

POLIO NSW

formerly Post-Polio Network (NSW)

NETWORK NEWS

Incorporating – **Polio Oz News**

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Editor's Report:

Happy New Year to all our members, may 2024 bring you good health, peace and joy.

This issue of Network News is full of interesting articles and reports starting with Merle Thompson's report on the AGM held on 30th November, 2023. This is followed by two articles from Gail Hassall who reports on the AGM webinar and then a request for your suggestions for future seminars.

IDEAS (Information on **D**isability, **E**ducation and **A**wareness **S**ervices) reminds us about assistance that the NRMA can offer scooter/powerchair users as well as two specific services that IDEAS provides to support all who have a disability.

On page 5 Dr Marny Eulberg writes about Carpal Tunnel Surgery; Carpal Tunnel Syndrome is a common complaint for those who use canes, crutches or walkers with some weight bearing on hand/wrists as well as for those who use their hands to push themselves up to standing.

Exercise is always a concern for polio survivors; Dr Bruno's article discusses exercises after surgery or after a period of immobility due to illness. The article also covers the muscle strength chart that gives a reading out of 5 and when not to attempt non-fatiguing exercise i.e. when muscles are graded less than 3 out of 5 (3/5).

It is always interesting to read Bruno Bytes; on p8 Q & A topics such as non-paralytic polio (someone who may have contracted the polio virus but did not appear to have any paralysis) - a controversial topic. It has been known that some siblings of polio survivors that didn't appear to have even contracted the polio virus find that many years later they show symptoms of PPS. Other questions cover PPS, bowel, bladder and gut issues, tracheostomy/tracheostomy and lastly, vision issues.

Consumer Health Forum is Australia's leading advocate on consumer health care issues. See page 11 for an article on 60 day prescriptions.

The last two articles come from Polio Perspective, Editor Millie Malone Lill – Odd Ball and Polio Long Healers Must Be Their Own Advocates.

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ANNUAL GENERAL MEETING REPORT

By Merle Thompson, Polio NSW Secretary

The Polio NSW Annual General Meeting 2023 was held by Zoom videoconference on Thursday 30 November. Thank you to those who participated. Unfortunately, some members had difficulty with the link to the meeting and we apologise to them.

The meeting endorsed all the relevant documents, that is, the annual report, financial report and the 2022 AGM minutes.

Treasurer, Alan Cameron, discussed the financial situation and explained that thanks to the generous donations from members and the Board's decisions to reduce expenditure, he is more optimistic on the future viability of the organisation despite on-going reductions in membership income.

It is apparent, however, that we may be more dependent on volunteers in future.

John Tierney AM presided over the election of office bearers.

President Gillian Thomas :
Vice President Gail Hassall
Secretary Merle Thompson
Treasurer Alan Cameron
Board Members: Ella Gaffney Bill McKee Rosalie Kennedy Esther Smart

Sue Ellis, who has been on the Board for many years, including having the official role of Vice President, and has done a sterling job as newsletter editor and, previously, as seminar coordinator, had advised that she wished to stand down from the Board. We thank her most sincerely for all her friendship and commitment and her work in these roles. Sue has indicated that she will continue to edit the newsletter for this coming year.

Di O'Reilly also retired from the Board for health reasons. Di has also been a volunteer in the office.

Vasa Murimuthu has stepped aside for the time being for employment reasons. He has been the only Board member for some years who is in full-time employment.

We thank them all for their service.

Their resignations mean that the Board is reduced in size. We encourage all members to consider whether you could take on a position. Apart from Fatma, our office assistant who only works one day per week, we are totally a voluntary organisation and it would be good to spread the load a little more broadly.

In General Business, in response to a question on notice from Chris Keun, there was a wide ranging discussion on the future of support groups now that fewer people are able to participate in person and of how to engage with members using digital technology. It was suggested that we have a "round table" discussion on zoom to which all members are invited in association with the Board's annual planning session in January or early February. Please consider participating in this discussion. If you would be interested could you let me know using the email address team@polionsw.org.au.

As indicated previously, we have engaged two volunteers to assist with our operations. Arasan joined in the meeting and was able to talk about his experience and what he will be

able to provide to us. Unfortunately Poulomi has commitments on Thursdays which prevented her from joining.

Following the AGM Gail introduced a webinar with Shirley Glance as presenter. Shirley showed members the film with which Post Polio Victoria won a competition for a short film about disability. Shirley was one of three people featured in the film. The aim of the film was to show how much polio survivors have achieved in life despite the impact that polio had on them. Shirley also showed the video of the presentation at which the award was announced.



