

NETWORK NEWS

Incorporating – Polio Oz News

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President's Corner

Gillian Thomas

At our 31st Annual General Meeting (AGM) held on 27th November 2019 the following members were elected to the Management Committee:

| | | |
|----------------|-----------------------|------------------|
| Gillian Thomas | <i>President</i> | Ella Gaffney |
| Susan Ellis | <i>Vice-President</i> | Bill McKee |
| Merle Thompson | <i>Secretary</i> | Janette McKenzie |
| Alan Cameron | <i>Treasurer</i> | Diana O'Reilly |
| Anne Buchanan | | Shirley White |
| Nola Buck | | |

At the AGM we were sorry to farewell Chris Keun who retired after two terms on the Committee. Chris did a lot of work to get our updated accounting software operational and bedded in. We are very grateful for his efforts which will stand us in good stead in the coming years. The Committee vacancy due to Chris' retirement was not filled at the AGM. If any member would like to offer their talents to the Committee to fill this vacancy I would love to talk to you about the opportunity so please just get in touch with me.



On World Polio Day in October, I was thrilled to be asked to launch an autobiography written by long-term member Bill Bradley: "Life After Polio". I was standing in for Doug Sutherland, three-time Lord Mayor of Sydney in the 1980s, who as a 1950 polio epidemic survivor was in Prince Henry Hospital with Bill. Doug unfortunately was unable to be at Bill's launch event. Bill has had a long and varied life and his book is a great read – I have included the first two pages of his polio chapter after page 26 of this newsletter.

Pictured left: Gillian Thomas, the Honourable Philip Ruddock, Mayor of Hornsby Shire, and Bill Bradley at the launch

After 106 issues of *Network News*, this is my last "President's Corner" page. Regrettably, I can no longer give the time to the newsletter that it, the co-Editors, and you deserve. It has been my absolute privilege to have brought the newsletter to you for thirty years. I am confident that *Network News* is in safe hands with Sue and Nola, and that in 2020 and beyond you can look forward to receiving more regular and timely newsletters.

In closing, on behalf of the Management Committee I wish each and every one a peaceful festive season and a healthy New Year, and hope you enjoy the holiday reading in this newsletter.

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CONGRATULATIONS

John Tierney, Member and past Vice President of Polio NSW and Patron and past President of Polio Australia, has been awarded an AM in this year's Queen's Birthday Honours List. Well done, John – a just reward for your many years of service to the polio community.



MEDAL OF THE ORDER OF AUSTRALIA (AM)

IN THE GENERAL DIVISION

**Dr John William TIERNEY AM
Newcastle NSW 2300**

For significant service to people with polio

Polio Australia

- National Patron, current
- Chair, Patron's Circle, current
- President, 2012-2017
- Representative at a range of international conferences

Awards and recognition includes:

- Medal of the Order of Australia, 2012

REMINDER: MT WILGA LEOP CLINIC

For an assessment under the direction of Mt Wilga's Rehabilitation Physician, Dr Helen Mackie, you will need to obtain a referral from your GP or specialist. We encourage those that have already been assessed at the Clinic to return annually for follow up treatment.

To make an appointment and to discuss assessment options, or for more information, please contact Dr Mackie's office on **(02) 9847 5085**. You can fax your referral on **(02) 9847 5013**.

Where does the Assessment take place?

Mt Wilga Private Hospital is a specialist dedicated rehabilitation hospital and day therapy centre.



66 Rosamond Street
Hornsby NSW 2077
<www.mtwilgaprivate.com.au>

VALE - KATHLEEN GECELIA STEMPEL

By Paul Stempel

Ed. Kate Stempel was one of our international members, as she lived in the USA for many years.

Sadly, my wife Kathleen Stempel nee Glanville passed away on 8th April 2018 from a ventricular fibrillation.

Her health had been getting progressively worse from the latent effects of polio since early 1998. It first affected her legs and her ability to walk independently. At first, a walker was needed. That was followed by a power wheelchair as her upper extremities were also affected. In November 2017 her respiratory function had diminished to the point that she required full time oxygen support. It was her diminished capacity to take on oxygen that affected her heart to the point that it stopped. It should be noted that she spent six months in an iron lung during her acute phase in 1954, and had only approximately 55% lung function afterwards.

Kate was a stalwart advocate of the Polio population in Sydney. She was President of the Canterbury Hospital's Polio Club for a number of years. She was recognised with an award for service to the disabled community by Rotary International for her years of service. She spent the 26 years of her working life with Para-Quad NSW, and helped it grow from the small organization it was into one of Australia's premier disability advocates. She was their Public Relations Director for nearly 20 years. She edited the organization's monthly magazine, dealt with dignitaries, including NSW Governor-Generals, Premiers and Prime Ministers. She also organized and supervised various fund-raising projects for the Australian music's fund-raising group, the Golden Stave, as well as Para-Quad, and other charitable groups to which she was seconded.



SAD NEWS FROM THE SOUTH COAST SUPPORT GROUP

By Lorna Symes

Early on Christmas Morning 2018 our Convenor, **Dorothy Schunmann** sadly passed away.

She had over the last 6 months been troubled with a leaking cyst on the left side of her chest area, this was the same side she had been affected by polio – her left arm was affected by post-polio results. Although she sought medical help from her GP and a specialist from Sydney, neither was able to help her. Our polio group met at Shoalhaven Heads prior to Christmas Day, and as she was by this time unable to attend, four of our members called in to see her and as it happened, said our goodbyes. It is a tragic loss for us and all who knew her.

Dorothy, (or "Dotty" as she was known by) contracted polio in 1955 at the age of 8 years. She was an aspiring ballet dancer at the time and she did return to dance but because of her arm she was not able to reach the standard required by the Ballet Academy and so as a teenager she was unable to receive her certificate. However, she continued to dance and teach dance not only in ballet but many forms of dance, Scottish country dancing and circle dancing being some examples.

In 1996/97 Dotty became a convenor for the post-polio survivors group. Her first two members were Bert and John from Vincentia on the South Coast and they met at a Vincentia Café. Margaret, Bert's sister, attended as well.

I met Dotty in 1997 at a Scottish Kayleigh in Bomaderry and she persuaded me to join her group which I was glad to do. She also went on radio to advertise our group and in the next year or so our list of members had grown quite considerably. At this stage Dotty approached Nowra Library Management who allowed us to meet once a month in their downstairs meeting room from 1 to 4pm. By this time our numbers totalled up to 14 per meeting and there was ample room for wheelchairs, walkers etc which was much appreciated by us all. As the numbers started to decline we all decided to have a lunch meeting at one of the clubs, Bomaderry Bowling Club being the most convenient, though we did try out other clubs from time to time.

Unfortunately, by 2018/19 we only have 4 survivors and 2 partners attending, they have been most supportive of our group.

We are so grateful to Dotty for bringing us together and the memories of our happy times will remain with us.



We were also saddened recently to learn of the death of Bob Tonazzi (Matraville). Bob gave dedicated service to Polio NSW as Treasurer from 2002 to 2007 and paid scrupulous attention to his duties. Gillian represented Polio NSW at Bob's funeral.



The 1,000 Brains Project

Reprinted from The NeuRA Magazine, Issue 29, Winter 2019 www.neura.edu.au
"Our vision is to prevent and cure disease and disability of the brain and nervous system"

New Research

The 1,000 Brains Study is a ground-breaking research project to identify the elements in the brain that cause life-changing neurodegenerative diseases like Alzheimer's disease, Parkinson's disease and other types of dementia. This study will focus on the key unresolved question: why do some of us develop devastating neurodegenerative diseases, while others retain good brain health?

The study will not only compare the genomes of people who reached old age with those who have died from neurodegenerative disease, but it will also conduct post mortem examinations to compare the brain tissue in these groups as well. Collecting and researching brain tissue takes place at NeuRA's Sydney Brain Bank.

The Director of the Sydney Brain Bank at NeuRa, Dr Claire Shepherd, said Brain Banks are essential to underpin research into neurodegenerative disorders.

"We can collect brain tissue and do our own research on this in the hope that we can find a cure or a treatment for these diseases and disorders", said Dr Shepherd.

The 1,000 Brains Project is about understanding the genetics behind neurodegenerative disorders. *"We hope to sequence the genome of these people and understand what genetic risk factors and genes contribute to the disease process"*, said Dr Shepherd.

Holding the genetic information as well as the clinical information and the brain tissue greatly enriches the research outcomes that can be achieved.

“Research organisations like NeuRA are at the forefront of neuroscience research that’s why I support them because dementia is going to affect so many people and it’s not just the person who gets it, it affects the whole family and the community.” Janet Cameron, a NeuRA Financial Donor.

Why do we need Brain Banks in Australia?

- ❖ Researchers rely on brain banks to **access well-characterised brain tissue** to drive dementia research efforts
- ❖ Brain banking is essential to **confirm dementia diagnoses**, which is used to further educate clinicians making diagnoses during a patient’s life
- ❖ Brain banks **supply both the healthy control and disease case tissue** for research that may eventually lead to potential treatments for dementia
- ❖ Advances in dementia research will **reduce the cost of dementia** in Australia, which is estimated to reach \$36.8 billion by 2056
- ❖ Some types of dementia research that require **access to brain tissue** are **only possible through brain banks**

| Over the last five years at the Sydney Brain Bank: | | |
|--|---|---|
| <p>133</p> <p>Tissue requests approved and tissue supplied</p> | <p>Countries where brain tissue has been sent</p> <p>UK USA SWEDEN KOREA CHINA FINLAND NEW ZEALAND BELGIUM</p> | <p>Number of tissue Samples supplied:</p> <p>18,656</p> |
| <p>Currently</p> <p>623</p> <p>brains in storage</p> | <p>The number of scientific <i>publications</i> or <i>presentations</i> generated from tissue requests</p> <p>186</p> | <p>TISSUE SUPPLIED TO STUDIES IN:</p> <p>Parkinson’s disease Frontotemporal lobar degeneration</p> <p>Multiple system atrophy Alzheimer’s disease</p> <p>Motor neurone disease Huntington’s disease Healthy Ageing</p> |



Power Wheelchair or Scooter?

A Bruno Byte from Dr Richard L. Bruno, HD, PhD, Director, International Centre for Polio Education. Reprinted from Pa. Polio Survivors Network, June 2019.

There is a Post-Polio Institute rule of thumb, or more correctly a rule of arms and legs: if you're wearing a short leg brace you need to use a cane; if you're wearing a long leg brace you need to use two forearm crutches; if you have two long leg braces you need a wheelchair.



Obviously, there are lots of polio survivors with and without braces who need assistive devices, including a wheelchair. But, after more than 35 years of experience, I no longer recommend either manual wheelchairs or scooters for polio survivors. If your arms are weak or your shoulders hurt too much to use crutches, you shouldn't be using a manual wheelchair or a scooter. Both put tremendous physical stress on polio-damaged, overworked neurons, muscles and joints. The wheelchair requires that you propel yourself using your arms.

And you steer the scooter using your arms and shoulders to move a "T-bar" tiller that turns the front wheel while you use your hands to squeeze levers that make the scooter move. What's more, the tiller forces you to lean forward in the seat, putting you in a forward flexed position that causes neck and back pain.



On the other hand, there is the power wheelchair. Steered by a joystick, like those used for video games, power wheelchairs have a knob attached next to one of the armrests. The joystick allows you to steer with only one hand -- or even just your fingers -- with arms at your sides and shoulders relaxed while sitting with "painless posture." Also, the new power chairs have mid-wheel drive, instead of the old rear wheel motors, that allow the chair to turn in its own space, make it smaller and very manoeuvrable.



Power chairs can be fitted with special rigid backs that have adjustable foam inserts to provide the right amount of lumbar curve to insure proper posture. If you have trunk weakness or scoliosis, you can get a back made from custom-formed foam to cradle and hold your body in place. And if you have upper back or neck pain or muscle weakness, you can order a shoulder-height or head-height back, or an additional head rest, that will allow your muscles to be supported and relaxed while driving.

Power chairs can also accommodate custom seat cushions. If one butt cheek is smaller than the other, or if you have scoliosis and your upper body tilts, an adjustable cushion that has separate inflatable air bladders or foam inserts of different heights and firmness can lift one side of your pelvis and balance your body. Those with leg swelling can get manual or electric elevating leg rests. You can even get a special power seat riser to allow you to reach high cupboards, and chairs whose backs recline and allow you to take your twice daily 15-minute rests breaks (or even a nap) without leaving the comfort of your custom-designed chair.

By Dr Richard L. Bruno, HD, PhD

[Editor's Note: The Post-Polio Coffee House is a closed group listed on Facebook by Dr Bruno. It is a safe place for polio survivors to get to know each other, provide mutual support and helpful ideas and get the latest information vital to polio survivors.]

On the topic of "Jumping and Twitching" legs (3/26/2019)

Original Post: *Is Valium a good substitute for Xanax? Without Xanax my arms and legs jump all night long.*

Dr Bruno's Response: From our studies, low dose Xanax (alprazolam) seems to be best for muscles twitching and jumping at night. However, Valium (diazepam) has a longer half-life and lasts in the body longer so it is much better to treat anxiety. Valium is not by itself a treatment for depression.

On the topic of CPAP and a Sleep Study (3/8/2019)

Original Post: *I had a sleep test and they say I have mild to moderate apnea and recommended I use a CPAP. But most polio survivors in the Coffee House have Bi-Pap? Should I be concerned about using CPAP?*

Additional Post: *I had two sleep studies. The results showed that I stopped breathing an average of 43 times per hour. Used CPAP for 6 months but the average was 32 times each hour. I started using Bi-Pap 2 weeks ago and I'm feeling a little better.*

Dr Bruno's Response: Carbon Dioxide retention is as big a problem as is too little oxygen! So polio survivors should *always* talk to their pulmonologist about using Bi-Pap (if not a volume ventilator), and not using CPAP.

On the topic of "Stem Cells" (3/18/2019)

Original Post: *I've been inundated by friends and family sending me emails about PPS and a possible cure through stem cells. What's the latest on this?*

Dr Bruno's Response: Stem Cells won't help polio survivors. There are two Stem Cells articles in the Encyclopedia under "Treatment:" Stem Cells and PPS and Stem Cell Therapy and Polio Survivors.

Pa Polionetwork Editor's note:

Encyclopedia articles can be found at <www.papolionetwork.org/encyclopedia.html>



Websites to explore

Remember to check out Polio Australia's websites for up to date information. They are a great resource for polio survivors and medical practitioners to learn more about post-polio and the late effects of polio.

www.polioaustralia.org.au

www.poliohealth.org.au



Top Five Tips for Wheelchair Posture Support

From Invacare and the American Academy of Orthopedics, published in Pa. Polio Survivors Network June, 2019

Author: Clare Schwalbe, the OT Agency

Having good posture when sitting in a wheelchair is extremely important; it reduces undue stress on your body, maintains your comfort, improves the manoeuvrability of the wheelchair, and reduces injury or pressure risks.

Correct posture requires that each part of your body is in the right position in relation to the next, from your head down to your feet. Each part influences the next, so it is important to ensure your wheelchair fits well and provides good posture support for every part of your body.

1. STABILIZE YOUR PELVIS:

Your pelvis is the foundation of a good body position. Start by ensuring your wheelchair seat is supporting and stabilizing your pelvis.

Check the seat size. The correct depth ensures that you sit all the way back, with your weight spread evenly throughout your thighs and buttocks. The correct width stops your pelvis from sliding to one side or twisting, which can damage skin and alter your spine position. The seat angle can sometimes be adjusted as well, which can reduce forward slipping or provide more support if you have poor sitting balance.

Always ensure you use the right wheelchair cushion and it is well maintained, as the incorrect cushion can undo the posture support of a good seat.

❖ Pressure Care Principles

Whether you use a power wheelchair or manual wheelchair as your primary means of mobility, immobility alone is a high-risk factor for pressure injury. Direct pressure is a vertical force on the body. $\text{Pressure} = \text{Force} \div \text{Area}$. The larger the area to disperse pressure on your buttocks and thighs will result in less overall pressure on the bones and tissues.

This is a primary means to decrease overall sitting pressure. The size of the seat cushion is determined based on your body measurements and the size of the wheelchair seat. If it is sized correctly, you will decrease the overall sitting pressure. If it is too small, it can increase pressures under the buttocks and cause an increase in a pressure injury.

❖ Important features of the products to consider when selecting a wheelchair cushion

1. The shape and materials used to create the cushion.
2. The overall weight of the cushion, especially if it is being matched with a light weight wheelchair.
3. Care and maintenance of the cushion. Does it need to be inflated or kneaded to maintain its effectiveness?
4. The Temperature and climate where it will be used, as this can change the effectiveness of the material for posture and pressure management.

5. How will the shape and dimensions affect functional transfers and propulsion, meaning how easy is it to move forward on the cushion to transfer in/out of the wheelchair.

Remember, an assessment with a wheelchair specialist will help you identify your seating goals and minimize pressure injuries. They will assess your skin integrity, sitting balance, spinal asymmetries, range of motion, flexibility, tone, and reflexes. These factors among others will help in the selection of the wheelchair and seating system.

