



POLIO NSW INC

formerly Post-Polio Network (NSW) Inc

NETWORK NEWS

Incorporating – Polio Oz News

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Patrons: **Michael Lynch CBE AM**

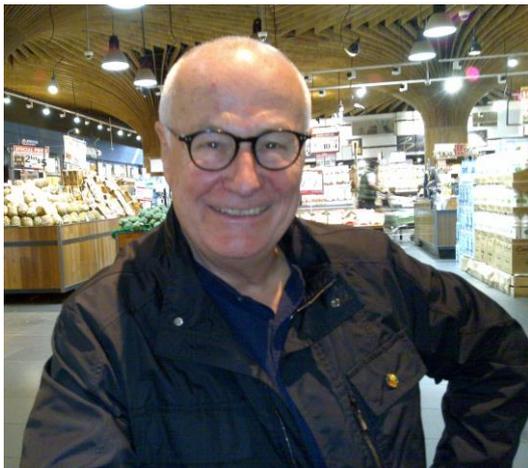
Professor Emeritus Sir Gustav Nossal AC CBE FAA FRS

President's Corner

Gillian Thomas

The publication of this newsletter has been held back so we could be in a position to bring you exciting news on a couple of fronts, as well as bring you all our regular features. First, though, full details of our next **Seminar**, to be held on **Tuesday, 27 June** at **Burwood RSL** appear on page 2. As usual, there is a varied line-up of speakers so there is something of interest to all. The Seminar Registration Form is enclosed – please be sure to book as soon as possible!

We are thrilled to announce that **Michael Lynch CBE AM** has accepted our invitation to become a **Patron of Polio NSW**. As well as his eminent qualifications for the position as outlined below, Michael is also a polio survivor, having contracted polio in the early 1950s. We are hopeful that Michael (*pictured below wearing one of our polio badges*) will join us at the AGM on 2 December – more on that in upcoming issues of *Network News*.



Michael Lynch was Chief Executive of London's Southbank Centre from 2002 until 2009 and was responsible for the major renovation of Royal Festival Hall and the transformation of the Southbank cultural precinct.

Previously, Michael held positions as Chief Executive of the Sydney Opera House, General Manager of the Australia Council and General Manager of the Sydney Theatre Company.

From 2011 to 2015 he was Chief Executive of the West Kowloon Cultural District, an ambitious project which will see a huge arts precinct built on the shores of Hong Kong's Victoria Harbour.

Michael was awarded the Order of Australia (AM) in 2001 and in 2008 he was named a Commander of the British Empire (CBE), both for services to the arts.

Our second exciting news concerns some work currently underway (*see below*) which will hopefully result in a **model of care** being developed in the **NSW public health system** which, for the first time, is targeted to **meet the specific needs of polio survivors** in this state.

The NSW public health system is currently reviewing the needs of people living in NSW with the Late Effects of Polio. A Steering Group has been convened at the NSW Agency for Clinical Innovation (ACI) to lead this work. The ACI will shortly be surveying people living with this condition and encourage all who receive the survey to participate. While there are no plans at this time to enhance health services for people living with the Late Effects of Polio, this is encouraging news and we look forward to providing you with an update on progress later in the year.

Robyn Speerin, Musculoskeletal Network Manager, Agency for Clinical Innovation

This is a long-sought development which is the culmination of many years of submissions and lobbying by your Management Committees. Merle Thompson and I are on the Steering Group for the review, and you can be assured that we are committed to getting the best possible outcome for members. In particular, we are stressing that a focus on education and training of health professionals about the late effects of polio is an essential component of any model of care considered. The survey details will be circulated separately. It will be online only which is regrettable but due to the tight timeframe for responses. Nevertheless, we urge as many members as possible to respond to have our voices heard.

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Mid Year Seminar

- Date:** Tuesday, 27th June 2016
- Time:** 9:30 am – 3:00 pm
- Venue:** Burwood RSL Club, 96 Shaftesbury Road, Burwood
Parking is available on site but, as always, you are advised to be early
- Refreshments:** Morning tea and a light lunch will be provided
- Cost:** \$15 per person – ***please RSVP by Friday, 23rd June 2017***

Return the enclosed **Registration Form** with your payment to the Polio NSW Office by 23rd June. Alternatively, you can pay on the day when you arrive at the Seminar, however, if you elect to do this, you **MUST** still contact the Office [*email office@polionsw.org.au or Phone 02 9890 0946*] by Friday 23rd June to confirm your attendance so sufficient catering can be arranged.

- Program:**
- 9:30 *Registration and Tea/Coffee*
 - 10:00 **Frank Higgins** – NRMA Older Driver Education Program
“Years Ahead Driver Program”
 - 11:00 *Morning Tea*
 - 11:30 **Kerry Highley** – Author of *“Dancing in My Dreams”*
 - 12:30 *Lunch*
 - 1:30 **Roberta Flint** – Director, Department of Health (NSW Office)
 - 3:00 *Close*
-

Frank Higgins: Frank is a presenter from the NRMA’s *Older Driver Education Program*. His presentation will include the following key topics – a road rules refresher, safe driving tips, pedestrian safety, health and driving, older driver licencing, and mobility alternatives.

Kerry Highley: Kerry grew up in the Sydney beachside suburb of Manly, and remembers with great clarity the first time she saw children with their legs in calipers, a memory that remains with her to this day. Her initial career was in medical laboratory science at Sydney’s St Vincent’s Hospital, a profession in which she worked for many years before returning to study History at the Australian National University in 2000. In 2009 she received her PhD in the History of Medicine for her thesis on the polio epidemics in Australia. Kerry will speak about her research into the epidemics and her book *“Dancing in my Dreams: Confronting the Spectre of Polio”*.

Roberta Flint: Roberta joined the Australian *Department of Health* in 2000, and is currently a Director in the NSW office. Roberta will be presenting on the interface between aged care and disability care for people over the age of 65 who are not eligible for the National Disability Insurance Scheme. In particular, we have asked Roberta to address how the *Aged Care Reform* program will adapt to the diverse needs of younger, although 65+, people with a disability without them being disadvantaged, both financially and in quality of life, as compared to the NDIS meeting their needs.



We are grateful to Mt Wilga Hospital
for providing sponsorship
towards the costs of
presenting this Seminar

REMINDER: LEOp Assessment Clinic - Mt Wilga

The LEOp Assessment Clinic is a one day clinic, held fortnightly, and includes a Medical, and Physiotherapy and Occupational Therapy assessments under the direction of Mt Wilga's Rehabilitation Physician, Dr Helen Mackie. **We have recently been advised that the waiting time for appointments is currently reduced, so if you have been thinking about going to the Clinic, put it off no longer. Those who have already attended the Clinic, particularly those who went to the Clinic's early appointments, are also invited to return for a follow up appointment to check on their progress.**

How do I make an appointment to attend the Clinic?

Obtain a referral from your GP or other specialist who can fax it to Dr Helen Mackie on **02 9847 5013**. Once it has been received, Dr Mackie's secretary will telephone you to make an appointment for assessment. If you would like any more information, please contact Dr Mackie's office on **02 9847 5085**.

You will also be sent a medical questionnaire to be completed by you prior to your appointment.

Where does the Assessment Clinic take place?

Mt Wilga Private Hospital, a specialist dedicated Rehabilitation Hospital and Day Therapy Centre. The address is:

66 Rosamond Street
Hornsby NSW 2077

www.mtwilgaprivate.com.au

Seminar Report - Managing Shoulder Pain

by Susan Ellis

Wednesday, 18th May 2016

Melissa McConaghy: *Melissa is a Specialist Neurological Physiotherapist and Fellow of the Australian College of Physiotherapists. She holds a Master of Health Sciences in Neurological Physiotherapy and Bachelors and Physiotherapy. Melissa is the Managing Director and co-founder of the Polio Clinic at Advance Rehab Centre, St Leonards*

Care of the Shoulder

The majority of the audience agreed that they had shoulder problems. The talk today would be broken down into three priority areas: **OVERUSE ACUTE INJURY DENERVATION**

Pain in the shoulders can come from **overuse**, particularly those who weight-bear using their upper limbs, i.e. using your upper limbs for activities that they were not really designed to do. Shoulders are not designed as weight-bearing joints and yet the majority of polio survivors would be using walking aids and devices and will be weight-bearing through their arms – this will cause overuse injuries over time.

Acute injuries result from trauma e.g. a fall, a fracture, a dislocation, a sprain, degenerative arthritis, a tear.

Denervation is from polio-caused weakness in the shoulder, this will lead to a biomechanical disadvantage and that over time can then result in overuse concerns or acute injuries.

Assessment Questions:

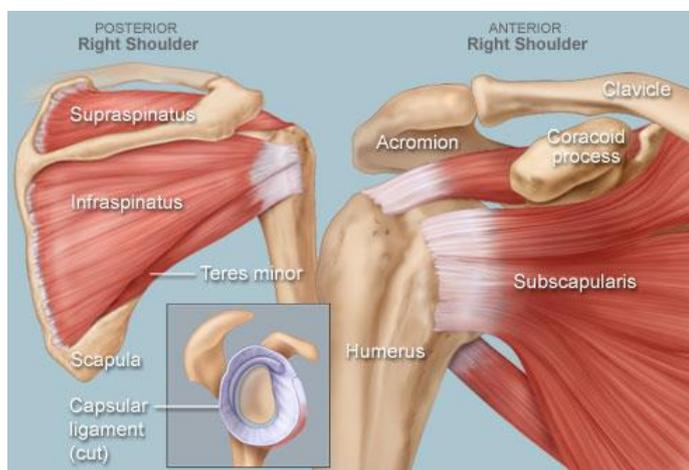
These questions will give you a better understanding of what might be causing underlying problems in your shoulders.

