

Polio Perspectives



polio
network
victoria



Chair
report
Bev
Watson

PNV Chair Bev Watson with Rotary speaker and Gardening Australia presenter
Costa Georgiadis

Sharing the stage with Costa

IN April I had the privilege of being a Keynote Speaker for the Rotary District 9800 Bendigo Conference 2024, themed 'Gathering on the Goldfields'. The list of fellow speakers was awe inspiring and it was amazing to share the stage with them.

Members of the Rotary District 9800 Calder Cluster have been strong supporters of Polio Network Victoria with their willingness to volunteer at Polio Days and provide contributions to our running costs. It was a highlight to have the opportunity to share the Polio story with Costa Georgiadis of Gardening Australia fame.

I believe it is important to take every opportunity we can to speak about our experiences as Polio survivors to raise awareness and provide information wherever we can.

Chair report Cont: P2

Contact PNV: PO Box 205, Woodend, Vic. 3442 Phone: 0407 227 055
E: polionetworkvichelp@gmail.com

Chair Report from Page one:

As most of us are in the midst of Winter, I hope you are managing to keep warm and comfortable through this time.

For some, it has been wet as well as cold and for others, like myself, have had to water areas of the garden owing to absence of rain. Our various locations provide a wide range of conditions.

It is important we all take care to maintain our body temperature, to avoid extremes of cold or heat. Cold really affects Polio limbs. Warm clothing and a regularly maintained temperature for our homes helps us to keep up daily tasks.

Plans are well underway for our Polio Day 2024 to be held at Seaview Williamstown with a focus on keeping upright - this is preventing "falls". Polio Services Victoria will present valuable information to help us all stay upwardly mobile. Other interesting areas will also be explored across the day. Remember to keep October 23 highlighted on your calendar. Further details will follow as plans are finalised and able to be forwarded to all on our contact list.

Another Support Group Convenor has provided information about their neck of the woods. This time we hear from Robyn Aulmann about the Hume Polio Support Group:

"Our Hume Post Polio Support Group has enjoyed meeting socially each Second Saturday of each month. Our meeting is more a meal and social interaction of up to 12 members (we have phone interaction with our shut in members). We will have the Chinese New Year and our Christmas in July celebration.

We continue to meet at Wangaratta Club and enjoy the interaction within the club! Sometimes we do have a speaker otherwise it is interchange of what we are finding what works and what doesn't! We enjoy sharing the ideas from Polio

newsletters. I continue to be the coordinator!

Cheers, Robyn Aulmann.
email: robynja1144@gmail.com

I am sure all would like to hear from other groups, so please send me your stories/histories so we can share the wonderful work our convenors are doing and the amazing support they provide to their group members.

We have had a couple of our Committee members unwell or injured as a result of chair accidents. Our best wishes go to Graham P and Lyn B and we sincerely hope all the difficult times are behind you.

I am hopeful that before our next Polio Perspectives is ready to be produced, Polio Network Victoria will have a brand new Webpage. With better access to our Network information it will be possible to have more timely notifications and news available.

As always, I encourage you to let me know if there are specific topics you would like covered in Polio Perspectives or matters you would like the PNV committee to highlight.

Stay safe and warm.

Bev Watson
Chair – Polio Network Victoria

To book for Polio Day 2024:
<https://events.humanitix.com/polio-day-2024-keeping-your-feet>

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Flu and fatigue - PPS? Or?

From Dr William de Mayo (written pre-Covid)*

Question:

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

ANSWER :

TO provide a specific clinical answer to the above, much further information would be needed, including information regarding age, prior diagnosis of post-polio syndrome, level of disability, medications, sleep patterns, and other diagnoses. The question does, however, provide the opportunity to talk about the issue of fatigue and post-polio syndrome.

First, is important once again to remember that the diagnosis of post-polio syndrome is a diagnosis of exclusion. Therefore, all other causes of symptoms such as fatigue, would need to be excluded before concluding the cause is post-polio syndrome. It is interesting that many patients and clinicians jump to the conclusion that post-polio syndrome is the cause of fatigue, when in fact this is one of the few causes of fatigue that has no specific treatment. As a rehabilitation physician, I am always focused on issues that we can do something about and pay less attention to the things that are not under our control. Therefore, I will use this opportunity to focus on some of the many causes of fatigue that are treatable.

