

POLIO NSW

formerly Post-Polio Network (NSW)

NETWORK NEWS

Incorporating – Polio Oz News

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Editor's Report

Yet another of our members has received an OAM in this year's Australia Day Honours List, life member Nola Buck – see article on page 2. Nola also appears in an article on page 6.

At our 32nd Annual General Meeting (AGM) held on 8th December, 2021 the following members were elected to the Polio NSW Board.

Gillian Thomas	<i>President</i>	Gail Hassall
Susan Ellis	<i>Vice-President</i>	Rosalie Kennedy
Merle Thompson	<i>Secretary</i>	Vasa Marimuthu
Alan Cameron	<i>Treasurer</i>	Bill McKee
Nola Buck		Diana O'Reilly
Ella Gaffney		Shirley White

We welcome two new members to the board, Rosalie Kennedy and Vasa Marimuthu and look forward to working with them when we meet for our Planning Meeting in February.

The position of Online Engagement Officer was taken up by Stephanie Cantrill on 27th October, 2021 and since then Steph has hit the ground running. A seminar was organised and presented via zoom on 8th December, 2021 and was followed by the AGM. Steph works 10 hours per week, Wednesday and Thursday, she has a background in Occupational Therapy. Steph has also commenced setting up an online support group program available to all Polio NSW members. These meetings will be held via Zoom on the 3rd Wednesday of each month at 11am, the first meeting was held on 19th January, 2022. Read Steph's report on page 13.

We encourage you to get involved in the new online projects and to assist you we have included an article written by Steph – "Zoom Step-by-Step Guide" - on page 14. Steph can be contacted by email steph@polionsw.org.au.

If you are on Facebook look up Polio NSW facebook page and "like" us!

In this issue of Network News we have a personal story by member Russell King, articles on Steroids, Good leg/Bad leg, Swallowing Problems, Polio Arms and more.

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CONGRATULATIONS

Nola Buck, current Polio NSW Board Member, life member and past President of Polio NSW has been awarded an OAM in the Australia Day 2022 Honours List for her service to people with disability, and to the community. This is an award that is well deserved by Nola who has been a tireless supporter of polio survivors and of Polio NSW. The lists below outline the many achievements and contributions Nola has made to so many.



MEDAL (OAM) OF THE ORDER OF AUSTRALIA

IN THE GENERAL DIVISION

**Mrs Nola BUCK
NSW**

For service to people with disability, and to the community.

Ability Options

- Board Director, 2002-2019.
- Life Member.

Polio NSW

- Board Member, since 2011.
- President, 1992-1997.
- Public Officer, 2016-2020.*
- Volunteer, 2004-2020.
- Host, International Conference, 1996.
- Co-Editor, Network News, since 2012.*
- Life Member, 2005.

Chisholm Cottage (now managed by Sisters of Charity Outreach, now Open Support)*

- Committee Member, 1995-2006.
- Volunteer, 11 years.

Catholic Women's League

- Diocesan President, 1999-2003.
- Diocesan Vice President, 1997-1998.
- Diocesan Treasurer, 1994-1996.
- Branch President, 1991-1993.
- Branch Vice President, 1996-1998, and 2005-2006.
- Former State Delegate, New South Wales.
- Public Officer, Diocese of Parramatta, current.*
- Life Member.

Other

- Life Member, People With Disability Australia.
- Former Volunteer, Walking with Refugees group.



MY POLIO STORY

by Russell William King, member of Polio NSW

January 1950, my first day at school, Mum was in hospital, and I was staying with Uncle Jack and Auntie Freda. That morning Auntie Freda took a photograph of Frances and I holding hands ready to go off to Thirroul Public School.

Life was normal for the next 18 months until the winter of 1951 when I caught Polio. I can remember having a headache, aching all over and not being able to move very much. Mum had called Doctor Cook from Bulli, he arrived in the afternoon only to confirm my symptoms, that I had Polio, he had arranged for an ambulance to take me to Wollongong Hospital to the quarantine ward.

That night in cold bed not knowing what was wrong and on my own, only with a plastic racing car and a piece of plasticine is a night that I will never forget. The next day doctors came and checked me over and I was then moved out to another ward out on the veranda with 2 other boys that were older than me, I think their names were Peter and Keith.

At this stage I could not move at all, lying on my back with sandbags either side of me. Days later more sandbags around my arms and between my legs, they put an iron frame over the lower part of my body and covered it with a blanket. It was so cold at night that I tried to get the covers over my head to try and keep warm.

Being in quarantine is no joke; nobody came in and nobody went out. Mum used to catch a bus into Wollongong each day to visit but she could only stand on the hill outside and look in through the window. Dad would come at weekends if he did not have to work. Us patients had to take it in turns to talk to our visitors through the window.

The only time that we were moved was at 5am each morning when we were put on a trolley and wheeled down the corridor in the dark for a bath.

Two months later I was able to stand up without falling over and able to walk, this was a good feeling as now I could get things for the other boys and at times we would borrow a trolley and go for a ride down the corridor, the boys would push the wheels with their hands and I would steer them, most of the time we got caught and a nurse would push the three of us back into the ward and then hide the trolley.

The days were long, and the nights were cold, the food was not even a one-star rating, and the other services were poor, and nurses worked off their feet.

Some ladies from a service organization did come and by remote control taught me to basket weave and leather thonging, making wallets and handbags. Occasionally a minister of the church would visit, this was great as it was a new face to talk to. My own minister, Rev William Pollak, came one day and left me a Golden Book and he was allowed into the ward. Ronald MacIntosh's mother bought him in one day to visit, Mr and Mrs Brown and five or six of their children came another weekend and they played outside on the hill, it was nice to see them, but I was still confined to barracks.

During my stay, the hospital had made me a large frame that fitted around my body, and it came out at right angles to support my arm. I looked like a policeman on point duty.

Then one spring day, it was a Friday, I was up at daylight. It was the day for me to come home. I cannot remember how I got home or who brought me, but I can remember walking into my bedroom and seeing a new bed, lots of cards and toys.

The next morning Mum let me go outside to see all the kids in the street, I felt like a stranger in a new country walking slowly across the street hoping that somebody would know me. It did not take long, and all was back to normal and off to school on the Monday morning.

Looking back my parents must have gone without many things to help me. After leaving hospital I had to have physiotherapy three times a week at Miss Ruth Ross's, this meant catching a bus into Wollongong after school. Sometimes when she was running late, she would drive us home in her little Morris Minor about 6pm.

Later I went to Mr Tom Gibson, a Physiotherapist in Thirroul. He was in the First World War, while there he was hit on the side of his head with a bullet, this had left him blind. On his return to Thirroul, he opened a Physiotherapy Centre next to the Kings Theatre. He was an incredibly quiet natured man who felt his way around the surgery with precision, knowing exactly where everything was.

I had to visit him twice a week after school, after my session I would catch the bus home. The cost of the visit was 20 cents and the bus fare 1 cent. Mr Gibson said that if I could lift my arm above my head, he would give me 20 cents, sometimes I would give him my good arm, but he always knew. After a couple of years, I succeeded, and he made good on his promise.



DID YOU HAVE POLIO?

Want to connect with other survivors of polio online?
Join our monthly support group on Zoom!