WEBINAR REPORT

By Gail Hassall, Webinar Co-ordinator

“Lives Well Lived”

A Webinar Presentation for the Polio NSW AGM, Thursday 30 November 2023

The Webinar, “Lives Well Lived”, was based on a video made by Post-Polio Victoria, and entered into the **“2023 Focus on Ability Short Film Festival”**.

A few months ago, on Polio Australia’s Facebook page, there was reference to the video “Lives Well Lived” made by Post-Polio Victoria and I was curious about the video and why it was made. After I watched it, I wondered its purpose, so I thought why not find out – so here we are!

The Webinar took the form of an interview or question-and-answer session with Shirley Glance OAM, President of Post-Polio Victoria.

I asked questions about the origins the video and why PPV chose to make it and subsequently enter it into an international competition. Apart from winning, what did they hope to achieve by undertaking such a project?

Shirley Glance said the origins came from a conference held sometime earlier in Adelaide where there was considerable amount of video footage of the speakers at the conference, who were the three people featured in the video, Shirley Glance OAM, Robyn Abrahams, and Peter Freckleton.

PPV heard about the Focus on Ability Short Film Festival and decided to make the footage into a video to enter in the competition. Shirley said PPV engaged a professional filmographer to make the video with Shirley, Robyn and Peter writing additional material.

What did they hope to achieve by undertaking such a project, and did they? Shirley said PPV wanted to raise awareness of polio and its late effects. She thinks we are a forgotten cohort of people, and we still need to fight for what we need. She hopes the video will send the message that “we’re still here” and we need to be recognised and supported.

In November, Post-Polio Victoria learnt that they had won the 2023 Focus on Ability Short Film Festival. Polio NSW extends our congratulations to Post-Polio Victoria for creating the video and helping to raise awareness of the late effects of polio.

Sunday 3 December is International Day of People with Disability, a day to promote awareness, understanding and acceptance in our community.

The Focus on Ability Short Film Festival will be showcased nationwide on SBS on **3 December**. This 65-minute documentary, featuring the PPV video and other stories from various corners of the globe, will be broadcast at **4:25 pm** and subsequently accessible through SBS On Demand.

You can watch the video directly at <https://www.youtube.com/watch?v=47E4aLenXbM>

POLIO NSW WEBINARS

By Gail Hassall, Webinar Co-ordinator

Polio NSW Webinar program has been successful in offering members a range of education and information topics such as speech and swallowing, continence and travelling with a disability and many others.

In the next few months, we hope to tackle more topics, but we would like to know what you would like to learn or have more information about. What do you suggest?

Please email your ideas to team@polionsw.org.au or contact Gail on 0493 029 099.

ROADSIDE ASSISTANCE

This article is from Ideas e-News December 2024



Roadside assistance services are available to help you should your wheelchair or motorised mobility scooter or gopher have a flat tyre or breakdown.

NRMA Roadside Assistance provides a service for members with nonregistered motorised mobility scooters or wheelchairs in case of tyre problems. If you carry a spare, the technician may be able to assist you.

The customer should contact roadside assistance at 13 11 11 for service. The operator will advise when service can be provided.

If the mobility scooter or wheelchair is registered to drive on the road, it must be listed for roadside assistance on the customer's membership. For more information about membership fees, contact NRMA using the details below.

NRMA's service is limited as patrols do not carry spare parts or tyres for these vehicles. However, if the customer has the part, the patrol may be able to repair the vehicle. NRMA do aim to make sure you are out of any bad weather conditions and in a safe place.

Contact NRMA on 13 11 22.

Further helpful services that Ideas provide:

Infoqore is a Disability Directory developed and supported by IDEAS, the leading independent information provider for people with disability across Australia. With over 35

years of experience in supporting people with disability to make informed choices - we collect, collate and disseminate information to assist people with disability make informed decisions about their daily living. Verifying the information supplied by the organisations, to ensure the information being provided is accurate, relevant and current.

Information categories:

Aids and Equipment, Care and Support, Financial Assistance, Health and Wellbeing, Housing and Accommodation, info by disability type, info by NDIS registration groups, learning and Life Skills.

