



POLIO NSW

formerly Post-Polio Network (NSW)

NETWORK NEWS

Incorporating – Polio Oz News

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Editor's Report:

This edition of Network News has some interesting articles from Australia and overseas.

The board has been discussing ways to support our members and ask for your thoughts and ideas. Chris Kuen a past board member who attended the planning meeting has written an article on what was discussed and what ideas were suggested on moving forward.

Gail Hassall, Webinar Co-ordinator, submitted two reports on recent webinars; "Bone and Muscle Health held in March, 2024 was presented by Michael Jackson, Clinical Educator for Polio Australia and "Seniors Rights" held on 20th May, 2024, was presented by Seniors Rights Service, represented by five Aged Care advocates.

It is particularly sad that a past member of Polio NSW's Board has passed away. Diana O'Reilly was also a member of the Hills District Support Group and often said how she had found her 'tribe' when she joined the group. Merle Thompson writes of Di's contributions to Polio NSW.

Two stories by Millie Lill, editor of Polio Perspectives, appear in this issue of Network News. I always find Millie's stories humorous and thought provoking. The first is called "Three Little Words" (I Don't Care!) and the second "Do it While You Can".

At this time of year when winter is upon us, Dr Marny Eulberg's article on the dilemma of knowing when to see a doctor is pertinent. Is it allergies, a cold, COVID, Influenza or RSV?!

A second contribution by Dr Eulberg is controversial; "Hanging up the Car Keys" something to consider now or in the future.

Lastly, from IDEAS newsletter an article regarding disability parking permits, 'Things You Should Know About Disability Parking Permits in NSW.'

I hope this issue provides you with some useful information.

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Polio NSW - Support

By Chris Kuen/Merle Thompson

The Board, at their planning meeting on 1 March 2024, had a robust discussion on the topic of Support Groups.

The meeting acknowledged there were potential benefits for polio survivors when they were able to gather in small groups to share their polio related and other day to day experiences. These meetings, which may be held in a venue such as a club and include a meal such as lunch, generally provide a pleasant outing for those attending.

However, the meeting also acknowledged that members are now older; many are coping with issues that arise following an increase in age and the late effects of polio. Travel and getting around are becoming more and more difficult.

As a consequence, over the years support group memberships have dwindled and some support groups have had to disband. There are still one or two groups operating.

The meeting noted, despite the decline in support groups, there are still a number of activities open to members where they can discuss issues with other members or where they are able to obtain information and help when needed.

The Board agreed that it was important to let members know what resources are currently available and how to access those resources. With that in mind the following list has been compiled and the Board hopes that members find the information helpful.

Support Services already available to members include:

- Regular email updates from the secretary of Polio NSW
Members are encouraged to make sure they have provided their email address.
- A newsletter (produced approximately quarterly).
- Support provided and available digitally:
 - Webinars
 - Online support groups
 - Human Library
Where members can gain access to, or contribute their own, individual polio survivor stories
 - Facebook
 - Access to Polio NSW and Polio Australia online resources
 - Polio Australia online education and awareness sessions

Digital services are normally delivered using the Zoom platform. If you would like assistance with setting up and using Zoom, contact team@polionsw.org.au to arrange help. The Board would welcome your input on which of the above listed support services you would like to use. They are also looking for suggestions and comments for future support options for members.

Some of the additional possible options could include using other phone or computer based programs such as Whatsapp, a phone based “buddy” system, an email friendship group or individual contact similar to having a pen pal. If you are used to keeping in contact with family or friends by Whatsapp or Facebook you could link in with other polio survivors in this way.

You might also like to see what is available in your local area from the library, community organisations or seniors’ groups to help you learn some of these techniques and have a mentor to help you get started.

If you have any suggestions or comments, please let the Board know using the contact details below. Your suggestion or comments would be very welcome.

Polio NSW contact details:

- Office Tel: 02 9890 0946 Email: team@polionsw.org.au

VALE - Diana O'Reilly

by Merle Thompson OAM, Secretary Polio NSW.



The Polio NSW Board has lost a special former member with the death of Di O'Reilly. Di didn't accept nomination at the last AGM because of health problems.

Di joined the Management Committee/ Board at the 2017 AGM. She has been a quiet, friendly presence on the Board. In the first couple of years she contributed to the planning of seminars. Her last task was to organise a farewell lunch for George Laszuk at Parramatta Leagues Club.

From a personal perspective, I valued the common sense and perception which she showed when we had private conversations. She always had the best interests of the organisation and our members at heart.

For several years Di gave voluntary service in the office. In particular, she organised the library and worked on other records. Di was also a member of the Hills District Support Group where she was regarded as a dear friend by all.

We will greatly miss her and extend our sympathy to her family.

POLIO NSW WEBINAR REPORT

By Gail Hassall

BONE AND MUSCLE HEALTH WEBINAR, MARCH 2024

Presenter Michael Jackson, Clinical Educator for Polio Australia

The human body naturally maintains the right balance between your muscles and bones. Together they work to make your body move, the harder the muscles tug, the more your body strengthens those bones. As you age that balance can change, and if you throw polio into the mix that balance becomes much harder.

Polio survivors often refer to their “good” limb and that is relative, but there are no unaffected muscle groups.