- ★ Learn about polio's late effects ★
- ★ Share and learn from each other★
- ★Hear guest speakers★
- ★Meet others from the polio community across NSW and ACT★
- ★Third Wednesday of each month, 11.00am★



www.bit.ly/PolioNSW

Australia's polio survivors: 'they've forgotten that we're still here'

by Sophie Black

The Guardian, Sunday 17th October, 2121

For most, our previous pandemic is a distant memory. But for these five polio survivors new health problems have just begun.

Australia was officially declared polio-free in 2000. Two decades later, for many people the only time they've stopped to think about the disease was the moment the poliovirus vaccine certification was stamped into their medical records, or later, their children's. But for many polio survivors in this country, and there are approximately 40,000 of them, the last 18 months have served as a reminder of living with the last virus to shut down public places and spread fear through communities.

Polio (poliomyelitis) is a disease that mainly affects children under five years of age. The highly infectious virus attacks the motor neurons that relay messages from the spinal cord to muscles, often leading to muscular degeneration. One in 200 infections leads to irreversible paralysis. Among those paralysed, 5% to 10% die when their breathing muscles become immobilised.

Like Covid-19, [vaccination](#) is the only effective preventive measure against polio. Australia began mass vaccination against polio in 1956, and the country's last polio epidemic was in 1961-62, after a second wave took hold due to vaccination rates not being high enough to achieve herd immunity.

Many of those who contracted polio in the 1950s, after leading active lives with what they considered the scars of a disease they'd survived, are now experiencing symptoms recognised as post-polio syndrome (PPS) and/or the late effects of polio. The symptoms can include muscle weakness, pain and debilitating fatigue, with some people developing severe neurological symptoms.

As they grapple with a series of health challenges that many never anticipated, survivors have watched as the country has scrambled to contain the latest pandemic and [distribute vaccines](#) that were produced at light speed compared to the years it took to produce the first polio vaccine, a vaccine that for various reasons, they missed out on.

Gary Newton, Geelong



Photograph: Alana Holmberg/The Guardian

I'm the youngest of five kids. I was a healthy baby, learned to crawl and stand and walk by the age of nine months. Just after my first birthday, 15 months, in the summer of 1954, my older sister came home from school and went to get me out of my cot like she always did. But when she tried to lift me out I couldn't raise my arms ... I was kind of like a rag doll. So that was the beginning of the journey. I had 32 days in complete isolation at Fairfield Infectious Diseases Hospital.

At that time, polio was a disease that came in waves, mostly during summer. Public places were closed down, like cinemas and pools, and there was a lot of fear. And there was a stigma associated with having a child with polio, I think that was probably part of the reason why my mum and dad never really spoke to me about it. It was a fairly traumatic time, for many parents, not just mine. Imagine putting your child into isolation for 32 days. No one to

stop them crying. I was left with permanent paralysis in my legs. So I've worn callipers or braces every day of my life.

More recently, I've lost about 30% use of my arms. About five years ago, I started to read about people who were holding chickenpox parties [in order to deliberately infect children]. I thought, I don't think these people really know what preventable diseases can be like, I need to do something. Maybe I could use my voice to change people's perceptions of these diseases, which people have forgotten.

Polio survivors are now the forgotten generation because we've lived two generations of not having the virus in Australia. I don't dwell on what polio has taken away, I focus on what it has given me and the gratitude that I've got for all the things around me.

Gabe Mostafa, Melbourne



Photograph: Christopher Hopkins/The Guardian

I was born in Egypt – Cairo – in 1958, and moved to Australia in 1967. I wasn't on a ventilator or anything like that, but my right side was affected. My sisters and brothers say that my body looks like Hercules on one side and the other half looks like Peewee. At the time I didn't go to hospital because mum thought they couldn't do anything for me. Mum kept me at home and basically looked after me and massaged my legs and arms – back then there was very little knowledge about polio.

I learned to live with it and was very active in adulthood, I used to run 10kms a day, did things like helped a friend build a house. Now I'd be lucky to do any of that stuff because fatigue sets in and all I want to do is go to sleep. I started to get pain in my back, pain in my legs. But it wasn't until last year when I read an article about post-polio or late effects of polio that I realised I ticked a lot of the boxes. They told me I'd need a back brace, and an arm splint. I'd been falling over a lot too. Earlier this year I bent over to pick up something at my office and I fell and really injured myself. My right side is very weak. My wife won't let me get my own dinner out of the oven. I can't carry it with both hands, and I could lose balance. They're the things that are challenging now. I'm glad I didn't know it was coming though, I would've wrapped myself up in cotton wool.

Back in Egypt and Gaza, all my siblings and cousins used to go to the beach, and they'd all go out swimming but I was left sitting on the shoreline because I was in callipers. So when I eventually came out of the callipers I was like a bull out of a gate.

I asked mum a while back about how I contracted polio. All my brothers and sisters got the vaccine, but I couldn't – she told me, "you always had a cold, so you couldn't get in to get the vaccine". And then I got it, I contracted polio. Mum used to sit for hours crying when I was a kid, one of my brothers told me recently.

My children went and got vaccinated [against Covid] recently. It wasn't an issue. Everybody in my family has been vaccinated.

Nola Buck, Sydney

I'm 86 years old. I was born in Broadford in Victoria, and then my father went to New Guinea during the war so we came over to Sydney to stay with my auntie and uncle. I contracted polio when I was about two and a half.



Photograph: Carly Earl/The Guardian

It was only as an adult after I started getting new symptoms that someone suggested I ask my parents for a bit of a brief history of when I contracted it. So I asked my mother to write a few things down. She took a big breath and said “well, here we go ... ” It was obviously painful for her. There were two theories about how I contracted polio. One was from a traveling salesman, who was going around selling a calendar between Kilmore and Broadford. I still have that calendar. The other theory was that I caught it from the children next door that I used to play with through the fence.

I was away for rehabilitation for about three to four years on and off. While I was away my younger brother was born and that’s one of the memories I remember about hospital ... mum bringing the baby to visit and as she walked away to leave, I was just screaming ... When I came back, I still wasn’t walking. So someone used to come in and help with the house work while my mum gave me the exercises. I still have the big chart, the list of exercises she had on the wall.

As a kid I didn’t really know anyone else with polio, and I didn’t really think about it. My grandmother remembered people would cross to the other side of the street when they saw her. I could never walk very far. I knew that I could never jump, but I was always pretty good, you know, I studied at uni, I travelled a lot, in my twenties I hitchhiked around England. When I started getting new symptoms in my sixties, fatigue and such, I hadn’t put it down to anything like the late effects of polio. I got married when I was 34 and had four children. So this is what I’d put the fatigue down to. It’s very hard to distinguish sometimes between the effects of ageing and the effects of having had polio.

Lyn Lillecrapp, Adelaide



Photograph: James Elsby/The G

I caught polio when I was six weeks old. Really young. But the best way to do it. Because I’ve not known anything else. Some people I know caught it when they were eight and older and they had to relearn life. I was about 18 months old before it was actually diagnosed as polio. My parents realised something was wrong because I wasn’t kicking off my blankets. They took me to see [renowned doctor] Dame Jean McNamara and she confirmed it. She said, “well, I will get her up and walking,” and at 24 months, I was walking with callipers. I graduated to crutches and stayed on them for 40 years until the doctors recommended the permanent use of a

wheelchair because of the damage to my shoulders and elbows.