- *Does the pain or discomfort wake you at night?* – might indicate more of an inflammatory problem e.g. bursitis or tendonitis, which are overuse syndromes, or maybe a tear.
- *What makes it feel worse?* – will indicate if it's a structural or biomechanical problem e.g. impingement or a degenerative spur on the bones of the shoulder, this would only get worse with use, needs options to relieve the inflammation surrounding these areas, there might be impingement which might need surgery. If it doesn't get worse but gets better with movement, then this would indicate that it is something more inflammatory and we would need to design a program to reduce the inflammation long term so it doesn't keep flaring up with activity.
- *What makes it feel better?* If it is heat i.e. hot shower then it is probably not an acute injury and more likely to be an overuse injury; something like arthritis would respond to heat, or tendonitis or bursitis which is chronic and would also respond to heat.
- *Does the problem affect other parts of your body?* E.g. shoulder pain that is radiating down to the elbow and into the arm would indicate reticular (nerve) pain which would warrant further investigation around the neck area; or it could be carpal tunnel syndrome and that would radiate into the hand giving numbness and pain throughout the hand.
- *Does the problem interfere with daily function?* This is probably the most significant question. When pain is starting to impact on your day-to-day activities and you can't do what you want or need to do and you have to draw on other people for help. Most can put up with some level of pain to a certain degree but when it becomes chronic that's when it becomes harder to deal with because it is relentless. When it starts to impact on your day-to-day function that's almost the tipping point for most people and is when you will start to seek help as you are no longer able to dress yourself, cook for yourself, transfer in and out of car or bed.
- *Are you taking pain relief for the problem – does it help?* E.g. Celebrex, Panadol, Ibuprofen. Often these medications are not helping but people take them anyway. You may need to go off these medications when considering long-term side effects. Panadol is not an anti-inflammatory, good for pain in the 0-4 range, Ibuprofen, Nurofen or non-steroidal anti-inflammatory are more important when you have an inflammatory presentation. It is important to find out the underlying cause of the pain to decide how to treat it.
- *Have you received any intervention to date?* What treatments have worked or have not worked in the past for you?

Risk Factors:

- *Age* – the most important i.e. 75% of people over 65 would have some degree of shoulder pathology, it is a normal part of the ageing process that people have wear and tear of the shoulders (degeneration). So if you are overusing your shoulders by using them as a weight-bearing joint, or compensating by using one side more than the other, then you should expect problems to crop up and the sooner you deal with the problem the more likely you will be able to maintain function. For those who are more inclined to let things lie until you reach a tipping point, then you run the risk of losing function completely. Seek help early; it is an investment in your health and function.

- *Weakness and imbalances* – if you had polio in your arm it is likely you will have some biomechanical disadvantage. The shoulder is a ball and socket joint and it is completely mobile through 360 degrees. With that flexibility and range comes instability. The shoulder is supported by a group of muscles called the rotator cuff comprising four muscles that lie over the shoulder joint, it is these muscles and the attached ligaments that create stability of the shoulder. So if any one or two of these muscles have any weakness then it no longer does what it's designed to do and the joint loses its normal biomechanical rhythm between the humerus and the scapula. This can cause problems such as impingement, tendinitis, bursitis, degenerative changes. Only muscles that have a Grade 3 muscle strength should be given a muscle strengthening program; an assessment needs to be done for polio patients.
- *Compensation of upper limb for lower limb* – if you use one arm more because the other is weak, or if you fall then you will use the stronger arm to stop your fall and this can lead to acute injuries. If you use aids for walking then you will use your arms to support you. So when looking at what is causing problems it may be necessary to look at unloading that arm by using short- and long-term strategies.
- *Repetitive activities* – assessing your activities of daily living and how you do those activities. People over the age of 65 only raise their arms above 90 degrees less than 4% per day, it makes sense to lower things i.e. hanging space in wardrobes, clotheslines, storage in lower cupboards. For those with leg weakness who use their arms to stand, an electric lift chair is going to help unload your arms that suffer with overuse; when away from home, a higher chair with arms is useful, taking a cushion when going out; all practical suggestions.
- *Use of assistive devices (weight-bearing)* – such as walkers, crutches, Canadian crutches, walking sticks – all involve weight bearing on non-weight bearing joints.
- *Overweight.*
- *Previous trauma or injury to the shoulder* – there may be residual weakness.



1. Overuse – caused by using the shoulder to do things it is not meant to do, either because of a biomechanical disadvantage, a degenerative body spur, from doing a repetitive activity, or overloading the joint with weight-bearing activities.

- Impingements
- Tendinitis – inflammation of the tendon.
- Bursitis – inflammation of the bursa (fluid sac), this will cause pain which prevents you from sleeping on that shoulder. It is important to find out what is causing the bursitis.
- Frozen Shoulder – most common, best practice is to do nothing for this problem, it can take up to 18 months to resolve, physiotherapy is not recommended. Gentle

hydrotherapy may be useful to keep muscles mobile.

- Arthritis – degenerative changes.
- Compression neuropathy – i.e. in wrist from using walking stick, or whole arm from using crutches, causing numbness and tingling.

2. Acute Injury – Falls are a big consideration here, running the risk of a fracture, dislocation or tear, both soft tissue and bony injuries. This is further complicated if you have a history of osteopenia or osteoporosis, a common condition with polio people.

- Fractures
- Dislocations and separations
- Torn rotator cuff
- Sprains and Strains



3. Denervation

- Weakness – damage to the anterior horn cells by the polio virus caused weakness to muscles resulting in scoliosis, deformity, changes in the neck – all of which cause problems with range of movement in the shoulder resulting in compensatory overuse injuries.
- Structural changes – you may be challenged by biomechanical changes in the shoulder.
- Trauma.
- Ageing – remember most people over the age of 65 will have shoulder problems.

Treatment Ideas for Overuse:

There is a need to get to the underlying cause of the problem. If it is an overuse injury you need to look at your day and map out what is causing your problems i.e. lifting arms above your head, pushing up out of a chair, rolling over in bed and pushing yourself up, pushing a shopping trolley, pushing a car door closed, painting walls, washing windows.

What can be done to resolve and remedy your pain? It might be stopping some of these functions, trying some strengthening exercises, moving items that you need to reach up for to a lower level, not carrying heavy shopping bags, not vacuuming if it causes pain, delegate tasks to others, outsource i.e. cleaner, online grocery shopping. If something is bothering you, then you need to find ways to stop doing it. Put strategies in place to avoid activities that are going to stir up your pain. **Work smarter not harder.**

Practical ideas to make your daily activities manageable

Using a ‘hubby’ pillow or U-shaped pillow in bed to support your shoulders will help you to sleep more comfortably.

It is important to get a good night’s sleep, fatigue will increase your perception of pain.





Melissa showed this polio client who came in with bilateral compression neuropathy in his wrists and brachial plexus concerns, he used axillary crutches and he could no longer go on with the problems caused in his arms. So he came in with shoulder and wrist problems and he went out with an orthotic! It freed up his arms and he was no longer weight-bearing on his upper limbs and he had no more discomfort or compression neuropathies.

This emphasises the need for a holistic approach not just symptomatic management.

Treatment Ideas for Acute Injuries:

This requires tailored therapy from a physiotherapist who understands polio.

Rest Ice Compress Elevate REHABILITATE

Rest to recover; use **ice** to reduce any additional inflammation; **compress** if possible which again will reduce swelling (it is the swelling that will give you the pain, if you can reduce the swelling you can reduce the pain); **elevate** – again to reduce the pain; all within the first 72 hours, after that is when you need **rehabilitate** – something that is often forgotten.

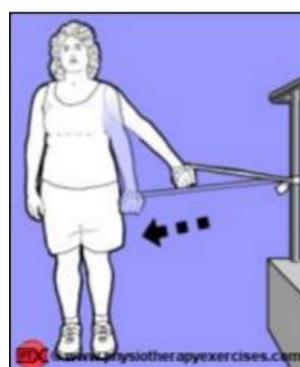
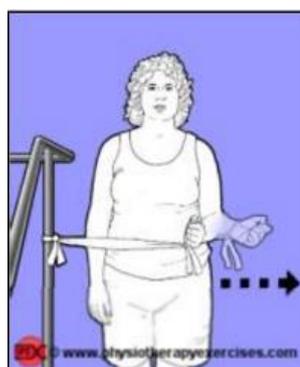
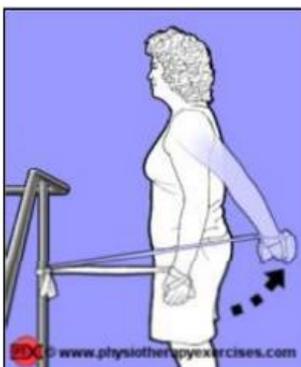
It was emphasised that **ice NOT heat** is best used within the **first 72 hours** to reduce the swelling; heat will dilate the blood vessels and increase the swelling, causing increased pain. Heat **after** 72 hours will give pain relief.

You may need a brace, a sling, manual therapy (after the first 72 hours), injection of anaesthetic into joint, or later on a steroid injection to reduce inflammation and pain.

Exercise prescription (Strength Training Program):

For muscles that can move through range without support i.e. Grade 3 or higher:

- 3 x weekly for minimum of 3 months
- Start with low weight and increase slowly
- Frequent rests during session
- Interval training + rest days in between weights



Start slow with 3-5 reps with a yellow Theraband.
48-72 hours between sessions.

Exercise Precautions for People with Polio:

- Monitor closely for side-effects, it can be a really fine line
- Do not work muscles to fatigue:
 - Limbs feel 'heavy'
 - Quality of movement impaired
 - Quivering observed
 - Compensation from other movements
 - Facial grimacing etc



Get specific advice for **YOU**, some things might not be appropriate for your pathologies.