Infoqore is the latest iteration of our database. <https://infoqore.com.au/>

eBility is a one-stop accessible marketplace to buy or sell all disability equipment and accessible vehicles. <https://ebility.com.au/>

1. To make it easier and quicker for people with disability to find relevant new and used products in an accessible format so that you can power up your life.
2. To offer value by connecting sellers and buyers and free access for those wishing to donate items to new homes and users.
3. To support and promote web accessibility with tips, tricks and hacks written by subject experts.

Classification Categories:

Accessible Vehicles, Equipment and Assistive Technology, Children's Equipment, Vehicle Parts and Accessories, Modified Properties, Free Items.

CARPAL TUNNEL SURGERY - WHAT SHOULD I DO?

The PA Polio Network Update www.papolionetwork.org – September 2023

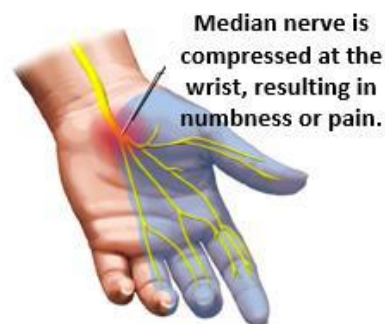
A Conversation with Marny K. Eulberg, MD

Question: I had polio when I was 5. 36 years later, I discovered I needed additional support with a full left leg brace and assistive devices. I've also been diagnosed with arthritis and carpal syndrome.

Now 80, I have tingling sensations in the first three fingers of my right hand. My Family Physician suggested I contact an Occupational Therapist. Years ago, a fellow survivor told me NOT TO HAVE Carpal Tunnel Surgery, but I didn't have a chance to learn why not. What do YOU advise?

Dr. Eulberg's Response:

It does sound like your symptoms could be from carpal tunnel syndrome. Did you have an EMG/Nerve Conduction Velocity test done? If so, and it clearly showed slowing of the nerve conduction at the wrist, the diagnosis is confirmed. If you use a cane, a crutch or a walker with some weight bearing on your right hand or if you use your hands to push off and get from sitting to standing, you will be advised to not use your hand/wrist to do these things during the post-operative period (usually



for about 10-14 days). This is an important part of your recovery, so you'd need to figure out how to deal with those restrictions. One option is to get an attachment for the walker (forearm support) that allows you to bear weight on your forearm but not on your wrist. There is also a similar crutch. These are frequently used by persons who need to use a walker or crutch/cane for some leg weakness but have recently broken their wrist/forearm/hand. Here are two examples of "platform crutch attachments".



There is no absolute reason that a polio survivor should not have carpal tunnel surgery if they have carpal tunnel syndrome. If the pressure on the median nerve through the wrist is severe enough it can lead to permanent paralysis of some muscles in the fingers and/or thumb in addition to the tingling and /or pain that occur when the nerve is partially compressed.

You need to make an informed decision, in consultation with your doctors about the pros and cons of various treatments for carpal tunnel syndrome. The one thing that is unique to polio survivors and others with leg weakness is the need to use their hands/arm for some activities that others can do entirely with their legs -that complicates how one cares for themselves as they recover from the surgery.



IF they decide to have surgery, polio survivors need to make their surgeon/anesthesiologist aware of any previous Anesthesia issues. For carpal tunnel surgery, most often the procedure will be performed under local or nerve block anesthesia and the patient will not need general anesthesia. The anesthesiologist/nurse anesthetist may use "conscious sedation" which means they will administer a mild sedative, so you are in "la-la" land but not fully unconscious. This would be similar to the "conscious sedation" used during a colonoscopy or cataract surgery. (If you have never had surgery or anesthesia of any kind, please let your surgeon know that you are a polio survivor). More information regarding surgery along with a card you can give to your physician is easily available. <https://polionetwork.org/anesthesia-card>

I have seen several polio survivors who have had successful carpal tunnel surgery and did well, but it required some temporary change to their normal daily routine during the post-op period.



The PA Polio Network Update www.papolionetwork.org – October 2023

Is Exercise Okay in Polio Survivors After Surgery or Immobility?



By [Richard L. Bruno, HD, PhD](#)
Director, International Centre for Polio Education

New weakness can be caused by a leg, arm, hip or shoulder being immobilized or after having had surgery. Is exercise okay to treat new muscle weakness after surgery or immobility, say having your leg in a cast for six weeks? I'm sure you think my answer is no. But the answer is a very qualified "possibly".

Let's first talk about muscle strength, which is measured on a six point scale from 0 (paralyzed, having no strength) to 5 (muscle so strong that the therapist can't "break" your muscle's contraction).