Secondly, the word "fatigue" can be used in a variety of contexts. One can complain of physical fatigue, including a sense of exhaustion or feeling physically drained.

Additionally, emotional fatigue can occur over time due to a variety of stressors and contribute to a feeling of being weary/worn out. Some individuals can also experience cognitive fatigue as the brain simply does not process information as efficiently over time. For purposes of this article we will lump these together, but when reporting symptoms to a clinician, it is sometimes important to be very specific.

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

Insomnia (lack of restorative sleep). Lack of appropriate duration OR quality of sleep can lead to somnolence (an intense feeling of sleepiness). Chronic lack of restorative sleep can be a major contribution to physical, emotional and cognitive fatigue. Poor sleep habits, sleep apnea, restless leg syndrome, medications, pain, and other factors can compound this problem.

Depression/anxiety/stress These common causes of fatigue are often overlooked or unaddressed.

Medications Always check with your pharmacist regarding side effects of medications you are taking.

Over activity or "Overdoing it" Does this sound like anyone you know? This is certainly not an uncommon issue in the polio population.

Under activity and deconditioning This is a problem not unusual for individuals who adhere strongly to the "conserve to preserve" mentality. At the same time, it is also a problem for many individuals who regularly "overdo it" causing so much pain that they then need to "rest" for prolonged periods of time.

Management of fatigue often requires more than one approach since the above contributing factors rarely occur in isolation. For example, chronic pain can contribute to sleep problems and depression as well as poor nutrition. Subsequently these can

worsen fatigue. Some of the interventions most helpful for fatigue, that I would recommend for you to talk to your physician about include the following;

- Appropriate testing and management of underlying medical conditions
- Appropriate goal setting and pacing
- Use of appropriate equipment, braces, mobility aids, or wheelchairs/scooters
- Behavioural management and counselling
- Physical Therapy and Occupational Therapy
- Energy conservation techniques
- Appropriate home exercise program
- Aerobic
- Strengthening
- Flexibility
- Yoga or Tai Chi (preferably with an instructor familiar with disabilities)
- Meditation or scripture
- Medication changes
- To remove medications that might be causing fatigue
- Consider talking with your physician about any medication or supplements that might reduce fatigue

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

Addressing medical problems can significantly increase exercise tolerance and both lead to less fatigue over time. Physical exercise (as appropriate for your limitations), professional counsel and meditation can all have a profound effect on mood and emotional fatigue. As one factor improves there is a “snowball effect” on other areas. In summary, I greatly appreciate the above question as a lead-in to even better questions - “What would be causing fatigue other than post-polio syndrome?” and “Where can we intervene to eventually improve disability?”

Dr. DeMayo has 35+ years of clinical experience in the field of Physical Medicine & Rehabilitation. Medical Director for several comprehensive inpatient rehabilitation units and, for most of his career, has also maintained an active outpatient practice in Pennsylvania, USA. Areas of special interest have included Spinal Cord Injury Medicine, Polio, musculoskeletal/neuropathic pain management and bracing. Pictured at the 2016 Post Polio conference in Sydney where he spoke on sleep hygiene and Telehealth opportunities.



Polio Day, PP, and our support groups exist for us to keep in touch with fellow survivors. We have special relationships going back to childhood. We may not have known each other then, but that friendship today runs deep. Was there a pal from childhood polio days at Fairfield, Lady Dugan, Mt Eliza, Mt Macedon Golf House, Hampton, the various base hospitals, you'd like to talk to again? Let us know and we'll try to help that happen. polionetworkvichelp@gmail.com

Q&As on restless legs at night and muscle tears

Question to Dr Richard Bruno: I've had restless legs for years. It feels like I need to get up and move my legs because they won't stay still.

Dr. Bruno's Response: "Need to get up and move my legs" is the definition of RLS, restless legs syndrome. Legs that "won't stay still" is the definition of PLMS (Periodic Leg Movements in Sleep). At the Post-Polio Institute, we discovered that about 1.0 mg of alprazolam 30 minutes before bed stops the leg movements.

Question to Dr Fred Maynard : I have questions about two conditions. One is Restless Leg Syndrome, experienced on and off since about the time I had polio, and I wonder if polio survivors are especially prone to it. My other concern is with random "muscle tears" in my lower and upper legs, experienced since my early 40s during time I was running frequently. Curiously, the tears don't happen when I am in the act of running, but more likely when I am rambling through the house. I have worked with a sports physical therapist who does not believe I have PPS. Do you see any relationship between these two conditions and polio or post-polio?