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Q & A Seminar with Dr Bill DeMayo

by Susan Ellis

Thursday, 15th September 2016

William DeMayo MD has been practicing in the field of Physical Medicine and Rehabilitation for 25 years. He completed medical school and his Physiatry residency at Columbia University College of Physicians and Surgeons at Columbia Presbyterian Hospital in New York City. He went on to be Medical Director of several inpatient rehabilitation units including a Spinal Cord injury unit in Connecticut and The Chrichton Center for Advanced Rehabilitation in Johnstown, Pennsylvania, USA.

Dr DeMayo serves as the Medical Director for the Speciality Clinics of the John P Murtha Neuroscience and Pain Institute including the Post-Polio Clinic, Concussion Clinic, and CMT Neuropathy Clinic. Dr DeMayo has extensive expertise in the areas of chronic pain, sleep and bracing. He has a private practice in Johnstown where he sees a wide variety of patients with disabilities.

Dr DeMayo presented at the Australasia-Pacific Post-Polio Conference in Sydney in September 2016.

As a rehabilitation physician Dr DeMayo looks at function – he deals with people from spinal cord injuries, to traumatic brain injuries, to neuropathies; basically anyone with a functional disability, and he tries to come up with a plan to reaching their long-term goals by achieving short-term goals.

In terms of his experience with polio survivors, he ran a bracing clinic where he saw a number of polio patients and later started a Post-Polio Clinic in 2002 in Johnstown. This clinic was supported financially by government funding. Johnstown is not a metropolis, it is about 1.5 hrs east of Pittsburgh, people come from all over the region and all over the country to attend, and some come from overseas. They had a wonderful multidisciplinary clinic which included a physical therapist, massage therapist, water yoga and stretching, a teaching program to take away to help others in other locations, sleep issues, psychology support, nutritionist, an outstanding orthotist, it was an integrated program. Once a year all who attended would travel back to the Clinic for a reunion and Dr DeMayo saw how important this meeting of people dealing with similar issues was and how it made a big difference to individuals. Unfortunately, the funding dried up and the clinic has now changed in what it can provide.

The focus of the Post-Polio Clinic was on education and self-management. People with PPS can be empowered to manage themselves and manage their providers so that they can get their needs met. Dr DeMayo also works on medical management such as medications and injections. He is not an interventionalist and only uses medications when it is going to make a long-term difference, a functional difference, he doesn't prescribe narcotics or medications that simply treat the symptoms but don't treat the underlying issue. His approach is very much holistic, so not only the body but the mind and spirit also, he looks at the whole person.

Most of us focus on "Body" and ignore "Mind" & "Spirit"

- **Body** -
 - Pain, Ortho/Neuro impairments
 - Loss of physical function.
- **Mind** - (Will discuss with Self Awareness)
 - What motivates me to do what I do?
 - How can I change what I do or adapt?
 - "Self talk"
- ****Spirit**** -
 - Why am I here ?
 - Why is this happening to me ?

When managing sleep issues and managing stress, use your beliefs to help you manage your anxiety that might be affecting your sleep. Sometime it is the need to get things done that is the cause of sleep issues. We can look at things from the body perspective, the mind perspective, but also the spiritual perspective, and so when we look at things differently we come up with different answers and therefore solutions that help our problem.

One example of this is when you see it work with the cycle of myofascial pain – a specific type of pain that is due to the muscle and the fascia, where you see the muscle tightness that becomes chronic and leads to pain. Then there is the reflex response where the pain leads to more muscle tightness, so you get tightness leading to pain and the tightness leads to a chronic problem.



It is important to look at this holistically because things like sleep and insomnia issues, stress management, anxiety issues and then spiritual questions like saying "why me"; all of these factors can lead to that cycle either slowing down or can feed into it. So if someone is having these issues it can result in muscle tightening and over a long-term period that leads to problems of pain issues. So it is important to look at all the contributing factors not just the muscle tightness, looking at all the things that are feeding into that cycle.

In terms of self-awareness and self-empowerment, really the question is "What can I do to reduce my pain and increase my function?" The first place to start is to look for secondary factors; Dr DeMayo tells his patients that by the time they have come to him they have often seen many physicians. If there was one single treatment that was going to get rid of their pain or improve their function it probably would have happened if it was that obvious. So what he tends to say is that if he can find five things that would help by 10%, then we are half way there. We need to look at a multitude of issues. We also try to look upstream, we try to look at the factors that are contributing to the chronic issue e.g. we need to identify and stop doing those things that are causing your pain.

Factors Exacerbating Pain

- “Secondary Factors” often need to be addressed before the Primary Pain Generator can be addressed
 - *“Shutting off the Gas before putting out the fire”*

A. Behavioral Issues – Drive to “Overdo”

- Listening to “Self Talk”

B. Sleep Issues

C. Stress Management

In that light Dr DeMayo is big on self-talk, we all talk to ourselves and we listen to ourselves. He often hears non-polio patients say to him “*I can’t*” which means they are not going to; it has a significant impact on these patients. It’s not something that most of Dr DeMayo’s polio patients use. Words that are a problem that are said by polio people are “*I have to*” or “*I need to*” or “*I should*”.

These are all guilt laden words, they are words that tie your hands so that you don’t have any choices, because if you need to do something then you don’t have any options, and when you stop thinking about your options then you’ve already created the result. You are not going to have a different result because you are going to continue to do the same thing. So what Dr DeMayo recommends is trying to eliminate those words from your vocabulary – have to, need to and should – and always substitute the words “want to”.

There are consequences to behaviour as there is a cost to what you want. So you might want something but the cost of this isn’t something you are willing to pay. But because you have used the words ‘*want to*’ at least you can entertain then what are some options. You might ask yourself, “*how can I get this?*” – you’ll start to look for other options. So the power of words and how we think are very important to making changes, to have options. So “*what do you want?*”. What is your final answer, what is your decision, you’ve looked at the cost and at the benefits, so what is it that you want?

The “problem” in Post-Polio



VS

“I Want to...”



...It is essential to take responsibility for choices in order to establish a plan for pacing activity and minimizing effects of overuse.

Spectrum of Activity



All of us have a “capacity” on a given day or for a given activity - beyond which we have “over done it” ... and we cause harm to our body

From a behavioural standpoint there are some common ways that most of us will tend to underdo or overdo e.g. the couch potato at one end of the spectrum and, at the other end, the ultra-marathon runner.

We are somewhere in the middle, we all have our capacity i.e. how far we can walk, what we can do during the course of the day. So when any of us surpasses our capacity, when we overdo it, we are injuring ourselves, it might only be micro-trauma but we are still injuring ourselves.

When people talk about wanting to do more, what they are really talking about is trying to get their capacity to stop slowing and going downhill. We all know what happens with age, we slowly lose capacity. Inactivity (the couch potato) will lead your tolerance slowly downhill. The marathon man has reached his tolerance capacity by practising with **appropriate** exercise. If you chronically overdo it, i.e. passing your capacity, then your body is paying for it, damaging your body from a long-term standpoint.

Dr DeMayo has noticed that as a general rule the majority of polio survivors are over-achievers, they have lived their whole life doing more with less and they are very driven i.e. higher levels of education, higher incomes, lower rates of depression, lower rates of divorce – a very remarkable group. As they get older they keep this mentality in their head, which is to be very driven and this will have a tendency to, as with age, result in their capacity slowly shifting down. Folks with polio, more than other individuals, will have a real tendency to overdo it. They will push, push, push to the point that they have to rest. They will overdo it until the point that their bodies say they can't do this. So then what do they do? They rest, become inactive, then they get frustrated with not doing anything and then they get to overdoing again. So they spend a lot of time either overdoing or being inactive, both of which are anti-productive and over the long-term makes your capacity shift down.

Dr DeMayo thinks about folks with polio the same as he would an athlete, they too can get here with appropriate exercise i.e. working right at the capacity, not overdoing it and not underdoing it, but right at the capacity. That will cause your capacity to slowly, over time, to shift or at least slow the amount that it decreases. But if we get frustrated and we overdo it, in the long-term it becomes anti-productive. The way you know you are overdoing it is again in the way your body is telling you that you are paying for it.

The real point is how do you know where this point is? What should I be doing, what is healthy for me to do, and what is this productive point? And the point is that you do have to cross the line, you cross the line a little bit at a time and your body tells you that it can tolerate that, and that means your capacity has now shifted. You can then do that level for a while, and then do a little bit more, and that is how the ultra-marathoner got there at the top. However, if you increase your activity level and your body is telling you the next day or even two days later that you have soreness, and you are paying for what you did previously, then it is important to listen to that as it is telling you that what you are doing overall is making your capacity shift down. It is important to know that everyone's capacity shifts as we get older and it is more of an issue and the impact is greater when we have had polio.

Behavioral Issues
Factors that make us "Step over the Line" To Far or To Often

- Pressure to "Overdue"
 - From within
 - From others
- The "Overachiever"
- "Should have", "Would have", "Could have"

Some of the factors that drive people to overdo: some come from within – people will say well this is just the way I am. Sometimes it comes from outside in that people feel that there is a social pressure, or family pressure, or other people are expecting these things of them, or that they have got to cook for Thanksgiving or they have to, the family is expecting this. Again you use those words 'have to' where there are no options, no other possibility of saying "well why not let the kids do some of these things and I'll do this part".

It is really important to do a check in terms of where that drive is. If somebody finds themselves overdoing it currently, then it is important to ask "where is this coming from, why am I doing this?".

Another big factor from a chronic standpoint is sleep. It is important to know if there is an underlying sleep disorder; it is not uncommon for sleep disorders to go undiagnosed for years, or even a lifetime e.g. obstructive sleep apnoea, periodic leg movement disorder – both of which would limit deep sleep, a time when healing occurs. So if we are pushing our body and are not having that healing time, then that will feed into the chronic pain cycle.



The sleeping position is also important, often polio back pain is due to a sacro-iliac problem, so sleeping with a body pillow, in a correct position that supports the curve of your spine and your sacro-iliac joint and limits rotation, is very important.