Say you have a knee replaced and your quadriceps (thigh muscle) strength drops after surgery from 4/5 to 3/5, from "pretty strong" to just being able to raise your lower leg against gravity. This

Score	Description
0	No contraction.
1	Flicker or trace of contraction
2	Active movement, with gravity eliminated.
3	Active movement against gravity.
4	Active movement against gravity and resistance
5	Normal power

loss of strength likely is not due to new post-polio muscle and neuron failure, but to the effects of surgery. Is it okay to exercise to bring your strength from 3 back to 4?

Canadian physiatrist Rubin Feldman developed a protocol for just this situation: 50% non-fatiguing exercise (Orthopedics. 1985 Jul; 8(7):889-90).

- 50% non-fatiguing exercise is when a patient does *half* the amount of exercise that causes any symptom: be it muscle weakness, fatigue, shaking or pain.

Polio survivors are amazed when this often piddling amount of exercise increases muscle strength and endurance following immobility or surgery. But, Feldman warns never to perform even 50% non-fatiguing exercise in muscles with less than antigravity strength – muscles graded less than 3/5 that can't lift their limb's weight against gravity -and is not intended to treat post-polio muscle weakness.

Why is non-fatiguing exercise okay after surgery but not recommended for treating post-polio muscle weakness? Think of your muscle strength as a bucket of water. Surgery or being in a cast scoops water out of the bucket and non-fatiguing exercise puts the water back. Post-polio muscle weakness is like having a hole in the bucket that is draining off your muscle strength and exercise will just make the hole in the bucket bigger.

Take this article with you to your first session with the physical therapist, explain that you are a polio survivor and must only do non-fatiguing exercise to prevent further motor neuron damage. Count the number of repetitions of exercises that you are given to identify the point where you feel any symptoms: muscle weakness or shaking, fatigue or pain. Then, talk to the therapist about doing only half of the number of symptom-causing repetitions to protect your neurons.

Please know that the success of 50% non-fatiguing exercise completely depends on polio survivors being aware of their symptoms, stop exercising when symptoms are felt and not being cowed by therapists demanding that you "push through and feel the burn".

Source: The use of strengthening exercises in post-polio sequelae. Methods and results





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

The Encyclopedia of Polio and Post-Polio Sequelae

<https://polionetwork.org/encyclopedia>

contains all of Dr. Bruno's articles, monographs, commentaries and
"Bruno Bytes"

"Non-Paralytic" Polio

Original Post: Why is it when polio is discussed in literature only "paralytic" is mentioned: Bulbar and Bulbar/Spinal. Is "Non -Paralytic" the ugly step child?? Talking to a doctor today he said NO SUCH THING AS NON-Paralytic. He made me feel small.

Additional Post: It has only been in latter years that asymptomatic polio has been properly recognized and this has only occurred when patients started to present with PPS. That certainly took a mindset change as PPS is a diagnosis of exclusion - one of the first prerequisite was someone having a history of paralytic poliomyelitis! It is now recognized, (certainly in Europe through medical centers and the European Polio Union) that asymptomatic polio can result in PPS.

Without question, this should be the case when we realized that under WHO (World Health Organization) definitions: a single paralytic case is counted as an epidemic. Therefore, up to 1,000 persons may have had the virus pass through the gut. Only the few were paralyzed by this "gastro-enteritis virus". The Poliovirus enters the body through the intestinal route, e.g. most commonly by mouth (although in rare occasions it has been shown to enter the bloodstream directly through an open wound such as a cut).

Those who have had asymptomatic polio are just as much a part of the "polio family" as those affected with paralysis.

Dr. Bruno's Response: "Non-paralytic" polio can mean that you had:

- 1) No poliovirus invasion of neurons and no neuron damage;
- 2) Widespread neuron damage that was not severe enough in any spinal cord or brain area to cause symptoms that could be detected but that now leaves you vulnerable to Post-Polio Sequelae;
- 3) Neuron damage that was severe enough in a spinal cord or brain area to cause symptoms, symptoms that were not obvious but could be detected had someone tested you.

Two studies during the polio epidemics found that as many as 40% of "non-paralytic" polio survivors had detectable muscle weakness WHEN THEY WERE TESTED in hospital. Once again, as with "the 3 types of polio," there is a semantic problem, here is the difference between the physiology and clinical findings:

- "Non-paralytic" polio meaning no neurons damaged and
- "non-paralytic" polio meaning nobody bothered to see if you HAD muscle weakness caused by neuron damage.