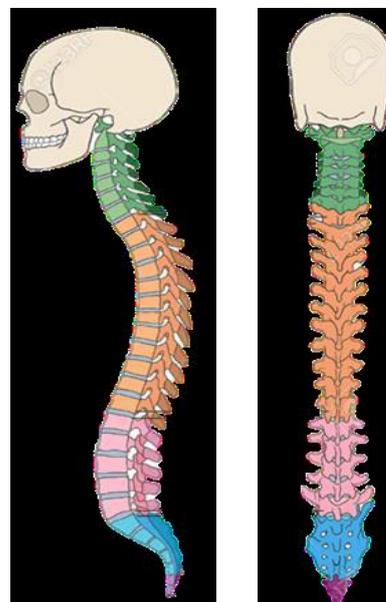
Manual pressure relief refers to the ability to independently adjust your own position in the wheelchair. This helps reduce the risk of pressure build up under the IT's (seat bones). If you are unable to shift your own weight to protect your skin, your therapist may recommend other means to effectively shift your weight, or discuss the need for a power wheelchair with "power seat actuators". Specifically power tilt and power recline can help you shift your own weight for pressure relief. In addition to reduced sitting pressures, changing positions can provide postural support, improve sitting balance and comfort.

2. STABILIZE THE 'S' CURVE OF YOUR SPINE:

Your spine has three natural curves that provide the most stable position for your back. If these curves are not properly supported, it can cause abnormal positions, discomfort and potential long-term damage.

Your spine is made up of three segments. When viewed from the side, these segments form three natural curves. The "c-shaped" curves of the neck (cervical spine) and lower back (lumbar spine) are called lordosis. The "reverse c-shaped" curve of the chest (thoracic spine) is called kyphosis.

These curves are important to balance and they help us to stand upright. If any one of the curves becomes too large or small, it becomes difficult to stand up straight and our posture appears abnormal.



Abnormal curvatures of the spine are also referred to as spinal deformity. These types of conditions include kyphosis of the thoracic spine ("hunchback") and lordosis of the lumbar spine ("swayback").

Scoliosis is another type of spinal deformity. When viewing the spine from the front or back, scoliosis is a sideways curvature that makes the spine look more like an "S" or a "C" than a straight "I."

Sit upright, bring your shoulders back and ensure you are not slumping or leaning to one side. If you cannot maintain this position, then the back of the wheelchair may not be providing sufficient posture support.

Ensure the back height and width are correct, as these support the lower curve of your back. The back tension and back angle may also need to be adjusted to provide further posture support. Or, for those with difficulty even in a well measured chair, additional back support systems may be required to properly align your spine.

Parts of the Spine –

- **Vertebrae.** Your spine is made up of small bones, called vertebrae, which are stacked on top of one another and create the natural curves of your back. These bones connect to create a canal that protects the spinal cord. The cervical spine is made up of seven small vertebrae that begin at the base of the skull and end at the upper chest. The thoracic spine is made up of 12 vertebrae that start from the upper chest to the middle back and connect to the rib cage. The lumbar vertebra consists of five larger vertebrae. These vertebrae are larger because they carry more of your body's weight.

- **Spinal Cord and Nerves.** The spinal cord extends from the skull to your lower back and travels through the middle part of each stacked vertebra, called the central canal. Nerves branch out from the spinal cord through openings in the vertebrae and carry messages between the brain and muscles.

The spinal cord ends around the first and second lumbar vertebrae in the lower back and continues as nerve roots. This bundle of nerve roots is called the cauda equina. They exit the spinal canal through openings in the vertebrae (foramen), just like other nerve roots. In the pelvis, some of the nerves group into the sciatic nerve, which extends down the leg.

- **Muscles and Ligaments.** These provide support and stability for your spine and upper body. Strong ligaments connect your vertebrae and help keep the spinal column in position.

- **Intervertebral Disks.** These disks sit in between the vertebrae. They are flat and round, and about a half inch thick.

- **Facet Joints.** Between the back of the vertebrae are small joints that also help your spine move. These facet joints have a cartilage surface, very much like a hip or a knee joint does. The facet joints are important for allowing rotation of the spine but may develop arthritis and become a source for low back or neck pain.

3. SUPPORT YOUR FEET:

Your feet support some of your weight and provide additional stability for your pelvis. Insufficient foot support can pull your body out of alignment.

Check that the height and position of the footplates are correct. The height should place your hips and knees at right angles, and ensure your weight is evenly distributed. If your feet are too far out in front, this tilts your pelvis and causes slouching or risk of pressure damage. If they are tucked too far back, this pushes your pelvis the other way and alters the normal curves of your back.

4. SUPPORT YOUR ARMS:

Your arm position can pull your shoulders down or push them up, which affects the upper curves of your spine and your head position. Ensure your armrests are the correct height to support your arms, keep your shoulders level and maintain the natural curves of your neck.



5. CENTRALIZE YOUR HEAD:

Your head should be upright, in the middle, with your chin slightly tucked, and with sufficient stability to look in different directions. If your head tilts forward, backwards or to one side this will pull your spine out of alignment and cause discomfort.

If you are unable to maintain a central head position after other parts of your posture have been stabilized, you may need additional neck or head supports.

Use these tips to ensure your wheelchair is providing good posture support from your head through to your feet.

[https://www.passionatepeople.invacare.eu.com/top-5-tips-wheelchair-posture-support/#Below are 5 tips to ensure good wheelchair posture support](https://www.passionatepeople.invacare.eu.com/top-5-tips-wheelchair-posture-support/#Below%20are%205%20tips%20to%20ensure%20good%20wheelchair%20posture%20support)



Wheel Chair? Power Chair? Scooter?

Reprinted from Pa. Polio Survivors Network June, 2019 www.papolionetwork.org

Your body is hinting that you need one. Your doctor has been hinting that you need one. Where do you buy it? What's the right one for me? How do you buy it? Will Medicare cover it? Will your medical insurance pay for it? How can you get it in your car? All of these questions can be answered. Be thorough.

Your doctor along with your physical/occupational therapist will be very specific in terms of your needs. If your doctor is a physiatrist (a rehabilitation doc that does a medical residency learning to help people thrive with their disabilities) who is educated in the area of PPS you are one step ahead of the game.

First Think through, very carefully, what you think you need and **why** you think you need it.

- Will you be using it only in the house?
- Will you want to be outside in it? How often will you need to use it?
- Does your house have a ramp?
- Do you want it to be portable?
- Do you have limitations to be able to break down your new 'wheels' to put it in the car? If you are not able to break it down, can your car 'handle' a lift? Do you have a spouse/caregiver that can help with the lifting?
- Do you have one side more affected by your PPS than the other? Keep this in mind. This equipment is available with the controls (steering and seat) on either side.
- If you are thinking you might put a lift in/on your car, research them at the same time (for compatibility as to your car, power chair/scooter and YOUR needs).
- Many power chairs/scooters are marketed as "light weight". Know your limitations.

Second Let your doctor/physical therapist help you decide if your goals are realistic.

- They must conduct a "face to face" examination prior to writing a prescription.
- You may like the scooter you saw, and think it's great. Your doctor/PT will help you understand if that scooter works or if a power chair "fits the bill" for you in a better way.
- Be honest to yourself and to your physician as to **how** you want to use it.
- Be open minded.

Third Hopefully you can find a recommended dealer in your area that has inventory on hand, and who will let you try different products. Ask them about their return policy.

- Talk to the dealer about what you've discovered in the process to determine what you need.
- Realize that your body has certain requirements because of your physical limitations. Don't let them convince you to purchase something that your physician/PT hasn't recommended.

Fourth When you get your new piece of equipment, make sure it's right.

- If it's not right, contact your supplier immediately. If they do not respond, contact your physician for help.
- If you are purchasing your equipment online, verify you are purchasing from a credible company. Know their return policy and get it in writing.

Things are changing rapidly in the world of this equipment. Careful planning is not the key to getting what you want, but for getting what you really NEED. The result? FREEDOM

**www.papolionetwork.org/uploads/9/9/7/0/99704804/power_mobility_equipment_-_making_the_right_purchase.pdf



Editor's Note: Advice regarding any mobility product can be found at the Independent Living Centre where a large range of products are on display to try. Phone for an appointment with the Occupational Therapist on site who can help you choose the most suitable product for you. They do not sell any product but will provide you with the details of a supplier nearest to you for purchasing of the product.

Assistive Technology Australia (Independent Living Centre NSW)
Shop 4019 Westpoint Blacktown, 17 Patrick Street, Blacktown 2148
(Level 4 – Roof top – Enter car park via express ramp at the Alpha Street roundabout)

Phone **1300 452 679** Reception: 02 9912 5800
Email: welcome@at-aust.org Website: www.at-aust.org

Funding through ENABLE or NDIS is a possibility, see articles below.



NDIS for 65+

Taken from Newsletter of IDEAS May/June, 2019 and sourced from NDIS and My Aged Care

The Commonwealth Continuity of Support (CoS) Programme was established to ensure older people with disability who are not eligible for the NDIS, will still be supported.

Eligibility for the CoS Programme is:

- based on an individual's circumstances and criteria
- only for pre-identified clients and service providers

The CoS Programme will make sure that:

- older Australians who are receiving state and territory-managed specialist disability services are supported to receive similar services to those they received before the change.
- services for clients will not need to change and people will not need to move.
- continuity of support arrangements will allow clients to continue to receive services.

Your services should not change and you will not need to move. You will continue to receive your current disability services from your current service provider. If your service provider decides to stop your services, the Australian Government will endeavour to find another suitable provider so you receive a similar level of support.

If you are not eligible for the CoS Programme and are aged 65 and over, other support options are available to enter aged care. My Aged Care is a free service that provides information on how to access aged care services.

For more information visit: agedcare.health.gov.au

MY AGED CARE

My Aged Care is the start point to access Australian Government funded aged care services for people aged 65 and over or 50 and over if you are Aboriginal or Torres Strait Islander. You may be eligible to receive a home care package to get you help at home, short-term help to get you back on your feet, or care in an aged care home.

You need a comprehensive assessment by an Aged Care Assessment Team (ACAT) or Aged Care Assessment Service (ACAS) in Victoria, to work out if you are eligible for a home care package, residential care in an aged care home, residential respite care, short-term restorative care, transition care or other services that you need. These are known as Consumer Directed Care (CDC) packages.

Home Care services include things like domestic assistance and help around the house, gardening assistance, home maintenance, personal care including bathing, toileting and dressing and assistance with food preparation, taking medications, continence management. Home Care is all about maximizing your independence and allowing you to live in your own home for as long as possible.

If you are not eligible for a Consumer Directed Care (CDC) option, you may still be eligible for home care services under the Commonwealth Home Support Programme (CHSP). Eligibility for the CHSP is also determined at an ACAT assessment.

Contact the **My Aged Care** call centre Mon-Fri 8am-8pm, Sat 10am-2pm on **1800 200 422** or visit their website www.myagedcare.gov.au any time for more information.

EnableNSW

Sourced from EnableNSW website.

EnableNSW provides equipment and services to people in NSW with chronic health conditions or disability to assist them with mobility, communication and self-care.

They also provide financial assistance for people who have to travel significant distances to access specialist medical treatment which is not available locally.

As part of HealthShare NSW, Enable NSW is responsible for the administration of NSW Health disability support and other assistance programs including:

- Aids and Equipment Program
- Continence Assistance
- Home Respiratory Program (HRP)
- Away From Home Haemodialysis
- Travel Assistance (IPTAAS)
- Prosthetic Limb Service (formerly known as ALS)
- Repairs and Maintenance
- Specialised Equipment Essential for Discharge (SEED)
- Home Modifications (SASH)

The Enable NSW team is based in Parramatta in Western Sydney. Service Centre officers receive thorough, ongoing training to ensure they can provide the highest standard of service.

For more information or assistance contact ENABLE on **1800 362 253**
Email: enable@health.nsw.gov.au or www.enable.health.nsw.gov.au



Flying with mobility equipment

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Requiring mobility equipment shouldn't hold you back from taking to the skies, but the reality is that it does take a bit of extra planning before you can board the plane. Most airlines have improved their mobility assistance services over the last couple of years, and it's now much easier than it used to be to communicate your needs. So what can you take, and how can you make sure it arrives in one piece?

Do your research

The first step is to do your research. Each airline has its own restrictions, procedures and costs around bringing your own mobility equipment on board. For example, some airlines charge extra if you need a lift to get up the stairs for planes that don't have an aerobridge, while others offer this service free of charge. Each airline will have this information listed on its website. Alternatively, you can call the airline and talk to someone about your needs. Another complicating factor is that while many newer, larger aeroplanes can accommodate

full-sized mobility scooters and wheelchairs, older and/or smaller aircraft may not have this capability. Where you can go or what you can take may be restricted by the aircraft that flies this route. Again, this is a question you can ask the airline. Finally, it's important to let the airline know that you will be bringing a mobility aid early, as many aeroplanes can only accommodate a small number of these, and there may already be other people who have booked a spot for a wheelchair or scooter on your flight.

Communicate early and often

Once upon a time airlines understood "I need mobility assistance" as "I need a wheelchair", but these days you can communicate your needs with a level of nuance. Communicating your specific needs with the airline well ahead of time will ensure you have the best possible experience. Start by calling when you are booking your ticket to ensure the airline can accommodate your needs. Then call again the day before your travel, to confirm your plans and go over what will happen when you arrive at the airport. Finally, ensure you arrive at the airport with plenty of extra time, as it may take you longer to get to your gate. Whatever your specific needs are, if you communicate them early and often you are more likely to get the individual support you require, rather than being treated as 'generic disability'.

When you arrive at the airport

If you give them enough notice some airlines will meet you at your car with a wheelchair. You can request a golf buggy ride if you are more mobile, but may still find the long trip between check in and the final gate too long and strenuous. If you use crutches or walking sticks let the staff at security checkpoints know that you require these aids to walk – if you require these aids to walk – if you communicate your needs, they can pass your walking stick(s) through the scanner, and then bring them back to you, to allow you to walk on your own through the security checkpoint.

Alternatively, they may provide a wheelchair to get you to the other side. Finally, if you are checking in a wheelchair or scooter, ensure you bring the manual and any tools you may require to disassemble it. Most airlines will require that tall backrests are removed, or they may have other requirements. Ensure you arrive with plenty of time to undertake these tasks, and that you bring someone to assist you, as airlines may not be able to do so.

On the plane

Remember that being on the plane itself may take some planning. Airline staff are not expected to assist with eating, administering medication, using the toilet or lifting or carrying a passenger. If you are likely to require this type of assistance, you'll need to bring someone with you who can perform these tasks. If you need a carer, they may be eligible for a Companion Card discount from the airline, which can provide tickets at a significantly reduced cost.

Touchdown

If you have a stopover, it's worth checking whether you will have access to your mobility aids. If they have been stored under the aeroplane, the answer is likely no, so come up with a plan for a stopover ahead of time in consultation with the airline. It's also important to plan what will happen at your final destination. Talk to the airline about where you can pick up your mobility aids, or what assistance may be available in terms of commuting through the airport to pick up your luggage.



Accessible Beaches

Reprinted with permission from Independence Australia and Inform Issue no. 26 www.informonline.org.au

What are accessible beaches?

Accessible beaches have been made more accessible for people with wheels – whether you're in a wheelchair, using a mobility scooter or even pushing a pram. There are usually a few considerations when making a beach accessible. Accessible beaches offer ramps or stair-free access to the sand. They also have beach matting, to make rolling across the sand possible in a standard wheelchair. Many also offer beach wheelchairs for hire. Beach wheelchairs have buoyant armrests and wheels that allow the chair to float in the water. They also have straps to secure the rider. Beach wheelchairs are designed to enter the water, up to the waist height of a support person, so that everyone can enjoy the beach and have a dip. Finally, some accessible beaches may offer access to Changing Places facilities.

Changing Places

Changing Places is a project to advocate for public toilets with full sized change tables and hoists in major public spaces across Australia to meet the needs of people with disabilities. If you are looking to hire a beach wheelchair, but will need the help of a hoist to transfer from a standard wheelchair to a beach wheelchair, then looking for an accessible beach that also has a Changing Place is going to make the process much easier. Not all accessible beaches have a Changing Place.

Where can I find my nearest accessible beach?

The Accessible Beaches Australia website has a good list of accessible beaches. You should also check in with your local city council. And, if you are looking for a beach with access to a Changing Place, the Changing Places website offers a searchable map of accredited facilities.

How can I get my local beach made accessible?

Although Accessible Beaches Australia has a vision to make most patrolled beaches accessible by 2020, local councils need to know there is a demand for this service. When they are presented with the idea of making a beach accessible, most councils are concerned about the work and the cost involved. To counteract this, Accessible Beaches Australia hosts accessible beach days, where they demonstrate to local councils both how easy it is to make beaches accessible, and how high the demand is in the local community. Councils can contact Accessible Beaches Australia through their website to request a trial accessible beach day. In many cases the trial can be provided free of charge. As a local resident you can always contact your local council to let them know that services like these exist – the fact that they can be tried risk (and cost) free makes it a much more appealing proposal!

To find out more, visit accessiblebeaches.com and changingplaces.org.au

Could you be suffering from malnutrition?