Sleep hygiene and stress management: A lot of us bring daytime stress into our night time. So stress hygiene is an all-encompassing approach of trying to be careful of your sleep habits.

Firstly, have a very disciplined sleep time and wake time, schedule 8 hours. Avoid things that are stimulating at night time before you go to bed, and also try peaceful relaxation prior to bed, avoiding the stresses of the day. Take just 10 minutes to disconnect from all those day time stresses by using something that switches us off. Some people have told Dr DeMayo that they watch the evening news and that puts them off to sleep, it is a distraction to their own stimulating thoughts. So try something that takes you from a place of stress to a place that is peaceful, it might be a mantra, a prayer, deep breathing, reading.

If a person is chronically sleep deprived and is also having pain issues, then getting very strict on sleep hygiene can make a huge difference once you've ruled out any sleep disorder.

Stress management is another chronic problem. Medical management of stress/anxiety using medication is usually overdone and overused; it is not something Dr DeMayo uses for treatment. These medications affect your whole brain, including your ability to problem solve and your ability to cope and ability to work through that stressor, because the drug is impairing your brain. You might look better or feel better in the short-term but it is not managing in the long term. Dr DeMayo prefers complimentary approaches: yoga, aromatherapy, tai chi, massage, aquatics are all helpful in stress management.

Frustration is caused by not meeting your expectations (struggling) – when you are feeling frustrated you only have three options:

- 1. Continue** to be frustrated: you wake up every day and continue to do the same things and you are frustrated. However if you decide that you don't want to be frustrated then you are down to two options ...
- 2.** Work harder to meet your expectations; this is probably **NOT** the answer for most of us. Dr DeMayo prefers **work smarter**. How can I meet my expectations in a smarter way? Ask yourself how many of your options are smarter?
- 3.** This option is the most important. So if you are feeling frustrated and you **change** your expectations your frustration goes away. You might say that you weren't raised to give up, to lower your goals, but Dr DeMayo is not saying **LOWER** your expectations but **CHANGE** your expectations. Life has changed, you changed your life when you got married, went to high school, got a new job, or lost your job, or your parents, **AND** we coped and over time we changed our expectations and got on with our life. There are certain times when it is hard to change our expectations and it is usually when we don't

even know what our expectations are. When we are so frustrated we are often expecting something that is really 'dumb', but if you change that expectation then the frustration goes away e.g. we want to keep everyone happy, this of course is not possible (and therefore 'dumb') so if you change your expectation to say we make some people happy some of the time then we are not frustrated.

The Role of Exercise:

There is a role for exercises for physical well-being i.e., in stretching tight muscles, increasing strength, cardiovascular conditioning, but also as a stress reliever.



Hopes and dreams for the future:

Using technology to do interactive healthcare encounters over the internet e.g. counselling and education. It provides the opportunity to connect the individual polio survivor with a specialist who has some understanding of their condition, both in the short-term as an educational platform, and in the long-term in connecting polio experts with physiotherapists or with their family physician, in fact multiple people during this interaction.

This is complicated due to the need for licencing in each individual state (in the USA) to treat patients; it is OK to provide education but a licence is needed to treat individual patients. This is trying to be changed but it is a long process. Technology has its downsides but it has some major pluses in terms of healthcare.

Question Time

Members submitted written questions to Dr DeMayo prior to the Seminar for general discussion.

Lymphodaema:

Lymphodaema is an issue where your heart pumps fluid/blood down to your leg and it is not being pumped back, causing swelling. If your muscles are not contracting then the blood doesn't get pumped back. This then requires the leg to be raised up above the heart level (which is not practical all day long), the use of prescription compression stockings (which can be very difficult to get on), or Tubigrip – use a double layer of it to cause compression. So elevation and compression are the two elements to treat lymphodaema. Medical management could be Lasix (fluid tablet) to get the fluid out of the system.

Broken sleep:

Can it affect your general health? For example, waking when changing position, turning over?

The amount of sleep needed reduces as we age, someone in their 70s should get 6-7 hours of sleep. Broken sleep is a very big issue; pain issues can be the cause. Dr DeMayo says that it is a cycle where broken sleep and being awake can be creating your pain. It's another cycle that is really important to be looked at, looking at the sleep hygiene issues and the relaxation issues and the environment in terms of controlling everything that you can in order to sleep. When you have removed all of those things and reduced some of the 'wakenings' and then get a deeper sleep, then that can positively affect the pain which leads to a further decrease in sleep disruption. This is where the body pillow (*see picture on*

page 12) helps with positioning and comfort and pain reduction. A body pillow, often used by pregnant women, is a long tubular pillow about 5 feet long, of fairly dense foam, used when lying on your side with a slight roll forward i.e. not completely on your side but not on your face. Place the pillow along your body from your chin to your feet with your arm, your leg and foot draped over it, this allows your hips, knees and feet to be all in alignment eliminating a lot of that torque on your back resulting in a reduced pain.

There are other spine problems such as stenosis (narrowing of the spinal cord) but the most common in polio people by far is sacro-iliac joint pain. This is mainly due to muscle weakness issues and tightness as well as leg-length discrepancies and gait issues. Drop foot, for example, with a steppage gait which requires you to pick your foot up high, or circumduction where you bring your leg out; all of these movements will put a tremendous amount of torque on the sacro-iliac joint.

One of the problems with waking up is that if you go into a deep sleep your muscles will relax and, because those muscles are stabilising your sacro-iliac joints, as you sleep you are stretching those ligaments out, they then relax AND if your leg is not supported then your sacro-iliac joint pops out and then you will have a lot of pain. That is the fundamental reason for keeping them in alignment by using the pillow and lifting that leg up and relieving the torque (a force that produces rotation/twisting).

Have you seen patients who have new weakness in muscles that were thought to previously been unaffected by polio?

Absolutely! It may have been that one limb was completely paralysed and that it was not noticed that the other limb was also weak i.e. it was affected by polio but was overshadowed by the other more acute limb. To actually see a weakness you have to have a significant drop off of your neurons. So when the reinnervated neurons start to drop off as you get older you see a bigger impact, everyone loses neurons as they get older and the impact of that for someone who has had polio is much larger because the reinnervated muscle has been doing several times the amount of work and is responsible for much more muscle mass, so when it goes for a polio person it is a lot worse.

Diagnosis of fibromyalgia:

Fibromyalgia is a label; it is a condition where there is diffuse pain in muscles of the back, arms and legs. It is a neurological issue where you are acutely aware of pain coming from muscles. Other factors of fibromyalgia include impairment of sleep and depression.

The term fibromyalgia became a term used for any chronic muscle pain. There is treatment for it. So sleep hygiene, stress management and treatment for depression are extremely helpful with this condition. There appears to be an overlap in the terms of management of fibromyalgia and PPS. PPS can also have an effect on the central nervous system.

What are the benefits of exercise or otherwise:

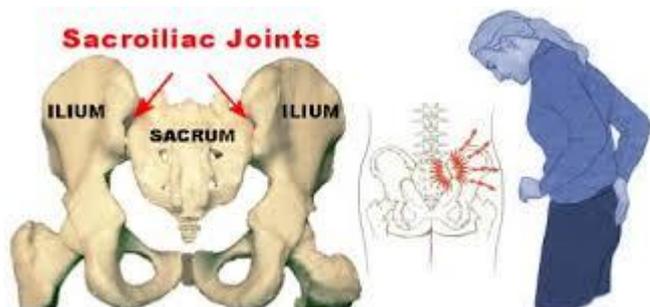
Be careful how you define exercise i.e. stretching, strengthening, weight training. Maintaining appropriate strength and flexibility is essential, but it is important to do it carefully. There are times when muscle tightness can be advantageous so not always staying loose is better. Working with a rehabilitation physician or physiotherapist who does an individual assessment and gives you exercises that are helping not harming is important.

Also remember that daily activity is exercise. There are people whose capacity has shifted down as they have gotten older but they still feel the need to keep exercising. However, if they do then they can't function for the rest of the day and so they are not out there doing the things that they want to do because they have pushed themselves so hard doing the exercises. They think that they are trying to get better like the ultra-marathoner, they are

pushing, pushing, pushing, but because they are overdoing it with their exercises they are actually going the other way, plus they are missing out on life.

You might ask, can you get more exercise by **walking** from point A to point B rather than using a wheelchair, or using a manual chair instead of a power chair? Well that maybe true but, from a functional standpoint, if it is going to exhaust you to do it the hard way (or add to your pain) then you are not going to be able to function for the rest of the day so then what is the point!

In regard to equipment: for folks who are ambulatory and have back problems or other types of problems and are limited to walking only a few hundred feet or yards, I would recommend a walker, it has four wheels, handbrakes, and has a seat. If someone can walk a few hundred metres but are not able to walk far enough to go out and walk in the neighbourhood or walk around the block and have confidence that they will make it back, then they will stop doing that activity. If they can use a walker and go out for a walk around the neighbourhood and if they get tired they can sit and rest for a while and get back, they are now doing an activity that they weren't doing before. Plus a lot of the injury that comes with walking with a gait deviation, i.e. with a steppage gait, can be alleviated when you have your hands on the walker which is stabilising your spine (reduces limping etc); you are not getting a lot of the negative effects (pain, fatigue). You are strengthening the muscles without causing the biomechanics that lead to injury.



Pain in the buttocks is often from the sacroiliac joints, the sacro-iliac joints are where the dimples are in your back near your backside. For people who have had polio, muscle weakness, and lack of stabilisation, then the sacro-iliac joint is by far the most common cause of pain. To indicate your pain use one finger to point out the exact area.