Additional Post (from original): I understand now. You have made so much sense of my insensible youthful experience. No one tested me. The weakness must have shown itself later, and always confused me. Paralytic or Non-Paralytic –How do you know?

Dr. Bruno's Response: The weakness was probably there at the beginning and nobody took the time to do a manual muscle test. Sadly, some polio survivors weren't "bad enough" to get care at the peak of the 2 epidemics. And even more sad? Some parents realized there were weakness issues, and didn't want to discuss them.

PPS – Is it Progressive?

Question: I had Polio in 1950 at age 3. I was active in sports, outdoor activities and hobbies until about four years ago when PPS set in. Balance, weakness and fatigue issues progressed pretty quickly especially with my left 'power' leg. I went to a cane, then walker and then now a portable power chair. I feel like I've hit a period of stasis over the last 12-18 months. What happens with the periods of 'plateaus' vs. progressive deterioration of muscular capabilities? I realize now that my PPS prognosis factors heavily in our decisions over the next few years.

Dr. Bruno's Response: I think you've answered your own question. Sixty-six years of being "Active in sports, outdoors activities and hobbies" has extracted a price, notably in your "left 'power' leg." Your reduced number of remaining overworked, poliovirus-damaged motor neurons don't last forever.

The good news is that, when you started using a cane, then walker and now a power chair, you feel like you've hit 'stasis' over the last 12-18 months. That stasis is a result of your using those devices and "Conserving to Preserve" remaining, poliovirus-damaged neurons. There is no separate process causing progressive deterioration of muscular capabilities; deterioration is caused by overuse abuse that you have stopped. Listen to your body. It will tell you what to do...and not do.

PPS – Does everyone get it?

Question: Does everyone who had polio as a child, and have it seemingly go away, always see symptoms return as PPS later in life? Does PPS occur only in certain polio survivors?

Dr. Bruno's Response:

The degree of initial damage by the polio infection and the degree of RECOVERY OF FUNCTION is the best predictor of PPS. The worse the damage and the better the recovery with the acute polio, "the harder you fall" with PPS.

Our years of research makes me think that all polio survivors who had neuron damage -- muscle weakness evident or not -- will have some symptom that can be related to the original poliovirus-damage to neurons.

PA Polio Network www.polionetwork.org 4th Quarter, 2023

Bowel, Bladder and Gut Issues

Question: Dr. Bruno, I keep on trying to block out anything to do with the Polio . . . and I truly think this is not healthy. That being said, if I had any medical training, I'd look into the neuro-pathways of the very few times that I felt the throat muscles give out when I was taking a sip of water; causing me to really choke. In addition, I'd research the very few instances that for about 2 to 3 days, my bowels just seem to get into a 'funk' and decide not to push what they should (like in a rhythmic sequence); but yet I'll be in cramps with nothing moving until I gather up the courage to buy over the counter, what I seem to need.

I'm uncomfortable bringing up issues like this at our Support Group. Deep down, I know it has something to do with the Polio.

Dr. Bruno's Response: I think I get the gist of your question. It sounds like you are asking about the polio being related to occasional constipation and how to handle it.

The polio belly article dealing with constipation is [Slow Guts and Polio Survivors](#).

You can find more information in the [Encyclopedia of Polio and PPS](https://polionetwork.org/encyclopedia) <https://polionetwork.org/encyclopedia>. Look in the Index under the topics of Muscle Weakness and/or Bowel/Bladder.

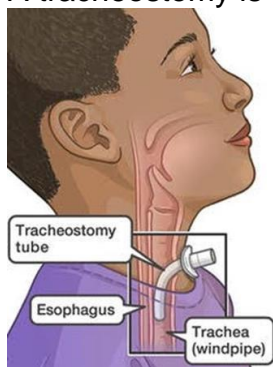
With regards to not blocking out your thinking about past polio experiences or current symptoms that may be related to polio, I agree that that's not the best thing that one can do for their mental or physical health. This is where a good psychotherapist comes in handy so that you can discuss the underlying fear of just “thinking” about polio. I hope this helps.

Tracheostomy vs Tracheotomy

Question: I read that a breathing specialist at Rutgers University does NOT recommend tracheostomies for polio survivors. Can you give me more information? And what is the difference between a tracheostomy and a tracheotomy?

Dr. Bruno's Response: A tracheotomy is an incision made on the front of the neck, below the vocal cords, opening a direct emergency airway to the lungs through the trachea (windpipe) allowing a person to breathe without the use of the nose or mouth.