My mum left home when I was eight years old. She couldn’t handle the thought that it was going to be a lifelong job. I sometimes wonder if one of the reasons she left was the local chatter as to what she did that led to me catching polio. I was the only case at that time. “Small town” talk in those days was very much in place. My father raised me. We actually

just got on with life. He had the attitude that this is a cruel world, it isn't going to change for you – you have to learn to live in it.

I contacted my mother again when I was about 19. She was still very embarrassed about it and for a number of years kept introducing me as her niece. We were never close. She didn't cope with sickness.

Dad died when I was 18 and I was out in the big wide world by myself. I worked at the Department of Defence for 42 years. I'm a swimmer. I still swim three to four times a week with a senior squad in my local club. I represented Australia at 10 international sporting events. I do all four strokes and then put them all together in the medley.

I was vaccinated for polio when I was 11. We didn't get a choice. That was 1966. We were pushed into a crocodile line at school, marched down to the local clinic and jabbed. None of us had any problems. There were no conspiracy theories.

Gayle Kennedy



Photograph: Carly Earl/The Guardian

I was born in Ivanhoe, New South Wales in 1955. I contracted polio when I was two years old and had to be sent away from the family [for treatment]. It was about three years before I went back to my family. It was just a different world. I didn't even realise I was black. It's pretty much the same for other survivors who had long stints away from their family ... People forgetting their language, forgetting their ways. It was very disruptive.

One minute living a fairly carefree, easy-going Aboriginal lifestyle, and then back to hospital life.

It's a lonely thing being a polio kid ... A lot of polio people end up being very creative and living inside their heads. I spent some time in an iron lung. When I came to Sydney as a young adult I met like-minded people that were into music and the arts, and I just made a different life for myself, an amazing life. But post-polio syndrome virtually stopped me in my tracks when I was about 55. I was very active, I had a well-paid job with the NSW attorney general's department, but I had to leave because of the intense fatigue. And that's when I decided to become a writer.

Post-polio is horrendous. You think that you've gone through all the bad times and suddenly you find yourself getting weaker and begin experiencing pain and brain fog and fatigue. I went into a deep depression. But I allowed myself that. I allowed myself the sadness ... Eventually, I started to build a new life for myself. And I've done all my traveling overseas in a wheelchair.

At 66, I'm one of the youngest survivors. But people have forgotten about polio, they've forgotten that we're still here, dealing with the after-effects. It annoys me immensely when I see people raging against vaccines ... Don't they realise that these diseases could take hold again? That's a thing that terrifies me. I worry that there could be another outbreak. It's possible, because it's always there. It's kept at bay by vaccinations.



AGM SEMINAR REPORT

by Stephanie Cantrill

Emerging Out of Lockdown

Adjusting to a new routine or stepping back into the old one

With lockdowns, restrictions, and the recent COVID-19 outbreaks, many of us have been spending a lot more time at home over the last two years. But how do we make sure we come out strong on the other side? This post contains a few suggestions – but remember, everyone's different. You need to do whatever works best for you!

Changes to routine

Whether it's underdoing or overdoing, changes to what's normal for you can have a big functional impact. Our clinical health educator talks about polio survivors' balance of activity and routine as like walking on a narrow ridge line – you don't have much scope for movement before you really notice the impact. For others who don't have disability or chronic illness, it's more like walking on a wider path – big changes will be noticeable, but they can ride out little alterations to their routine without feeling it too much.

You might find yourself trying to “catch” up on all the things you missed out on – whether that's exercise, social activity, hobbies, or even medical and personal appointments. But that's probably not the best idea. It's better to take it one step at a time.

You might want to prioritise, so that you don't get too overwhelmed and try to do everything at once. Which of the things you've missed out on should come first? Which things can wait a while?

Time marches on

As well as recognising that changes to your routine will have affected you, it's also worth noting that it's been about two years. If you're dealing with progressive changes due to Late Effects of Polio, it's likely that things may have changed in that time anyway.

Here's some research to explore that a bit:

- Loss of motor units and strength – [a 2014 study](#) found a 20% loss of motor units and 15% reduction in strength over 10 years among polio survivors.
- Changes in mobility – [another 2014 study](#) (possibly the same cohort?) found average walking capacity declined by 6% over ten years, and self-reported mobility reduced by 14%. But for almost a fifth of the cohort studied, walking capacity reduced by 27%, and self-reported mobility by 38%. That's quite a big change.
- Reduction in activities of daily living (ADL) – [a third study](#), from 2021, noted a reduction in ADL performance, including indoor and outdoor walking and eating, over a ten-year period. However, this study didn't assess things like housework. Still, it once again shows us that things can – and do – change over time.

Two years isn't much compared to a whole decade, but it's not nothing. Because you haven't been doing all the usual things you'd normally be busy with, you might not notice any reduction in function. But when you start to get back to doing all the things you were doing before, some changes might become evident. This is just something to be aware of – and something you might need to adapt to.

Reassess your capacity

As you start to get back into normal daily life, it might be worth taking stock of your current

function, and making any necessary changes in response to what you're able to tolerate. Some people might get an assessment every now and again at a rehab facility or polio clinic. Here you can have a formal review of your muscle strength, fitness, walking etc. If that's you, now might be a good time to make that appointment. (If you're thinking it might be good to be assessed by a health professional who knows something about polio, try searching our [health professional register](#).)

For a self-assessment of your capacity, an activity diary can be a useful tool. Here's how it works:

- Write down all the things you're doing over a week or two, and how long you spend on each activity.
- Rate your energy (or pain) levels out of 10.
- This helps you to see what you're doing – and what you're overdoing. The idea is that it gives a summary of what you're able to tolerate.

[This video](#) explains a bit more about activity diaries, and here's a sample:

(https://www.youtube.com/watch?v=n0EMU-PZ5Zg&ab_channel=PolioAustraliaInc)

Time	Activity	Duration	Energy
0800-0900	Shower + dress	30 min	4/10
	Breakfast	30 min	5/10
0900-1000	Gardening	60 min	3/10
1000-1100	Still gardening	30 min	2/10
	Take washing off line	30 min	1/10
1100-1200	Prepare/eat lunch Crash!	20 min	0/10
1200-1300	Bed	60 min	0/10
1300-1400	Bed	60 min	0/10
1400-1500	Bed	60 min	0/10
1500-1600	Bed	60 min	0/10
1600-1700	Bed	60 min	0/10
1700-1800	Bed	60 min	2/10
1800-1900	Eat leftovers	20 min	2/10

This (hypothetical) person has written down what they did and for how long. I've categorised the activities into things that are fatiguing in **red**, restful in **green** and somewhere in between in **orange**. You'll see their energy went up and down a bit, but they clearly overdid it and had to spend the entire afternoon in bed. We often refer to this as "**boom and bust**".

As you see, this person spent an hour and a half gardening, even though they were pretty much spent after the first hour. Sometimes it's tempting to just get things done and then it's done. But you can pay for that, as I'm sure you know.

I will add that there will always be some things, like a major event or family gathering that you might choose to prioritise even though you know it'll exhaust you. That's up to you, and as you learn your limits you'll also learn ways of managing that – resting before and after, for example. But gardening can wait!

Pace yourself

The activity diary can help you see where you're overdoing it, and in what ways you might need to make changes. Once you know what you can tolerate, you can start to plan activity

around your capacity.

If you're just getting back into things after a period of reduced activity, remember to build up slowly. And remember – pacing means stopping BEFORE you feel like you need to. Don't wait until you hit the wall!