What can you do? Firstly, try to eliminate the biomechanics of what is causing the problem e.g. if someone is walking with unequal leg lengths causing a limp, then partially correct it with a build-up. Walking with an exaggerated gait to compensate for the unequal leg lengths is putting an enormous amount of stress on your sacro-iliac joints. If someone has a steppage gait i.e. drop foot, and they are not wearing a brace to correct it, they have to pick their leg up higher (bearing in mind that your leg may weigh 30 pounds), if you are picking up far enough to be able to swing it through and taking a thousand steps a day then you are picking up 30 pounds a thousand times a day using up a lot of energy, instead of swinging your leg through using a proper brace to support the foot.



With regard to the sacro-iliac joint, whenever we have to use our muscles to pick up a whole leg it puts a torque on the sacro-iliac joint. So using something like a walker or a brace (depending on the specifics of an individual's problems), correcting the biomechanics and relieving the torque on the sacro-iliac joint is number one. Secondly, if the strength and flexibility deficit can be undone then that can decrease the torque. Sometimes that means stretching appropriate muscles, sometimes strengthening other muscles.

There is a role for anti-inflammatories, non-steroidal anti-inflammatories, and sometime steroidal anti-inflammatories on a limited basis. More rarely, sacro-iliac steroid injections in conjunction with physiotherapy is recommended, this can give up to 90% improvement

(which is usually only temporary). It can then be helped by adding therapy to correct a tightness or weakness issue which has a tremendous long-term benefit. It is important to see somebody who understands sacro-iliac joint issues. The sacro-iliac joint is often overlooked as the cause of the problem.

Pain can come from not only the buttock but also down the leg typically down to the knee but not past it. In the 1920s if you had back pain and leg pain the doctor would say you had sacroiliitis. In the 1930s if you had pain going all the way down to your foot, then the pendulum went from always being sacroiliitis to it being always a lumbar problem and it's a nerve getting compressed. Now if you go to the doctors with back pain and leg pain, most are going to presume that it is a pinched nerve, but the fact is that there are still a lot of people with sacro-iliac problems, and in the polio population you need to look for a radicular nerve compression, or things like spinal stenosis, and be very aware that sacro-iliac problems are by far the most common.

Poor posture, sitting for long periods without moving i.e. at computer:

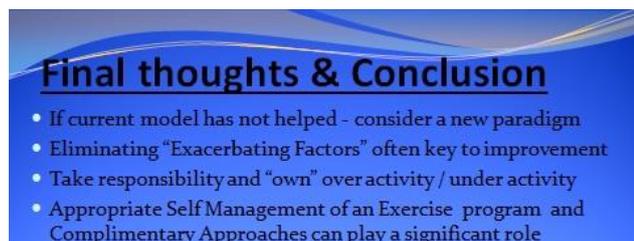
When you sit, the leg muscles that attach to your pelvic wings are in a shorter position; if you sit like that for a long time, they become tighter and tighter and it gets harder and harder to pull them apart (to stretch them). Imagine if you put a bandage around your arm and it was bent and then you left it there for a few hours before taking the bandage off, you are going to have a lot of pain trying to stretch your arm out again. If you did the same thing but were told to take the bandage off every 15 minutes for 1 minute and then stretch out your arm, loosen it and then bend it again bandaged, then you are not going to have nearly as much of the same problem.

The same goes for sacro-iliac problems and sitting for too long. If you sit continuously those muscles are going to get tighter and tighter, and then when you try to get up you have a problem – you have to change your position to straighten your hips, tilting your pelvis, you're trying to straighten up by stretching those muscles, your spine is trying to pull up, your pelvis is being pulled down – it is difficult and painful. The connector between your spine and your pelvis is your **sacro-iliac joint** and that is why sitting for too long, standing for too long, driving for too long, is a big problem. Dr DeMayo suggests that people with sacro-iliac problems should take breaks very frequently. If someone can physically get out of a car without a problem then I suggest that they get out **every** 15 minutes on a long trip, so just get out of the car, do a quick stretch then get back in the car and now you can drive for several hours without taking that risk of having severe increase in your pain. You may not have the pain when you are sitting there, a lot of the time it is when you try to get up.

Leg length discrepancies:

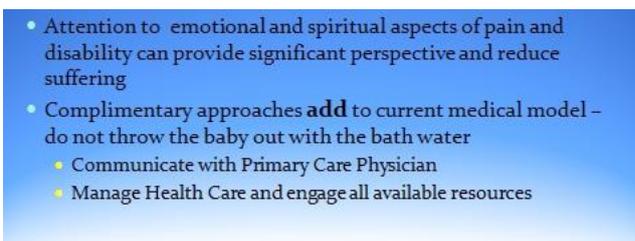
Told left leg short when it was previously right leg that was shorter?? Confused.

With the sacro-iliac joint problem, if it pops out of place it can lead to the hip joint socket dropping down which can then look like you have one leg shorter than the other until it pops back into place. Another way for this to happen is if you have muscle spasm, which is a most common problem, e.g. if you have muscle spasm along one side of your back and it pulls your pelvis up, then it will make the other side look shorter. It is difficult to measure with a tape measure.



Final thoughts & Conclusion

- If current model has not helped - consider a new paradigm
- Eliminating "Exacerbating Factors" often key to improvement
- Take responsibility and "own" over activity / under activity
- Appropriate Self Management of an Exercise program and Complimentary Approaches can play a significant role



- Attention to emotional and spiritual aspects of pain and disability can provide significant perspective and reduce suffering
- Complimentary approaches **add** to current medical model – do not throw the baby out with the bath water
 - Communicate with Primary Care Physician
 - Manage Health Care and engage all available resources

2016 AUSTRALIANASIAN-PACIFIC POST-POLIO CONFERENCE REPORT

by Ruth Hatton, Convener of the Sutherland Post-Polio Support Group

This conference, a first for **Polio Australia**, ran over three very full days at the **Four Seasons Hotel**, Circular Quay, Sydney. The speakers, health professionals and polio survivors from Australia and overseas shared their expertise, research, knowledge, experience and questions. Most sessions were run concurrently. Choosing which to attend was not easy, as topics varied greatly, and all were relevant! Educational sessions were held for health workers to aid in their recognition and management of the **Late Effects of Polio** and **Post-Polio Syndrome**.

From the USA, the first speaker, **Dr Marny Eulberg**, had polio when four years old. She spoke on **“What Polio causes, does not cause and might cause”**. She stressed the need for doctors and health workers to **learn and understand the late effects of polio** in order to **prevent** misdiagnosis which can incur **further damage**. Dr Eulberg emphasised the **condition** and **symptoms** of **post-polio** must be **managed appropriately**. She identified **muscle atrophy** in the affected limb(s), **muscle fatigue** (due to decreased endurance), **muscle pain** (from overuse), loss of joint reflexes, **some** headaches, breathing and swallowing difficulties, biomechanical processes, polio “cold leg/arm” (not circulation problems), osteopenia/osteoporosis of affected limbs amongst the problems directly caused by polio.

Secondary effects were caused over time by wear and tear on the joints, tendons and ligaments, as well as **some nerve compression syndromes** e.g. with shoulders. Other outcomes included **weight gain** due to reduced exercise, increased fatigue from energy expended, **“generalised” fatigue**, **“hitting the Polio Wall”** and **emotional issues** linked to childhood hospitalisation/isolation, as well as the experience of polio and its later effects. Dr Eulberg claimed 90% of us have not had counselling, but need to. She also made the point that there can be separate age-related problems present, together with the “life stuff” that can affect anyone.

These themes were echoed by other speakers, including **Dr Stephen de Graaff** from Victoria who addressed the challenges of managing pain in polio survivors. He spoke of the multiple factors which influence pain, including **physical symptoms, beliefs** and **concerns**, (the “high achiever” drive), with other **psychological symptoms**, e.g. reduced social contact. He said polio survivors say, *“Help me help myself”*, and tend to ignore pain initially.

Dr de Graaff stressed that **the cause of the pain must be defined**, and that **persistent acute pain indicates a physical problem which must be treated**. He recommended **caution with drugs for nerve pain** as they are not specific to the pain’s source, but impact the whole of the nervous system, often causing a “fuzzy” head and blurry eyes, complicating the problem and impairing our capacity to deal with it. He advocated the use of “simple” analgesia and injections when needed and also emphasised that **all pain must be managed**. For biomechanical pain, often also present in the unaffected limb, he suggests physiotherapy, orthotics (improves safety, use of energy, quality of life, reduces pain and fatigue), maybe surgery, and **avoiding the “no pain, no gain” motto**. Wrists, thumbs, back, neck, shoulders, hips, knees, hands and feet are all common sites involving muscle and nerve pain. He identified fatigue as a prime issue for those who have had polio.

As well, Dr de Graaff stated that **pain impacts quality of life, physically, psychologically, socially** and **spiritually**, and all these aspects need to be addressed for our well-being. He advocated **early detection and intervention, a partnership between doctor and patient** with the goal of patient understanding and self-management, along with a goal-oriented rehab plan. He encouraged sufferers to keep a pain diary recording the severity and specific ways the pain impacted them. He also promoted family involvement. He stated that **ongoing, long-term pain** may be a fact of life for many with post-polio effects; therefore **we need strategies to live with it**. His suggestions included having a positive approach, dealing with fears, using counselling, cognitive therapy, stress management and relaxation techniques, possibly self-hypnosis, and while pacing yourself, to “move on”, and live life.

Dr Lise Kay from Denmark reported on her study comparing the hospital admission rates over time of post-polio patients with a control group who never had polio. Interestingly, **there was no difference in rates within the polio group**, whether or not they'd had paralytic polio. However, they all had significantly more admissions than the control group. The study also indicated that, after 50, the paralytic group died slightly earlier than the other two groups.