With normal ageing there is 25%-40% global loss in the motor neurone pool by aged 70. If there is no polio, it's not likely to breach the 50% loss. For polio survivors add in the late effects of polio and a loss rate of about 2% per year.

Muscle grades in polio survivors versus their functioning muscle fibres

5	53% or more	
4	42.5%	
3+	9.5%]
3	9.1%]
3-	6.3%] Simply no capacity
2	2.5%] (beyond some hypertrophy)
2-	1.9%]
1	1%]
0	0.7%]

The better the bone density the less potential of a breakage, eg, the more impact activity a young adolescent experiences the denser the bones are which means the bones are not likely to break. The higher the T-score in adult bone densitometry scans (DEXA) the less minerals which could mean bones are more likely to break.

A study a few years ago highlighted that up to 96% of polio survivors had osteoporosis or osteopenia in the affected limb and the major osteoporotic fracture incidence in this cohort was as high as 38% over 5 years. Almost all fractures involved the femoral neck of the affected or atrophic limb.

Exercise for polio survivors should be prescribed and monitored by a LEO-P-informed therapist. When initiating exercise programs: think low-strain, slow, conservative. Weakness from LEO-P can be stabilised or slowed, but never normalised. The goal is to “stabilise function” NOT to “get stronger”. Avoid unnecessary “extra” stress and strain on all muscle groups.

Michael's last point was the most important thing to remember:

AVOID FALLS AT ALL COSTS

An item from ABC News on 10 March says the Geriatric Trauma Service at the Alfred Hospital in Victoria noticed a 20 per cent increase in falls from a standing height over the financial year 2022-2023.

Comorbidities and fragility can be factors contributing to a fall, and they can also mean older people sustain more severe injuries in a fall or have more complications once they're in hospital.

The Alfred admitted more people for low falls of less than a metre than for road trauma in the financial 2022-2023 – 253 road trauma cases and 480 falls. There is no doubt there is a much larger cohort that is presenting to suburban hospitals and regional hospitals,



SENIORS RIGHTS, 20 MAY 2024

This webinar was presented by Seniors Rights Service which is a community organisation dedicated to protecting and advancing the rights of older people, particularly vulnerable and disadvantaged groups. They provide free and confidential telephone advice, aged care advocacy and support, legal advice and community information to seniors across New South Wales.

The presenters were Jen Tilocca, Rachel Muscarella, Sophie Swart, Rosemary Chapman, and Jodeane Anderson, all are aged care advocates and are located in various regions across NSW.

The Seniors Rights Service comes under the umbrella of Older Persons Advocacy Network which is funded by the Federal Government to provide advocacy and legal services for older people. It is underpinned by a Charter of Aged Care Rights required under the Aged Care Act 1997.

The presenters gave an outline of the services the SRS offers and an awareness of rights of older people. Did you know that one in six older people experience abuse each year, most common are: financial, physical, psychological, sexual abuse or trauma, and neglect. Everyone has the right to live free from abuse; there is NO excuse for abuse.

The World Health Organisation defines Elder Abuse as a single, or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust, which causes harm or distress to an older person.

NSW Police has people who specialise in aged care crime and who can help.

Your rights in Aged Care are important and if you think they are being breached you can contact Aged Care advocates at Seniors Rights Service who can assist with complaints as they are agents for My Aged Care.

Seniors Rights Service is also able to help in situations where a person has no family or support person to assist with accessing My Aged Care registration or services.

You can contact the Seniors Rights Service on 1800 424 079 or (02) 9281 3600

Older Persons Advocacy Network on 1800 700 600, or at

https://seniorsrightsservice.org.au/?gad_source=1

About Seniors Rights Service:

We provide targeted rights-based information to a diverse range of older people regardless of cultural background or sexual orientation.

Our aged care advocates, solicitors and education staff travel across NSW to support aged care recipients and the wider community.

We hold information sessions at community groups, clubs, social and professional groups,

aged care homes and retirement villages. We also organise forums and discussion panels. We collaborate with organisations and community groups to develop and implement projects on specific issues such as financial abuse of older people.

Seniors Rights Service receives funding from:

- Older Person's Advocacy Network (OPAN)
- NSW Fair Trading
- Legal Aid NSW
- NSW Department of Communities and Justice

This is information only and not legal or financial advice. If you have a legal or financial problem call our service directly, see your lawyer or a financial advisor. Laws vary from state to state.

The following information has been provided by Seniors Rights Service as points of contact for additional information and resources. Don't put up with any situations that may be resolved with the right support or intervention.

If you think your rights have not been considered or upheld, complaints may be referred to **Aged Care Quality and Service Commissioner**, at <https://www.agedcarequality.gov.au/>
<https://www.agedcarequality.gov.au/contact-us/complaints-concerns/what-do-if-you-have-complaint>

Complaints and Concerns contact – 1800 951 822

Food, Nutrition and Dining Complaints contact – 1800 844 044

For elder abuse or aged or disability crime

NSW Police has people who specialise in aged care crime and can help you.

Police – Triple Zero contact - 000

Crimestoppers contact - 1800 333 000

For NDIS Disability Advocacy contact – 1300 365 085

For assistance with residential aged care contact Aged Care Decisions

Aged Care Decisions is a fast, free and independent service that works with individuals and families to assist in finding aged care and home care services for a loved one.

They have Placement Specialists who are ready to help provide a customised list of home care and nursing home vacancies to match all of your care needs.