A tracheostomy is a permanent, surgically-created stoma (opening) into the trachea.



Dr. John Bach, the physician that I describe as the world's expert on breathing and polio, says NO polio survivor should have a tracheostomy unless there is damage to the upper airway stopping the flow of air. The treatment for sleep-disordered breathing or inadequate breathing during the day is the use of positive pressure ventilation via a volume ventilator, not CPAP.

Dr. Bach's website, videos and contact information:

• www.BreatheNVS.com(or) www.doctorbach.com

• Videos:

- John R. Bach, MD -Faculty Video Profile
- John R. Bach, MD -Noninvasive ventilatory care in patients with breathing muscle weakness
- John R. Bach, MD -Ways to Avoid Respiratory Complications with Polio and Post-Polio Syndrome

• Email Contact: bachjr@njms.rutgers.edu (He does answer emails).

For more information – **go to www.polionetwork.org**.

- See Living with Post-Polio Syndrome (under the Header Post-Polio Syndrome).
- Look in the Index under “JohnBach”.

Vision Issues and PPS

Dr. Bruno's Post: Polio survivors occasionally ask if poliovirus affected vision. The poliovirus was actually injected into the visual part of the brain of monkeys and had no effect on the neurons, as if they had no poliovirus receptors and couldn't be damaged. The optic nerve is not affected by poliovirus and muscles that allow the eyes to focus should not be affected.

Since sympathetic/vagus nerves were damaged, pupil opening/closing could be affected. But I have not seen pupil problems treating hundreds of polio survivors.

Certainly, voluntary facial muscles (that move the eyes and open and close the lids) could be affected by poliovirus. Polio survivors can have lag ophthalmias, where they don't completely close their eyes, causing dry eyes and disturbed sleep.

This article explains more: “Abnormal Eye Movements and PPS”.

60-DAY SCRIPT CHANGES FOR SOME PBS MEDICINES



PRESCRIPTION CHANGES EXPLAINED

What is the Pharmaceutical Benefits Scheme?

The Pharmaceutical Benefits Scheme (PBS) is funded by the Australian Government to subsidise the cost of around 950 prescription medicines. When you buy a medicine listed on the PBS, the cost is shared between you and the government. The amount you pay the pharmacist for each script is called the co-payment. In 2024, the maximum you pay for most PBS medicines is \$31.60. If you have a concession card, the most you pay is \$7.70.¹

What is changing?

The Australian Government announced that from 1 September 2023, many eligible people living with a chronic condition will be able to buy 60-days' supply of PBS-listed medicines in a single visit to the pharmacy on a single prescription.² The changes will happen in three stages over 12 months. The 60-day script option will apply to the first batch of medicines from 1 September 2023 with more medicines added in March and September 2024. By September 2024, the 60-day script option will apply to more than 300 out of approximately 950 prescription medicines listed on the PBS. You can download a document listing the medicines by clicking [here](#). The government estimates that the new 60-day script option will save Australians more than \$1.6 billion over the next four years.

¹ Unless there is a brand price premium.

² If you are a general patient your saving will be lower if the dispensed cost of the medicine is less than the \$31.60 PBS co-payment.

Will I need a new prescription?

Yes, once the PBS item with increased dispensing quantities for your medicine is included on the PBS schedule, your doctor may write you a new prescription with the higher dispensed quantity. You can still use your existing 30-day scripts as normal then discuss your medicines with your doctor when you need a new prescription. It is important to remember that your doctor will use their clinical judgement to decide whether your condition is stable and suitable for the higher maximum dispensed quantity item.

How does the change benefit consumers?

- If your medicines are on the list and your prescriber considers you eligible, you will only need to pay a single PBS co-payment for two months' supply, compared to the previous one-month supply.
- People who pay the general co-payment of \$31.60 are expected to save up to \$189.60 per medicines per year. If they reach the PBS Safety Net, they will save even more.
- People whose PBS medicines cost less than \$31.60 will still save money, and the cost of their medicines will be further reduced if they reach the PBS Safety Net threshold.
- Concession card holders who do not reach the PBS Safety Net could save up to \$46.20 per medicine per year.
- As well as the financial benefit, the changes may save time and reduce travel costs for people in rural and remote areas who live far from their pharmacy.
- Prescriptions for some of the medicines eligible for a 60-day supply with five repeats may provide up to 12 months supply of medicine.