The **Polio Services Victoria** model of care was discussed by **Dr Yan Chow**, a rehab specialist at **St Vincent's Hospital**, Melbourne. Begun in 1998, it now has around 3,000 clients in the 60-69 year age bracket, with significantly more men than women. 57% were Australian born, the remainder from Vietnam, India, Africa, the Middle East and South East Asia. Referrals are mainly from GPs and health providers. A multidisciplinary team, with an orthotist, provides assessments, management plans, support and advice, and services – including clinics, hydrotherapy, workshops on fatigue and self-management, as well as referrals to community services and links to **Post-Polio Support Groups**. This Melbourne team also visits 6 regional areas a year and is looking to further develop assistance to doctors, health workers and their clients through “**telehealth**” – modern technology and visual links.

The report supplied by physiotherapist **Russell Ambiah** of the 10 week hydrotherapy programme (water temp 36/37 degrees Celsius) indicated it has impacted clients physically, mentally and socially, **increased their understanding and confidence, so improving their quality of life**. On completion, some participants have transitioned to other pools to maintain their routines.

Margaret Petkoff, Occupational Therapist, also with **Polio Services Victoria**, reported on her work to **help polio survivors understand the causes of, and contributing factors to, their debilitating fatigue**. She anticipated they would then modify their behaviour, so reducing their fatigue, and improving their quality of life. She initially did home visits on an individual basis, but found no change or improvement occurred. She then tried small group sessions (4-8 members) of two hours each week for 5 weeks. Fatigue scales (she recommends the **Canadian Occupational Performance – COPM** and **Modified Fatigue Impact Scale – MFIS**) were used before and after the Self-Management Workshops, as well as oral feedback from participants. The qualitative and quantitative data did not match. Group members had gained insight and made some changes, but their fatigue levels had not greatly improved. Margaret says **fatigue is a complex, multidimensional problem**. The fatigue may not greatly improve, but **the self-management** of it can, and has a positive impact on the affected person.

From the **Mt Wilga Late Effects of Polio Assessment Clinic**, **Catriona Morehouse**, a physiotherapist, said their goal is for people to reach their full potential. In Australia, 32% of the 40,000 confirmed paralytic polio cases were in NSW. To date, a common problem is **the lack of quadriceps strength**, (causing difficulties getting in and out of chairs and doing stairs), while 80% of their clients report **problems with fatigue**. With consenting clients, Catriona is researching the correlation between fatigue and quality of life using the **Fatigue Severity Scale (FSS)** and the **WHOQOL-BREF** questionnaire covering physical, psychological, social relationships and environment domains. As perception of the client and therapist may differ, this research, **clarifying the client's issues**, can help therapists develop **treatment strategies to positively impact that person's quality of life**.

Marmaduke Loke, a prosthetist and orthotist from **Bracing Solutions USA**, reflected this theme, referring to the new solutions as “not device driven”, but designed to assist “structural and functional deficits” in individuals. He said the **new technologies and Triplanar Management enable 3D alignment of the skeleton, provide better support and “harness gravity to assist standing and walking”**. The resulting **sense of balance and security** for the user **reduces fear, builds confidence, prevents excessive muscle usage, and conserves energy, reducing fatigue**.

In her talk on **Best Practice in Providing Assistive Technology and Environmental Adaptations to the Polio Community**, **Dr Natasha Layton**, Occupational Therapist, Victoria, claimed it was necessary “**to stand in the shoes of the consumer**” to identify what they valued and the outcome they desired. Assessment should take a **capacity-building approach** and be

systemic, reflecting the person, their environment, task, and occupation. Such assessments take time, but are **cost-effective in the long run.** Intervention options were to **reduce the impairment, compensate for it, redesign the activity** or to **use assisted technologies.** She acknowledged cost is a factor. The **immediate goal must be possible and realistic.** See the websites of the ***Aids and Equipment Action Alliance***, and ***Assistive Technology Solutions***.

Two speakers, **Tim Lathlean**, Exercise Physiologist (Victoria), and **Dr Eric Voorn**, researcher (Amsterdam), addressed the need for, and difficulty with, exercise for polio survivors. Tim cited motor neuron loss, inflammatory response, muscle atrophy, fatigue, weakness (often in quadriceps), pain, gait changes and age related issues as the underlying causes. He recommended hydrotherapy and exercises using **resistance**, as well as **short bursts** (up to 5 minutes) of **light aerobic activities.** His test for the **appropriate level** is that while exercising, the person can **talk, but not sing.** Tim emphasised the need for rest periods following any tiring activities, and to “exercise right”. Dr Voorn’s research appeared to confirm Tim’s message. He studied a group using exercise bikes for **high intensity aerobic activity** 3 times per week and found there was no aerobic improvement, **no change to their muscle strength or endurance, and none to their cardio-respiratory function.** He proposes the reason is that these **polio survivors** were **unable to reach, or maintain, the aerobic exercise levels** required for such change.

Enable NSW is a state government organisation providing **assistive technology** to people with a disability. Around 330 of their clients have polio/post-polio related needs, which like those with other disabilities, can increase over time. Assistance covers many items including powered wheelchairs, breathing and sleep apparatus, specialised footwear and personal care needs. For further details and eligibility criteria see their website. [www.enable.health.nsw.gov.au] The age range of current clients is from 19 to 95.

The last session of the day, ***Every Bite Counts – Why Food Matters***, was taken by **Melinda Overall**, a Sydney nutritionist. Melinda said that while a “diet” needs to be individualised, there are **general principles for healthy eating to boost general health, energy and the immune system, while decreasing fatigue, some mood disorders, and obesity.** She claimed only 4% of Australians eat serves of the **5 recommended vegetables per day.** Other essentials included **proteins** – 30 grams per day to prevent muscle atrophy and decrease inflammation, as well as **fruit, whole grains** and “**good**” **fats.** Processed and refined foods, along with alcohol and sugars, need to be limited. She said some people may need protein or other supplements, but their liver and kidneys must be checked out first, then only proceeding with professional advice (e.g. from a dietician or naturopath) for the appropriate product. She reminded us that appropriate exercise/activity is a necessary complement to what we eat to maximise our health.

The final day of the Conference began with **Mary-ann Liethof** (***Polio Australia***), **Joan Headley** (***Post-Polio Health International USA***) and **Gordon Jackman** (***Polio New Zealand***) sharing what their organisations are doing to ensure support and services for all polio survivors with ongoing disabilities and for those experiencing **Post-Polio Syndrome** or other **late effects.** All use their **websites** to **provide information and support for survivors.** In addition, they are working to **educate health professionals, to encourage research** and to **advocate for funding and services.** Mary-Ann pointed out that although Australia has been free of new cases here for 50 years, there are younger **migrants and refugees who contracted polio overseas,** so the need for post-polio support will continue on here and in other host countries. **Post-Polio Health International** also assists international ventilator users, “**builds bridges** and bonds, not bureaucracies, **promotes participation** and process, not personalities”, Joan said. They were incorporated in 1960, and all their published articles are available on their website. [www.polioplace.org]

Polio New Zealand works also with **other disabled people who have similar needs to polio/post-polio survivors.** Following contacts here, Gordon is looking to assist with the establishment of Support Groups in Fiji and Taiwan. Concern was expressed for the care of disabled survivors seeking resettlement, as many countries, including our own, will not accept them.

In the future, though the number of polio survivors worldwide should be smaller, many living in isolated places or emerging economies would be unlikely to receive the support and assistance they need.

Jenny Horton from *Rotary International* spoke of their campaign to rid the world of polio through vaccinations. The policy, originally conceived by Sir Clem Renouf, a Rotarian in Nambour, Qld, was adopted in 1979 and begun in 1988. Only Pakistan and Afghanistan opted out of the program, but access to Nigeria has also not been possible for some time due to terrorist activity. But, it seems the Health Department there is now working to get the vaccine in again. Vaccine has been distributed to the surrounding areas. **Worldwide, \$14 billion has been spent, with the reported number of cases going from 1,000 per day, to 74 in 2015.** Children are also checked for measles, malaria and malnutrition and put on a worming program. Statistics are posted Friday mornings. [www.polioeradication.org]

Several people then shared their polio stories, which all demonstrated the need for post-polio follow-up. **Catherine Sharp's** father was working in Kenya in 1954 when she became very ill with polio. She remembers the dangerous night-time dash to the hospital, and other disturbing details of her illness. She recovered, has her own family and a successful professional life. For some time now, Cate has experienced various post-polio symptoms. A nurse consultant and researcher, she is concerned that "**poliomyelitis**"/"**polio**" **does not appear on admission forms** to hospitals, and nursing homes, so **staff are not alerted to the increased risk of falls and pressure areas.** Also, **very few staff are aware of post-polio with its range of potential problems.**

Sai Padma Bellana, a lovely Indian lady in a wheelchair, described as an "Advocate and Social Activist", was accompanied by her husband, **Pragjnanand Busi**, "Therapist, Global Ability in Disability". She began by **singing**, beautifully and unaccompanied, a song in her language. Her story was of **being transformed**, despite her pain, weakness and 80% disability, from negativity and feeling "out of sync" with life to now working full time in different projects and **having "a very active life"**. She attributes this to **using both modern and ancient methods**, including highly-customised carbon graphite callipers, the power of positive thinking, acupuncture, yoga, **Ayurveda**, and changes to her lifestyle. **This journey has been over 20 years.** It began when a friend encouraged her to sing, then to look outside herself and **seek others whom she could help.** She paid **tribute to her husband**, much valued life partner who has treated her (yoga, alternative therapies) and assisted her to help others. She has not taken any medication in the past 7 years, and now dreams of walking effortlessly.