They work with over 70% of providers in metro Australia – big and small – to make sure you have choice and control. This means that their provider partners pay them for the services, leaving you with no fee as a result.

<https://agedcaredecisions.com.au/>

The following is an information brochure from SRS.

A GUIDE FROM SENIORS RIGHTS SERVICE

Charter of Aged Care Rights - What they mean for you

YOU HAVE THE RIGHT TO:

1. Safe and high-quality care and services

You should be cared for by highly qualified staff who adhere to best practice in the delivery of personal care, clinical care and services and supports for daily living.

2. Be treated with dignity and respect

Your individuality is recognised and respected and aged care providers work with you to live your life the way you choose to.

3. Have my dignity, culture and diversity valued and supported

The care and services you receive are responsive, inclusive and sensitive to your individual cultural identity. All interactions with you, as well as the delivery of your care and services, reflects you as an individual.

4. Live without abuse and neglect

You have the right to live free of abuse and neglect, and the freedom to speak up and tell staff if you have any feedback or concerns.

5. Be informed about my care and services

Your individual needs are recognised and staff communicate with you in a way that is clear and easy to understand. Where you have authorised a nominated representative to act on your behalf, the aged care provider will also communicate with your representative to ensure they are informed about your care and services.

6. Access all information about myself including information about my rights, care and services

You will be provided with access to your personal information in accordance with privacy legislation, as well as aged care providers' own privacy policies. Sometimes you or your nominated representatives may be asked to put your request for information in writing.

7. Have control over and make choices about my care, and personal and social life, including where the choices involve personal risk

Your right to make decisions that affect your life are respected, even where your choices may involve some level of personal risk. In these instances, aged care providers will have discussions with you and your nominated representatives to understand these risks and how they can be managed. Where your wish involves unacceptable risk, such as a wish that impacts the rights or safety of others, you will be supported in identifying alternative solutions.

8. Have control over, and make decisions about, the personal aspects of my daily life, financial affairs and possessions

Your right to have control over your personal life, financial affairs and possessions is respected. You have the right to make decisions about your life and how you want to live. You are supported to choose your social networks and have regular contact and care evaluations by staff to ensure your needs and preferences are understood and met.

9. My independence

You are supported and provided assistance to help you maintain your optimal independence. You are also supported to maintain the level of control you want and are encouraged to exercise your rights under the Charter.

10. Be listened to and understood

Staff listen to you, understand your needs and preferences and encourage feedback about your care and services. You are provided with opportunities to have your voice heard and understood.

11. Have a person of my choice, including an aged care advocate, support me or speak on my behalf

Your right to have any person of your choice to speak on your behalf is respected. Your advocate is treated in the same way you would be treated, and your advocate is supported to be involved as little or as much as you would like.

12. Complain free from reprisal, and to have my complaints dealt with fairly and promptly

Your feedback is valued and you have a number of ways that you can submit feedback or a complaint. Your feedback or complaint is treated seriously and dealt with fairly and promptly.

13. Personal privacy and to have my personal information protected

Your personal privacy is respected and aged care providers comply at all times with privacy legislation.

14. Exercise my rights without it adversely affecting the way I am treated

Your individuality is promoted and respected. You will not be adversely affected in any circumstance where you exercise your rights. Everyone involved in the delivery of your care must respect your rights.

To contact an aged care advocate call Seniors Rights Service 1800 424 079

Your Rights. Your Voice.

Legal | Aged Care Advocacy | Information

1800 424 079

info@seniorsrightsservice.org.au

seniorsrightsservice.org.au

The Charter of Aged Care Rights was drafted by the Australian Government Department of Health and the Aged Care Quality and Safety Commission - July 2019

THREE LITTLE WORDS

by Millie Malone Lill, Editor, Polio Perspectives

Those three little words that make life so much better. Nope, not the ones you probably thought of, not I Love You. Those words are wonderful, but the ones I'm talking about are "I Don't Care".

Those are three of the most powerful words in the English language. For instance, remember when you were young and had to wear those ugly shoes and the even uglier brace or braces? Had we only known those magic words, our lives would have been so much easier.

Think about it. Did hating them, pouting about them, risking punishment by refusing to wear them actually change anything? Not in my case, for sure. I had to wear them whether I liked it or not. If I had only had access to the Magic Phrase of "I Don't Care", I'd have been a much happier kid.

Were you bullied as a kid? Made to feel "less than?" Facing the bullies with a big fat "I Don't Care" would have taken the wind and most of the fun out of their bullying. It might not have completely stopped the bullying, but if there is no reaction to the taunts, the bullies soon lose interest. To go in a different direction, suppose your kid has dropped a carton of eggs on the floor. You could yell at him/her and make him/her cry, but guess who is still going to clean up the mess. You can just say "I Don't Care" and clean it up or have a fit about it, upset your child and you still have to clean it up.

You can sit in your lonely space feeling sorry for yourself because it's a holiday and you were not invited to a party or you can think "I Don't Care" and do something fun for yourself. Feeling bad is not going to make you any more welcome at that party than if you just don't care, in fact a mooney face is generally going to make you even less welcome.