Aim to alternate activity and rest through the day, and throughout the week. It's easy to say, and quite hard to implement. But practice makes perfect!

Balance

Balance means doing not too much, but also not too little. Of course, every day and every week will be different, but look for a general routine that you can manage and maintain.

As you re-emerge into normal life, this might mean starting small, and working into doing a bit more each week until it's a workable routine that you're happy with – remember that it's not about catching up on every lost activity all at once.

Plan your day and your week to some degree, to enable balance – alternating activity and rest (more on that below). Also, try to find balance by alternating the way they use your body – e.g. sitting, standing, moving. The aim is not to be stuck in any one position for too long.

Keeping doing – without overdoing

To help you find that balance, you can change the **duration** of some tasks. This can be especially true for tasks we enjoy.

For example, social engagements can be really tiring, and you might not feel it until later. The increased fatigue might make you want to say no next time – or, you might say yes and then end up overdoing it again.

How about shorter social engagements? You could try something like this: "I'd love to have lunch, but can we make it coffee?" or "I'd love to see everyone, but I'll skip the movie and just come for dinner".

Hobbies and interests can get put aside too – maybe they're physically tiring, or maybe we don't feel we have time. But rather than all or nothing, try doing a bit at a time. It helps to schedule activities, so you can prioritise the things you love doing among all the things you really need to get done.

Planning and scheduling

Time	Activity	Duration	Energy
0800-0900	Breakfast	30 min	6/10
	Shower + dress	30 min	5/10
0900-1000	Phone with friend	35 min	6/10
	Gardening	25 min	4/10
1000-1100	Cup of tea, check emails	30 min	5/10
	Start lunch prep	15 min	5/10
	Sit and read paper	15 min	6/10
1100-1200	Put a load of washing on	10 min	5/10
	Continue reading paper (write, draw, puzzle...)	15 min	6/10
	Continue lunch prep	15 min	5/10
	Eat lunch	20 min	5/10
1200-1300	Read book after lunch	30 min	6/10
	Hang washing	20 min	5/10
1300-1400	<i>And so on...</i>	60 min	0/10

Above is an example of achieving activity balance through planning and scheduling. Remember, everyone's tolerances are different – this one is based on the imaginary person

from before. They've recognised that they were overdoing it with the gardening and falling into a boom-bust pattern, so they're now trying to pace and balance.

That doesn't mean they stopped gardening. This person loves gardening, so they want to continue doing it – but they're doing less today, and spacing it out across the week.

The restful activities (in **green**) can be somewhat productive as well – just using your body differently. And you can balance mental activities with physical ones, and also with total rest. Some people need an afternoon nap, and that's ok. It's about learning what you need and incorporating that into your routine.

And for the less meticulous planner, here's a more basic activity plan:

	MONDAY	TUESDAY	WEDNESDAY
MORNING	VACUUM 30 min RESTFUL ACTIVITY MAKE LUNCH	LIGHT GARDENING 30 min RESTFUL ACTIVITY MAKE LUNCH	VACUUM 30 min RESTFUL ACTIVITY MAKE LUNCH
AFTERNOON	EAT LUNCH, READ OUT WITH FRIEND RESTFUL ACTIVITY	EAT LUNCH, READ GROCERY SHOP (split across two trips) RESTFUL ACTIVITY	EAT LUNCH, READ HANG WASHING RESTFUL ACTIVITY
EVENING	PAINTING 45 min RESTFUL ACTIVITY MAKE DINNER EAT DINNER, TV	GENTLE WALK RESTFUL ACTIVITY MAKE DINNER EAT DINNER, TV	REST BEFORE GOING OUT DINNER WITH FRIENDS BED

This person is still balancing activity and rest, but not planning it all to the minute. Still, you'll see it generally alternates between something active and something restful. Remember, it's about whatever works best for you.

Also, note that on Wednesday afternoon they do a bit more rest than usual – you can see two **green activities** in a row – because they're going out for dinner with friends and they know that will be a **fatiguing activity**. But it's a priority for them, so they're working it out as best they can.

Adapting everyday tasks

Here are a few more suggestions for making everyday changes to everyday tasks, in order to save your energy for the things that are important to you. This is by no means an exhaustive list!

Where you can, use **assistive technology** to save energy and make things easier. This can include:

- Shower chair and rails to make showering easier and safer
- A scooter or wheelchair so you can get out and about more without overdoing it
- Orthotic braces to preserve muscles and energy when you're walking
- Electric lift recliner or higher chairs to reduce effort in your legs
- Raised garden beds to avoid bending
- Laundry and/or kitchen trolley to carry things around the house, groceries from the car etc

Consider other **gadgets** that might help:

- Robot vacuum
- Slow cooker, rice cooker etc
- Steam mop
- Self-propelled lawn mower

Sit where you can – this will save your energy and limit prolonged standing. Tasks you might be able to do sitting down can include:

- Chopping vegetables
- Showering (on a proper shower chair)
- Ironing
- Folding laundry

Avoid overdoing tasks – keep it simple! Take cooking for example – you can cook simpler meals, and even freeze leftovers to save cooking on busy days.

Get help if you need it! Don't forget to accept those offers of help, or arrange services if you need them. The idea is to save your energy for the things you love doing!

Any lasting changes?

Can you think of anything that changed during lockdown or restrictions that you might consider keeping? Are you an online shopper now? Or could you occasionally do virtual social catch-ups still, to continue to see friends but without having to go out all the time?

We asked this question on Zoom recently and here are some things people intend to continue doing:

- Online grocery shopping
- Not overbooking myself
- Appreciating the simple things
- Not caring as much about hiding my disability

As we start to emerge back into the “real world”, now is a really good time to think about changes we want to continue.

In summary

- Don't expect to just return to “normal” instantly
- Choose which things you want to do first
- Reassess so you know what you can tolerate
- Pace yourself and build up
- Develop a sustainable routine
- Prioritise what you really want to do – cut back on other things, or accept help (or use gadgets)

So what will you prioritise as you step into the “new normal”?



ONLINE SUPPORT GROUP REPORT

Our new online support group for polio survivors commenced on the 19th of January. The first session was largely introductory, but it was a great way to connect people and share some ideas of what we hope to gain from the group. The value of hearing from others and the sense that you're not the only one experiencing post-polio symptoms were certainly common themes.

The majority of people in attendance were already Polio NSW members, and we hope this continues to be a valuable way to connect with your fellow members. We also had some completely new people who found us via social media, and it was great to see some new faces and provide this opportunity for support and community.

This group will continue to meet monthly, on the third Wednesday of each month at 11:00am. If you are interested in joining us, please feel free to register at www.bit.ly/PolioNSW, or contact Steph for more information – steph@polionsw.org.au.

Zoom Step-by-step guide

by **Stephanie Cantrill, Online Engagement Office, Polio NSW**

When you think of buzz words that have come out of the COVID-19 pandemic era, terms like “social distancing” or “self-isolation” might come to mind. But **Zoom** is definitely one of the words of the moment!

What is Zoom?

You probably already know this (it’s hard to avoid!), but Zoom is a **videoconferencing platform** that uses the internet to connect. You can talk to people over video, share what’s on your screen, and “chat” (via text-based messages). It’s been a game-changer for a lot of people during periods of isolation, and it can allow people to “attend” meetings or gatherings without needing to leave their homes.

If you haven’t used Zoom before, there’s still time! We hope this guide is a helpful start.