Reprinted with permission from Independence Australia and Inform Issue no. 27 www.informonline.org.au

The global obesity epidemic receives a lot of attention. We've all heard about the health consequences of an expanding waist line.

At the other end of the nutrition spectrum, there is another concern that receives much less media coverage.

Malnutrition often brings to mind images of drought and famine stricken countries. But the problem of malnutrition is a lot closer to home. In fact, a recent Australian study found just over 40 per cent of community-living older adults who were receiving home nursing services were either at risk of malnutrition or already malnourished.

Malnutrition can have a significant impact on your quality of life.

People who are malnourished are more likely to become unwell, and when unwell they take longer to recover and are more likely to suffer complications.

People who are malnourished will need to see their GP more often, will need to be admitted to hospital more often and are more likely to need to move into an aged care facility at an earlier stage than someone who is well nourished.

As we age we become more vulnerable to malnutrition for a number of reasons:

- Our requirement for a number of nutrients increases, such as protein, calcium and vitamin D
- We experience change in our ability to taste and smell food as we get older. This can mean we no longer get the same enjoyment out of eating as we once did
- Physical changes can also make it more difficult to buy, prepare, cook and eat food without help

Take this quick quiz to find out if you could be at risk of malnutrition
Not sure about your nutritional status? Answer these questions below to find out.
Read the statements below and circle the number in the column that applies to you

| Questions | Yes | No | Add up all the numbers you have circled. If your nutritional score is |
|--|-----|----|--|
| 1 I have an illness or condition that made me change the kind and/or amount of food I eat. | 2 | 0 | <p>0-3 Good! Recheck your nutritional score in 6 months</p> <p>4-5 You are at moderate nutritional risk. See what can be done to improve your eating habits and lifestyle. A Healthcare Professional can help. Recheck your nutritional score in 3months.</p> <p>6 or more You are at high nutritional risk. Bring this checklist the next time you see your doctor, dietitian or other qualified health or social service professional. Talk with them about any problems you may have. Ask for help to improve your nutritional health.</p> |
| 2 I eat at least 3 meals per day. | 0 | 3 | |
| 3 I eat fruit or vegetables most days. | 0 | 2 | |
| 4 I eat dairy products most days (e.g. milk, cheese, yoghurt), | 0 | 2 | |
| 5 I have 3 or more glasses of beer, wine or spirits almost every day. | 3 | 0 | |
| 6 I have 6 to 8 cups of fluid (e.g. water, juice tea or coffee) most days | 0 | 1 | |
| 7 I have teeth, mouth or swallowing problems that make it hard for me to eat. | 4 | 0 | |
| 8 I always have enough money to buy food. | 0 | 3 | |
| 9 I eat alone most of the time. | 2 | 0 | |
| 10 I take 3 or more different prescribed or over the counter medicines every day. | 3 | 0 | |
| 11 Without wanting to, I have lost or gained 5kg in the last 6 months. | 2 | 0 | |
| 12 I am always able to shop, cook and/or feed myself. | 0 | 2 | |
| Total | | | |

Source: The Australian Nutrition Screening Initiative Checklist by P.S. Lipski. Aust J on Ageing 1996;15(1):14-17
 This checklist was developed to increase the awareness of malnutrition among the community-living elderly. It is not a clinical diagnostic tool and is not a substitute for a full nutritional assessment by a Qualified Healthcare Professional. It provides carers with an indication where improvements may be made to reduce the risk.

BLADDER BASICS

From Pa. Polio Survivors Network March, 2019 www.papolionetwork.org

By Dr William DeMayo, MD

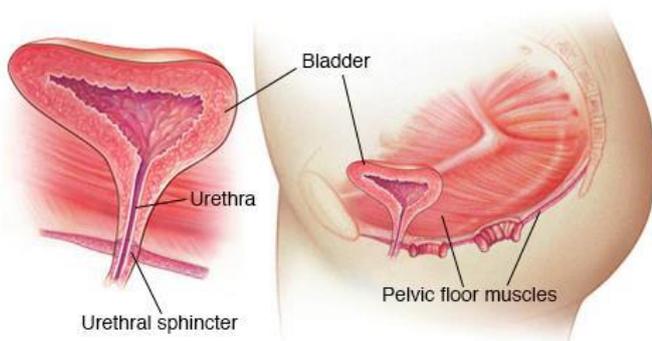
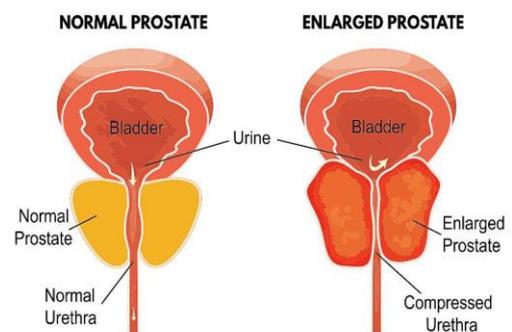
DeMayo's Q&A Clinic

Q: *Dr DeMayo, I have PPS. In the last few years I have experienced bladder issues. I have urine retention. On a recent CT Scan, it showed pelvic muscle atrophy. Is there a connection with Bladder problems and Polio? Were Pelvic muscles effected by the virus?*

A: Great Question! Unfortunately, there is not a great, short answer. Nevertheless, like most good questions, there is an opportunity to use this as a learning opportunity.

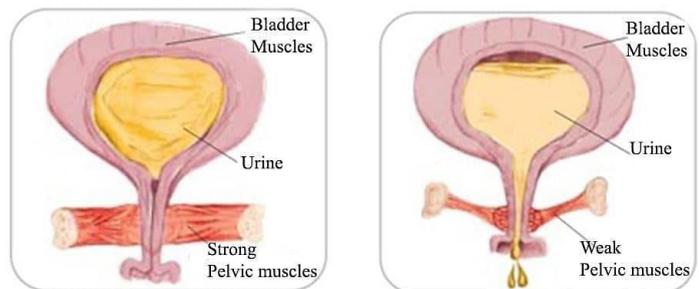
First a few basics...

1) The first Basic Bladder issue is that bladder issues in men are far different than in women. As the question above was forwarded to me, I don't know which gender it came from. By far, the most common source of urine retention (inability to empty the bladder) is obstruction of outflow caused by the prostate in men. PPS itself does not cause urine retention in the bladder. Having said that, one needs to be sure that retention is in fact the problem. This is usually done with an ultrasound of the bladder after a void to see if too much urine still remains. Of note, frequent urine incontinence (inability to control urine / wetting one's self) can be either due to urine retention with "overflow" leakage OR due to a lack of resistance to flow. The latter is far more common in PPS due to weakening of the pelvic floor as discussed below.



Also, incontinence is far more common in women compared to men due to multiple factors including a shorter urethra (the tube connecting the bladder to the outside), the urethra having less of a bend (especially when the pelvic floor drops), and lack of resistance of the prostate. Additionally, the bladder storage capacity in women tends to be smaller (partly due to presence of the uterus).

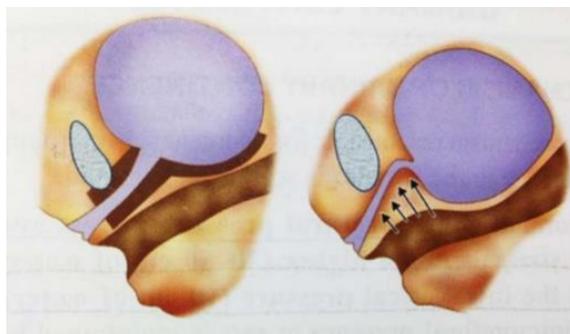
2) The second Basic Bladder issue is that neurological issues can have a major impact on urologic function. The bladder can become either over active or one can lose the awareness of bladder filling. Coordinated control of the bladder storage and emptying requires the interaction of muscles in the bladder wall, nerves from the bladder to the spinal cord, reflexes co-ordinated within the spinal cord and control from the brain (both with conscious awareness and



Weak pelvic muscles causes poor bladder control and Urinary Incontinence

without). Stroke, Brain Injury, Spinal Cord Injury, Multiple Sclerosis and many other neurological conditions can result in incontinence due to what is termed an “upper motor neuron bladder”. Since Polio is a lower motor neuron problem, we won’t discuss these more other than to say that Polio patients are not immune from any of the above conditions so they should always be considered. Also, the normal aging process can create a “hyper reflexive bladder” that can mimic an upper motor neuron problem.

3) The Bladder Basic that is most pertinent to Polio survivors is that the pelvic floor muscles play a profound role in bladder function. Any older individual is subject to this issue but those who have restricted mobility or a prior reason to have pelvic floor weakness are certainly more at risk. “Stress Incontinence” results when a cough, a laugh or a sneeze increases the pressure in the abdomen and thereby increases pressure on the bladder. It occurs when the resistance to outflow is low and this is especially the case in women. Polio can certainly cause weakness in the pelvic floor muscles and this weakness can progress in cases of PPS. Additionally, a history of child birth, recent sedentary lifestyle and weight gain can all add to relative weakness of the pelvic floor. Weak pelvic floor muscles are directly associated with less resistance to outflow. They play an important role in supporting the bladder, directly tightening the area around the urethra as well as creating a “kinking” effect with cough, sneeze or other activity which further increases resistance.



4) The last Bladder Basic is that many times bladder management is NOT Basic. Urine infection, bladder/kidney stones, stress, physical activities, behavioural concerns and many other issues can significantly impact bladder function. As such, all significant symptoms that do not resolve, should be evaluated. Referral to a urologist should always be considered if symptoms fail to resolve with treatment by a PCP (Primary Care Physician).

Additionally, some Physical Therapists specialize in Pelvic Floor therapy. They can often be found through your urologist, PM & R physician or GYN (gynaecologist). Like any muscle, the pelvic floor can be over fatigued and so treatment of a patient with PPS should be individualized and not focused on just intensive pelvic floor strengthening. A good PT specializing in this area can often provide lots of tips to improve symptoms. An example would be an older person who repeatedly has incontinence on the way to the bathroom. By the time they realize the bladder is full they risk an accident because the act of moving from sit to stand causes a reflex spasm of the bladder and the pelvic floor is not strong enough to resist this. Thankfully, there is an opposing reflex that inhibits the bladder (briefly) after 3 strong but quick contractions of the pelvic floor (Kegel type contraction). Thus, if this person takes 10 seconds to do these 3 contractions prior to standing, they can sometimes counteract the reflex bladder activity just long enough to get to the toilet.

A full explanation of bladder management is obviously well beyond the scope of this brief article. At the same time, I hope I have provided some insight into the way some bladder issues arise and provided hope that there are solutions.

Rehabilitative Physician, Dr William DeMayo has written an enormous number of outstanding articles about issues facing Polio Survivors. They are all easily downloaded for printing and sharing. You can see the full collection and watch his video presentation on our Website: www.papolionetwork.org



Staying free from Urinary Tract Infections

Reprinted with permission from Independence Australia and Inform, Issue No. 25 www.informonline.org.au

A urinary tract infection (UTI) is a relatively common but unpleasant problem that affects the bladder and/or kidneys. Symptoms may include; changes in bladder habits, burning pain with urination, back or tummy pain, urinary urgency, incontinence, a high fever and even delirium if left untreated.

Not all infections are easy to detect, and some people may feel only mildly unwell or have unexplained changes to their bladder habits. Carers of people who cannot communicate clearly often report that the only outward indication of a UTI is strong smelling urine or a change in mood or behaviour.

Fact: women and the elderly have a slightly higher risk of UTI

Most urinary infections are caused by a bacteria that has made its way into the bladder via the urethra or via continence aids such as a catheter. This requires direct contact between the entrance to the bladder and the bacteria. Bad smells and public toilet seats are not to blame for UTIs, because they do not make contact with the entrance to the bladder.

UTIs are more likely caused by:

- 1. Poor wiping techniques after toileting.** It is important to wipe from front to back, particularly after a bowel action. Bacteria that belong in the bowel can cause problems if they get into the urethra and bladder.
- 2. Bacteria on your hands or other surfaces making contact with the urethra or continence aids.** Make sure you know the correct clean techniques for using catheters and use single-use catheters where possible. Care workers should wash their hands well and wear gloves for intimate care.
- 3. Broken, wet and fragile skin, which is more susceptible to infection.** Good skin care and appropriate use of continence aids can ensure skin is healthy and more resistant to infections. Powders and harsh soaps should not be used on intimate areas.
- 4. Poor fluid intake.** A good flow of urine can wash away any stray bacteria that may be in or near the urethra, therefore preventing an infection. Drinking about 1500ml of fluid a day ensures a good amount of urine.
- 5. Not emptying your bladder fully.** If you hover instead of sitting properly on the toilet, some urine stays inside the bladder which encourages stray bacteria to multiply rather than being flushed out. Other causes of incomplete emptying include constipation and prostate enlargement.



Promoting Positive Solutions

By Dr Stephanie T. Machell

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Dr Machell is a psychologist in independent practice in the Greater Boston (MA) area. She specializes in working with those affected by polio and other physical disabilities. Her father was a polio survivor.

Question: *I know it's really important to have end-of-life discussions sooner rather than later, but I'm a procrastinator by nature and that's not exactly something I want to have to think about. Where do I even start? Do you have any ideas on how I should approach this?*

Response from Stephanie T. Machell, PsyD:

As no lesser authority than Hank Williams observed, we'll never get out of this world alive. Most of us would prefer to live longer and die more gently than he did. Had he been given a choice it's likely he would have, too.

We don't get a choice. Few of us know when or how we will die. It would make sense for everyone to have end-of-life plans in place at an early age, especially if we have dependents and/or beliefs and wishes we want respected.

Yet most people don't. We procrastinate and avoid. Our families collude with us because they don't want to think about our death, let alone their own. Our culture encourages us to speak in euphemisms, as if the "d-word" is somehow obscene

Whether we say the word or not, talking about death makes just about everyone uncomfortable. Even for those who have unquestioning faith about what does (or doesn't) happen, death is the ultimate unknown. We may be afraid it will involve suffering, be frightened of the loss of control it represents, or of no longer existing. And thinking about death brings up other deaths, those losses we've failed to fully grieve.

A surprising number of us procrastinate out of superstition. I'm not proud to admit that this is part of my own procrastination. It's irrational, yet some part of me fears that getting things settled will hasten my own death, in spite of knowing people who died never having completed a will or advance directives, and many more who lived for years after putting them in place.

I share this to let you know that while our reasons may not be the same, I understand your resistance. How are you (and by "you," I really mean "we") going to get past this? By dealing with what is in your way. Identifying the reasons you're procrastinating may mean acknowledging that thinking about your eventual demise makes you afraid or sad or otherwise uncomfortable. Or recognizing that it's "just" one more thing you procrastinate over.

Procrastination doesn't really make you feel better. It keeps whatever you're procrastinating over present in your thoughts. Set a date and use Dr Olkin's excellent checklist to get it done. If you're not sure what your wishes are, take the time to clarify them. If you're afraid of having an uncomfortable discussion with those who will carry them out, remember that doing so models the importance of having such conversations. Your significant others have likely thought about what you will want and may be relieved that you brought it up first. And because you've taken the time to decide what you want, all you will need to do is make

sure the person(s) you name are comfortable carrying out your wishes *as you want them carried out*.

I wish you success in completing this necessary task. And now that I've written this column, I'm out of excuses for not calling the attorney I was going to call last year!

Response from Rhoda Olkin, PhD:

Dr Olkin is a Distinguished Professor of Clinical Psychology at the California School of Professional Psychology in San Francisco, as well as the Executive Director of the Institute of Disability and Health Psychology. She is a polio survivor and single mother of two grown children.

This is one of those tasks that most people dread. The problem is that the task requires thinking about our own demise, and of course we'd rather not do that!

The good news is that when you finally do tackle the issues the decisions you need to make can be completed in about twenty minutes. There are many forms online, and each state has different forms, but no one form that you *must* use. You really could finish all the major decision making in the time it takes to answer the questions in this column:

1. Do I want to be buried (Where? Paid for?), cremated (Where? Paid for?) or donate my body? If donating, is it okay for the donation to go to (a) education; (b) donor organ; (c) for-profit; (d) overseas?
2. Who do I trust to make end of life decisions for me should I be unable to make them myself? Who is my back up for this person?
Name 1 _____ Name 2 _____
3. Have I given someone a list of who is to be notified in case of my death?
4. Do I have a will?

I'm going to make this as easy as possible for you. Fill out the form below and give it to your primary care physician.

A. Regarding life prolonging measures, I would like my agent to approve:

| | Yes | No | Agent to use own judgment |
|----------------------------|-------|-------|---------------------------|
| Breathing tube in the nose | _____ | _____ | _____ |
| Intubation | _____ | _____ | _____ |
| IV nutrition | _____ | _____ | _____ |
| Urinary catheter | _____ | _____ | _____ |
| Dialysis | _____ | _____ | _____ |

B. I would consider that I did not have sufficient quality of life and would not want my life prolonged in the following circumstances:

| | Yes | No | Agent's judgment |
|---|-------|-------|------------------|
| Unable to breathe on my own indefinitely | _____ | _____ | _____ |
| Unable to take in nutrition orally | _____ | _____ | _____ |
| Unable to control bladder and bowels | _____ | _____ | _____ |
| Unable to communicate orally | _____ | _____ | _____ |
| In pain indefinitely, unmitigated by non-narcotic medications | _____ | _____ | _____ |

If you answered the questions 1 to 4, and completed the form, you have done 90% of the work you need to do. Making a will is the other 10%. Now you can go back to not thinking about it.