Pick up that book you have been wanting to read but hadn't had time to do so. Now's your chance. There is absolutely no defense against that powerful phrase. It is a shield the likes of no other. It can be whipped out at a moment's notice or put away for a better occasion. It's OK to care, don't get me wrong, but if your caring or not caring is not going to make a

difference either way, why let it upset you? You can hate winter or not, but part of the year will be spent in winter anyway.

The world will keep on twirling whether you are happy or unhappy. It's up to you to have a good life. No one can make you happy or unhappy. That is always an inside job.

So care about the things and people you love. Care about things you enjoy. Just don't waste your time caring about things that matter very little in the long run. If you can fix it, fix it. If you can't, just go on doing what you can and caring about the important stuff.

In his review of Millie's book: "Square Pegs, Round Holes 'n' Pigeonholes", Richard L. Bruno, HD, PhD described her as the "Mark Twain of polio survivors, with her combination of mid-western charm and razor-sharp wit".

Hanging Up the Car Keys

By Marny K. Eulberg, MD Primary Care Perspective

Taken from the PA Polio Network Newsletter www.polionetwork.org February 2024



I hope that it doesn't take your dog or your passengers to have this look on their faces before you consider whether you should continue to drive!

Driving, for many of us, provides a world of independence, but likely there will come a time when it is no longer safe, prudent, or cost effective to own a vehicle and drive. I'd hope that it does not take a family member taking away your keys or the authorities taking away your license, but if they do, it is

out of concern for your safety and for the safety of others.

Most of us who contracted polio in the developed world are now 65 years or older and many of us are octogenarians! One of my friends (who never had polio), was a nun. The religious order she belonged to required that all nuns over age 80 who were insured drivers using the order's vehicles have a formal driving assessment and she fiercely fought the process. She may have secretly known the outcome because the testing showed her reaction time and problem-solving abilities were significantly impaired.

Here are a few warning signs of unsafe driving:

- Delayed response to unexpected situations.
- Becoming easily distracted while driving.
- Decrease in confidence while driving.
- Having difficulty moving into or maintaining the correct lane of traffic.
- Hitting curbs when making right turns or backing up.
- Paint scrapes from getting too close to obstacles
- Needing to use your hand to lift your foot onto or off the brake or accelerator.

Or, You can answer these questions for yourself by using this checklist from the National Aging and Disability Transportation Center:

Note: More than 2 to 3 "yes" answers should have you seriously considering looking into an adaptive driving evaluation or giving up your keys.

- ✓ Other drivers honk at me
- ✓ Busy intersections bother me
- ✓ I avoid left-hand turns
- ✓ Other cars seem to appear out of nowhere & drive too fast
- ✓ I have been stopped by police recently for my driving
- ✓ Turning the steering wheel is difficult for me (there may be some fixes for this!)
- ✓ I've had more "near misses" lately
- ✓ I have trouble seeing street signs in time to respond to them (go get an eye exam!)
- ✓ I have recently caused a car accident or fender bender
- ✓ I get confused or lost in familiar places
- ✓ It's hard for me to look over my shoulder when I'm backing up or changing lanes (Some technology in newer cars may be able to help with your visual field in these circumstances)
- ✓ My friends and family tell me they're worried about my driving or that they are afraid to ride with me when I'm driving.

The AARP Driving Program, in person or online, now includes information on how to know when you should consider stopping driving and how to access alternative transportation options.

There are specially certified driver rehabilitation specialists or adaptive driving specialists, but they may not be available in less populated areas. These specialists often have driving simulators that allow them to simulate driving situations without any danger to you or anyone else. Many driver rehab specialists have an occupational therapy background. Health insurance may cover part of the cost, but this may also not be a covered service.

Many companies that install adaptive driving aids, such as hand controls, require that you have a driving assessment by a driver rehab specialist and any necessary training using the device so that you can safely drive using the adaptive equipment before they will install the adaptive driving aid.

Have you answered "yes" to two or more of the questions above? I suggest that it may be time to evaluate your options.

Here are some things to consider:

- Owning a car is more expensive than most of us realize. AAA estimated that in 2023, the average cost of owning a new car, driven 15,000 miles per year, is now slightly more than \$1,000/month (\$12,182 per year). There are several calculators available on-line that apply to your location, miles driven, etc. if you Google, "annual cost of owning a car". Giving up your car keys might save you a bunch of money! Imagine how many taxi rides or trips in a ride share or other transportation you could purchase for \$1,000 per month?
- What are the options for alternate transportation in your area? Which ones are you aware of and what other choices are there? There will be less choices in rural areas than in urban areas, but often neighbors in rural areas are eager and very willing to help drive elders to appointments, run errands, and sometimes even to socialize.

In part 2, I'll discuss resources for information about transportation for someone who doesn't drive or no longer drives.

Patients With A Polio History - What Anaesthetists Need to Know

By Liz Telford OAM, Post Polio Victoria for ANCZ Bulletin



When presenting for surgery, people with a history of polio are often told that they are a rarity. It is estimated, however, that up to 40,000 people contracted paralytic polio in Australia between 1930 and 1988. It is also reported that migrants and refugees are increasingly attending polio-related services, so although there are no official figures, we know that there are thousands of people with polio-related issues across Australia from as

young as 30 years old. Hospitals will be seeing polio survivors for at least the next six decades, with needs as broad ranging as childbirth to heart repairs.