Response: Congratulations on remaining in such good physical shape at age 71! I am impressed that you have pursued many good strategies to get help with your concerns. Here are my thoughts about the two issues you raise.

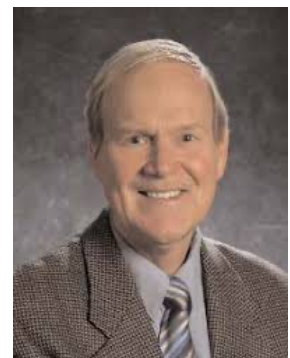
Restless Leg Syndrome (RLS) remains a poorly understood condition and probably represents a spectrum or variety of conditions in regard to etiology or cause. A number of studies on polio survivors suggests that RLS is more common and particularly in relation to sleep apnea syndromes. I would also say that strenuous use and possible "overuse" does lead to muscle aches and restlessness in anyone. If you have experienced some of these symptoms ever since your childhood polio, then it makes sense that you would experience it more during periods of long distance running. If it does not persist when you are not running a lot and your overall leg muscle strength has not declined over the years more than expected with aging (hard to judge but certainly modest), then I would not be concerned about your polio history in relationship to these RLS symptoms.

Regarding your "muscle tear" symptoms, I think stretching exercises are probably the best strategy to manage them. Again, they probably relate to your strenuous use of the muscles which is normally followed by microscopic muscle-damage changes and make muscles more vulnerable to minor injuries during unplanned non-focused normal-activity related contractions. I would say that if you have had these for a long time, the soreness subsides/ resolves fairly quickly and your overall leg strength has been maintained, I would not be particularly concerned about the relationship of these symptoms to your polio history.

Overall, I would agree that you do not have PPS. I think it is fine for you to remain involved in running as you like and enjoy it and to continue to vigilantly monitor your symptoms and their intensity vis-a-vis the intensity and duration of the strenuous running-related use of your leg muscles. Clearly these activities continue to be happy and healthy.



Dr Richard Bruno



Dr Fred Maynard

Patient and Doctor - Dr. Harry Eeman's story

Australian Medical Association, December 2014

IN a twist of fate, I ended up being a patient half-way through my training as a University of Sydney medical student. Rapid onset ascending paralysis should ring a few bells to those of you who know anything about Guillain Barre Syndrome.

I knew this as a second year medical student but no idea that it would change my life's trajectory forever-more. Five months in ICU, ventilated, and then a subsequent 16 months of inpatient rehabilitation and another year of hard outpatient physiotherapy, I was ready to return to my medical studies at the Canberra Clinical School. I started in Canberra as a skinny young man in his early twenties but I left it as a more confident, albeit wheelchair dependent doctor. This transition wasn't easy for me or for the 'medical establishment'. There were lots of questions, challenges and meetings to face and steer through.

The Clinical School and The Canberra Hospital were stellar in their support. I really did get by with a little help from my friends. A whole new renovation to suit my increased requirements for space was undertaken by the Clinical School so that I could lodge on campus in the 'Ressies'. I was invited to contribute to the design of the floor-plan of the soon to be refurbished emergency department. This is why there are ramps onto the viewing platform. My year as an intern was facilitated by being supernumerary so that I'd always work with a fellow junior colleague. As far as I'm aware this had never been done before, I was the first intern in Canberra with tetraplegia.

My residency year saw me flying solo. By this stage I had confidence in my skills and so did my colleagues. You may wonder about this - I actually spent 12 months working in the ED and loved it. I had a clear sense of what my physical limitations were and knew I could always count on my colleagues to lend a hand (or sometimes an index finger for a PR). I reciprocated with gratitude and food bribes from Cafe Hoz for my unlucky co-workers. I tried my hand in Radiology but found myself missing patient contact. I decided to train as a Rehabilitation Physician because I had a unique perspective that would benefit my patients. I left TCH and moved to Melbourne to further my training in specialised areas such as Brain Injury, Spinal Cord injury and Amputee rehabilitation. Once I completed this training I decided to tackle the least glamorous and most challenging type of patients, people with chronic pain. I completed my Pain Fellowship and I'm now working at one of Melbourne's premier public pain clinics. I balance this interesting but exhausting work with a couple of days in Rehabilitation Medicine. You've got to stay sane somehow!