Tae Shibata, Welfare Officer, led a delegation from the **Japanese Network of Polio Survivors (JNP)**. In 1998 a newspaper ran an informative feature on **Post-Polio Syndrome**, which also urged people not to overuse muscles affected by polio. In **2001 the JNP was formed** and in February 2016 there were 800 members among 8 regional groups. They have produced information leaflets, circulate a regular newspaper, surveyed members which led to the production of a book, edited by a doctor, and they come together biannually. There are several **hospitals/centres** in Japan with large multidisciplinary teams which focus on post-polio. They **assess, review**, have **treatment clinics**, **collect and compare their data.** The benefit is **mass screening with observable results and available data** (as well as **convenient access for the clients**). They said Japan is trying to meet the **UN recommendations** for appropriate services and assistance for disabled people. **An Act of Parliament was passed to overcome physical and social barriers.** Information is disseminated to health professionals, industry, and post-polio survivors.

Neena Bhandari was born in India. At 3, she had **polio after vaccination** – batch left in sun? Sick children were not admitted to hospital, but stayed home with the family. Neena's grandfather, who was a doctor, arranged for her leg to be treated with **intensive physio and hydrotherapy.** She then had a **rigid steel calliper** and **heavy different-sized boots**, to fit her feet. Neena went on to become a **journalist.** When the family **moved to the UK** in the late 1990s, she discovered, and was **greatly helped by, post-polio support groups.** She also enjoyed being in a culture where she could be out and about "**without stares and glares from the people around**". Later,

in Australia, Neena with her severe post-polio issues was “shocked and surprised” at attitudes here to her disabilities. Experiencing weakness, balance problems, falls and fractures, she had difficulty finding doctors and therapists with the knowledge and expertise for managing her post-polio needs. She has now worked out management strategies for herself, including the alternative therapies used by Sai Padma Bellana, with hydrotherapy, massage, “proper” callipers and mobility aids, breathing and upper body exercises, as well as learning to pace herself. Neena says that Australians need to train people in Asian countries to deal with post-polio as they will have many such patients there in the near future and for many years to come.

In the session entitled **Post-Polio Dreaming**, table groups compiled wish lists for the “perfect” **Post-Polio Health Service** to support them now and into the future.

- The **ONE STOP SHOP** with doctors, multidisciplinary teams, counsellors, orthotists, technicians, mobility aids, alternate therapies, tailored hydrotherapy with pools heated with ultra violet rather than salt or chlorine – all the post-polio expertise, equipment, therapies, orthopaedic aids etc in one place, ideally regionally, but at least one in each state.
- **Financial assistance for travel and accommodation** costs for time required.
- **Consultations/treatment to be covered by Medicare**, including proven alternative therapies.
- Some prefer one **Centre of Excellence**, but that could reduce access and prolong waiting time.
- Restore case management, linking clinical access/input and community service provision.
- More post-polio training for doctors, health professionals – neurological and biomechanical issues.
- More publicity to alert polio survivors and the public e.g. using magazines, groups.
- **Hospital/residential care facilities alert** to identify post-polio clients’ risks/needs.
- **Appropriate residential care.**
- **Adequate recurrent government funding** of medical and therapeutic services, community support services and equipment for disabled people.
- **Increase funding of Aged Care packages** – very high costs for services and equipment.
- **Greater respect for individual differences**, with disabled people seen as an integral part of Australian society and with improved access.
- **Connections and information exchange internationally.**
- **A general Disability Centre** – not just for polio – to assess, develop management plan, then follow-up at the local level.
- **Swallowing and breathing assessments.**
- **Post-polio specific weekly exercise classes.**
- **CEO make case to government that funding a post-polio wellbeing clinic will be cost effective in the long run.**
- **Recycling of orthotics.**
- **Video link for patient and GP with specialist.**
- **Post-polio research component linked to University.**
- **Increase funding of current health care plans** – 5 sessions per year insufficient.
- **Study on costs of being disabled**, with increased concessions e.g. for water.
- **Protocols for hospitals with PP patients** (See e.g.’s from *PP Network of WA*).

Some dreams come true – with a little help from their friends!

IDEAS Travel Database

Website Search: www.ideas.org.au/category/front/out-about

A searchable online listing of accessible accommodation, attractions, restaurants etc. This section of the IDEAS website is aimed at supporting informed decision making centred around travel and tourism.

Lonely Planet – Accessibility Guide

Website: <http://shop.lonelyplanet.com/world/accessible-travel-online-resources-2016>

This is the world's largest list of online resources for accessible travel. A downloadable collection of online resources filling the information gap and introducing you to people who haven't let their disability get in the way of their love of travel.

Have Wheelchair Will Travel Website

Website: www.havewheelchairwilltravel.net

An ex-travel consultant, Julie, and her family, share all their trips, experiences, research and great travelling discoveries, including day trips at *Have Wheelchair Will Travel*. This is to help others who are either planning a trip, or are feeling nervous about giving it a go.

Sydney Wheelchair Walks

Website: www.sydneybywheelchair.webs.com

Glenn Kesbah documents his travel around Sydney in an electric wheelchair to the most scenic and spectacular paths/walking tracks. The site includes maps marking wheelchair suitable trails.

Freewheeler Website

Website: www.freewheeler.com.au/html.index.html

The Freewheeler site commenced to give people with mobility issues access to information that will help them make informed choices when travelling. Their aim is to find accessible accommodation and activities around Australia.

Mobility Maps

Website: www.mobilitymaps.com.au/nsw.htm

A centralised place that has all of the mobility maps in Australia. These maps are a great way to assist navigation in local government precincts.

CHOICE

Website: www.choice.com.au/travel/general/advice/articles/travelling-with-a-disability

Set up by consumers for consumers, CHOICE is the consumer advocate that provides Australians with information and advice, free from commercial bias. This guide to accessible tourism for people with a disability looks at the challenges and the how-to of accessible travel including booking and boarding flights, airport security, accommodation, the rights of travellers with a disability, tips for flying, and more.

Changing Places

Website: www.changingplaces.org.au

Changing Places toilets are different to standard accessible toilets in that they have extra features and more space to meet these needs. Each Changing Places toilet provides: a height adjustable adult-sized changing bench, a tracking hoist system, enough space, safe and clean environment. A location map of Changing Places and other fully accessible toilets is available on their website.

The National Public Toilet Map

Website: www.toiletmap.gov.au

As part of the National Continence Program, the Toilet Map provides information on over 16,000 publicly available toilets across Australia, including accessibility, opening hours and facilities, such as showers and baby change. It is also available as an App.

Master Locksmiths Access Key (MLAK)

Website: www.masterlocksmiths.com.au/mlak.php

The Master Locksmiths Access Key (MLAK) is an innovative system that enables people with disabilities to gain 24/7 access to a network of public facilities.

The MLAK system has been fitted to elevators at railway stations, accessible toilets in Council municipalities and National Parks and in adaptive playground equipment (Liberty Swing) across Australia. People with a disability are able to purchase an MLAK master key which will open all toilets, playgrounds and other facilities which are fitted with this specially designed lock.



Yarrangobilly Caves Adventure

[The Yarrangobilly Caves are located in a 12 km long karst region along the Yarrangobilly River valley in the north of Kosciuszko National Park, New South Wales]

Home to some of the most beautiful caves in Australia, the opportunities are endless at Yarrangobilly. The whole family can explore underground caves followed by a swim in the thermal pool, keen bushwalkers will appreciate the trails and summer wildflowers, and bird watchers will enjoy waking to the sounds of birdsong. Yarrangobilly Caves also offers accommodation.

Accessibility at Yarrangobilly Caves – All-terrain wheelchair

Newly available to Yarrangobilly Caves for customers who have impaired mobility is the Hippocampe wheelchair (max 130kg limit recommended). This wheelchair can be borrowed and used to access the Glory Hole Cave entrance and the Thermal Pool.

Jillabenan Cave

Despite being the smallest cave on show at Yarrangobilly, the Jillabenan Cave is possibly the oldest. It features impressive displays of some of the most delicate cave formations to be found. Straws, stalactites, shawls, cave corals, and mysterious helictites can be readily seen throughout this amazing cave. Limited wheelchair access is available (a specially designed cave wheelchair is provided), so please contact the staff at Yarrangobilly Caves for wheelchair booking information.

For more information: Call Yarrangobilly Caves Visitor Centre: 02 6454 9597

www.nationalparks.nsw.gov.au/kosciuszko-national-park/yarrangobilly-caves/historic-site

www.nationalparks.nsw.gov.au/whats-on/snowy-mountains/aboriginal-cultural-experience



WheelEasy Access Information Website

WheelEasy's aim is to create **better access to leisure activities for wheelchair users and their family and friends**. WheelEasy is not just for wheelchair users, but also for everyone who wants to enjoy life to the full with them.

One of the biggest problems has always been **finding the right information**. So, we're launching this month with our first project - the **WheelEasy Access Information website** at www.wheeasy.org.au, it is a **geolocation-based one-stop-shop for everything about access**. There is access information to all sorts of things - from flat beach and bushwalk access, beach wheelchairs and picnic areas to theatres or train stations, and much more.

WheelEasy.org.au has specifically been **built with mobiles in mind** so that people can use it when out and about, without having to plan ahead.

Our ultimate aim is

- to make every wheelchair user in Australia aware of our site, and
- ask them to share their local knowledge and experience as a wheelchair user, so we all know what's great to see and do, as well as what's not.

We'd love it to become a permanent feature on every wheelchair user's mobile.