We are generally not keen on having surgery due to the unique risks; however the misconception that we are a rarity indicates a lack of awareness by those who should be informed. Often with a background of negative childhood medical treatment, we have the responsibility of educating the medical staff looking after us in hospital, which creates a stress beyond the normal preoperative concerns.

Not only is the onus on us, the patients, to remember to inform the hospital of our polio history, we must also provide information on its surgery and postoperative implications, not knowing how this potentially lifesaving information will be received or if it will be heeded. Polio does not “end” with the attack on the anterior horn cells of the spinal cord.

To manage anaesthesia risks anaesthetists must understand the post-polio sequelae (PPS), the neurological and muscular skeletal condition that develops 20 to 40 years later. The resulting cold intolerance, skeletal deformity, muscle weakness and denervation, osteoporosis and respiratory issues pose a number of risks. There is often increased sensitivity to sedating drugs, opiates, muscle relaxants and anaesthetic drugs (4)(5).

The usual question about drug allergies is not enough, as while the patient with PPS may not have any allergies they may not be aware of the sensitivity of their central nervous system.

“The power imbalance between doctor and patient is often exacerbated when there is a history of childhood disability.”

Anaesthetists need to know that not all people with a history of polio will raise these issues. Some will not realise that their polio history is relevant to their impending surgery, or have the knowledge, confidence or the command of the English language to provide this information. The power imbalance between doctor and patient is often exacerbated when there is a history of childhood disability. It is important for the anaesthetist to take the time to understand the patient’s polio history. We have many and varying hospital experiences. One anaesthetist initially refused to read the online resource regarding anaesthesia and polio provided by a patient about to have emergency surgery at a Melbourne hospital. With only a tense and brief preoperative discussion of her polio history, postoperatively the patient experienced hypotension, extreme cold and suffered a lower back injury from poor positioning.

Positive examples occur such as when the anaesthetist took the polio history of a patient, read the information offered and discussed the PPS implications. The risk for the patient was reduced, and she had her surgery with the confidence that the anaesthetist understood her specific situation. Polio already affects all aspects of our lives. It should not also be our responsibility to ensure that hospitals are safe for us. The COVID-19 pandemic, and those affected, will be considered and studied for years to come. Those of us living with the impacts of the global polio epidemic or lack of vaccination programs would like to have the

confidence that when in hospital we are in the hands of people who have taken the time to educate themselves about our condition.”

Article Source: ANZ Bulletin, Spring, 2020

Is it Allergies? A Cold? COVID? Influenza? RSV? How do I know when to call my physician

By Marny K. Eulberg, MD

Taken from the PA Polio Network Newsletter www.polionetwork.org April 2024



Every fall, going into winter, people who have sniffles, coughs, and/or fever ask themselves and their health care providers, “What causes that?” or “What is this thing that is making me feel sick?”. Fortunately, after the first killing frost, many of the allergies to plants go away until next growing season, but indoor allergens can bother people all year. In 2020 COVID-19 got thrown into the mix. And then in 2023 & 2024 RSV (respiratory syncytial virus) got added to the list. Colds, flu, allergies, COVID and RSV may have many of the same symptoms. And yes, it is even possible to have allergies and COVID, or flu and COVID, or allergies and the flu, or the so called “triple-demic” of flu, COVID and RSV all simultaneously. COVID seems to be the only malady out of this list that can cause a person to have a new loss of the sense of taste or smell, but not all people infected with COVID lose their sense of taste or smell. Therefore, no one can say with certainty that because you can still taste and smell that you do not have COVID !

RSV used to be thought of as only a childhood disease, but now we’ve learned that adults can also become ill from RSV. RSV is a common “cold-like” infection in children (almost all children will have had a RSV infection by age two years). Symptoms of RSV usually include runny nose, decrease in appetite, sneezing, coughing, fever, and possible wheezing. Most RSV symptoms go away on their own in 1 to 2 weeks, but RSV *can* be serious, especially in those less than 2 years old and in adults and infants with impaired respiratory function. They may need hospitalization to treat low oxygen levels or dehydration.

If the problem is only due to allergies it is very, very unlikely that the person affected will have a fever but they often have bothersome sneezing, stuffy or runny nose, and itchy eyes. The National Foundation of Infectious Diseases put together a chart of possible diagnoses (see page 2) for those with respiratory symptoms to help determine whether a person might have a cold, COVID, Influenza or RSV.

The best preventatives for COVID, flu, and RSV are the vaccines that are now easily available and in the US, the cost is covered by Medicare. Additionally, frequent hand washing, wearing face coverings when outside one’s home, and maintaining a distance from others that do not live in your household can be very effective. And, there is the old rule that applies whether it be colds, COVID, Flu or RSV - if you are sick? Stay home! These hygienic measures will decrease your risk of getting and spreading these contagious respiratory infections.

There are vaccines that can prevent and/or decrease the severity of Influenza, COVID, and RSV. Since the vast majority of us in the US who had polio are 65 years or older, it is generally advised that we be given these vaccines including the “high dose” flu vaccine.

Note: This is not based on the fact that we had polio but is purely based on our age. The “high-dose” vaccine has four times the amount of flu antigen that is in the flu vaccine given to younger people to each of 4 different flu viruses (hence the term “quadrivalent”) that are expected to be the cause of influenza in any given year.