What kind of device do I need?

To use Zoom for video calls, you need a **laptop/computer, tablet or smartphone**. You will also need a reliable internet connection, whether that’s through the internet in your home (NBN/WiFi), or the mobile data from your phone. If your computer doesn’t have a camera, you may want to purchase one.

You can buy a webcam (portable camera for your computer) at Officeworks, Harvey Norman or similar stores. Prices start at around \$30 and go up from there. Talk to the staff at the store about how to install the webcam.

For a good step-by-step guide to installing a webcam on your computer - <https://www.lifewire.com/install-and-connect-a-webcam-to-your-pc-2640488>.

Otherwise, ask the staff at the store for detailed installation instructions.

What if I don’t have a smart device or access to the internet?

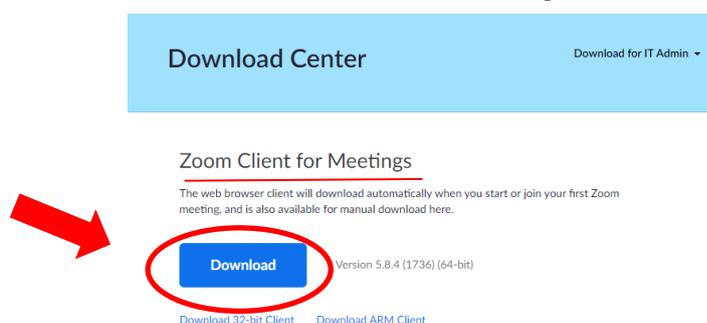
Never fear! Zoom has an option for you to simply **dial in to the call** from any phone. You won’t see people’s lovely smiling faces or be able to view anything that is being shared on the screen, but you’ll be able to participate in the conversation.

If you want to use Zoom from a phone, please scroll down to the relevant section below.

Downloading the app

Zoom works best when you download the free app. If you are on a computer you don’t *absolutely* have to download Zoom, but you would need a Zoom account and it’s a bit complicated. So downloading the app is easier.

- To **download on a computer**, go to <https://zoom.us/download> and click on the blue download button under “Zoom Client for Meetings”



- The installer will appear at the bottom of your screen, in the task bar.

- When you click on it, it might ask you something like: “Do you want to allow this program to make changes to your computer?” – click “yes”.
- It will then install the app on your computer. You will use it when you join a meeting (see below).
- **To download on a phone or tablet**, go to your App Store or Google Play (or wherever you get your apps). Put “Zoom” into the search bar, and you will be directed to download the app.
- To make sure you get the right app, look for this Zoom logo:



Joining a meeting

When you are joining a Zoom meeting, you will be given a specific Zoom **link** that contains a lot of letters, numbers and symbols.

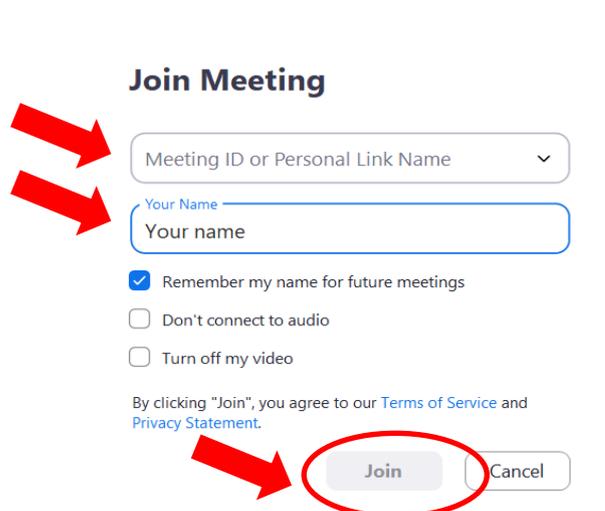
- You can just **click this link** on your computer, tablet or smartphone to be taken directly to the meeting.
- On a computer, it may ask you if you want to open Zoom meetings – click yes.

You may also be given a Zoom **meeting number and password**.

- Open the Zoom app on your device
- Select “Join a Meeting”

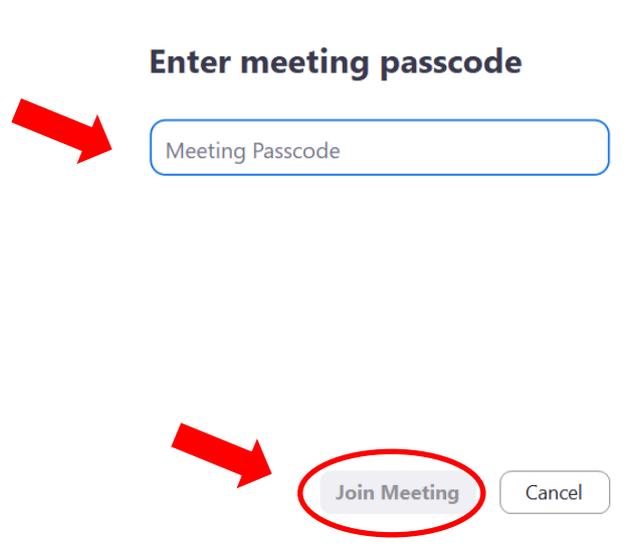


- Enter the **Meeting ID or Personal Link Name** you were given – it’s usually a number
- Enter your name (you can check the box to remember your name for future meetings to make it easier for next time!)



- Click “**Join**”

- It will then connect, and ask for the **Meeting Passcode**. Enter it into the box and then click “**Join Meeting**”



(Images will look different on a tablet or smartphone, but the basic steps are the same. For example, instead of clicking “Join Meeting” you will click “OK”.)

- If the meeting has a **waiting room**, the host will let you in. Otherwise you will go straight into the call, as long as the host has already started the meeting.
- When given the option, select “**join with computer audio**”

Joining a meeting from a phone (dialling in):

- Call one of the numbers below, according to the area code in your state (normal call charges will apply):
 - 07 3185 3730
 - 02 8015 6011
 - 03 7018 2005
 - 08 6119 3900
 - 08 7150 1149
- It will ask for the **meeting ID** – enter the number, followed by #
- It may ask for your host key – ignore and just press #
- It may ask for the “participant ID” – ignore and just press #
- Finally, it will ask for the **password** – enter the code, followed by #
- It will then take you into the meeting, where you’ll be able to hear and speak but won’t have video access
- To **mute** or **unmute** yourself, press * 6
- To **raise your hand** to make a comment or ask a question, press * 9

During the meeting:

If you are dialling in to the call, you’ll be able to hear and speak but you won’t have video access.

If you are joining the video call, there are a few handy functions to know:

- There is a **Zoom menu bar** which appears at the bottom of the Zoom window once the meeting begins

- If you don't see the menu bar, move your mouse slightly or touch your screen and the bar will appear
- The bar disappears after a few seconds when in full-screen mode
- You can turn your **microphone** on and off by clicking the small microphone icon on the menu bar
 - On a computer, you can also do this by holding down the alt key (to the left of your space bar) and pressing A (a is for audio)
 - If you have an Apple computer, press Command, Shift and A together
- If you are muted, you can also hold down the space bar to unmute temporarily – hold it down while you are talking, and then let go to put it back onto mute
- You can turn your **camera** on and off by clicking the small camera icon
 - On a computer, you can also do this by holding down the alt key and pressing V (v is for video)
 - If you have an Apple computer, press Command, Shift and V together
- If there are more people than you can see on one screen, you can use the **arrow keys** on the side to see who else is on the call
 - On a phone or tablet, you can always swipe from side to side

Chat and other features:

Here are some other options you can access from the Zoom menu bar:

- “**Chat**” allows you to type messages to the group
 - You can also select an individual to send a direct message
- “**Reactions**” allows you to give someone a thumbs-up, clap your hands and a few other options
- “**Raise hand**” allows you to put your hand up to ask a question or make a comment

Leaving the meeting:

On the Zoom menu bar you'll see a red button that says “**leave**” – press this, and press “**leave meeting**” when it prompts you.