As a first step towards making our database more comprehensive and useful, **please start adding your own information. Please like us on Facebook and Twitter.**

POLIO SUPPORT GROUP MEETING LOCATIONS 2017

AREA	CANBERRA
CONVENOR	Brian Wilson
PHONE	02 6255 0875
MEETING	2.00pm 1 st Saturday of every 2 nd month, commencing February
PLACE	Pearce Community Centre, Collett Place, Pearce ACT
AREA	ALBURY / WODONGA
CONVENOR	Margaret Bennie
PHONE	02 6021 5568
MEETING	Lunch on Sunday at least 4 time a year
PLACE	Commercial Club, 618 Dean Street Albury
AREA	CANTERBURY / MARRICKVILLE
CONVENOR	Maura Outterside
PHONE	02 9718 5803
MEETING	6.00pm 1 st Thursday night of each month
PLACE	Lantern Club, Roselands
AREA	CENTRAL COAST
CONVENOR	Wayne Woolley
PHONE	02 4342 6145
MEETING	10.00am – 12 noon 1 st Saturday of each month
PLACE	Kincumber Neighbourhood Centre, Kincumber St, Kincumber
AREA	COFFS COAST
CONVENOR	Shirley Barnett
PHONE	02 6651 9098
MEETING	NO MEETING NEEDS MEMBERS
PLACE	

AREA	CONDOBOLIN
CONVENOR	Bill Worthington
PHONE	02 6895 2870
MEETING	NO MEETING NEEDS MEMBERS
PLACE	
AREA	DUBBO
CONVENOR	NEED CONVENOR NO MEETING NEEDS MEMBERS
PHONE	
MEETING	
PLACE	
AREA	GRIFFITH
CONVENOR	Dawn Beaumont-Stevens
PHONE	02 6963 0880
MEETING	NO MEETING NEEDS MEMBERS
PLACE	
AREA	HILLS DISTRICT
CONVENOR	Moya Adams
PHONE	02 9144 3830
MEETING	10.30am 2 nd Tuesday of each month
PLACE	West Pennant Hills Sports Club, New Line Road, West Pennant Hills
AREA	HUNTER
CONVENOR	Wendy Chaff
PHONE	02 4957 5254
MEETING	10.30am 1 st Wednesday each month commencing February
PLACE	Toronto Workers Club James Street Toronto

AREA	INNER WEST
CONVENOR	Claire Dawson
PHONE	02 9713 6565
MEETING	11.30am to 3.30pm 2 nd Saturday each month
PLACE	29 Halley Street, Five Dock NSW
AREA	NEPEAN
CONVENOR	NEEDS CONVENOR
PHONE	
MEETING	NO MEETING
PLACE	NEEDS MEMBERS
AREA	NORTHERN BEACHES
CONVENOR	Carol Gerrard
PHONE	02 9982 1685
MEETING	10.30am last Thursday of each month, except DECEMBER
PLACE	Dee Why RSL Club 932 Pittwater Road, Dee Why
AREA	NORTHERN RIVERS
CONVENOR	Rosalie Kennedy
PHONE	02 6687 9640 / 0412 827 926
MEETING	1.30pm to 3.00pm Last Saturday of each month except DECEMBER
PLACE	Ballina RSL in March -- Lismore Workers Club in June, Sept
AREA	NYNGAN
CONVENOR	Ruth Williamson
PHONE	02 6832 1220
MEETING	NO MEETING
PLACE	NEEDS MEMBERS

AREA	PORT MACQUARIE
CONVENOR	Gail Hassall
PHONE	02 9581 4759
MEETING	10.30am to 12.00 noon 1 st Saturday of every 2 nd month commencing February.
PLACE	9 Rivergum Drive, Port Macquarie NSW
AREA	SHOALHAVEN
CONVENOR	Dorothy Schunmann
PHONE	02 4448 7541
MEETING	2.00pm 3 rd Friday every month
PLACE	Bomaderry Bowling Club, 154 Meroo Road, Bomaderry NSW
AREA	SUTHERLAND
CONVENOR	Ruth Hatton
PHONE	02 9252 3987
MEETING	2.00pm 1 st Wednesday every month except January
PLACE	Club Menai, 44 Allison Crescent, Menai
AREA	WAGGA WAGGA Group in Recess or Suspended
CONVENOR	Isabel Thompson
PHONE	02 6926 2459
MEETING	11.00am 2 nd Wednesday every second month except January
PLACE	Senior Citizens Rooms, Tarcutta Street, Wagga Wagga



Dear Editors

I thought this photo may be an interesting item for your newsletter. I have passed this finger board many times over the years and it was a broken down old wooden sign, which has recently been replaced with this new steel one. The sign stands beside the Gwydir Highway on the eastern approach to Warialda in north west NSW. Warialda was the birth place of Elizabeth Kenny (sometimes known as "Sister" Kenny) where she lived until the age of nine when her family moved north to the Darling Downs town of Nobby.

The Gwydir Highway runs from Grafton on the Clarence River, west over the northern tablelands at Glen Innes, then down through Inverell, Warialda, Moree and on to Collarenebri. The word "warialda" is actually an aboriginal word meaning "a place of good honey". I assume most newsletter readers would know the name Elizabeth Kenny. Even at the age of 75 I have very clear memories of sitting on a chair with my feet in a dish of very warm water with my mother sitting on the floor beside me bathing my legs, then turning on the infrared lamp to maintain the heat as she massaged my legs, to restore life to them. This she did four days per week, and a physiotherapist worked through the same procedure the other three days. I feel that I owe it to my mother, to that physio and Elizabeth Kenny, that at the age of 75 I am still able to walk despite a terrible experience with PPS in 2013.

My best wishes, thank you for what you do for us all.

Regards

Neville Bryant



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Gillian Thomas	President	president@polionsw.org.au	02 9663 2402
Susan Ellis	Vice-President	vicepres@polionsw.org.au	02 9894 9530
Merle Thompson	Secretary	secretary@polionsw.org.au	02 4758 6637
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Committee Members (for contact details please ring or email the Network Office):

Anne Buchanan, Nola Buck, Ella Gaffney, Anne O'Halloran, Alice Smart and John Tierney

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Ella Gaffney	Webmaster / Support Group Co-ordinator	webmaster@polionsw.org.au	0407 407 564
Nola Buck/Susan Ellis	Co-editors <i>Network News</i>	editor@polionsw.org.au	02 9890 0946

About Polio NSW

The Post-Polio Network (NSW) Inc was formed in 1989 by polio survivors for polio survivors. In 2011 the Network changed its name to Polio NSW Inc but our services for polio survivors remain unchanged.

Polio NSW is a self-help, self-funded organisation governed entirely by volunteers. Polio NSW provides information about polio's late effects and supports those who may be affected now or in the future. We conduct regular Seminars and Conferences, publish *Network News*, foster the establishment of regional Support Groups throughout NSW and the ACT, and maintain a comprehensive website.

Polio survivors, their family members and friends are all welcome to join Polio NSW, as are health professionals and anyone else who supports our aims. Membership provides information and support that can maximise the physical and psychological quality of life of polio survivors and their families.

If you live in Australia, we can post you a free Information Kit and Membership Application Form. The Kit includes a copy of our booklet *Helping Polio Survivors Live Successfully with the Late Effects of Polio* which explains the late effects of polio and details the many benefits of Network membership. This booklet can be emailed to those enquiring from overseas.

The annual membership subscription (payable in Australian dollars only) is \$10 not employed or \$20 employed. On first joining, new members also pay a \$5 once-off joining fee. Those initially joining between 1 April and 30 June in any year are deemed to be financial until 30 June the following year. Membership renewal is due on 1 July each year and members are alerted to their financial status with each Network mailing. Over 80% of Polio NSW's income, which is used to provide its services, comes from membership subscriptions and donations.

Resources for Members

On joining Polio NSW, members are issued with free resources including a brochure *Hospital, Medical And Dental Care For The Post-Polio Patient – A Handy Reference*, and a *Medical Alert Card* which can be carried in the wallet.

Polio NSW also stocks various publications which further describe the late effects of polio and their management. The prices quoted below are for members and postage is included. To order, just write to us – please make cheques / money orders payable to Polio NSW Inc.

Books etc (* indicates Post-Polio Network publication)	Size	Cost
<i>Managing Post-Polio: A Guide to Living and Aging Well with Post-Polio Syndrome</i> Second Edition Edited by Lauro S Halstead MD (<i>see description below</i> 📄)	288 pages	\$40.00 <i>incl 10% GST</i>
<i>A Practical Approach to the Late Effects of Polio</i> Charlotte Leboeuf	39 pages	\$2.50
* <i>Living with the Late Effects of Polio</i> Conference Proceedings, edited by Gillian Thomas	170 pages	\$29.00
* <i>Polio – A Challenge for Life – The Impact of Late Effects</i> Report: Survey of Members, Merle Thompson	54 pages	\$12.00
* <i>Post-Polio Network - Helping Polio Survivors Live Successfully with the Late Effects of Polio</i> , Dr Mary Westbrook	12 pages	\$3.00 <i>1st copy free</i>
Polio NSW has for sale a four-colour enamelled badge featuring a stunning polio virus design. The badges are suitable for men or women. Each badge comes with a description of the virus and information about Polio NSW. Not only is the badge a great fashion statement, it is an innovative way to promote Polio NSW.	23 mm x 23 mm	\$5.00 <i>plus \$1 postage</i>

📄 ***Managing Post-Polio: A Guide to Living and Aging Well with Post-Polio Syndrome (Second Edition)***

The second edition was published in 2006. Editor Lauro Halstead writes about the rationale for this edition:

As with the first edition of *Managing Post-Polio*, the major goal of this volume is to summarize the best advice available to diagnose and manage PPS in an easy-to-read, authoritative format for polio survivors, their families, and friends, as well as for health care professionals. The majority of contributors to this book are either polio survivors or experts who have worked closely with polios in clinical settings.

Another important objective of the earlier edition was to reach as wide an audience as possible – an objective that far exceeded our expectations with more than 15,000 copies in circulation. As news about PPS spread, the demand for more information continued to grow. This new edition is in response to that continued demand for information. Also, we have added a new theme to this edition – aging with disability, as once again polio survivors are “pioneers” – the first large group with a chronic physical disability to undergo aging. Since the initial edition, we are all nearly 10 years older, and, hopefully wiser. Quite possibly, we are also more disabled and, therefore, more challenged. It is my hope that this book will help guide us as we journey along this new path together.

Audio tapes of many of the Network Seminars and Conferences held since 1989 are also available at reasonable prices. For further details please contact the Office.