The ACT AMA and I fought together in 2008 to get a better deal for junior doctors and I believe this was achieved. The status-quo approach to EBA negotiations by senior doctors (for conditions affecting junior doctors) was challenged. The outcome was a better EBA for junior doctors. It's amazing how competition can motivate change ;).



Dr Eeman is Rehabilitation and Pain Specialist with Polio Service Victoria, Pic from recent clinic at Hastings.

FOLLOWING several bad falls among members and family of Mornington Peninsula group (one hospitalised for weeks) our plan to put on another Falls clinic altered. In 2019 we held a successful Falls clinic with Peninsula Health's Falls OT as guest speaker, inviting all comers. Full house, very useful. Having written Peninsula Health's first falls brochure, when working there, when in Frankston Hospital last year, Falls staff came round wanting patients to review the new brochure. Someone pointed at me. Flier was too long and said so.

The idea of A5 size cards presented as a more effective and economical medium. Printed by VistaPrint, they have been distributed at a Seniors Expo, to various health professionals and reprinted. A second card on After Care was made when a friend with early dementia fell, needing basic advice on care. PLS advise if you would like cards sent for your group or health professionals, or changed to suit. - Fran Henke.



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Falls Alert!

Falls are Australia's leading cause of injury, representing 43% of injury hospitalisations & 42% of injury deaths.



- Majority of falls needing hospitalisation happen on a single-level surface in the home, from slipping; due to collision; insecure footwear; poorer eyesight.
- Many falls leading to serious injury involve stairs or steps however.
- Fear of falls adds to likelihood, mostly occurring in the afternoon.

- Regular falls can be sign of new medical problems: eye sight; medications side effects; fatigue; reduced feeling in feet and legs; poorer balance - be sure to tell your GP

e: polionetworkvichelp@gmail.com

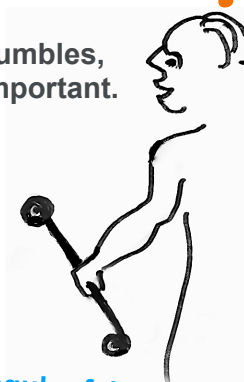


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Falls Prevention tips

Tell your doctor about falls, also stumbles, don't dismiss as clumsiness or unimportant.

- Gentle exercise can help strengthen muscles to improve strength, reduce fear of falling - and help to get up!
- Do balance training to ensure stepping over carpet, onto escalator, on an off public transport.
- Use light at night when going to the toilet
- You know your own home of course, but adding rails, grips can keep you safe.
- Expect to feel shocked after fall, so rest!
- More information: www.peninsulahealth.org.au - falls



- Regular falls may be sign of new medical problems: eye sight; meds side effects; slower reaction times; fatigue, tell your GP.



Falls After-Care

polio network victoria

Falls always come as a shock. We need to know what to do next, who to call, when:

- Firstly, never try to catch the person if you see a fall in progress. It is not possible to 'control' a fall by intervening without risking injury
- As the faller, take deep breaths to help get over the shock. Getting up too quickly can make it worse. Inevitably elbow, hip, knee, ankle will take the brunt, check for grazes, bruising, jarring, breaks.

Do see a doctor after a fall. You may feel okay now, but many injuries won't show symptoms right away. If you wait, they could become worse before you realise you are hurt. Especially if you hit your head.



e: polionetworkvichelp@gmail.com

Falls After Care



If you think you can get up without assistance:

- Roll onto your side.
- Rest for a few moments.
- Get onto hands & knees, crawl to sturdy chair.
- Place hands on chair seat, come to kneeling position if possible. slowly rise and turn to sit in the chair.

If you need assistance to get up:

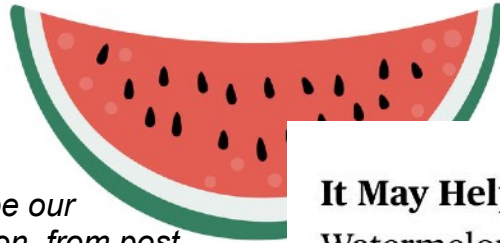
- Call for help. If alone, ideally able to reach a phone, dial 000 or use medical alert device
- Move into a comfortable position with warm rug and wait for help.
- Keep limbs elevated to prevent swelling building up. Rest on cushion.

e: polionetworkvichelp@gmail.com

Ouch! How to relieve pain and swelling after a fall?
Cold packs help to relieve pain and swelling. Switch to **heat packs** after the first few days to help increase blood flow and relieve pain.
Rest: An injury needs healing, take it easy during your recovery.