If the host ends the meeting for all participants, you won't need to do anything.

And that's about it! Happy Zooming everyone!

If you have more questions about installing Zoom, it might be worth asking a friend or family member, or bringing your computer or other device to your local library.

If you have questions during the meeting, the host will do their best to help you – but bear in mind it may be hard for them to see what the problem is.



STEROIDS: The GOOD and the BAD

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

Reprinted from PA Polio Survivors Network www.papolionetwork.org
 August 2021

Question: I've had growing neck and upper back pain for six months. My doctor is talking neck surgery. He has suggested that I first try steroids. I have read that steroids are not recommended for polio survivors. How do I decide?

Response: The issue of whether polio survivors should take steroids comes up often and can be both complicated and confusing. Here's a simple overview that hopefully will decrease the confusion.

WHAT ARE STEROIDS? Steroids are *the* super anti-inflammatory drugs used to treat rheumatoid arthritis, lupus, multiple sclerosis, asthma, chronic obstructive pulmonary disease, sarcoidosis and other serious inflammatory conditions. Examples of steroids are cortisone, methylprednisolone and dexamethasone.

Steroids can be administered orally, intravenously, intramuscularly or by local injection. When used to decrease inflammation associated with bursitis or a pinched spinal nerve (caused by arthritis or a herniated disc) steroids can often be almost immediately effective in reducing inflammation that is causing pain.

ORAL STEROIDS. As helpful as oral steroids can be to treat inflammation, they also can have significant side effects in anyone taking them, not just in polio survivors. Side effects can include weight gain, diabetes, cataracts, glaucoma, increased susceptibility to infections, depression, delayed wound healing, easy bruising and stomach ulcers.

Notable for polio survivors, steroids also can cause fatigue, muscle weakness, muscle atrophy, osteoporosis with increasing the risk of fractures and even bone death. What's more, steroids have been found to impair and even damage brain neurons, which likely explains findings of difficulty maintaining concentration and impaired memory, especially with long-term treatment using high doses of steroids. (mayoclinic.org/steroids/art-20045692)

For polio survivors, it's the long-term use of oral steroids for the treatment of pain that we found problematic. Post-Polio Institute patients taking oral steroids, most often for hip pain, reported increased weakness, fatigue and trouble with attention and memory. These side effects unfortunately amplified PPS symptoms patients already had.

Given the side effects, long-term use of oral steroids to treat pain is not appropriate. See a rehabilitation doctor and discuss treatment for acute, significant inflammation-related pain (ex: bursitis, pinched nerve) with 6 days of a self-tapering oral steroid -the Medrol dosepak- as a first treatment step. (drugs.com/mtm/medrol-dosepak.html)

STEROID INJECTIONS. If oral medication does not manage pain, steroids can be injected locally, for example into the hip bursa, into the neck or back spinal facet joints or as an epidural.

Since the amount of steroid injected is limited, and since it's targeted to the area where inflammation is causing pain, there are many fewer side effects. But local injections shouldn't be overdone. Repeated local steroid injections also can cause bone death. The general recommendation is for no more than three injections in the same location per year. (www.mayoclinic.org/tests-procedures/cortisone-shots/about/pac-20384794)

The Encyclopedia of Polio and Post-Polio Sequelae contains *all* of Dr. Richard Bruno's articles, monographs, commentaries, videos and "Bruno Bytes"
(www.papolionetwork.org/encyclopedia)



BRUNO BYTES

Taken from PA Polio Survivors Network www.papolionetwork.org



A Bruno Bytes

Third and Fourth Quarter 2021
From Dr. Richard L. Bruno, HD, PhD
Director, International Centre for Polio Education

www.papolionetwork.org/encyclopedia

On the topic of a “Good” Leg and a “Bad” Leg

Dr. Bruno’s Original Post: It’s well-known that “good” limbs, those thought to be unaffected by polio, commonly show electromyography (EMG) evidence of prior poliovirus damage. A large study from India brings home this point (*Ann Indian Acad Neurol.* 2016; 19(1): 44–47). EMGs were performed on all four limbs (not something we recommend) in 116 polio survivors. In 42% of limbs that survivors said were “unaffected by polio,” EMG revealed evidence of poliovirus damage. On manual muscle testing, 26% of the “unaffected” muscles with poliovirus damage on EMG had decreased strength.

This study is a reminder that “non-paralytic” polio (NPP) wasn’t necessarily “damage free” polio. For example, it was reported in 1953 that 39% of those diagnosed with NPP had measurable weakness on manual muscle testing in at least one muscle group. A 1954 paper - “The Infrequent Incidence of Non-paralytic Poliomyelitis” - documented that 89% of polio survivors who were acutely “persuasively non-paralytic” had “very definite muscle weakness” as long as three years after the diagnosis of NPP.

So, it should be no surprise that more recent studies have documented late-onset weakness and fatigue in NPP survivors. A study of 828 polio survivors found new muscle weakness and fatigue, respectively, in 38% and 34% of those who had been paralyzed and in 14% and 21% of those diagnosed with NPP.

What’s more, study of 34 sets of twins found PPS symptoms in 71% of the twins who had had paralytic polio and “PPS-like symptoms” in 42% who had had no symptoms of paralysis. (Bruno, RL. [Paralytic Versus “Non-Paralytic” Polio: A Distinction without a Difference?](#) *Am J Physical Med Rehabil*, 2000; 79: 1-9.)

I wasn’t surprised when Post-Polio Institute patients would report that their “good” (unaffected) muscles were becoming weaker while their obviously polio-affected muscles were not. Taken together, the studies above are reminders that overworking your “unaffected good muscles” could make a good limb turn “bad.”

On the topic of Strain on Poliovirus affected Legs

Question: Which is more strenuous, standing or walking?

Dr. Bruno’s Response: In general standing is actually more strenuous than walking. It’s more tiring to stand in one place because muscles in your feet, legs and back are continuously turned on by already tired, poliovirus-damaged motor neurons. When you’re walking, the muscles aren’t all activated at the same time but turn on and off as you walk. This prevents any given muscle(s) from staying turned on and getting exhausted. Standing also reduces blood flow to the muscles, causing muscle fibres to tire more easily and can produce pain in the feet, legs and back.

Swallowing Problems. Do you have them?