- It is expected that having more medicines on hand will support people to take their medication as prescribed with less chance of running out at home or when travelling.
- The changes will benefit many people living with chronic conditions as the medicines that will be eligible for a 60-day supply include medicines for conditions such as heart disease, high cholesterol, diabetes, asthma, epilepsy, and high blood pressure.

What medicines are included in the 60-day script rule change?

The list of medicines that are suitable for the 60-day script option was decided by the Pharmaceutical Benefits Advisory Committee, which advises the Australian Government on the listing of medicines on the PBS. These include some medicines for stable chronic conditions, such as asthma, cardiovascular disease, chronic obstructive pulmonary disease (COPD), constipation, chronic renal failure, Crohn's disease, depression, diabetes, epilepsy, eye drops for glaucoma and dry eyes, gout, heart failure, high cholesterol, hormonal replacement and modulation therapy, hypertension, osteoporosis, Parkinson disease and ulcerative colitis.

Some medicines are not considered suitable for the 60-day script rule if:

- larger quantities of a medicine could be a safety risk to patients and the community, or if a medicine is new and rare side effects may not be well known
 - patients taking certain medicines require regular monitoring such as blood tests, or the dose of a medicine may need to be adjusted often, or where symptoms are unpredictable
 - a medicine is prescribed for short-term management of symptoms in chronic diseases.
- Your doctor or prescriber will decide whether you are best suited to a 60-day or 30-day script according to their clinical judgement.

Will the changes cause medicine shortages?

The new 60-day script option is not expected to cause medicine shortages. People will still receive the same amount of medicines per year, they just need to visit the pharmacy less frequently to buy them.

The Therapeutic Goods Administration (TGA) actively monitors and responds to current and anticipated medicine shortages. Medicine suppliers must inform the TGA if there is not enough medicine to supply normal demand in Australia over the next six months. The majority of the over 300 medicines chosen for the 60-day script option are not in short supply in Australia and the policy will be phased-in over 12 months to allow a smooth transition.

What do patients and health experts think of this change?

The introduction of 60-day scripts for some PBS-listed medicines has been welcomed by patients' and doctors' groups, including the Consumers Health Forum of Australia, the Heart Foundation, the Lung Foundation, Breast Cancer Network, Rural Doctors Association, the Australian Medical Association, the Royal Australian College of General Practitioners and many others.

Will my local pharmacy lose money and what will the Government do with the savings created by this change?

The change will apply to more than 300 medicines out of approximately 950 medicines listed on the PBS. Australian pharmacies already do much more than just processing scripts and still have many other sources of income, such as vaccinations. Every dollar saved by the Government will be reinvested straight back into community pharmacies. This funding will help to secure the ongoing strength of the sector and ensure our trusted pharmacists play an even larger role in the healthcare of Australians.



ODD BALLS

by Millie Malone Lill, Editor Polio Perspective

The following two articles are from Polio Perspective, October, 2023

During a discussion last week the subject of making friends came up. Most of us seemed to have had a bit of trouble making friends once they got older. It is true that as we age with PPS, our options for social activity can become limited. Spontaneity is a thing of the past. Going anywhere at all requires advanced planning close to the level of war strategy. You want to see a particular movie but is the theater accessible, if yes, then are the bathrooms accessible, do you have transportation, have you gotten enough rest to hopefully allow you to stay awake through the whole movie?

Friends you've had for a long time sometimes forget that you are disabled and that the planning process sometimes takes longer than the actual event. If they are in good shape, they very likely will be unaware of things that are a minor inconvenience to them and the Berlin Wall to us. I've been to a friend's house where she was so happy that her house would be accessible for me. It kinda was, but not really. There was a ramp, but the threshold from the porch to the inside was just an inch too high for my chair to get over. She was devastated and embarrassed, but how was she to know how much difference one inch would be?

Sometimes we lose friends and miss out on social activities because it takes too much planning to be able to go. We say No, sorry, can't make it. Soon these people stop asking, then they forget about you. This leads to depression and isolation.

I always felt left out as a kid. I had this big heavy brace to haul around. My friends wanted to play softball or volleyball, but I couldn't do that. So I sat on the sidelines. Many of us have abandonment issues to start with, due to being in the hospital for such long periods of time, unable to see our families and friends. The world seems so very able to get along without our participation that we become withdrawn.