How to Manage Disability-Related Pain as You Age

From Pa. Polio Survivors Network May, 2019 www.papolionetwork.org

“Aging with a Disability”

From the University of Washington and Post-Polio Health International

People with physical disabilities often experience pain related or in addition to their disability condition. When this pain lasts for more than three months, it is called chronic pain. Chronic pain seems to be most common in middle age (45-65 years). However, as some individuals with physical disabilities age, the frequency and severity of pain may increase. Chronic pain can have negative effects on sleep, mood, fatigue, thinking, work, and daily activities.

With help from health care providers, you can learn to manage your chronic disability-related pain and limit its impact on your life.

Types of Pain:

You can have chronic pain in different parts of your body for different reasons. Three common types of chronic pain in people with physical disabilities are:

- **Musculoskeletal** – This pain comes from problems in the muscles, tendons, and joints. It is often described as “aching” or “heavy”. People with physical disabilities are at a greater risk than those without disabilities to develop the kind of pain as they age. For example, people who use a manual wheelchair for many years may experience musculoskeletal pain in their shoulders due to overuse.
- **Neuropathic** – This pain is caused by abnormal signals from damaged nerves. It is often described as “sharp”, “shooting”, “electric”, or “burning”. People with physical disabilities are at a greater risk than those without disabilities to have neuropathic pain, especially if their disability condition involves damage to the nerves. For example, the most common symptom reported by people with multiple sclerosis (MS) is chronic neuropathic pain. Below injury-level neuropathic pain is also common in individuals with spinal cord injury (SCI).
- **Visceral** – This is pain in the abdomen or pelvis and can be caused by conditions such as ulcers, constipation, or appendicitis. This pain is often described as “squeezing”, “pressure”, or “aching”. Visceral pain is more common in people with SCI.

Maintaining a Healthy Lifestyle:

Maintaining a healthy lifestyle can help you reduce and manage your chronic pain as you age. It may be the most important thing you can do to minimize pain and its impact in the long run. A healthy lifestyle includes:

- **Activity** – Keeping busy and challenging yourself physically and mentally will help you have the energy and focus to manage your pain.
- **Diet** – Eating healthier can help to relieve chronic pain. Diets high in fruits and vegetables, legumes, and whole grains and low in sugar and red meat have been related to lower levels of pain.
- **Weight** – Added weight places more stress on joints and can make pain worse. Maintaining a healthy weight can help you move easier and with less pain.
- **Sleep and Rest** – Adequate sleep and rest can make it easier to manage your pain.

Seeking Help for Your Pain:

- Talk to your health care provider about your chronic pain. Pain is a personal experience, and health care providers often rely on your description of the pain to diagnose and treat it.
- When meeting with your health care provider, be honest about how much (or little) pain is affecting you.
- The best treatment plans for chronic pain are tailored to the person and the type of pain he or she has. Your treatment plan should include input from you, your family, and other members of your health care team.

Pain Management:

There are several treatments available to help you effectively manage your pain as you age. Chronic pain is often best managed by using more than one strategy.

Self-management

While it is important to rely on expertise from your health care provider, you play the most important role in managing our day-to-day pain. Self-management techniques for chronic pain include:

- **Tracking your pain** – Keep a record of your pain and take it with you to your medical appointments. You may discover that your pain is unpredictable. Notice what triggers and what relieves your pain, such as changes in your activities, time of day, weather, or other conditions like stress or depression. Track your strengths. What are you doing well to deal with pain and its effects?
- **Setting goals** – Use the information from tracking your pain to set goals for managing your pain. Ask your health care provider to help you create long-term goals, such as increasing your level of physical activity, learning relaxation techniques for pain, or decreasing the impact pain has on your mood. Break the long-term goals into smaller, more specific short-term goals.
- **Monitoring your progress** – Monitor how different pain management strategies are working or not working. If one strategy does not work, tell your health care provider and discuss trying a different strategy.

Behavioural and Coping Skills Treatments

Behavioural treatments can help you manage pain and reduce the impact of pain on your life. Behavioural treatments for chronic pain include:

- **Cognitive Behavioural Therapy or "CBT"** – Involves learning relaxation skills, goal-setting skills, strategies for becoming more active, and skills for pacing your activities. It can also include examining your thoughts about pain and learning new ways to replace any unhelpful thoughts with more helpful ones. CBT has been shown to reduce pain, improve mood, and improve function.
- **Mindfulness training or meditation** – Involves focusing on your present experience in a manner that is open and non-judgmental. Mindfulness can be helpful in managing the suffering that can occur with pain.

Physical Treatments

It is important to consult with your health care provider about physical treatment options to reduce risk of further pain. Physical treatments for chronic pain include:

- **Regular Exercise** – Exercise is often helpful in managing pain and improving function. Potential goals for exercise include aerobic fitness, improved flexibility, increased strength, and increased skill in performing physical activities. Some people report that movement activities such as yoga, Tai Chi, swimming, or water aerobics are helpful in managing pain. If you have limited mobility due to age or disability, there are modified at-home and group exercise programs available.

Complementary and Alternative Treatments

There is some evidence that complementary medicine approaches may provide additional relief from chronic musculoskeletal and neuropathic pain. These may include things like massage, acupuncture, or self-hypnosis training. Most evidence does not support the use of homeopathic remedies or herbal treatments for chronic pain.

Medications

Pain is often treated with over-the-counter or prescription pain relievers. Categories of medications and the types of pain they are used to treat include:

- **Over-the-counter medications**-These medications are effective for the management of mild to moderate pain. Common ones include:
 - Acetaminophen, such as Tylenol®, is often used to relieve pain associated with mild arthritis and osteoarthritis.
 - Non-steroidal anti-inflammatory drugs (NSAIDs), such as aspirin and ibuprofen, and Aleve®, are often used to relieve pain associated with mild arthritis, osteoarthritis, and rheumatoid arthritis.
- **Prescribed pain medications**-Prescribed medications are sometimes used to treat or reduce the symptoms of chronic pain. Some common ones include:
 - Anticonvulsants (also known as anti-seizure medications) are used to treat neuropathic pain.
 - Several kinds of antidepressants are sometimes used to treat neuropathic pain and depression and to assist with sleep.
 - Opioids are sometimes used to treat neuropathic pain, acute tissue injury, and musculoskeletal pain. Long-term use of opioids can result in tolerance and other health problems. It is important to discuss the risks and potential benefits of opioids with your health care provider.
 - Muscle relaxants and anti-spasticity medications are sometimes used to treat spasm-related and musculoskeletal pain.
 - There is some evidence that medical marijuana reduces central neuropathic pain and spasticity in people with MS, and more research is underway. As of 2018, medical marijuana is legal in 29 US states and Washington DC.

Although it is common to think that pain is "normal" as we age, there are treatments to reduce the impact of chronic pain on your life. Be open to the options your provider suggests for managing for pain but also be active in looking for solutions!

agerrtc.washington.edu/info/factsheets/pain





Susie Simmons from Scone emailed two newspaper clippings from the Sydney Morning Herald, 5th February 1954.

I found these interesting articles and thought they could be shared in your Newsletters.

Kind regards
Susie Simmons

DUKE STOPS FOR A TALK



As he left Sydney University yesterday, the Duke of Edinburgh found time to stop for a talk with these crippled children and their nurses. The children, from the Royal Alexandra Hospital for Children, were in a bus parked near the Duke's waiting car.

Duke's Gesture To Child Polio Victims

Seven child polio victims were "smuggled" into the University yesterday to catch a glimpse of the Duke during his visit there.

But they had more than a glimpse. Inside, a University official put them outside the building in which the Duke was lunching.

The Duke saw them almost as soon as they saw him. And, smiling his warmest smile, he walked across and talked to them.

Officially the University was closed to outsiders, but officials did not count on the persuasive capacity of the little band's chief almoner, Miss Judith Green.

The children are receiving part-time treatment at the Royal Alexandra Hospital for Children for various stages of paralysis.

Accompanied by several almoners and physiotherapists, they originally intended to stop near the University on their way home in an ambulance after treatment.

SERGEANT'S NOD

At the University gate Miss Green asked a gatekeeper if they could move to a more advantageous position.

A sergeant of police nodded and they moved in.

Attendants said the Duke asked the children what hospital they were attending, how they were feeling, and made some cheery remarks.

He spoke directly to nine-year-old Ann Barnes, of 61 Trafalgar Street, Belmore, and Peter Campbell, 6, of 25 Shellcote Road, East Bankstown.

The children, whose ages ranged from the baby stage to 11 years, were very excited.

The Medical Superintendent at Royal Alexandra Hospital, Dr. J. C. Fulton, said last night: "It was an impromptu treat for the kiddies. All of them are receiving after-care at the hospital, and are too crippled to accompany their parents to see any of the Royal tour activities."

"It was an experience they will never forget."

(Picture, p. 6)

I wonder if Ann Barnes or Peter Campbell listed in the article are members of Polio NSW.

Rose Cogger gave Network News some much appreciated praise following the inclusion of her previous emails in NN #105. These outlined her experiences with the late effects of polio.

Hi Sue

You are doing such a great job with the newsletter as it's so important that people with LEOP read as much as they can to help them.

Regards

Rose



Polio

If you would like to buy a copy of Bill's book, please ring him on 02 9489 3861 or email him at billclover@bigpond.com.au



First term of high school was commencing. Off to Eastwood Technical School I went to register and then back to my old primary school to say good-day. Not feeling too good, I went on home as I thought I had the flu coming on. That night the so-called flu got worse. Next morning Mum said, "you'd better stay in bed and I'll call the doctor". Having a day off school? That sounded great. During the afternoon Dr Howe arrived and examined me. Not many words were spoken in my presence.

That night, I had some tablets stuck down my throat that no doubt the doctor had prescribed. During the night as I was crawling across my bed after going to the toilet my right arm went from under me. Taking no notice, I went off to sleep. Next morning Mum came in to see how I was. I said, "my arm won't move". Mum grabbed the telephone and, twenty minutes later, the doctor was sitting on my bed saying, "you are going to hospital". His statement made no impression. The only thought I had was 'lattice biscuits'. In the 1950s lattice biscuits were luxuries in our kitchen pantry.

Mum sent my brother Noel off to the local shop to buy some. In the meantime with the house in disruption, the ambulance arrived. With all the unusual happenings, my three young sisters, Betty, Beverly and Cathy, took off with fright and hid in Dad's work shed.

My body was becoming limp with weakness as the ambos gently placed me on their stretcher bed. They then proceeded to carry me to the ambulance as a group of locals gathered to enquire what was happening. I was placed in the ambulance by myself. They closed the door and drove off to Prince Henry Hospital, as Noel rode home with the biscuits I was to miss out on. On arrival at Prince Henry Hospital's medical ward A Block, I was stripped of all my clothes and they were thrown into the incinerator. My Mum was there to see me stretchered in but wasn't allowed near me. Our next-door neighbour, Ben Swane, used to drive Mum to the hospital each day whilst I was in isolation; she would have to remain in the hallway during her visits.

My muscles were rapidly deteriorating. A team of doctors and nurses rolled me on my side and held me there whilst a doctor administered a lumbar puncture. Hovering in the back of the room were the physiotherapists with their plaster bandages ready to create plaster casts of my legs. Their ability to cut the tops out of the casts left a lot to be desired. About three hours after the lumbar puncture, a doctor was poking tubes up my nostrils to administer oxygen. This was the last thing I remembered before lapsing into unconsciousness.

Polio! I didn't know what polio was in the early 1950s. I was only interested in sport. I wasn't into reading newspapers. Sports magazines were the only thing I read when I could get hold of them. Television was years off and I only listened to the radio after the sun has gone down. Most of my radio listening was late in the evening when 2GB Radio Station had a programme all about the Strauss family and their wonderful music.

Mum told me, when she was able to communicate with me, that Doctor Howe mentioned that he thought that I had caught the virus whilst I was doing the three-week Learn How To Swim program at the Granville Baths. Professional medical personnel say polio, medically known as poliomyelitis, has a virus that is spread from person-to-person which can cause different levels of paralysis to the body muscles of the victim or even death. Polio was one of the most feared diseases of the 20th century.

Later I discovered that Australia's first polio case had been on the Clarence River, New South Wales in 1887 with further sporadic cases there between 1890 and 1893. The first small outbreak was at Port Lincoln, South Australia in 1895 with 14 cases of the spinal type. The second significant outbreak occurred in Sydney in 1903-1904, with 35 cases, mostly under the age of two, all held at the Royal Alexandra Hospital, Sydney. Another 16 cases were recorded up to 1946. In Sydney, the summer of 1950 was particularly bad as there were approximately 250 admissions, including mine in February, and in 1951 no less than 450 admissions. The weeks of November 1950 were the worst, with 40 admissions weekly. This was a particularly distressing time for the staff of the hospital as they were caring for children and young adults, many of the latter of their own age, who were crippled with severe respiratory paralysis as I was for many months.

The risk of the staff contracting the condition was of course always present and was another cause of anxiety. However, as history shows, only three nurses at the Hospital contracted the disease and they, fortunately, were affected mildly. This was a time when the spirit of service of the old Prince Henry Coast Hospital was seen as the finest level of care. When you look back to when all this was happening, there would've been numerous staff thinking, "it could be me".

For us with it, there was no treatment for this virus. It caused paralysis by targeting the nerve cells in the spine which control muscles. But, in 1953, something momentous occurred. An American researcher called Jonas Salk published a paper announcing that he had developed an effective vaccine against polio. It's hard to overestimate the impact of what became known as the Salk vaccine. Australia started using the vaccine in 1956, and by the end of the 1950s, our country had almost eliminated the disease.

In those days young athletes didn't take vitamins as a replacement as they do today. After playing team sports in Parramatta, I would then run all the way home to Ermington just for practice. During the January portion of the 1949 school holidays, I participated in the school's three week Learn To Swim program. Doctors nominated this to be the time when I contracted the virus. Later, it was realised that I was deprived of all resistance for what was to follow. Many days later when I came to and opened my eyes, I discovered, as I thought, I was in a coffin with my head sticking out. The box was as hot as Hades and I was lying there with just a sheet covering me. The only movement of muscle in my body was the big toe on my right foot.

As I looked up into the mirror above the coffin there, looking down at me, was this beautiful angel with these lovely shaped boobs. As my condition improved, and being an impressionable fourteen-year-old, I asked the nurse who sat by my iron lung during the night shift if she could take a photo of the angel. The night shift nurse had a box brownie camera and she took a whole reel of film. This is one of the photos of my angel with those lovely shaped boobs. At the 50th year reunion of the polio wards of Prince Henry Hospital, she was the only one I could remember by name: Mary Therese Davis, known as Terrie to all.





Polio Oz News

December 2019 – Summer Edition

Pandemic: Margaret's Experience

By Margaret Saunders



Margaret with her 20th great grandchild

My husband, Fred, and I were 2 of the original members of our Newcastle/Lake Macquarie Post Polio Support Group, which we attend every month in Toronto (NSW). I am happy for you to use my story in any way you can in order to get the message out that "We're Still Here!".

I met Fred in 1952, just 18 months after having polio, and we married in March 1954. We raised 5 children, and now have 24 grandchildren – the youngest is 10 years old – and 28 great grandchildren – who are all under 11.

In 1989, Fred and I moved into a Children's Home which was owned by our Church. I was the House Mother, caring for up to 8 children at any given time. Over the year we were there, we looked after around 20 children. The Home was sold once we left. I have also been a near to full-time Leader in The Girls' Brigade, working with girls of all ages from 6 years to 18 (photo right).

I was very fortunate for 50 years, until the Late Effects of Polio came upon me in 1998. There are some people I've come across who dispute that my disability originated from having had polio. I have had to watch my every step, and pick myself up when I fall, which is quite often. One lady tells me that it is only old age, as she has not seen me with any disability in younger years.

I told her that she needs to be in my body and then she would know.

As well as polio, I had level 4 melanoma taken from the front of my 'bad' leg back in 2002, along with losing 2 lymph nodes from my groin. I also needed to have my left knee replaced in 2004, as it crumbled after doing all the work for my polio-affected right leg.

Early this year, I saw a request from a young fellow named Jacob, who wanted to hear from people over 75 with stories from the 'early days'. As I was 84 at the time, I decided to contact him with my story of having had polio when I was 16 years of age. Out of all stories received, he chose mine.