According to the New England Journal of Medicine, the high dose flu vaccine was shown to be 24% more effective at preventing flu in persons 65 and older than the standard flu vaccine. Nevertheless, *no* flu vaccine is 100% effective at protecting recipients from getting the flu if they are exposed to someone with influenza. Reminder: It takes two weeks after you’ve had the vaccine for it to be fully effective.

In the past several years, flu vaccines have been shown to be about 40-50% effective. Those who should *not* get the flu vaccine are those with severe allergies to eggs and those who are sick with fever (or any suspected infection including possible COVID). Persons who are sick with fever or have been recently exposed to COVID, flu, or RSV should delay getting the vaccine primarily to avoid exposing the vaccinators and staff to whatever you may have.

Initial treatment for colds, flu, COVID, and RSV are pretty much the same - fluids, rest, and symptomatic treatment such as acetaminophen (Tylenol) or ibuprofen (Advil, etc.) for treatment of fever and body aches. Stay home to minimize the risk of you transmitting these respiratory viruses to others, with special avoidance of those with impaired immunity and infants under one year of age.

Can I Have Flu and COVID-19 At The Same Time?

Yes. It is possible to have the flu, as well as other respiratory illnesses, and COVID-19 at the same time. This is what happened with the “triple-demic” (when Flu, RSV, and COVID-19 cases collide). Some of the symptoms of flu, COVID-19, and RSV are similar making it hard to tell the difference between them based on symptoms alone. Diagnostic testing can help determine if you are sick with flu, COVID-19, or RSV.

Should vaccines be given to someone who feels ill? What if they have a fever?

No. Vaccination should ideally be deferred (postponed) for people who have a fever or severe respiratory symptoms. While mild illness is not a contraindication to vaccination, vaccination visits for these people should be postponed to avoid exposing healthcare personnel and other patients to the viruses causing these illnesses.

When scheduling or confirming appointments for vaccination, patients should be instructed to notify the provider’s office or clinic in advance if they currently have or have developed any symptoms of COVID-19, flu, or RSV.

Additionally, a prior infection with any of these viral illnesses does not protect someone from future infections, but the immunity resulting from the infection may give one protection from that same disease for a year or two. The best way to prevent these illnesses is to get vaccinated following the most recent vaccination schedule.

When should someone call their Healthcare Professional, go to Urgent Care, or to the Emergency Room?

Call your healthcare professional anytime you are concerned.

Consider going to an urgent care facility if you have a fever over 102 degrees Fahrenheit (38.9 C), are having trouble breathing including being shorter of breath than usual with ordinary activities, have had a fever over 101 degrees Fahrenheit (38.3 C) for more than 2-3 days or symptoms other than upper respiratory symptoms such as chest pain, urinary symptoms, or problems eating or drinking. It's time to go the ER – if you have severe shortness of breath, chest pain, fever lasting more than 3-5 days or over 103, severe pain anywhere, impaired level of consciousness, bleeding not related to a minor cut, or passing out.

HOW TO TELL THE DIFFERENCE BETWEEN FLU, RSV, COVID-19, AND THE COMMON COLD

Common symptoms may include cough, headaches, sneezing, runny nose, and congestion. Different symptoms may include:

	COLD	FLU	COVID-19	RSV
ACHES	✖✖	✖✖✖	✖✖	✖
DIFFICULTY BREATHING	✖	✖	✖✖✖	✖✖
FATIGUE	✖✖	✖✖✖	✖✖✖	✖
FEVER	✖	✖✖✖	✖✖	✖✖
LOSS OF TASTE OR SMELL	✖	✖	✖✖	✖
SORE THROAT	✖✖✖	✖✖	✖✖✖	✖
WHEEZING	✖	✖	✖	✖✖✖

Legend: ✖ Rarely, ✖✖ Sometimes, ✖✖✖ Often

SOURCE: CDC
www.cdc.gov/rsv/index.html

Image Source: National Foundation of Infections Diseases

Do It While You Can

By Millie Malone Lill, Editor Polio Perspectives

Taken from Polio Perspectives, April 2024

To be honest, I thought I was too old and too compromised by PPS to do any more traveling. In my younger days, that would be my 50s, I traveled a lot. I loved it! A friend and I decided to visit as many people in our polio group as possible. We had no money, or, as my kids told me later, no dollars and no sense, but we fixed up the van by lowering the backs of the back seats, putting a piece of plywood over them and padding with that foam egg crate stuff and blankets so that we could sleep in the van. Under that was our storage area. We cooked our meals on a Coleman stove at rest stops. We had an inverter so we could plug in a coffee pot. Yes, we got teased that we liked our coffee so strong that it took a 6 cylinder motor to run the coffee pot. Gas and oil expenses were shared, as were the groceries. Before we left, we let the group know who had invited us, where they lived and what route we would be taking. Then we asked any of our group who lived along that route to let us know if they wanted to meet up for coffee or a meal. And off we went.



We did this for about 5 years, being gone for a couple of weeks or, on one memorable trip, six weeks. It was so much fun. But eventually we came off the road. Life goes on. I remarried and moved to Canada. Then I got a divorce and moved back to Iowa. I continued to travel but I was not as portable in my 70s as I was in my 50s.

In 1999, a group of polio survivors, made up mostly of that group that my friend and I visited, gathered in Branson, Missouri. They met at a motel and had so much fun that it was decided to make it an annual event. I missed that first meeting because, surprise! I was traveling. This time it was a trip with two of my sisters to visit our brother.