Once I got online, way back in 1996, and found an online polio support group, things changed. I was accepted. Within this group, I was normal. There were lots of others with problems similar to mine. I quickly made friends. Later, I had the opportunity to travel and meet many of the polio survivors I'd met online face to face. Instant bond. Instant. Time spent with them was easy. If we had the energy to do touristy stuff, we did. Frequently neither I nor my hostess had the stamina to do much more than just veg out together but that was fine. If somebody needed a nap, they went to lie down. No apologies, no embarrassment, everyone understood.

I've made friends here in my senior housing Co-op, too. Most of them, while usually not polio survivors, are elderly and walkers, canes and scooters are great social levelers. We make plans, but sometimes we are not able to actually do what we'd planned. That's OK. Most of us understand because their health problems are limiting, too. I have always thought that the best way to make a friend is to be a friend. Be positive, be empathetic, and be a good listener. Just be yourself.

Accepting help can be hard for us, too. Sometimes, though, allowing others to help us actually is a blessing to them. One of my friends said she did not need the help offered. Her would be helper told her, "Don't steal my blessing!" The members of my Red Hat Society take such pains to make sure each meeting is held in a venue that is accessible for me.

They seem so very pleased to be able to do this. Of course, I am always sure to express my appreciation, too. Don't steal a helper's blessing.

POLIO LONG HEALERS MUST BE THEIR OWN ADVOCATES

By Dianne McTaggart Wall

World Polio Day is October 24, 2023. I am a polio survivor, contracting polio in 1953. Most polio survivors cannot tell you who gave them the virus or exactly where they contracted it. However, I can tell you the exact time I contracted polio and how I contracted it. My mother contracted polio in 1953 in her ninth month of pregnancy carrying me. Due to my mother's high fever and severe symptoms of polio, labor was induced three weeks before her due date. I was delivered by the hometown doctor who followed my mother's pregnancy from the beginning. When I was delivered my legs, my arms, my head and neck were paralyzed.

Today's world of medicine does not want to concentrate on the polio virus because they see no need. There are not that many of us survivors still around. I consider us the long haulers of polio. Some of us have been fortunate enough to have doctors with knowledge of polio and its affects. I now suffer from Post-Polio Syndrome, better known as PPS.

The symptoms of PPS vary in each survivor just as the polio virus did when we originally contracted it. Polio survivors who have been diagnosed with PPS live now with an ongoing decline of neuromuscular weaknesses, and sometimes failures of vital organs and body parts. Since we polio survivors are aging, most of our doctors have either retired or are planning on retirement soon. We must be our own medical advocates who can teach our future doctors. That's not an easy task.

Medical schools do not teach much about polio in their curriculum anymore because most people in the world have been vaccinated and that is a wonderful thing. However, not everyone has been vaccinated against polio. The virus lives on without total world vaccination. Even with polio still in existence, it's not enough to make medical school textbooks cover much of it.

My hope is that we as a society will start to discuss the importance of eradicating polio. The vaccine does work. I know that my mother wished there had been a vaccine when she was pregnant with me, but there was not. For this World Polio Day, let's start discussions with people about a virus that still has long haulers. We are still here. Let's not forget about an old virus. Post-Polio Syndrome usually strikes thirty to forty years after contracting the virus. We do not know what the future holds for the survivors of another virus we all know too well-Covid. I pray that 30 to 40 years from now the long haulers of Covid do not develop neuromuscular decline like I have and end up in a power wheelchair.

Please start believing in vaccines.

Dianne M. Wall

Winter Springs, FL

Author of *Somebody Told Me I Could: A Polio Survivor Who's In It For The long Haul*

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Sage Traveling



THE EUROPEAN DISABLED TRAVEL EXPERTS

An email from a Polio NSW member:

My son has sent me an email from the travel group he used when arranging a holiday for us to Italy. He was living and working overseas at the time. Much research was needed as I was using a wheelchair and accommodation had to be accessible. He found Sage Traveling “very very helpful”. He thought this information could be helpful to other polio survivors.

They also have a Newsletter and website with lots of information, reviews and travel stories. <https://www.sagetraveling.com/>

Hi Team Polio NSW

Just a quick email to let your team know that we have re-commenced orthotic practice at Advance Rehab Centre in Artarmon. Staffed by Tia Wedge & Darren Pereira, clients who have a neuromuscular disorder like polio can be assessed & fitted with advanced orthotic technology to assist walking fluency, safety & function.

Our practice details are as follows:

NeuroMuscular Orthotics
5 George Place Artarmon NSW 2064
1300 411 666
enquiries@neuromuscular-orthotics.com.au

We would be happy to support any NSW polio clients if they require orthotic assessment & management.

Thanks
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