Jacob wanted to make a short film for his major work for his Higher School Certificate (HSC). He came out to our home with his camera, sound recorder, and an umbrella to get the right lighting for his film. Over the months he was in touch with me by e-mail letting me know how things were progressing. By September, the film was ready to be submitted to the HSC board for marking. His teacher had given him 50/50, and suggested he enter his film into the Blue Heelers Short Movie Festival, which was coming up in October. His film came first and he received \$3,000 plus a new laptop, which he was very pleased about. 🌟

The film, titled "Pandemic: Margaret's Story" can now be viewed on YouTube:
www.youtube.com/watch?v=eNcfdtocwvs



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throughout Australia

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**Polio Australia's Websites****Polio Australia**

Representing polio survivors throughout Australia



Welcome to the Polio Australia website. Polio Australia is a not-for-profit organisation supporting polio survivors living in Australia. This website contains information about polio, the Late Effects of Polio, the work of Polio Australia and much more.

www.polioaustralia.org.au

Polio Australia

Improving health outcomes for Australia's polio survivors



The Polio Health website is a comprehensive resource for both health professionals and polio survivors. It contains clinically researched information on the Late Effects of Polio; the Health Professional Register; and where Polio Australia's Clinical Practice Workshops for Health Professionals are being held.

www.poliohealth.org.au

Australian Polio Register

Have you added your polio details?



The Australian Polio Register was established by Polio Australia in October 2010 to gather information on the numbers of polio survivors living in Australia today, whether or not they contracted polio in this country. To make the Australian Polio Register truly reflective of the unmet need for polio services throughout Australia, we urge every Australian polio survivor to join the Polio Register. Our strength lies in our numbers – please help us to get you the services you need by adding your polio details to the Register. You can register online or by downloading and completing a [paper copy](#).

www.australianpolioregister.org.au

Polio Australia

Honouring Australia's polio survivors - "We're Still Here!"



Polio Australia's "We're Still Here" website is a hub for sharing people's stories, polio survivors in the media, polio awareness raising campaigns, events of interest, Rotary talks, and so much more. It is constantly being updated, so check in often.

www.stillhere.org.au

President's Report



Gillian Thomas

At the end of the year it is time to look back and reflect on what was achieved in 2019 and what we can look forward to in 2020.

It is not only the end of the year but the end of an era as Maryann retires after working with Polio Australia since 2010. Although she will not be totally gone and will certainly not be forgotten, she will definitely be missed by the Board, staff and the community.

Unusually, there were a number of staff changes this year – besides Maryann's imminent retirement, we have farewelled Jake (June), Bonnie (July) and Paul (November). I have previously acknowledged the contributions of Maryann, Jake and Bonnie. Paul spent two years with us, and I greatly enjoyed working with him over this time and seeing the difference he made to the knowledge level of health professionals around the country who are working with polio survivors. During the year, we also welcomed Darlene (August) and Michael (November) to the team. They both hit the ground running and their skills complement the existing team skills. We certainly are very well served by our staff.

From the Editor



Maryann Liethof
Editor

Whilst this is my last newsletter as the National Program Manager for Polio Australia, you haven't seen the last of me yet!

My retirement date beckons, and there is still much to do before I leave at the end of December. However, over the past couple of years, I have been able to engage skilled people, who have evolved to

become an [amazing team](#). They are going to be just fine without me! They have already expanded Polio Australia's services beyond anything I could have hoped for, and are all passionate about their work on behalf of Australia's polio survivors.

Rachel Ingram and Darlene Felsch will be sharing the management role as Program Operations Manager and Resource Manager, respectively. Steph Cantrill continues her fine work as Community Engagement Officer, and we have a new Clinical Health Educator, Michael Jackson (he's heard them all!). Short reports from the Team can be read in this edition.

We were sorry to see Paul Cavendish leave in November, but travelling across Australia can be

The Board had its usual annual face-to-face meeting in October as we came together for the AGM. This year we reviewed our 2018-2020 strategic plan to update it in view of staff and program changes. The updated plan will be presented to the Board for approval at its next meeting and will then be available on our website.

Our biggest challenge remains ongoing funding to maintain our core operations. We were very pleased this year to receive a 3-year extension to our Department of Health grant to enable the Clinical Practice Workshop program to continue until 30 June 2022. Similarly to this program, most of the available funding sources are directed towards discrete projects. Such funding is vital to maintain and expand the services we can provide to Australia's polio survivors and the state networks who support them. However, it doesn't pay the rent or other operating costs – such expenses must be met through other sources, primarily donations and bequests.

After another busy year it will be good for all to have some downtime to recharge our batteries and return invigorated to meet what 2020 has to offer.

Best wishes to all for a healthy and peaceful festive season. 🌟

Gillian



challenging for a young family. Paul made great inroads in his two years with Polio Australia, and we wish him all the very best. Hundreds more health professionals are now educated in the Late Effects of Polio thanks to his efforts.

I will continue to edit *Polio Oz News* for the foreseeable future. I have also put myself forward to serve as a Board member for Polio Australia. I have accumulated a lot of information in my head which could be useful. A summary of my involvement with the post-polio community can be seen in this edition.

As usual, there are also many stories and articles I have collated over the past few months, which I am sure will be of interest. Our cover story is proof that 'ordinary people' do amazing things, especially polio survivors!

Perhaps some of our readers will benefit from the fresh injection of federal government funding in response to the Aged Care Royal Commission's Interim Report (p 17).

And a reminder that we must remain vigilant with polio (and other) immunisation, with the return of polio to the Philippines (p 22).

As we are rapidly approaching the end of 2019, I offer Seasons Greetings to all, however you choose to celebrate! 🌟

Maryann

Rachel Ingram



Program Operations Manager

Polio Awareness Month and the Launch of Clinical Advisory Group

October was Polio Awareness Month, and this year we focused on

"Equality—Inclusion—Access"

highlighting the desire for all polio survivors to:

- have appropriate access to services;
- feel included in all aspects of society; and
- have equality in all areas of life.

We also used Polio Awareness Month to launch our new-look [Clinical Advisory Group](#). The purpose of this assembly of polio-savvy health professionals is to support Polio Australia to achieve organisational goals. We utilise the knowledge, skills and expertise of these health and medical professionals to advise on key health issues. This includes contributing to Polio Australia's [Fact Sheets](#) series and informing key projects such as our [Clinical Practice Workshops](#).

The Polio Australia team also participated in a Polio Awareness Month fundraising activity, [Two O'Clock Around The Block](#). The office staff completed a daily walk "around the block" at 2pm every workday in October. Why?

- To build/maintain fitness so we can stay strong and functional;
- To give us clear space to think creatively and share ideas outside the normal office routine;
- To reenergise our bodies and minds with fresh oxygen before we get back to work;

Darlene Felsch



Resource Manager

I joined Polio Australia three (3) months ago and I am enjoying the role immensely.

In the time I've been here, I have:

- automated payroll using the MYOB payroll module;
- implemented Single Touch payroll to comply with ATO requirements;
- introduced Salary Packaging for the staff, which takes advantage of the tax concessions available to staff who work for a charity; and
- attended the AGM and the October Board meeting.

I am providing ongoing support for our bookkeeper to record transactions in MYOB.

During October's World Polio Awareness month, I enjoyed attending an event in Warrnambool, run by Polio Network Victoria. I got to meet polio survivors and their families and listened to their stories and how they were dealing with the Late Effects of Polio.

I am looking forward to all that we will achieve together next year. 🌟

- Because we can? We acknowledge that not everyone is able to do a walk around the block, but we invite everyone to participate in any way that works for them.

Grant Seeking Update

Polio Australia relies primarily on philanthropic grants to fund its programs/projects. The Polio Australia team have been busily applying for grants, and despite the highly competitive nature of grants, are excited about six pending applications:

1. Gambling Community Benefit Fund: to run a Polio Health and Wellness Conference in Queensland.
2. ILC Individual Capacity Building (ICB) Program Grant Opportunity 2019-2020: to fund Community Development Workers in each State.
3. Aurizon - Community Giving Fund: to deliver Community Information Sessions in Western Australia.
4. Grants SA Major Grants: to run a Polio Health and Wellness Conference in Adelaide (partnering with Polio SA).
5. EastWeb Grants: to translate key resources into various community languages.
6. Budget Direct Sponsorships: Printing of resources. 🌟

The team out and about on one of our Two O'Clock Around The Block walks.



Welcome Michael Jackson



Hello All!

I'd like to introduce myself as the new Clinical Educator for Polio Australia. I am stepping into the role that Paul Cavendish has performed since its inception in 2017. While I feel I have some big shoes to fill, given the amazing efforts of Paul expanding

the program from the initial pilot workshop, there is still much to be done to improve polio education levels amongst health professionals across Australia.

My professional background lies in two fields—education and physiotherapy. I spent about four years primary teaching in the Wide Bay area in Queensland, before transferring to a Brisbane school for a few years. Needing a change, and taking the opportunity to pursue a shelved dream, I headed to the US to travel and study for a few years. (I am fortunate enough to be a dual citizen, thanks to my mother.) A few years in the US turned into sixteen years. These years included obtaining my Physical Therapy degree in California, getting married, moving to Colorado,

working in a rehabilitation hospital in Northern Colorado, and raising a young child.

During my physio training I successfully applied for, and then spent twelve clinical weeks at, Rancho Los Amigos Rehabilitation National Hospital, in Downey, California. It was there that I found my calling for managing and treating complex patients, and where I had some invaluable time in their Polio Clinic.

Serving as the therapy department clinical educator for a number of years in Colorado, I noted a lack of awareness about Post Polio Syndrome amongst our staff. This, and the relief expressed by patients who I spoke to that *"at least someone knew"* about their condition, led me to educate our staff on the topic.

Recently, I had the opportunity to meet with those attending Polio Australia's Health and Wellness Retreat, and to present a session on "Falls", which serendipitously led me to accepting this role and writing this introduction!

I look forward to meeting you when I am in your area, and helping those who care for you to do so from a position of knowledge and understanding.

Michael Jackson M.P.T., B.Ed. 🇦🇺

Community Engagement



By Steph Cantrill

Community Engagement Officer

It's been an interesting few months. With such a small team, you don't expect to say too many good-byes, but we've already farewelled our outgoing Clinical Educator (Paul) and welcomed his able replacement (Michael) –

and the next person to leave will be our very own Maryann. It's hard to say how much our organisation will miss her, but as I'm sure you can imagine things are going to be very different after the end of this year. It's a lot of change for a small team to handle, but we can do this!

My recent trip into New South Wales was very rewarding. Most of the sessions had a few "new" people – polio survivors who had not previously been connected with support groups, Polio NSW or Polio Australia. Hopefully that will lead to an increase in membership with Polio NSW, and a few new people meeting up with others regularly for support. And, of course, we hope that people

now feel more informed, and better able to manage their condition and communicate with their health professionals.

Something we've been discussing lately as a team is that, as Polio Australia is a national organisation and exists to support the state networks across the country, it's important for the Community Engagement role to have a national focus. Up until now, I have mostly travelled to areas I can get to by car. This has kept costs down, but has limited the scope of my outreach. As our finances stand at the moment, it isn't possible for me to travel everywhere unless we get grant funding. While it's rather limiting to let the grants guide our work, the reality is that we can't spend money we don't have! Therefore, we have been concentrating on fundraising through grant applications, and my work will focus on the locations and priorities of successful grants.

Due to one such grant, from the James Kirby Foundation, I am working my way through NSW. The aim is to complete a total of 15 community information sessions around the state including the four sessions we had in October.

Community Engagement *(cont'd from p5)*

While they are by no means set in stone, the draft schedule for early 2020 looks like this (please check www.polioaustralia.org.au/community-information-sessions as details will be added when things are confirmed):

| | |
|--------------------------|--|
| 3 rd February | Bathurst Library , 3pm |
| 4 th February | Orange Senior Citizens' Centre , 10.30am |
| 5 th February | Dubbo, Milestone Hotel , 10.30am |
| 6 th February | Tamworth (venue and time TBC) |
| 7 th February | Newcastle/Maitland (venue and time TBC) |
| 16 th March | Ballina (TBC) |
| 17 th March | Coffs Harbour (TBC) |
| 18 th March | Port Macquarie (TBC) |
| 30 th March | Bairnsdale (VIC – TBC) |
| 31 st March | Eden/Bega (TBC) |
| 1 st April | Ulladulla area (TBC) |
| 2 nd April | Wollongong (TBC) |
| 3 rd April | possibly Sydney (TBC) |

So, exciting things ahead! While fundraising continues to be a challenge, it's been so worthwhile connecting with polio survivors around the South-East of Australia, and I look forward to bringing the community outreach programs further afield. 🌍

Clinical Practice Workshop Review

And Communication in Healthcare

By **Michael Jackson**

Clinical Health Educator, M.P.T, B.Ed.

With the Polio Australia Clinical Practice Workshop (CPW) program changing hands, it is a good time to reflect upon Paul Cavendish's achievements in building and establishing the program with Polio Australia. It is also time to look at what we need to solve and modify to continue to bring impactful workshops to Australian healthcare professionals.

The CPWs are designed to bridge the *information* gap that exists between healthcare providers and polio survivors, on the topic of the Late Effects of Polio (LEoP). In my recent meeting with the members of Polio NSW, we also discussed the *generation* gap that exists between the same stakeholders. The following summary of the CPWs essentially reveals the way Polio Australia, with Paul at the program's helm, has been bridging these two gaps.

The table opposite shows the raw numbers of workshops held and number of attendees. Growth is certainly evident, and you can see that in 2019, the program targets were almost reached.

The program has reached metropolitan and regional facilities in all six states and territories. NSW accounts for about 30% of the attendees to date – with other states each accounting for 10% to 15% of attendees.

The majority of attendees are from allied health professions, with 45% being physios, 20% nurses, and 18% occupational therapists. As a group, medical professionals account for about

| WORK-SHOPS | Count | Attendees | Mean Attendees |
|----------------|-----------|-------------|----------------|
| 2017 | 5 | 74 | 15 |
| 2018 | 43 | 514 | 12 |
| 2019 | 50 | 728 | 15 |
| TOTALS: | 98 | 1316 | 14 |
| DoH TARGET: | 55/yr | 800/yr | 14 |

2% of our attendees. This is a known and expected problem, and the solution requires a creative multifaceted approach.

97% of attendees would recommend or highly recommend the CPW. This tells us that the topic, content and delivery is hitting the mark – attendees see value and want to share it.

96% of attendees state they have a good to better understanding of LEoP after completing the CPW. This tells us that we are getting the message across, and that the presentation is effective and provides adequate topic learning.

48% elect to join the [Health Professionals Register](#), which you can find on the Polio Australia website. While this is below 50%, we should consider a few factors: we did expand our professional register with the 48%; a healthcare professional can be reluctant to label themselves expert enough to be on a register; and identity security concerns can occur with freely accessible registers.

Looking to 2020, there are numerous projects on the CPW horizon: consistently targeting hospitals

Clinical Practice Workshop Review *(cont'd from p6)*

and utilising the resources that their systems offer; increasing the number of workshops at aged care facilities; solving medical professional learning and education barriers; and forming partnerships for building programs.

Reaching and subsequently educating medical professionals has proven to be challenging. Given that medical professionals' insufficient education and awareness of LEOp and PPS is a recurring complaint, and a reason for healthcare dissatisfaction amongst survivors, it is worth addressing this with some perspective as we enter 2020 and beyond.

While the CPW is certainly building an army of allied health professionals able and willing to advocate for you, it is still essential that you – the polio survivor – continue to self-advocate. Ideally, you shouldn't have to be your own advocate – your doctor should fully understand your post-polio needs and how to address them because accessible training and materials exist for LEOp.

There are many ways to approach self-advocacy, and we will explore several over the remainder of this article. Knowledge is a useful tool we possess (and wish to share!) – it is particularly impactful when handled both wisely and timely.

Understanding the consult or appointment interaction, is helpful for patients. These interactions usually occur in an environment in which we have little control. In non-medical terminology and simply put, there are three main elements of the interaction from the professional's position:

- **INPUT:** your history, the medical condition/topic, your status, your needs. These four things are consistently needed in order to act in the next element.
- **PROCESS:** decision-making, trials or testing, diagnosing, establishing locus of control. These are variable based on the initial input information.
- **OUTPUT:** improvement, monitoring, something solved, closure. These are variable based on the character of the input and process elements.

If you are able to help the practitioner in front of you clearly define all the INPUT items, the consultation is on its way to being impactful and meaningful.

Understanding How Doctors Learn (Slotnick, 1999 article) can help a patient present information and their case more effectively. A doctor needs to quickly decide if the problem you are presenting is:

Specific (requires hot action; fast response), or
General (requires reflection; time to respond).

In the case of presenting and discussing LEOp and PPS during a consultation, we want the doctor to think of the problem as general (because it is).

The next stage – *taking the problem on* – is the tricky stage. This stage is where patients with less prominent conditions (or an unclearly defined primary concern) can get verifiably frustrated by a lack of response or interest. Doctors, as people, are influenced by many personal and workplace factors and pressures. We want our doctors to learn new skills and gain knowledge, because it will be better for our outcome, and the next polio survivor's outcome.

Taking the problem on is the stage where the CPWs hit a barrier in obtaining the attendance of medical professionals. While Polio Australia (and other organisations!) are trialling strategies to overcome this, as a patient the best thing to do is be prepared for it and provide an *impetus for learning*. (This will be the topic for my next article in *Polio Oz News*.)

In the meantime, it is useful to remember to "*teach one thing, not everything*", when leading a doctor to educationally invest in your condition. Giving them the key to the most pertinent entry door is better than describing the whole house – they will find what they need if they have an entry point and are motivated to learn.