Since then I have missed three or maybe four of our annual gatherings. This year will be our last. It has been 25 years and we are getting older and, no offense intended, more and more decrepit...I mean disabled. I will miss those wonderful get-togethers so much but the work involved is becoming very difficult. Even the distances some of us travel is becoming a problem. For me, it is at least an 8 hour drive. My friend Jan and I break it up by getting a motel halfway there and again on our return trip. That turns it from an 8 hour marathon to a much more manageable and enjoyable 4 hour drive at a time.

I'm not advocating wearing ourselves out, and I definitely think we should take it slowly and carefully, but also life is very short and I think we should enjoy it, not simply endure it. I recently returned from a week in Arizona, visiting a childhood friend. I usually fly with Southwest Airlines and this trip was the same. Southwest is very helpful and accommodating, I have found. I'm home now and resting before I pack up again and head to Branson, Missouri.

These two trips may be my last ones as I am now in my 80s and getting less and less portable as time goes by. I will be relaxing more now and have taken up a new hobby in case my knitting gets boring. My friend got me hooked on genealogy. So please continue to Conserve to Preserve but add as much fun as you can possibly cram in while maintaining those guidelines.

Paul Alexander: 'Man in the iron lung' dies at the age of 78

Taken from the BBC News 14th March 2024 <https://www.bbc.com/news>

By Ido Vock and Cat Snowdon



Paul Alexander contracted polio in 1952 when he was six, leaving him paralysed from the neck down.

The disease left him unable to breathe independently, leading doctors to place him in the metal cylinder, where he would spend the rest of his life.

He would go on to earn a law degree - and practise law - as well as publish a memoir.

"Paul Alexander, 'The Man in the Iron Lung', passed away yesterday," a post on a fundraising website said.

"In this time Paul went to college, became a lawyer, and a published author.

"Paul was an incredible role model."

His brother, Philip Alexander, remembered him as a "welcoming, warm person", with a "big smile" that instantly put people at ease.

"He was just a normal brother to me. We fought, we played, we loved, we partied, we went to concerts together - he was just a normal brother, I never thought about it," he told the BBC.

Philip said he admired how self-sufficient his brother was, even as he dealt with an illness that stopped him performing daily tasks such as feeding himself.

"He was the master of his domain, helping people to help him," Philip added.

Paul's health deteriorated in recent weeks and the brothers spent his final days together, sharing pints of ice cream.

"It was an honour to be with him in his last moments," said Philip.

Watch: Philip Alexander remembers his brother, 'the man in the iron lung'

In 1952, when he became ill, doctors in his hometown of Dallas operated on him, saving his life. But polio meant his body was no longer able to breathe on his own.

The answer was to place him in a so-called iron lung - a metal cylinder enclosing his body up to his neck.

The lung, which he called his "old iron horse", allowed him to breathe. Bellows sucked air out of the cylinder, forcing his lungs to expand and take in air. When the air was let back in, the same process in reverse made his lungs deflate.

After years, Alexander eventually learned to breathe by himself so that he was able to leave the lung for short periods of time.

Like most polio survivors placed in iron lungs, he was not expected to survive long. But he lived for decades, long after the invention of the polio vaccine in the 1950s all but eradicated the disease in the Western world.

What is polio and how does it spread?

He graduated from high school, then attended the Southern Methodist University. In 1984, he gained a law degree from the University of Texas at Austin. Admitted to the bar two years later, he practiced as a lawyer for decades.

"I knew if I was going to do anything with my life, it was going to have to be a mental thing," he told the Guardian in 2020.

That year, he published a memoir which reportedly took him eight years to write using a plastic stick to type on a keyboard and dictating to a friend.

Paul's brother Philip said it was following its publication that he realised how much of an inspiration his brother was to people across the world.

Advances in medicine made iron lungs obsolete by the 1960s, replaced by ventilators. But Alexander kept living in the cylinder because, he said, he was used to it.

He was recognised by Guinness World Records as the person who lived the longest in an iron lung.



Polio Australia

Improving health outcomes for Australia's polio survivors

Who Helps Those Who are Experiencing Post-Polio Conditions?

This video from Polio Australia explains the value of a multi-disciplinary approach that is effective in treating polio survivors.

This is the 10th in their outstanding video series.

All 10 videos in this series and more from Polio Australia are available on the Living with Post-Polio Post-Polio Syndrome



<https://polionetwork.org/archive/evtu33icr7bhml6ctgf9fsg0u88v8g>
<https://www.polioaustralia.org.au/>

Things you need to know about Disability Parking Permits in NSW



Taken from the IDEAS newsletter, March 2024



The Mobility Parking Scheme provides special parking conditions to eligible people with a disability. One of the key features of the Scheme is the Australian Disability Parking Permit, which will initially replace over 100 different types of permits across Australia. This will make travelling interstate with a Disability Parking Permit much easier. This information is relevant for NSW.

Did you know?

