between the factors and fatigue, and a multiple linear regression was carried out to explore factors for fatigue.

Methods

Fatigue statistically significantly correlated with age and the use of mobility assistive devices. The multiple linear regression model showed that the factors age and mobility assistive devices were associated with fatigue among persons living with late effects of polio, and the model partly explained 14% of the variation of fatigue.

Results

Fatigue could partly be explained by the extent of using mobility assistive devices and age. Healthcare professionals should provide and demonstrate the importance of assistive devices to ensure management of fatigue in persons living with late effects of polio. Persons not using mobility assistive devices and high age reported more fatigue.

Therefore, fatigue could partly be explained by the extent of using mobility assistive devices and the people's age. These two factors are important, but to understand the complex nature of fatigue, additional factors must be considered. Healthcare professionals should provide and demonstrate the importance of assistive devices to ensure management of fatigue in persons living with late effects of polio. This knowledge contributes with an additional piece in the puzzle to better understand fatigue among persons living with late effects of polio.

Recommendations for management – Dr Susan Perlman

PPS fatigue can be due to primary motor-unit (nerve/muscle) weakness. But it may also be caused by other neuromuscular diseases as well as other medical or metabolic conditions. In order to have better control over the symptoms of fatigue, PPS individuals are given these recommendations:

- protection of weakened muscles from overuse by use of appropriate equipment (braces, canes, power chairs, etc.)
- reduction of overall level of activity
- avoidance of excessive fatigue
- appropriate gentle exercise under supervision when disuse is suspected. (Dr. Perlman suggests gentle aerobics that are resistive, not repetitive, when appropriate.)
 - weight loss, when appropriate

Cognitive fatigue in Polio Survivors – from Dr Mary Westbrook's Polio Particles, 2009

At the American Neurological Association's conference in October 2007, Dr Olavo Vasconcelos and colleagues presented results of a study into cognitive fatigue in survivors of paralytic poliomyelitis. They used computerised tests to investigate the effects of fatigue on polio survivors' mental functioning.

Survivors who participated did not show any signs of diminished mental functioning when well rested. During the investigation the survivors were given a set of tests known as the Automated Neuropsychological Assessment Metric. After an hour's break they were given the tests a second time.

Most people improve on a second attempt due to having had previous practice, but the scores of more than half of the polio survivors decreased. Analysis of the survivors' actual answers indicated that the decrease in their scores was not due to a decline in survivors' accuracy but to increase reaction times as a result of fatigue.

Protein – from Dr Richard Bruno

The fuel that keeps on giving. Protein provides a long-lasting, “slow-release” supply of blood sugar throughout the day. Polio survivors who had protein for breakfast reported fewer PPS symptoms because their fuel tank stayed full longer. They didn't need to “fill up” throughout the day with short-lasting sugar fixes, like soda or candy bars.

Mom was right about one thing: Breakfast is the most important meal of the day.

Since a polio survivor can use more energy just getting showered and dressed than a non-disabled person does running a marathon, you need protein early and often. It's a good idea to eat breakfast before showering to “break your fast” and fill your tank before your neurons need the fuel. When we ask our post-polio patients to eat protein every day at breakfast, and have small, non-carbohydrate snacks throughout the day, they report an almost immediate reduction in nearly all the symptoms of PPS, especially fatigue. But the “protein power” diet is neither a fad nor a miracle; it's just common sense. No engine can be expected to run without fuel!



Chocolate may prevent memory decline!

Scientists at Harvard Medical School suggest that drinking two cups of hot chocolate a day could help keep the brain healthy and reduce memory decline in older people. The researchers found that hot chocolate helped improve blood flow to parts of the brain where it was needed. The lead author, Farzaneh A Sorond, said: “As different areas of the brain need more energy to complete their tasks, they also need greater blood flow. This relationship, called neurovascular coupling, may play an important role in diseases such as Alzheimer's.”

In a further study, published in 2014, researchers found that a cocoa extract called lavado could reduce or prevent damage to nerve pathways found in patients with Alzheimer's. This means that symptoms of the condition such as cognitive decline could be slowed.

Brain fatigue, white spots and fear of Alzheimers

From Life Skills for Polios - published by MPPPSG 2017

FATIGUE and brain fog are easily the most scary aspects of PPS. How do you describe to someone who says dismissively “oh we all get tired” that PPS involves an all- embracing exhaustion, absence of ability to concentrate, inability to find words and even lift an arm?