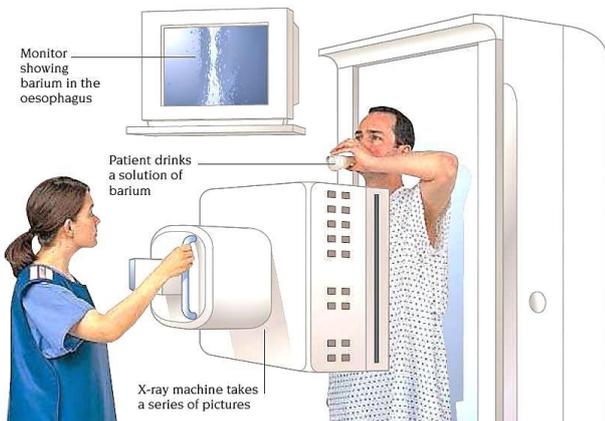
by Dr Marny Eulberg

Taken from PA Polio Survivors Network www.papolionetwork.org August 2021

Swallowing problems (Dysphagia) in polio survivors can be caused by two or more disorders:

- Muscle weakness in either the tongue or throat muscles –which can be due to prior polio damage or new problems such as a stroke affecting those muscles.
- Problems in the Esophagus –
 - Narrowing of the tube due to scarring from acid reflux or poor coordination of the muscles
 - **Presbyesophagus**-related to aging,
 - Some deformity of the esophagus itself -such as masses, out pouches (diverticulum), or even pressure from large bone spurs from severe arthritis in the neck.

The best diagnostic test I've seen is a modified barium swallow study (MBSS) that is done by a speech therapist/swallowing expert along with a radiologist, usually done as an outpatient at a hospital. It involves the patient swallowing barium in a thin liquid (consistency of water) and a thicker solution (milkshake consistency) and finally, something that resembles solid food (such as crushed Oreo cookies or marshmallows). During the test, the speech therapist concentrates on how the muscles in the mouth and back of the throat are working and the radiologist concentrates mostly on the function of the esophagus.



•Note: An endoscopy looks at the appearance of the esophagus and stomach but does *not* look at how it functions during swallowing.

The speech therapist not only determines the malfunction of the swallowing muscles but can also offer advice and treatment about how to deal with a person's specific problem.

For a person with neuromuscular swallowing problems, although it does not seem to make sense, thin liquids (like water, apple juice) and dry foods (bread, crackers) are usually the most difficult to swallow and most likely to cause coughing/choking. Thicker liquids (nectars like apricot nectar, puddings, milkshakes/



Symptoms of Dysphagia

smoothies) are easier to swallow than water, coffee or tea.

Thickening agents {some brand names are Thick-It or Simply Thick} can be added to thin liquids to make them easier to swallow. It is also important to follow bites of food with frequent sips of a liquid and to cut solids such as meat in small bites and chew thoroughly before swallowing.

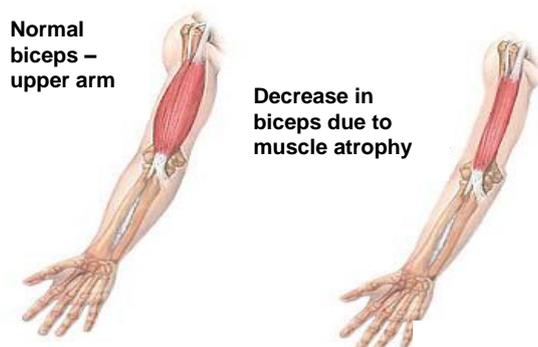
(Originally published by [Easter Seals Colorado](#), Spring, 2021)
Revised by Marny Eulberg, MD 2021

"Upside Down" Polio. What is it?

by Dr. Marny Eulberg MD

Taken from PA Polio Survivors Network www.papolionetwork.org December 2021

We all can learn from polio survivors living with upper extremity weakness. Polio survivors with the majority of their muscle weakness in their upper body have sometimes been called "upside down polios". This term is based on the fact that the majority of observable weakness and atrophy in most polio survivors is in the lower part of their bodies. Therefore, if a person has the reverse, with most of their weakness/atrophy in their shoulders, arms, and/or hand, it is "upside down" from what is usually observed.

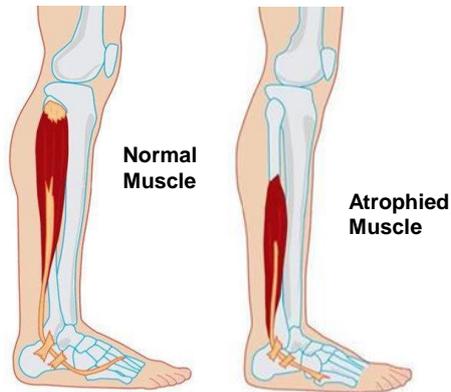


The muscle atrophy in the upper extremity may not be as obvious to the casual observer as it is in people with atrophy/weakness of their legs with an obvious limp, because the atrophy can often be hidden under clothing (ex: keeping a polio affected hand in a pocket most of the time). Upper body weakness, may take close observation in order to notice that these polio survivors perform daily tasks differently, such as using two hands to lift a glass up to their mouth or use some different movements to put on or take off a coat or sweater.

If the weakness involves a person's right hand, they may choose to "shake hands" using their left hand or use other movements (nodding their head, a slight wave) to convey a greeting. Polio survivors with marked weakness of both arms may need someone to feed them, dress them, and perform many activities of daily living. Some who had polio at a young age may have learned to use their feet to do many of the tasks that others normally do with their hands/arms such as writing, peeling vegetables, and even doing art work; others do tasks using their mouth such as using a mouth stick to type, write and paint.

Individuals with upper extremity weakness are more likely than those with lower extremity weakness to have some respiratory muscle weakness because some of the same nerves that control the arms also control the diaphragm.

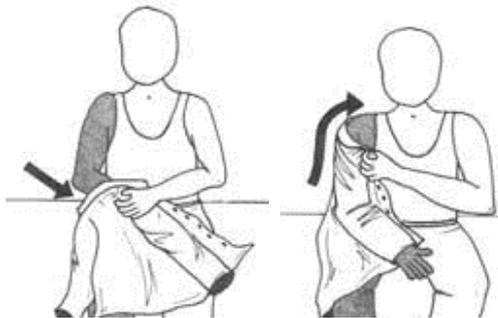
Persons who have had significant lower extremity weakness and have used their arms to assist with many activities that require leg strength (ex: getting up and down from a chair or walking with crutches) are quite likely to develop overuse problems in their shoulders, elbows, and/or wrists. Upper extremities were not designed to be used for long-term walking! This may be temporary after a particular period of overuse or can become chronic. It can be a tendonitis, a bursitis, wear-and-tear arthritis, or a tear of various tendons/muscles such as rotator cuff tears or biceps muscle rupture, etc. All of these can



initially result in pain which then can lead to weakness because if it hurts to perform certain motions, people stop doing that motion or severely limit the use of muscles that effect that motion.

Bottom line: Even if a person's initial polio primarily affected their legs, it is likely that over time they are at risk of developing some overuse symptoms in their upper body that can limit their use of their upper extremities.

Over the past few years, I began to have pain in my shoulders (right greater than left) that limits my ability to perform certain activities such as putting on or taking off certain clothing like sweatshirts, jackets, and blouses/shirts. After watching some polio survivors with upper body weakness, I learned that I could still do those activities with little or no pain. I just had to *change the way* I was doing things and use the techniques that those "upside down polios" used. So, now instead of removing a sweatshirt by crossing my arms in front of my body and grasping the lower left hem with my right hand and the lower right hem with my left hand and then pulling straight up and over my head, I now lean forward (getting my trunk nearly horizontal), grasp the back of the neck opening with one hand and pull slightly up and horizontally until the sweatshirt is over my head and off. (Note: graphic is for a jacket but the idea is similar).