After Care Falls card, front and back, to help getting up and recovering. Don't underestimate shock experienced by a fall, rest is needed, wounds can take a while to heal in later age. GPs nurses can help wth dressings until healed.



WHILE may not be our watermelon season, from post on the Post Polio Coffee House: “Found this in a Consumer Reports article about health benefits of watermelon. Maybe it’s my imagination or the power of suggestion, but I’ve been eating watermelon every day for a week or so and I have a little less muscle pain. Is it a result of eating watermelon? ...is it something else? I don’t know. But does it matter? I’m feeling better!”

It May Help Keep Blood Vessels Healthy

Watermelon is uniquely rich in a compound called L-citrulline, which can help relax blood vessels, thereby possibly improving blood flow and helping to control blood pressure. You may have heard that watermelon can improve soreness after exercise; L-citrulline is thought to help muscles recover faster. However, the studies have been small and of short duration, and results have been inconsistent.

Who’s who in our Polio world

Polio Australia is the national organisation representing Australia’s 400,000 polio survivors since 2008. Provides information, education and support services to polio survivors, families, carers, and health professionals. Has received Federal Government funding to provide educational services for GPs. Polio Australia continues to apply for project and operational funding through philanthropic sources while establishing a relationship with Rotary Clubs and Districts.

Polio Network Victoria since 1987 initially auspiced by ParaQuad Victoria, now independent, has supported polio survivors, carers and families through state-wide support groups and the quarterly newsletter *Polio Perspectives*. Funded by memberships, grants and bequests, managed by a representative committee.

Polio Services Victoria (PSV) established by the Victorian Government in 1998 to provide ongoing expertise and support for people with a history of polio. PSV consists of a core allied health team available to provide consultations to clients. A rehabilitation medicine consultant is also available to consult on polio-related medical needs. It is based at St Vincent’s Hospital, also conducting regular regional clinics.

Post Polio Victoria since 2012, advocates for Polio survivors to have access to information and services to live actively and independently. Has received some government funding; but relies on donations and volunteers to help achieve goals. Recently won Focus on Ability Film Festival 2023, Nova Employment Choice Award.

Readers of *Polio Perspectives* have indicated willingness to pay \$10 annually to receive the quarterly newsletter. No longer supported by an auspicing body, Polio Network Victoria relies on funding to print and email this newsletter, undertake other activities, so Dear Readers now is the time to send your \$10. Address to The Treasurer, PO Box 205, Woodend, 3442, or by direct deposit to: BSB 633 000 a/c 169 887320. A/c name Polio Victoria Inc. Be sure to put your name in the reference field and **provide email address** to save postage and paper. Thank you!

Useful info

Contact PNV:

PO Box 205, Woodend,
Vic. 3442

Phone: 0407 227 055

polionetworkvichelp@gmail.com

Contact Bev for any questions, venues of meetings, PP content.

PNV meeting: Sept 20.

Polio Services Victoria (PSV) 9231 3900

St Vincent's Hospital, ground floor, Bolte Wing, Fitzroy, 3065. Team of allied health professionals offers: access to a rehabilitation consultant (referral required); specialist assessment; referral to & collaboration with mainstream health providers to develop client service plans; information & education service to health providers, clients who had polio, & the wider community.

PSV online:

www.psv.svhm.org.au

Mobility Aids Australia

offers electric scooters, lift chairs, wheelchairs, walkers, electric beds, bathroom and toilet aids and much more. 1/820 Princes Hwy, Springvale
Ph: 9546 7700

Travellers Aid service

www.travellersaid.org.au/bookings

- Southern Cross station 9670 2072
- Flinders St Station: 9068 8187
- Seymour 5793 6210

Home & Community

My Aged Care

Australian Government website and phone line on aged care services available.

Ph: 1800 200 422

NDIS

If aged under 65 with a disability - requires assessment.

Contact 1800 800 110

Equipment funding

State Wide Equipment Funding – SWEP

Ph: 1300 747 937. Aids and equipment to enhance independence at home. Arrange through SWEP's physio or OT.

Leef Independent Living

Centre 652 Glenhuntly Rd, Caulfield South, Ph: 1300 005 333. Stocks scooters, walkers, assistive technology, shoes and clothing.