Understanding the persistent power of the written word is useful. You can deploy writing at various instances in your healthcare experience to procure attention and create influence.

- Write appreciation, thank you, positive, or encouragement letters, to show goodwill and optimism to the doctor (and their staff).
- Write additional notes on any form that both you and your doctor sign, to show attention to detail, and the inclusion of anything they may not be considering (but you are).
- Keep a diary of 'your end of the deal', related to what you were asked to do on previous interactions, and produce it to show your proactivity and accountability.

Also remember to write down (and bring!) your questions to your consultations with doctors. It is easy to be overwhelmed by the interaction and environment, and forget an important reason for being there. Exit the consultation with a list of answers and what you need to do.

My Rotary Story



By Sue Mackenzie

Polio Australia Board Member

I contracted polio at the age of 2 in NZ. Like everyone, I managed life as best I could.

In 2012, I started having nasty falls (more than usual). I thought my polio leg was causing the falls but the doctors' comment was, "Polio? But that's gone!"

I Googled 'Polio in Australia' and discovered . . . **I was not alone!** Never in my 65 years had I spoken to another polio person. At my first Polio Retreat in 2013, I learned, and am still learning, how to manage the Late Effects of Polio.

My question to Maryann Liethof was, "How can I help?" She responded with, "Go talk to Rotary Clubs, Sue. We need to reconnect. Oh, and don't expect any help from me!"

Oooh – OK – sounded a bit brutal . . . but off I went! (We all know that Maryann gives her help unconditionally.)

By 2015, I was presenting talks using the "We're Still Here!" campaign information provided by Maryann. I followed the script to the letter, with emphasis on raising much needed funds to help maintain the running of the Polio Australia office and Maryann's salary.

Five years later, and after more than 25 presentations to Rotary Clubs in Cairns, Tablelands, Townsville, Sunshine Coast, Gold Coast, and Brisbane (to name a few), I am pleased to report that I have contributed significantly towards generating funds for the Polio Australia office. This also includes organising several successful fundraising events.

Gaining public support was hard at first, with the usual comment "but polio has gone, hasn't it?" However, the fund and awareness raising

campaigns grew. I am proud to say that I can now gather together a crowd of 100 plus people for an event. And all those people are now more familiar with the concept of polio and its late effects.

Stepping out of my 'polio zone' – or even acknowledging it – was hard. I had managed to hide it most of my life, so no one knew I had a 'polio leg'.

It has been hugely therapeutic for me, and I am privileged to have worked with Maryann, Gillian Thomas, John Tierney and others connected to Polio Australia.

Rotary has gone full circle for me, from childhood Rotary picnics, to sharing the "We're Still Here!" story with Rotarians. And now, to complete the circle, I am a proud Rotarian myself!

Merry Christmas! 🎄



My Dealings With Rotary

And why I talk about POLIO!

By Gary Newton

Polio Australia Board Member

My journey as a Rotarian officially started on July 3rd last year when I was inducted into the Rotary Club of Geelong East. However, previous to this, in January I had been a Rotary Ambassador and travelled to India with my wife and 3 polio survivors to help Rotary's PolioPlus program (the Global Polio Eradication Initiative) and to talk to polio survivors in India about forming support networks with Rotary help.

Also last year, I spoke at two Rotary District Conferences (Sale, Victoria and Mt Gambier, South Australia) about my polio journey and the impact polio is having on its survivors. In particular, its late effects and the need for Rotary to refocus on its original resolution over 30 years ago: "the eradication of polio and *the alleviation of its consequences*" so as to provide support to polio survivors via Polio Australia's Clinical Healthcare Workshops.

Clinical Practice Workshop Review *(cont'd from p7)*



Ideally, we would like all our doctors, therapists – all our healthcare providers – to sound like this at the mention of LEOp:

"What I want to do, is be able to make any modification that you are interested in that would help you have a more comfortable, enjoyable life."

My Dealings With Rotary *(cont'd from p8)*

Over the past 12 months I have continued to grow in the role, giving talks to Rotary, Probus and school groups about polio, my lived experience and its lifelong impact, so as to help the wider community gain a greater understanding and awareness of polio.

During October's Polio Awareness Month, I gave four talks including Horsham, Boronia, Mt Gambier, as well as a MUNA guest talk to students at Berwick Grammar in Officer, near Dandenong.

MUNA is yet another of Rotary's many projects involving young people, and stands for Model United Nations Assembly. I feel it is so important to talk to tertiary students about polio and the value of vaccines.

Response to my talks has been very encouraging, with many in the room moved at times to tears when they hear about polio and its influence on the world, many for the very first time.

I enjoy being that 'switch', taking the often unfamiliar word 'polio' and turning it into something more by providing a 'human face' to create awareness.

Following my presentation, many of the Rotary clubs have made significant donations to both the Rotary PolioPlus eradication effort and to Polio Australia, in support of their vital education workshops.

The Rotary path is an interesting one and well worth exploring because Rotary takes ordinary

Intelligent words indeed, and undoubtedly experienced ones, given that they are from Dr Lauro Halstead (an advocate and campaigner of polio survivors for many decades).

Ultimately, healthcare is an interaction, with communication and some type of transaction. We can't choose the personalities and stressors that our healthcare providers have, but we can choose to be informed about how the system and the people working in that system operate.

The CPW program is one part of the multifaceted approach mentioned earlier, that is striving to reduce the information and communication gaps between healthcare providers and polio survivors. Your part is just as important: The ongoing interaction of many individuals prompting their healthcare providers to learn, and patients having reasonable expectations of informed treatment, adds weight and immediacy to the goal we share. 🌟

people and provides them with an opportunity to do something extraordinary, like eradicating polio.

As I see it, there's much to be gained by fostering a solid relationship with Rotary, such as: travel/educational scholarships; supporting clinical workshops and more; plus renewed energy for Rotarians when they learn firsthand what their hard work is achieving.

I'm enjoying my time in Rotary, spreading the word about polio and the fact that "We're Still Here!", so I shall continue locally, nationally and internationally doing so for as long as I am able. 🌟



Polio Health And Wellness Retreat 2019

By *Maryann Liethof, National Program Manager*

Polio Australia ran its final Polio Health and Wellness Retreat from Thursday 17 to Sunday 20 October, for 55 participants. Details of the sessions and available handouts, presenters, and photos can be found online here: www.polioaustralia.org.au/retreat-2019/. Thanks for the memories! 🌟

Feedback comments included:

Polio Survivors

- Another magic day – the facility, the outside environment, the program and support/attitude of staff are magic. I've had a ball – learnt a lot about myself and others. Enjoyed meeting people and sharing. Thank you all for your work and commitment to making this Retreat the meaningful experience it is for me and, I'm sure, everyone else. Many thanks for the new learnings and memory.
- Each presentation contains information that is applicable to me or if implemented would be beneficial. Getting the idea that LEOp can be complex and that regular exposure to information is required to maximise its usefulness and benefits.
- Excellent - professionally organised, peacefully executed – loved it!! Thank you for the experience.
- I've gained help in some way from each Retreat and look forward to what the new team can do to help us.
- Thank you – first time – very informative and well organised. Gave me directions to follow up.
- I don't know how you do it. Every year has been a 'pure gift'. Thank you from the bottom of my heart. I loath to think where we would be if not for our incredible Retreats and professional and personal input! Thank you! Thank you!!
- Thank you for allowing me to walk along God's Highway with other Retreaters.
- Excellent opportunity to meet other polio survivors and exchange information and history.

Carers

- The usual informative, uplifting occasion. It will be sad to see them go, but I can see the advantages of the day information sessions, particularly the names of local doctors and physios, etc, who know about polio.
- As the partner of a polio survivor, I have found this Retreat, its organisers and the beautiful people I have met, as a rewarding, life-long experience.
- In general, another well run, well presented event. Sorry it's the last, but looking forward to other new things to come.

The Bush Music Club



Guest Speaker: Michael Lynch AO CBE



Early Polio Memories Session

Polio Australia's Life Fellows

Submission to the Board of Polio Australia at the 2019 AGM
By Brett Howard
Vice President, Polio Australia



After more than 10 years of Polio Australia since Incorporation in the 2008/2009 financial year, there are some changes happening in the future. There has come a time when we MUST recognise the input of four very important people in the history of Polio Australia. I would like to speak to our official recognition of these four toilers.

Other organisations would offer "Life Membership", but Polio Australia Membership consists of States only, so individuals cannot be offered "Life Membership". Our four Superstars will be presented with a "Life Fellow" pin in recognition of service to Polio Australia.

So, to the nominees for the much-deserved accolades:

Gillian Thomas has been advocating for an Australia wide organisation to support survivors of polio since before a meeting in Victoria in 1991 which included input from New Zealanders, so people were beginning to talk about LEOp. There were almost annual attempts to get a single group to represent all Australians enduring LEOp. In 2005 at Polio Network Victoria's Polio Day, Gillian floated the idea of a "Think Tank". In May 2007 all networks met in Sydney and from this gathering a Memorandum of Understanding and Constitution were developed with agreement from all States, and incorporation followed. So, over the next 11 years Gillian almost needed an address in Canberra with the amount of time spent there lobbying Members of all political persuasions to support polio survivors. Gillian has also been President or Vice President of polio Australia since 2008 as well as being 'defacto' Treasurer and 'go to' person for any queries re Polio in Australia.

Dr John Tierney AM, our esteemed Patron and the First Parliamentary Friend of Polio Australia even before the title was adopted. John was a Member of the Australian Senate from 1991-2005 and was a special Parliamentary Advisor to the Minister for Community Services on Disability matters. He was also advisor to Polio Australia on the 'correct' way to apply for funding so that Government Departments would actually take notice of what was being requested. In December 2012, John was elected President of Polio Australia at the Annual Board Meeting, John served in this position until the Board Meeting in November 2017. John continues as Patron and Elder Statesman for Polio Australia.

Now we come to one of the most indefatigable people I have had the honour of meeting. After working at Polio Network Victoria from 2004 and representing Victoria on the Management Committee of Polio Australia, after a small

philanthropic donation, **Maryann Liethof** became the National Program Manager of Polio Australia in 2010. In 2007 Maryann was awarded a Churchill Fellowship which enabled her to tour North America to study "*techniques to better manage the Late Effects of Polio*" in 2008. The following year, in 2009, Maryann returned to Warm Springs in Georgia for Post-Polio International's Health and Wellness Retreat and 10th International Conference. The Warm Springs Retreat enabled Maryann to learn the benefits of the holistic self-management model for chronic conditions. From this experience came Polio Australia's first Health and Wellness Retreat in 2010 which of course was coordinated by Maryann. Wellness Retreats became an annual event except in 2016 when Australia hosted The Australasian Pacific Post-Polio Conference. The input for the Conference by Maryann again was immeasurable. Sadly, the final in this series of Wellness Retreats will be held at St Josephs from 17th-20th October. The editor of *Polio Oz News* keeps us all in Australia informed as to what is happening in the Polio world from around the world. Following a Board Meeting a few years ago which approved a pay rise in recognition of her work, Maryann made the decision to 'refund' it by way of an annual donation back to Polio Australia, stating the job provided its own rewards. In short Maryann has dedicated her working hours (and plenty more besides) to educating survivors about the LEOp and presenting Polio Australia as a very professional organisation.

Last but by no means least, **Jill Pickering** has been a very 'anonymous' philanthropist for Polio Australia since it began. Also from Victoria, Jill believes that brumbies in the Alpine National Parks need to be protected, but her second love is support of Polio Australia. Jill accompanied Maryann on her Churchill Fellowship tour. As a trained Occupational Therapist and polio survivor, Jill had informed insights to assist in understanding what was being shown to Maryann. Polio Australia simply wouldn't be the organisation it is today without Jill's unflagging generosity; her ongoing donations have paid for Polio Australia's office space and equipment, and now for Steph Cantrill's salary.

To finish, if the world were different there would be two more people on this list, and I would like to mention these friends of mine. **Neil von Schill** was the Treasurer for Polio Australia until his untimely passing in May 2014. Neil was one of the posse who haunted Parliament House, lobbying for better support for Polio Survivors. The other is **Peter Garde**, the partner/carer of our esteemed President, Gillian. Peter has accompanied Gillian on all of her lobbying trips to Canberra and to all the Wellness Retreats and all other polio events that Gillian has attended. Peter has supported Polio Australia in a selfless way. 🌟

Polio NSW Celebrates 30 Years

In 1987 a number of Australians attended the Fourth International Polio and Independent Living Conference in St Louis USA at which some 800 people were present. Many of these people were polio survivors and a high percentage reported noticing recent signs of one or more of undue muscle fatigue, muscle and joint pain, respiratory and muscle weakness.

In 1988 Professor Irving Zola, a member of the International Polio Network and himself a polio survivor, accepted an invitation to be keynote speaker at Australia's first post-polio seminar which was held in Sydney. The seminar elected a working committee of polio survivors to establish the Network with the aims of:

- Establishing support groups for polio survivors
- Providing information on polio and its late effects
- Encouraging research into the late effects of polio

The Network (now known as Polio NSW) was officially established in 1989. Fast forward thirty years and "we're still here!", continuing to provide information and support to polio survivors, their families and carers. 🌟

Picture caption: 30th Anniversary birthday cake, cut by three Polio NSW Life Members (l to r) Nola Buck, Gillian Thomas and Merle Thompson



What Are You Going To Do When You Retire?

By Maryann Liethof

This is a question I have been asked numerous times since I announced my retirement at the end of 2019. And fair enough, too! After all, I'm only turning 60 this month, and there's a lot of living left to do. However, I am very much looking forward to exploring my leisure options, and spending time with my older partner, Bill. Oh, and travel—LOTS of travel!

As mentioned in my Editor's piece on page 3, I will continue editing *Polio Oz News* as a volunteer, as well as become an independent Board member, i.e. not representing any of the state Polio Networks. Having worked with the post-polio community since 2004, I think I have something to offer in this space.

There are many polio survivors I have met along the way who have supported my 16 year journey in this career. Many have become friends, and the collective community, a kind of 'tribe' that adopted me. I have laughed and cried with people, and quickly developed a strong passion for advocating on behalf of the post-polio community. Although I have had many jobs since entering the workforce at the age of 17, supporting polio survivors has been both a calling and my life's work.

I joined ParaQuad Victoria in May 2004 as Polio Network Victoria's 4th Polio Community Officer. I

knew nothing about polio, but I was a qualified Community Development Officer. The work involved supporting 16 support groups, writing the *Polio Perspectives* newsletter, working with a very active Community Advisory Group, running the annual Polio Day, and more. I thought I had the best job in the world! A couple of years later, ParaQuad Vic became Independence Australia (IA), and strategic priorities changed, effectively reducing polio-related services and the scope of my role.

However, during my five years at IA, I was encouraged by a savvy polio survivor to apply for a Churchill Fellowship, which I was fortunate enough to get. Fellowships are awarded to individuals based on projects that can help improve the lives of Australians. My project was "To identify techniques to better manage the late effects of polio—USA, Canada". In 2008, I took off to North America for a 6 week tour of polio-related groups, institutions, and appointments with key individuals. I was joined by my volunteer and polio survivor, Jill Pickering.

This was a fantastic learning and networking opportunity, and an excellent insight into travelling with someone with a disability. (The time spent travelling was a combination of annual leave and leave without pay.)

What Are You Going To Do When You Retire? *(cont'd from p11)*

When I returned to Australia, I organised 8 separate Polio Days across Victoria, where I shared my experience and vision for our post-polio community. I was also invited to speak to groups in Tasmania, New South Wales, South Australia and Queensland, which was a real joy.

In 2009, I successfully applied for a grant which enabled me to return to Warm Springs, Georgia, to attend Polio Health International's Health and Wellness Retreat, immediately followed by a major post-polio conference. On this occasion, I was joined by 4 other Australian polio survivors. It was this trip that inspired me to introduce the Polio Health and Wellness Retreats to Australia.

In 2008, Polio Australia was incorporated with a vision to represent Australian polio survivors at a national level. I was on the Board of Polio Australia, representing Victoria. However, although all the state Polio Networks were keen to progress this vision, there was no paid staff to perform tasks. It is very difficult to realise organisational goals without dedicated workers!

So in 2009, as my role at IA was dissolving, I spoke to the President of Polio Australia and Polio NSW, Gillian Thomas, to discuss if funding could be obtained to pay a salary. Polio NSW successfully applied for a \$35,000 grant, and I subsequently resigned from IA in December.

I got to work immediately to set up an office for Polio Australia in January 2010. For the first year, I worked part-time; then we received a 3 year grant from the Balnaves Foundation, which enabled me to become full-time. Of course, the first activity I facilitated was a Polio Health and Wellness Retreat. Having now run 9 successful Retreats—according to the participants, that is—I can confirm that the Warm Springs trip was worth it!

In 2010, the connections I'd made during my 2 visits to North America notified me of a European Polio Union (EPU) Conference being held in Copenhagen in 2011. There was a lot of new research being done by the Europeans, so this was very appealing. With Polio Australia being a self-funded charity, we agreed to jointly fund the trip. I put in an abstract to do an oral presentation on Polio Australia's Health and Wellness Retreats, which was accepted. As with the Warm Springs Retreat and Conference in 2009, a few of the same Australian polio survivors also attended.