Paulette Bergounous, a polio survivor with little functional use of one hand/arm, has reported that many of the people accessing her blog and videos are previously able bodied people that now are scheduled for shoulder surgery that will require little or no use of one arm for several weeks to months. A good occupational therapist can assist you with methods that work for your particular limitations.

This graphic is a good series of illustrations that shows in detail pulling a shirt over your head with the use of a single arm



This graphic below is a good series of illustrations showing putting on long pants with the use of a single arm.



As in many aspects of aging, there are many useful tricks and techniques that we can learn from other polio survivors. We can adapt and use what we need as we develop some of the limitations of a long life. Marny Eulberg, MD

There's nothing "upside down" about the two polio survivors living with upper body paralysis, whose stories we've had the opportunity to publish. Martha Loudder and Deborah Stambaugh are determined, resilient and very much upright. Their stories are easily available on the Survivor Stories page of our website. www.papolionetwork.org/survivor-stories.html

You can find this article along with Dr. Eulberg's biography and additional work on our website:

Primary Care Perspectives-www.papolionetwork.org/primary-care-and-pps.html
All of her articles are available for easy download and sharing.

Sharing

By Millie Malone Lill

Taken from Polio Perspective, November 2021.

[Editor's Comment: Millie is the editor of Polio Perspective and has provided us with a number of comical and relevant articles for us to contemplate with an added lesson to learn as well.]

My dad was big on sharing, on fairness, on being kind. He taught us that everything tastes better when you share it with someone. He also taught us that "if you can be happy for yourself, and happy for the other fella, you will be twice as happy." Joy shared is doubled, sorrow shared is halved. That was his philosophy.

Which brings me to my love of support groups. I know people who shy away from support groups. Some think they are not bad enough off to need them. Some think their condition will make others stare. I'm here to tell you...my support groups are my lifeline. I love meeting polio survivors. We all have one thing in common, having had polio. But other than that, we are as diverse as can be.

I've had people ask me if I seriously look forward to going to Branson each year, not for the shows, but only to stay in the hotel and visit with other polio survivors at our annual reunion. Almost a week, spent talking to people on crutches, wearing braces, using wheelchairs? Isn't that depressing? Nope. It is actually very freeing.

I love people. Some of them more than others, true, but everyone has a story and as a writer, I live to hear other people's stories. Our Survivors Meeting at our annual reunion is a time that we can share our problems, our solutions to those problems and our frustration at

having all those problems. At the same time, the Supporters meeting, held in a separate room, gives our care givers a chance to blow off steam. We share things we wouldn't necessarily share with a neighbor. You sound mean if you complain to the neighbors about caring for your handicapped spouse/child/significant other. But if you are talking to another care giver, they will understand.

Polio survivors have been taught to be independent and for the most part, we are A students with Type A behavior. It's so good to be able to see how others handle things. One of the things I hate is asking for help. I have never been turned down when I ask, but forcing myself to ask someone else to do something I can no longer do ...that's a toughie. In my support group, that is not unheard of. Most of us hate to ask for help. It's something we need to work on, I know.

When you are with a group of other polio survivors, and all of a sudden you are exhausted, it is not considered rude to just leave and go lie down. If you are talking and your voice quits working, we understand. No one thinks it is odd for one of us to approach another and ask "Where did you get that walker?" We are not being nosy or rude, we genuinely admire it and would like to get one like it. It's OK to hike up a pant leg and compare leg braces, or demonstrate how the new power chair works and how fast it goes or how tight the turning radius is.

It is not only food that is better when it's shared, Dad. Joy and sorrow are also both better when shared with like-minded friends.



Enablers

by Millie Malone Lill

Taken from Polio Perspective, September, 2021.

Enablers have gotten a bad name. People think of them as those who enable drug addicts or alcoholics to continue their bad behavior and that is a bad thing. But what about the good enablers? I'm thinking of all the parents who helped us with those horrible exercises, enabling us to walk again. The nurses and doctors who enabled us to continue living after the polio virus grabbed us and shook the heck out of us were enablers, too.

I met a good enabler last Tuesday. He works for NuMotion, a DME supplier. His name is Lonnie Shafer. He and a Physical Therapist (notice that I did not refer to her as a Physical Terrorist as I usually refer to a PT) were so kind and so, well, enabling. I've worked with Lonnie before, when I got my current power chair six years ago. He understands PPS and is a dream to work with. It took a lot longer than I thought it would, but he and the PT were quite thorough. They will get me the power chair that I need, enabling me to remain independent awhile longer.

Think about it. The crutches, canes, wheelchairs that I've been trying to teach you to see as simple tools are actually enablers. They enable us to move from one place to another. My lift on the back of my van enables me to load my power chair into the van. The van enables me to go further than I could if I only drove my power chair. The power chair enables me to get my own groceries, take care of myself and my little dog Fiona (AKA Bossypants.)

The new power chair will have all the bells and whistles. It will have an elevating seat and I can actually drive the chair while the seat is elevated, enabling me to reach my cupboards and sink, maybe actually cook again, and reach stuff off the shelves in the grocery store. I

can even, if I choose and at my own cost, get a backup camera! I know this sounds a bit farfetched but are you aware of how many toes I've crunched when I back up? Most people do not actually see wheelchairs, even when a large chair with a purple polka dotted seat cover is parked directly in front of them. I cannot see behind me because the headrest blocks my view. Also, I tend to forget that I have eggs in the bags on the back of my chair when I get my groceries. Backing up too far in the elevator has resulted in a real mess of smashed eggs, let me tell you.

Lonnie, The Enabler, also gave me the contact information for a company that is nationwide and deals with used accessible vans! I spoke to someone there and she told me that if I decide I need a van that I can drive my chair into, she could set me up with a used van like that and I can trade in my current van. I've looked at used mobility vans and the cost made my eyes cross so hard they switched sockets, but she told me about one that is a 2010 and would sell for \$21,000, not counting whatever my current van's trade in value is. I don't know the exact details of this van, but with the condition my back and hips are in I can easily see that I will need something that does not require my walking from driver's seat to the lift and I will need it sooner than later.

So here's a shout out to all the Good Enablers out there. Thanks for enabling me and my fellow polio survivors to live our best lives.

Tips for Selling on eBility



eBility is a one-stop accessible marketplace for all disability equipment and products. Established in 1998, eBility is owned by [IDEAS](#), the knowledge experts in fact-checked verified disability information and connection.

Selling your pre-loved and no longer needed items can be a great way to earn some extra cash and free up space in your home.

Follow the steps below to make your advertisement stand out from the crowd and increase your chances of a fast and successful sale.

Photos

Take high quality photos from multiple angles in an area with good lighting and a clean and decluttered background. For vehicles, give the interior and exterior a good clean before taking any photos to make it look its best. Consider how the photos will look on eBility, landscape images and generally display best.

Descriptions

Be as descriptive as possible. Buyers want to know as much as they can about their potential purchase. Be upfront and honest about any issues or faults and include if you have a manual for equipment items or service history for vehicles.

Be friendly!

Use a positive and friendly tone in your description and in any communications with potential buyers. Show that you care about the buyer and are happy to answer their questions.

Start selling today. Watch our video on "How to post an ad on eBility"

https://www.youtube.com/watch?v=V3L2bgo0q8k&ab_channel=eBilityClassifieds

Website: www.eBility.com.au, phone (02) 8324 5691 or email sales@ebility.com.au