Disabled Motorists

Australia, 2A Station St, Coburg, Vic.

Ph: 9386 0413

Assists motorists with disabilities to gain independence through motoring. Referrals & support.

Neuromuscular Orthotics

NB: new address

Phone: 1300 411 666

25 Glendale Cres, Mulgrave, 3170.

Darren Pereira - Principal Orthotist.

www.neuromuscular-orthotics.com.au

Regional clinics for Polio Services Victoria 2023

currently accepting expressions of interest for clinics:

Wangaratta August 14/15

Bairnsdale October 9/10

Ballarat November 0/21

Contact PSV on 9231 3900 or 1800 030 324

Polio Support and Advocacy Groups

For all contact details:

Bev Watson: 0407 227 055

polionetworkvichelp@gmail.com

Bayside first Tuesday of month

Bendigo third Saturday bi-monthly

Hume second Saturdays

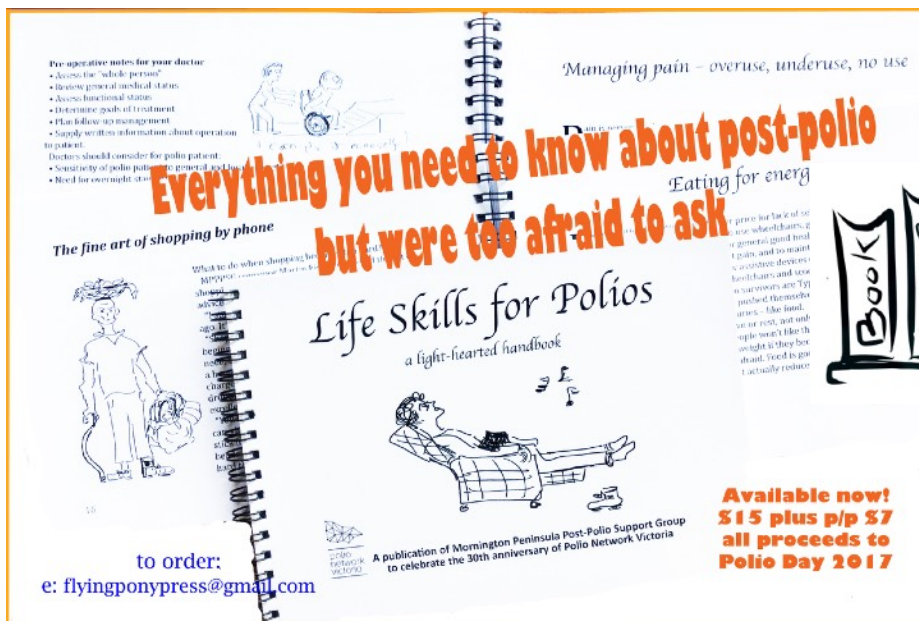
Lilydale/ Yarra Ranges meet second Wednesday, monthly social group.

Mornington Peninsula: second Saturdays, 11am @ Mornington Community House. Also luncheons, third Tuesdays.

Shepparton quarterly first Tuesday.

South Eastern Region second Saturday

Warrnambool fourth Tuesday.



Life Skills for Polios – a light-hearted handbook

Everything you wanted to know about post-polio but were too afraid to ask? The ideal book for health professionals, friends, family and polios wanting to know how to manage not only post-polio symptoms, but how gracefully to:

- go shopping when supermarkets are too big;
- downsize home and life;
- demand the right chair;
- avoid falls and worse;
- manage the big four painful body parts;
- exercise without overdoing it;
- and find much needed sleep.

Cost \$15 plus \$9 postage and packaging.

As an e-book \$US5: www.postpolioinfo.com/lifeskills.php

Iron Wills – Victorian Polio Survivors’ Stories

Stories from schooling to later life, *plus* a history of polio and founding of Polio Network Victoria. Cost \$20 plus \$9 postage and packaging.

Polio Network Satchels - \$15

Strong with strap for shoulder or scooter/wheelchair back. Also drawstring bags \$5

The Polio Day Cookbook

– fine food for the fatigued \$15 plus \$9 postage packaging

to purchase:

polionetworkvichelp@gmail.com

Polio Perspectives Editor: Fran Henke

Polio Australia/Polio Health

National information/advocacy:

<https://www.poliohealth.org.au>
(03) 9016 7678

Opinions expressed in this newsletter may be those of the writers only. 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.

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