Both Post-Polio Health International and the EPU scheduled international conferences in June 2014. What to do? Go to both, of course! I flew to St Louis at the beginning of June, then up to Canada to see my relatives, before heading over to Amsterdam. It was an amazing trip. Those keen Australian survivors I'd travelled with previously, also came to Amsterdam. We have now become firm friends.

These trips provided the latest post-polio research and management strategies, and also informed me in what to aim for in Australia. However, they provided vital links to the real 'movers and shakers' in post-polio services, research and management. Many expressed an interest in coming to Australia, if a conference could be arranged. But how could our small self-funded charity possibly afford it? On recommendation, I approached Simon from Interpoint Media, who magnanimously agreed to take on our 'charity project'. The result was the highly successful 2016 Asia-Pacific Post-Polio Conference in Sydney. This was definitely a career highlight for me. Hundreds attended from Australia and beyond, and the key presenters were world-renowned experts from Australia, New Zealand, the USA, and Europe.

Information on all the conferences mentioned can be found online here:

www.poliohealth.org.au/post-polio-conferences/

From 2010 to 2017, I was the only full-time, paid staff member for Polio Australia, which was both challenging and limiting. However, after years of lobbying federal government—led by Dr John Tierney AM (Polio Australia's Patron and past President), we were *finally* awarded a modest grant by The Hon Greg Hunt, the (then) new Minister for Health. It was enough for me to be able to employ Rachel Ingram, Health Promotions Officer, and Paul Cavendish, Clinical Health Educator, who established the much-anticipated Clinical Health Education Program. A further generous 'living legacy' donation from Jill Pickering, meant we could also employ Steph Cantrill as Community Engagement Officer. I finally had a TEAM! In 2017, we received another generous 2 year largesse from Spinal Life Australia to employ Bonnie Douglas to work on fundraising, and Samantha, a casual Bequest Officer. Jake joined us for a while as an Administration Officer. Samantha finished up in 2018, and Bonnie and Jake's contracts ended in 2019. This year, Paul has been succeeded by Michael Jackson, and we now have a Resource Manager, Darlene Felsch.

On my departure from the office, Rachel is stepping up to the role of Program Operations Manager, and she and Darlene will jointly manage Polio Australia's operations. Michael will be educating health professionals, and Steph will continue to work with the community.

I know Polio Australia is in safe hands with this passionate and proactive team, and I do believe the organisation is ready for the next phase in its development.

I am truly blessed to have found stimulating work that I have felt passionate about. I have done my best to help achieve better outcomes for Australia's polio survivors, who have always been my inspiration. It has been a pleasure and my honour to serve. 🌟

Supporting Polio Australia

Polio Australia would like to thank the following individuals and organisations for their generous support from 1 August to 30 November 2019. Without you, we could not pay our rent, core operating expenses, or management staff!

Hall Of Fame

Jill Pickering Dr Christine Tilley

Joan and Graeme Smith Pam Tierney

Total—\$64,200

General and Regular Donations

Anonymous x 3 Jill Burn Liz Telford Gillian Thomas Timothy Rowley

Bruce May Margaret Schneider Jeannette Aldridge Wyndham Ladies' Probus Club

Total—\$2,054

Rotary Donations

Rotary Club of Central Melbourne / Rotary Club of Horsham

Rotary Club of Mount Gambier West / Rotary Club of Boronia

Total—\$3,370.00

Walk With Me and Rotary Club of New Farm Wine With Me Donations

Total—\$4,957.75

Grand Total—\$74,581.35



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Post-Polio, My Wife, and My Dog

By **Alpheus Williams**

Source: [Seniors' Stories](#) – Volume 5, p131
Reprinted with permission from the author.

Four am, two days ago, I fell on my way to the office, walking down the ramp in the dark. I released the grip on my forearm crutches to open the door and collapsed. It was an unprotected fall. I went down like a puppet with cut strings. I didn't have time to protect myself. Hurts like hell especially falling on concrete. I fell on concrete. I don't think I broke anything this time but everything hurts.

Today I'm in the office, messing around on social media, I should be writing. My wife comes in at six am to take the dog for a walk on the reserve running along the river. I take my walking bike.

I modified the bike about five or six years ago. I bought it cheap. It's just a kids BMX bike. One of those short ones. I knocked the sprocket and peddles out of it, so I could take the weight off my body but still get around by using my legs. It works a treat and I can go for walks with my wife and dog in the morning. We walk a couple of blocks, cross the road and enter the reserve. 'J' lets the dog off her lead. She runs and gambols across the grass. We can't help but share her *joie de vivre*.

'G' stands at the boat ramp looking out over the river. He sips from a giant cup of coffee. He's on his own, all full of quiet and thought. Our dog runs up to him, says hello, gets a pat on the head. She sprints back to us, her tail is a happy blur as she bounds back to us with her mouth open and tongue hanging out in a smile gone all goofy.

The grass is wet with dew and the sun is coming up over the ocean at the river mouth. The sky is all flushed pink, purple and red. It's a beautiful thing. Three black faced spoonbills fly across the sky, graceful and white. They float like dreams, land across the river on the sandbank and wade in the shallows. Small fish scatter at their approach, ripples of retreat on the water. Our dog, a border collie, loaded with fun and energy sprints out in front of us and returns as if on some sort of giant rubber band.

The morning is mild enough to sit out on the deck for breakfast and why would you want to sit anywhere else on a day like this? Butcher birds sing in a large pine tree that looms over the neighbours' roofs. I've cooked *okonomiyaki*, or at least my version of it. J sets the omelets on the table. I lean my crutches against the wall and open the fridge to get the ice water and go down again. At least this time it's on the timber deck and not as painful, but it's painful enough. I roll around on the ground like a worm on a hot tile.

It hurts. The dog commando crawls on her belly towards me, I can feel her breath on my face. The eternal empathy, she's concerned. I'm touched. My wife is there too. I don't know who hurts most, me, the dog or my wife. I manage to get into the chair. Swallow the pain and settle in for breakfast. I feel a lot better after coffee.

After breakfast we drive into town and J does the shopping. I sit in the front seat and roll the windows down. The dog crosses from the back into the front and settles in next to me.

When J finishes the shopping and loads the car, I drive us back to the village. We stop at the little shop to pick up our mail. The river looks lovely. It's warm enough. We drive to the cottage and I change into swimmers. J drives me back to the river. She and dog sit at a picnic table as I go in the river. The tide is on the way out and the water is crystal clear. Small bream scatter beneath as I swim against the current for a time. When I finish, I join J and the dog at the bench and dry off. We drive home and prepare lunch. Eat out on the deck, watch birds flit in and out of the giant pine.

I haven't fallen in at least a couple of years. Twice in so many days is a bit unsettling. I weighed this morning and have put on a few kilos. It's essential that I lose them. Everything is different now. When you get polio you fight like hell to do what others can do, to stay mobile, to be independent. When you get post-polio syndrome you can no longer do that. The more the push the more damage so the less we can do. It's like mass murder on nerves cells. It's all about pace and planning.

I will think things out. Lose a little weight. Do what needs to be done. This is my life now. I love my wife. I love my dog. I love my life. 🌟



My Positive NDIS Experience

By Jan Williams

Contracted polio 1955—age 18 months

The National Disability Insurance Scheme (NDIS) in south east Queensland came online early in 2018. However, it was not until early July, just 3 months before my 65th birthday, that I telephoned the National Disability Insurance Agency (NDIA) to enquire about my eligibility for the scheme. And I must say, from the beginning my experience has been an extremely positive one.

For ease of explanation, I will dot point my journey through the system:

- Following my initial telephone call NDIA posted me the appropriate application paperwork for completion (received within a few days).
- I completed my section (surprisingly not as much paperwork as I expected). Then a visit to my GP for him to complete the relevant paperwork.
- Duly completed, I returned this to NDIA.
- Mid-August, I received a phone call advising that my application had been accepted and that I would be contacted in due course by an NDIA representative in my local area to arrange a meeting to discuss my needs and set up my plan.
- This meeting took place in early September in an unhurried (about 2.30 hours) session where my current and possible future needs were discussed with me at length, my entitlements under the system clearly explained, and a plan for the next 12 months set up.
- As I am self managing my plan, it was explained that the plan drawn up at that meeting now needed to go to NDIA assessor for approval, that I would be advised when this was done, and would have an area co-ordinator assigned.
- I received a call mid-October confirming approval of my plan and making an appointment to meet with my NDIS Area Co-ordinator. At this meeting, the self management of my plan was gone through in detail and my access to the NDIS online Portal explained.
- From here, it was over to me. My plan included a couple of items for which I needed an assessment by an occupational therapist, including relevant quotes from suppliers. The items were a replacement chair unit for my (20 year old) internal stair lift, and replacement of my much used and worn travel mobility scooter. NDIS website lists registered providers in my area and I arranged for a local Occupational Therapist to undertake these assessments. This was done promptly and the OT sent the necessary paperwork directly to

NDIA for approval. This happened early in January.

- By early March, approval had come through from NDIA and I had the items shortly thereafter.

A third item listed by NDIA as considered necessary, was the replacement of my 43 year old right, below knee orthotic, made in Melbourne in 1976. To this end, I required an assessment and quote by a registered orthotist. I elected to travel to Melbourne to meet with Darren Pereira at Neuro-Muscular Orthotics in Clayton. Prior to attending this appointment, I contacted my NDIA Planner to advise what I was arranging. I asked what timeframe I might be looking at for approval, particularly in light of the fact that I live in Brisbane (I point out here that travel to Melbourne was at my expense, as it was my choice to select this particular provider). My planner indicated that if the assessment and quote could be emailed from the provider while I was in Melbourne, every effort would be made to get approval almost immediately so I wouldn't have to make a second trip.

Long story short, this is exactly what happened! Hence, following a week in Melbourne, fitting, manufacture and trialling my new 'leg', I returned home.

The above covers the three things considered most important to assist with my daily life, and I cannot stress enough how impressed I have been with the assistance and support I have received. I do feel that being self managed is advantageous as it is up to me to make sure appointments for assessments are made, ensuring follow up with quotes etc.

I also believe that keeping both my NDIA and NDIS co-ordinators in the loop (in the main via email) with progress of what I was undertaking, was extremely valuable.

My plan continues to be monitored and I receive a phone call from my NDIS co-ordinator about every 8 weeks to check whether I need any further assistance.

All in all, my experience with NDIS has been extremely positive. Having said this, I must add that each State and Territory are independently managing the scheme, so I am only able to comment from a Queensland perspective. 🌐

[Click below for Polio Australia's NDIS Fact Sheet.](#)



Acting To Improve Aged Care

By Greg Hunt MP

Federal Member for Flinders
Federal Minister for Health

Source: [Media Release](#) – 25 November 2019

The Morrison Government is taking strong action to respond to the three priority areas identified in the Aged Care Royal Commission's Interim Report released on October 31, by increasing home care packages, reducing chemical restraints, and getting younger people out of residential aged care.

The Royal Commission's interim report is clear – as a country, the Government, the Aged Care Sector and the entire Australian community, we can and must do better in providing improved support for our older Australians.

In response to this interim report, we will deliver a \$537 million funding package across the identified three priority areas, including:

- investing \$496.3 million for an additional 10,000 home care packages;
- providing \$25.5 million to improve medication management programs to reduce the use of medication as a chemical restraint on aged care residents and at home, and new restrictions and education for prescribers on the use of medication as a chemical restraint;
- delivering \$10 million for additional dementia training and support for aged care workers and providers, including to reduce the use of chemical restraint; and
- investing \$4.7 million to help meet new targets to remove younger people with disabilities from residential aged care.

Increasing the number of Home Care packages

The additional 10,000 home care packages will be focused on the Royal Commission's identified areas of need and is strongly weighted towards level 3 and level 4 packages, which provide a high level of care. These packages will be rolled out from 1 December 2019.

Since the 2018-19 Budget, the Government has invested \$2.7 billion in 44,000 new home care packages.

Better medication management and dementia training

The Royal Commission has identified an over-reliance on chemical restraint in aged care, therefore from 1 January 2020, we will also establish stronger safeguards and restrictions for the prescribing of repeat prescriptions of risperidone.

Doctors will still be able to prescribe it but will be required to apply for additional approval if



risperidone is to be prescribed beyond an initial 12 week period. These changes have been developed following recommendations from the Pharmaceutical Benefits Advisory Committee, and in collaboration with doctors' groups and the broader health sector.

Education resources for prescribers will also be developed to support the appropriate use of antipsychotics and benzodiazepines in residential aged care and targeted letters will be sent to high prescribers.

Funding for medication management programs will be increased by \$25.5 million, including support for pharmacists to ensure more frequent medication reviews can occur.

The Royal Commission directed that restraint must only be used as a last resort, and amendments to regulations will make this clear.

The Government is also providing an additional \$10 million over two years from 2019-20 to increase dementia training and support for aged care workers and health sector staff.

This will better equip them to manage behavioural and psychological symptoms of dementia, deliver best practice dementia care and comply with the new standards for reducing the use of physical and chemical restraints in aged care.

We have also responded immediately to the Royal Commission's findings on antipsychotics in aged care facilities by declaring "Quality Use of Medicines and Medicines Safety" a National Health Priority.

Younger people in residential aged care

In March, the Government announced the Younger People in Residential Aged Care Action Plan. Since this time there has been a reduction in the number of younger people in residential aged care, including a decline in the number of younger people entering the aged-care system.

Acting To Improve Aged Care *(cont'd from p17)*

However, in response to the Royal Commission, the Government will strengthen the initial targets of the Younger People in Residential Aged Care Action Plan.

The new targets, apart from in exceptional circumstances, will seek to ensure there are:

- no people under the age of 65 entering residential aged care by 2022;
- no people under the age of 45 living in residential aged care by 2022; and
- no people under the age of 65 living in residential aged care by 2025.

The Government will invest \$4.7 million to help remove young people from residential aged care and further support these goals by:

- establishing a Joint Agency Taskforce (JATF) between the Department of Social Services, Department of Health and National Disability Insurance Agency (NDIA) to develop a new strategy that builds on the Action Plan and takes action to ensure these new targets are met;
- establishing a specialist team within the NDIA to prevent younger people with a disability who are eligible for the National Disability Insurance Scheme from entering aged care. The specialist team will grow to 80 complex support needs planners by end March 2020 to find suitable accommodation and match participants to vacancies;
- working with industry to identify all available Specialist Disability Accommodation and Supported Independent Living supports across the country to develop a database of existing and new housing options available now and in the future; and
- undertaking a detailed analysis of younger people currently living in aged care, as well as up to 2,000 young people at risk of entering aged care, to better inform new policies and pathways to find alternate accommodation.

Building on longer term reforms

These measures will complement the major reforms the Morrison Government has been undertaking to improve standards, oversight, funding and transparency in the care of older Australians.

In line with the long-term direction as identified by the Royal Commission, we will also progress further measures, including:

- providing simpler aged care assessments by creating a single assessment workforce and network; and
- establishing a single unified system for care of our elderly in the home.

We will unify the Home Care and Commonwealth Home Support Programs, in line with the Royal Commission's direction to deliver a seamless

system of care, tailoring services to the needs of the individual.

These changes will be guided by the final recommendations of the Royal Commission and will have the goal of improving care and ending the wait for home care packages.

Simplifying the system for consumers

The Government will streamline assessment by creating a single assessment workforce and a single network of assessment organisations that are able to undertake all aged care eligibility assessments.

This will help people to be connected to care sooner, reduce duplication and inefficiencies, and stop a revolving door of assessments where vulnerable older people get sent to multiple organisations depending on the programs for which they are eligible.

Key reforms continue

The Royal Commission's final report is due on 12 November 2020, however the Government's rigorous oversight of the sector and reform program continues.

The Government has established a new independent aged care watchdog in the Aged Care Quality and Safety Commission, upgraded Aged Care Quality Standards and introduced regulations to minimise the use of restraints, and we are developing a Serious Incident Response Scheme.

The Government is also expanding the powers of the Commission, with the new Commissioner responsible for the approval of aged care providers, compliance and enforcement actions in relation to the care being provided, and the administration of the responsibilities of approved providers to report assaults.

While we undertake these reforms we will continue to deliver record funding for older Australians of \$21.7 billion in 2019-20, growing to an estimated \$25.4 billion in 2022-23, up from \$13.3 billion in 2012-13.

There will be more work to do across aged care as we continue to listen and respond to the issues raised by the Royal Commission.

Like every Australian, we were appalled by the revelations of the Interim Report, however we will do everything we can to build an aged care system of the highest quality. 🇦🇺



Telehealth Changes

Telehealth Changes Improve Remote Australians' Access To A Doctor

The Hon Greg Hunt MP
Minister for Health

Source: [Media release](#)—29 October 2019

Australians in some of the most remote parts of the country will soon have greater access to a doctor, with the Morrison Government investing \$45.5 million in GP telehealth consultations.

Minister for Health Greg Hunt said, "From 1 November 2019, GPs will be able to conduct regular telehealth consultations with their patients in remote areas, with rebates available through the Medicare Benefits Schedule."