Being such a misunderstood subject, following is extracted from a paper by Dr Richard Bruno that explains some of the “techy” bits.

At the 2016 Sydney polio conference, Polio Australia’s deputy president Gillian Thomas advised “If you hit the wall, rest”. Your correspondent hit the wall. Coffee standing up in the crowd juggling stick and bags was not the answer. Go for a hot chocolate (spoiler alert) in the posh hotel cafe then to sit in comfy chair dozing, restoring brain, enjoying earwiggling on a couple of Victorians analysing what they’d seen and heard so far. No time available for questions, they commented. True but questions at these events can be risky as people start wandering into personal issues such as we realise we’re old and what about dementia?

When sharp enough to go back to the session, I asked about statistics on the rate of dementia among polios. Does the fatigue that leads to vagueness lead to worse? The answer was that no stats show dementia being any worse in the polio community.

Dr Bruno provided more technical answers in his paper “*Post-polio Brain Fatigue – Little spots mean a lot*” (revised in 2015).

“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 [Post-Polio Institute, New Jersey, USA] 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 computerised neuropsychological tests of attention, thinking or memory once, again one hour later.

“The so-called ‘practice effect’ typically improves scores the second time anyone takes neuropsychological tests. However, more than 40 per cent of polio survivors had a decrease in performance on the second administration of seven of the eight computerised tests, while 50 per cent 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 per cent to 67 per cent 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 other 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 per cent 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.

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?’

“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 per cent of polio survivors reported difficulty ‘thinking of words I want to say’. Thirty-seven per cent 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, 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. 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, try calling everyone ‘buddy’ or ‘honey’ [or mate – for Aussies].”

– Dr Richard L Bruno, chairperson of International Post-Polio Task Force, and director of the Post-Polio Institute and International Centre for Polio Education.



Bill on the frontline of Polio campaign

WITH polio set to be eradicated worldwide within the next two years, survivor Bill Peacock OAM, says it's important to remember those who survived and those who are still affected.

With World Polio Day commemorated worldwide each October, the Bribie Island resident and Spinal Life Australia member said thousands of Australians are still feeling the effects of the once-widespread disease.

"I had polio when I was just four-and-a-half years old and spent the next seven years in hospital, with several months spent in an iron lung," Mr Peacock said.

"I left hospital and so much had changed — I had new brothers and sisters I had never met."

While polio is an after-thought for many Australians, Mr Peacock said it wasn't well known that a large proportion of survivors can still feel the effects of polio decades after rehabilitation.

"Things were fine until 1998 when I had a major collapse that left me in a wheelchair," he said. "I thought I was just overworked but it ended up being post-polio syndrome."

As the facilitator of Spinal Life's Bribie Island Member Network, Mr Peacock has dedicated his time to raising awareness of post-polio syndrome in his local community and beyond. "We've made some great in-roads to ensure Bribie Island and its surrounds are as inclusive and accessible as possible," Mr Peacock said.

"We've been blessed with wonderful support from community members and politicians. That said, we still have some way to go, especially when it comes to raising awareness within the medical community. There used to be a very big stigma around polio but thankfully that has greatly decreased over the years.

"Talking openly about your history with polio when dealing with a GP will help ensure you get the proper care which is another reason open discussion and awareness is so important."



Former Victorian, Bill Peacock has worked hard to raise awareness of the late effects of polio despite everything. Last year his back was broken when a bus lurched, throwing his wheelchair across the vehicle. With the support of friends he is bouncing back. Pictured with honorary Rotary membership.

World Polio Day was established by Rotary International to commemorate the birth of Jonas Salk, one of the first developers of a successful polio vaccine. *Spinal Life Australia* supports people with the late effects of polio and hosts member networks for survivors to share their experiences and advocate for change in the local community. For more information on post-polio syndrome or to find your nearest support group, visit www.spinal.com.au/postpolio.

-The Queensland Times

The aims and objects of our group are to gather and disseminate information on Post-Polio Syndrome and Late Effects of Polio, to support each other in anyway we can. Opinions expressed in this newsletter may be those of the writers only. We do not purport to be medically qualified. Consult your doctor before trying any medication or new form of exercise. Give relevant information to your doctor and help them to help us. We do not endorse any product or services mentioned.