- A NSW Mobility Parking Scheme permit will also give you an **Australian Disability Parking Permit**.
- The NSW Mobility Parking Scheme permit entitles you to park in spaces marked with a symbol for people with disabilities. The permit also provides parking concessions in other spaces: Where parking is limited by a sign to more than 30 minutes, the vehicle can park for an unlimited time.
- There is no fee for an Australian Disability Parking Permit when it's issued with an NSW Mobility Parking Scheme permit.
- If you hold a mobility parking scheme permit, you can enjoy free parking for a certain period of time in designated parking zones. This applies to parking zones with meters or ticket machines.
 - Where parking is limited by a sign to less than 30 minutes, the vehicle can park for a maximum of 30 minutes.
 - Where parking is limited by a sign to 30 minutes, the vehicle can park for 2 hours
 - Where parking is more than 30 minutes, the vehicle can park for an unlimited amount of time.
- The parking concessions apply when the Mobility Parking Scheme permit is displayed on the vehicle and it is being used to transport the person to whom the permit is issued.
- Parking concession available under the Mobility Parking Scheme are only valid on street or council car parks. Car parking areas operating by boom gates are privately operated and no concessions are afforded in the areas.
- You need to insert your NSW permit card into the Australian Disability Parking Permit, and display both when parking.
- Displaying a Mobility Parking Scheme permit that is expired or invalid can result in a heavy fine being issued.
- To be eligible for a Mobility Parking permit, a person must be unable to walk because of permanent or temporary loss of the use of one or both legs or other permanent medical or physical condition is detrimentally affected as a result of walking 100 metres, or who requires the use of crutches, a walking frame, callipers, scooter, wheelchair, or other similar mobility aid.
- Permits are also available to people who meet the permanently blind criteria.
- Mobility parking scheme permit holders can stop in a no-parking zone for up to 5 minutes to drop off or pick up passengers or goods as long as the driver remains within 3m of the vehicle.

Mobility parking scheme permits do not allow a vehicle to stand or park in areas signposted:

- no stopping
- taxi zone
- bus zone
- loading zone
- work zone
- clearway

Quick Tips

- Always plan ahead, your card will be posted to you. When you apply for or renew a mobility parking card, your card will be posted to you at no extra cost. Cards will generally arrive within 10 working days.

- When applying for a Disability Parking Permit is knowing what is a Clinically Recognisable Disability.
- You do NOT need to hold a driver's licence to obtain a Mobility Parking Permit, you can apply for a permit as a passenger in the car.
- You cannot have a representative attend a Service NSW centre on your behalf. During COVID-19 changes to allow **online applications** have been made in NSW.
- If you have more than one car, you can be issued with an additional permit if you have a registered open-style vehicle (such as a convertible, motorcycle or motor tricycle) in addition to a standard vehicle (such as a sedan). This allows you to permanently fix one permit to the open-style vehicle for security purposes and carry the other permit in the usual way.
- If you have lost or damaged your permit, you can apply for a replacement.
- You can report the misuse of Mobility Parking permits.

What is a Clinically Recognisable Disability?

A Clinically Recognisable Disability is a permanent disability certified by a doctor for the purposes of issuing a Mobility Parking Permit. If you meet the Clinically Recognisable Disability Criteria, you will need a doctor to fill out Section 2 of your application form, when you first apply for a Mobility Parking Scheme Permit. Once your disability is recorded in the system, you don't need to provide a medical report to renew your permit.

The following conditions are considered Clinically Recognisable Disabilities

- Paraplegia
- Quadriplegia
- Leg amputations
- Motor Neurone Disease
- Cerebral Palsy
- Chromosomal or syndromic conditions
- Neurodegenerative Disorders
- Neuromuscular disorders
- Blindness

This list has been developed in consultation with the Disability Council and with reference to criteria used by Centrelink for carer allowance applications.

Does a permit affect my ability to drive?

When you apply for a Mobility Parking Permit Scheme permit you will need to have your medical fitness assessed to ensure that you are fit to drive.

The Roads and Maritime Services considers that minor disabilities generally don't prevent you from driving safely.

Minor disabilities include:

- Loss of up to three fingers on one hand
- Loss of toes
- Slight stiffness in a joint
- One limb shorter than the other

- Any other minor condition
- In most cases, serious disabilities mean that you would need to use special aids, appliances and or vehicle modifications.
- Serious Disabilities
- Loss or serious impairment of one or both legs
- Loss or serious impairment of one or both arms
- Any other serious physical or mental disability

How to apply

For an individual or temporary permit you can **download an application form** or get one from your nearest **NSW Service Centre**.

You will then need to get a Medical report from your doctor or your specialist. They need to fill out the medical section of the form.

You may be eligible for a photo exemption. You will need to apply for this before submitting your permit application.

See more information about this at:-

<https://www.nsw.gov.au/driving-boating-and-transport/driver-and-rider-licences/health-conditions-and-disability/disability-parking-permits/individual-and-temporary-permit>

Types of Permits

There are 3 types of permits:

- Individual (blue card) Issued for 5 years to people with a permanent disability.
- Temporary (red card) Issued for up to 6 months to people with a temporary disability, for example, a leg injury.
- Organisation (green card) Available only to organisations that provide transport for people with disabilities.

NSW Mobility Parking Scheme permits fees

- Individual - \$49 (concession - \$0)
- Temporary - \$16 (concession - \$0)
- Organisation - \$49 (concession not available)

All invalid permits should be posted to:-

Drives Assurance, Transport for NSW
P.O Box 3035, Parramatta NSW 2124

Apply, replace or renew mobility parking scheme permits online.

Information Sourced from **Service NSW**