"This expansion of Medicare rebates for telehealth will help improve the quality and continuity of care for patients in areas classified as Modified Monash Model 6 and 7, which encompasses remote parts of Western Australia, the Northern Territory, Queensland, New South Wales, Victoria, South Australia and Tasmania."

The Government will invest \$45.5 million over three years from 2019-20 for this initiative, which aims to encourage patients to maintain a strong relationship with their existing GP.

Minister for Regional Services, Decentralisation and Local Government, Mark Coulton said, "This initiative demonstrates the Government's determination to ensure that Australians who live in remote areas are able to access world-class health services."

"These changes will be implemented through 12 new telehealth specific items being included on the MBS. Expanding the range of services means that patients will get more access to health care," Minister Coulton said.

To be eligible for subsidised telehealth consultations, patients are required to:

- live in a Modified Monash Model 6 or 7 location;
- have an existing clinical relationship with the GP providing the telehealth consultation (defined as three face-to-face consultations in the past 12 months); and
- be at least 15 kilometres by road from the GP.

"A range of existing MBS telehealth arrangements are already in place, including extra telehealth support for people in drought-affected areas," Minister Coulton said.

Minister Coulton said Medicare also supports specialists, consultation physicians and psychiatrists to conduct telehealth consultations with eligible patients in non-metropolitan areas.

"Another telehealth program enables psychologists, GPs, social workers and occupational therapists to provide mental health consultations under the Better Access initiative," Minister Coulton said.

In the eight years to 30 June 2019, the Liberal National Government has funded more than one million telehealth episodes of care, representing an investment of \$155.9 million in the health of Australians living in regional areas. ●



New Pain Services Directory Launch

By Carol Bennett, CEO, Pain Australia

Source: [Painaustralia](#) Blog – 23 October 2019

Living in constant pain day in and day out, pain so all-consuming that it affects your ability to think, communicate, to move. A pain that seems to impact all aspects of your life. It would be an unbearable situation. You want to get help, you want to regain your life. What path might you take to get help?

You might go see your GP. Chances are (3 out of 4 times), she/he will give you a script for a medication. That might help you in the short term, it will dull your brain's perception to the pain, and for a while you will regain function and what may appear to be a measure of normality.

However, the medicine only targets the pain receptors in your brain, not the underlying condition that causes the pain. Over time you may need more, higher doses, as your body builds tolerance to the medicines or your brain becomes more sensitive to the pain. And like all medications, pain relief medicines come with side effects. You could find yourself on a long road, one that many consumers find themselves on, only to find way down in their journey that you are probably heading in the wrong direction.

Only 15% of all GP consultations end with a referral to another health practitioner. This situation is problematic on two fronts. Not only are we pushing millions of Australians towards a pharmacological pathway of pain management, we are also not providing them with an evidence-based way of best practice pain management.

The one consistent question Painaustralia has heard from many people living with chronic pain over the years is not surprising: How can I get the right help?

As always, the answer to the complicated question of chronic pain is never straightforward. For many years we have grappled with the complexities of chronic pain. Sometimes pain cannot be 'treated', cannot be explained, cannot be 'killed' with medication. Effective pain management, the way we respond to chronic and persistent pain, has now become one of those glaring public health challenges. Like pain itself, this challenge is often overlooked or invisible to the public eye.

Fortunately there is a way forward. We know that like all complex conditions, such as diabetes and heart disease, we need to build a team of health professionals around the person living with the condition. You may need a physiotherapist who helps you regain function and mobility for your osteoarthritis, you may

need a psychologist who can help you with the anxiety you experience every month living with endometriosis. It could be a dietitian who assists you in managing your rheumatoid arthritis, or a pharmacist who helps you juggle all the other chronic conditions you deal with along with your complex regional pain syndrome. It may be one, or more, or all of these allied health professions, but having access to them is the best possible chance that you can have at managing your complex chronic pain condition that is unique to you.

This approach to pain management, the psychosocial-bio approach, is central to the aims of both the [National Pain Strategy](#) and the [National Strategic Action Plan for Pain Management](#). Both these visionary documents provide a blueprint for the treatment of pain, recommending an interdisciplinary approach to deliver best practice pain management which takes into account the complex physical, psychological and environmental factors that underpin pain conditions.

This is why today, Painaustralia and the Federal Government have taken a step back to basics and provided consumers with the support they need to make informed decisions around their pain management options and pathways.

The [new interactive directory](#) launched by Minister Greg Hunt today includes a geographical location tool that can visually show the pain services nearest to your postcode. The Directory lists over 200 facilities both public and private, as well as offering the list of services provided by each facility.

Categorised by 3 levels, based on the [International Association for the Study of Pain's \(IASP\) recommendations for Pain Treatment Services](#), the Directory lists Multidisciplinary Pain Clinics, Pain Management Services as well as pain practices. With a focus on providing pain management and specialist care, these services are guided by an understanding that pain is influenced by biomedical, psychological, and social/environmental factors, and treatment that is evidence-based and safe.

The Directory takes us and each of the 3.24 million people living with chronic pain one step closer to achieving greater awareness of pain and pain management, and more timely access to consumer-centred multidisciplinary services, the gold standard in pain treatments available today.

If you can imagine constant pain, you can begin to imagine how useful it might be to find a pathway to best practice care. ●

Two Out Of Three Wild Polio Strains Eradicated

Global eradication of wild poliovirus type 3 declared on World Polio Day

Source: www.who.int—24 October 2019

In an historic announcement on World Polio Day, an independent commission of experts concluded that wild poliovirus type 3 (WPV3) has been eradicated worldwide. Following the eradication of smallpox and wild poliovirus type 2, this news represents a historic achievement for humanity.

"The achievement of polio eradication will be a milestone for global health. Commitment from partners and countries, coupled with innovation, means of the three wild polio serotypes, only type one remains," said Dr Tedros Adhanom Ghebreyesus, Director-General of the World Health Organization and Chair of the Global Polio Eradication Initiative (GPEI) Polio Oversight Board. *"We remain fully committed to ensuring that all necessary resources are made available to eradicate all poliovirus strains. We urge all our other stakeholders and partners to also stay the course until final success is achieved,"* he added.

There are three individual and immunologically-distinct wild poliovirus strains: wild poliovirus type 1 (WPV1), wild poliovirus type 2 (WPV2) and wild poliovirus type 3 (WPV3). Symptomatically, all three strains are identical, in that they cause irreversible paralysis or even death. But there are genetic and virologic differences which make these three strains three separate viruses that must each be eradicated individually.

WPV3 is the second strain of the poliovirus to be wiped out, following the certification of the eradication of WPV2 in 2015. The last case of WPV3 was detected in northern Nigeria in 2012. Since then, the strength and reach of the eradication programme's global surveillance system has been critical to verify that this strain is truly gone. Investments in skilled workers, innovative tools and a global network of laboratories have helped determine that no WPV3 exists anywhere in the world, apart from specimens locked in secure containment.

At a celebration event at the headquarters of the World Health Organization in Geneva, Switzerland, Professor David Salisbury, chair of the independent Global Commission for the Certification of Poliomyelitis Eradication, presented the official certificate of WPV3 eradication to Dr Adhanom Ghebreyesus. *"Wild poliovirus type 3 is globally eradicated,"* said Professor Salisbury. *"This is a significant achievement that should reinvigorate the eradication process and provides motivation for the final step – the eradication of wild poliovirus*



type 1. This virus remains in circulation in just two countries: Afghanistan and Pakistan. We cannot stop our efforts now: we must eradicate all remaining strains of all polioviruses. We do have good news from Africa: no wild poliovirus type 1 has been detected anywhere on the continent since 2016 in the face of ever improving surveillance. Although the region is affected by circulating vaccine-derived polioviruses, which must urgently be stopped, it does appear as if the continent is free of all wild polioviruses, a tremendous achievement."

Eradicating WPV3 proves that a polio-free world is achievable. Key to success will be the ongoing commitment of the international development community. To this effect, as part of a Global Health Week in Abu Dhabi, United Arab Emirates, in November 2019, the Reaching the Last Mile Forum will focus international attention on eradication of the world's deadliest diseases and provide an opportunity for world leaders and civil society organizations, notably Rotary International which is at the origin of this effort, to contribute to the last mile of polio eradication. The GPEI 2019–2023 Investment Case lays out the impact of investing in polio eradication. The polio eradication efforts have saved the world more than US\$27 billion in health costs since 1988. A sustained polio-free world will generate further US\$14 billion in savings by 2050, compared to the cost countries would incur for controlling the virus indefinitely. 🌍

Travelling To The Philippines Soon?

Please get a dose of polio vaccine.

By Mae Yen Yap

Source: sea.mashable.com—30 October 2019

[Polio has returned to the Philippines.](#) And if you plan to travel to and from the country, it is definitely a good plan to get a dose of polio vaccine.

In particular, Filipinos planning to travel to Indonesia are strongly advised to get a dose of the polio vaccine before taking their flights.

If you plan to travel between Indonesia and the Philippines, both embassies highly recommend getting polio vaccination before flying.

Indonesian authorities have recently instructed the Philippine Embassy in Jakarta to increase strict supervision and precautionary measures against Polio Vaccine Derived Polio Virus (VDPV) Type 2, [according to ABS-CBN](#).

Travelers who don't heed the advice and arrive in Indonesia without the immunization requirements will be given polio vaccination on site. They will be charged roughly US\$3 (IRP45,000) for the vaccination.

The embassy also emphasized that travellers who refuse to be vaccinated will be prevented from entering Indonesia and may face deportation from the country.

The Philippines's [third polio case](#) has been reported by the country's Department of Health just recently over the weekend.

Health Secretary Francisco T. Duque III confirmed that the latest case is a four-year old child from the Maguindanao who did not receive any dose of the oral polio vaccine (OPV).

"I enjoin all parents and guardians, to ensure that all of your children are protected from all vaccine-preventable diseases," Duque said.



Samples from another suspected case is currently undergoing examinations at the National Institute of Infectious Diseases in Japan.

If you're planning to travel soon, [the Philippines DOH has released an advisory](#) that can assist you.

- All travellers of all ages going to countries with ongoing poliovirus outbreaks should receive a dose of oral poliovirus vaccine (OPV) or inactivated poliovirus vaccine (IPV) between four weeks and 12 months prior to travel.
- Those undertaking urgent travel who have not received a dose of OPV or IPV in the previous four weeks to 12 months, should receive a dose of polio vaccine at least by the time of departure as this will still provide benefit, particularly for frequent travellers.
- Travelers must secure a Certificate of Vaccination that will serve as proof of vaccination prior to departure.

If you or a loved one haven't gotten a vaccination, please do so as soon as possible. 🌐

Surge In Polio Cases Predictable

By Faiza Ilyas

Source: Dawn.com – 30 November 2019

<https://www.dawn.com/news/1519610/surge-in-polio-cases-this-year-predictable-says-expert>

KARACHI: The surge in polio cases the country has seen this year was not entirely unpredictable given the fact that the environmental samples collected from across the country from March last year till now have shown presence of the polio virus in many districts.

Also, it is important to note that out of 91 polio cases that have surfaced so far, routine immunisation coverage was not found in 60 cases.

These points were highlighted by Dr Ali Faisal Saleem, paediatric infectious diseases specialist at the Aga Khan University (AKU), at a presser organised at the press club on Friday. The event was organised by the Medical Microbiology and Infectious Diseases Society of Pakistan (MMIDSP).

Surge In Polio Cases Predictable *(cont'd from p22)*



"While the country reported only 12 polio cases last year, the test results of sewage samples collected from 35 districts came out positive, suggesting that the situation could be bad this year," said Dr Saleem.

This year, 91 polio cases had been reported in the country, five times higher than last year. Of them, 66 were from Khyber Pakhtunkhwa, most from Bannu district, whereas Sindh had 13 cases.

"The good news, however, is that we have been able to eliminate type two and type three strains of polio," he said.

Speaking about the challenges being faced in polio eradication, he regretted public misconceptions about the safety and efficacy of

polio vaccine and contended one shouldn't have any ambiguity about the vaccine as other countries like Bangladesh and India used the same vaccine to eliminate the crippling disease.

Dr Saleem emphasised the need for strengthening the Expanded Programme for Immunisation and argued that success in the polio programme couldn't be achieved without enhancing the coverage of routine immunisation.

"Out of the 91 polio cases [that have] surfaced so far, 60 cases had no history of routine immunisation," he told journalists, adding that the government's commitments to the programme could be assessed from the fact that it's the first time that it was using its own funds on the cause.

Replying to another question about the negative report on Pakistan's polio programme by an international body, he said the government was engaging all stakeholders now and had set up committees in which all provinces had representation.

"All fears about the vaccine are unjustified and there is a strong need to create awareness and mobilise communities especially the educated segments of society showing hesitance and resistance towards the campaign," he said, adding that the government needed to focus on children being missed in campaigns. ●

Polio This Week

Source: [Polio Global Eradication Initiative](#) — as of Wednesday 27 November 2019

- A four-day regional emergency preparedness workshop is currently underway in Lomé, Togo, for senior public health officials to strengthen the capabilities within West African countries to respond to polio outbreaks. [Read more](#) about the workshop.
- "It was good to know that a country like India could eradicate polio. It gives us hope that Pakistan can do it too, and we will soon be polio free." These are the words of Aziz Memon, a Rotarian who has dedicated his life to fight polio in Pakistan. [Read about](#) his journey.
- Summary of new viruses this week (AFP cases and ES positives): Pakistan— five WPV1 cases, two cVDPV2 cases and one cVDPV2 positive environmental sample; Democratic Republic of the Congo (DR Congo)- five cVDPV2 cases; Benin – four cVDPV2 cases; Ghana— four cVDPV2 cases and two cVDPV2 positive environmental samples; Philippines – three cVDPV2 cases and five cVDPV2 positive environmental samples; Togo – two cVDPV2 cases.



Polio This Week

Source: [Polio Global Eradication Initiative](#) — as of Wednesday 4 December 2019

Wild poliovirus type 1 and Circulating vaccine-derived poliovirus cases

| Total cases | Year-to-date 2019 | | Year-to-date 2018 | | Total in 2018 | |
|---------------------------|-------------------|-------|-------------------|-------|---------------|-------|
| | WPV | cVDPV | WPV | cVDPV | WPV | cVDPV |
| Globally | 113 | 195 | 29 | 104 | 33 | 104 |
| —In Endemic Countries | 113 | 29 | 29 | 34 | 33 | 34 |
| —In Non-Endemic Countries | 0 | 166 | 0 | 70 | 0 | 70 |

Case breakdown by country

| Countries | Year-to-date 2019 | | Year-to-date 2018 | | Total in 2018 | | Onset of paralysis of most recent case | |
|----------------------------------|-------------------|-------|-------------------|-------|---------------|-------|--|-------------|
| | WPV | cVDPV | WPV | cVDPV | WPV | cVDPV | WPV | cVDPV |
| Afghanistan | 21 | 0 | 21 | 0 | 21 | 0 | 17 Oct 2019 | N/A |
| Angola | 0 | 60 | 0 | 0 | 0 | 0 | N/A | 21 Oct 2019 |
| Benin | 0 | 6 | 0 | 0 | 0 | 0 | N/A | 15 Oct 2019 |
| Central African Republic | 0 | 16 | 0 | 0 | 0 | 0 | N/A | 6 Oct 2019 |
| Chad | 0 | 1 | 0 | 0 | 0 | 0 | N/A | 9 Sep 2019 |
| China | 0 | 1 | 0 | 0 | 0 | 0 | N/A | 25 Apr 2019 |
| Democratic Republic Of The Congo | 0 | 50 | 0 | 20 | 0 | 20 | N/A | 7 Oct 2019 |
| Ethiopia | 0 | 3 | 0 | 0 | 0 | 0 | N/A | 8 Aug 2019 |
| Ghana | 0 | 9 | 0 | 0 | 0 | 0 | N/A | 23 Oct 2019 |
| Indonesia | 0 | 0 | 0 | 1 | 0 | 1 | N/A | 27 Nov 2018 |
| Mozambique | 0 | 0 | 0 | 1 | 0 | 1 | N/A | 21 Oct 2018 |
| Myanmar | 0 | 6 | 0 | 0 | 0 | 0 | N/A | 9 Aug 2019 |
| Niger | 0 | 1 | 0 | 9 | 0 | 10 | N/A | 3 Apr 2019 |
| Nigeria | 0 | 18 | 0 | 33 | 0 | 34 | N/A | 9 Oct 2019 |
| Pakistan | 91 | 11 | 8 | 0 | 12 | 0 | 7 Nov 2019 | 3 Nov 2019 |
| Papua New Guinea | 0 | 0 | 0 | 26 | 0 | 26 | N/A | 18 Oct 2018 |
| Philippines | 0 | 6 | 0 | 0 | 0 | 0 | N/A | 2 Oct 2019 |
| Somalia | 0 | 3 | 0 | 12 | 0 | 12 | N/A | 8 May 2019 |
| Togo | 0 | 3 | 0 | 0 | 0 | 0 | N/A | 16 Oct 2019 |
| Zambia | 0 | 1 | 0 | 0 | 0 | 0 | N/A | 16 Jul 2019 |