



POLIO NSW

formerly Post-Polio Network (NSW)

NETWORK NEWS

Incorporating – Polio Oz News

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Editor's Report:

Members of the Board have been busy ensuring that the continuation of our Webinars and online Support Group are sustained. New board members, Geraldine James and Esther Smart have been learning new skills in order to offer assistance in the running of these support services for our Polio NSW members. We also have board member Vasa Marimuthu to advise and assist the board with his computer and technology skills.

Rosalie Kennedy hosts an online support group meeting on the third Wednesday of each month. However, Rosalie will be unavailable to host an online meeting until Wednesday, 23rd August at 11am. Rosalie will contact members by email prior to this date.

In this edition of Network News you will find two webinar reports by board member Gail Hassall who organises and hosts these webinars via zoom. The first is on Continence and the other on Travel without limits. I hope you find them useful and informative.

Dr William DeMayo has returned from his 'stint' in Abu Dhabi and has written a very interesting article on Neuropathy and PPS. His many articles and videos can be sourced here <https://www.papolionetwork.org/demayos-q-a-clinic.html>

Dr Marny K. Eulberg's article on vaccinations was inspired by the COVID Pandemic and how it has been a great reminder to us that Immunizations are available for everyone, not just for COVID and not just for kids. Dr Eulberg's past articles are available at www.papolionetwork.org/primary-care-and-pps.html

Devalina Battacharjee, Polio Australia's Community Development Worker travelled to NSW in June to give Information sessions to polio-survivors, their families and carers. Devalina covered Current information about the Late Effects of Polio, What to tell your health professionals and Self-management strategies. These information sessions were held in Randwick, Hornsby, Parramatta, Glenhaven and Hurstville. A report on these information talks will appear in the next newsletter.

I hope you find this issue of Network News informative and helpful!

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Continence Webinar Report

by Gail Hassall, Webinar Co-ordinator

The Webinar was presented on 10th February 2023 by Paula Westwood, from the Continence Foundation of Australia. Paula's presentation was very good and offered a clear and concise picture of incontinence and how it can be treated or managed, or in some cases, cured.

What is Incontinence?

Continence is the ability to control your bladder and bowel. Incontinence is the involuntary loss of bladder and bowel control and if not treated can get worse not better.

Incontinence can range in severity from a small leak to complete loss of bladder or bowel control. Incontinence can have long term physical and emotional impact, and significantly affect a person's quality of life.

What is normal?

Urinating 4-6 times a day is normal, excreting 300-400mls per visit.

Bowel motions 3 times a day to 3 times a week is normal.

Needing to go to the toilet more than twice per night for over 65s is not normal and can equal incontinence.

Who is at risk?

Incontinence doesn't discriminate. 1 in 4 people aged 15 or over experience bladder or bowel control problems, that is over 5 million Australians. Incontinence is more common than diabetes.

- 80% of people with urinary incontinence are women
- 1 in 3 women who have had a baby wet themselves
- 70% of people with incontinence do not seek help
- Bladder and bowel control problems are not a natural part of ageing

Help is at hand

Incontinence can be managed, treated, and sometimes cured.

You can get help from:

- Nurse Continence Specialist
- Continence physiotherapist
- Pharmacist
- National Continence Helpline on 1800 33 00 66, open from 8.00am to 8.00pm. A Continence Nurse Specialist is available for advice, it's confidential and free.
- Continence Foundation of Australia website at <https://www.continence.org.au/>

If you consider getting an assessment by a professional it would include a discussion about:

- bladder and bowel health and concerns
- medications
- a physical examination or tests

A continence specialist can also help with appropriate products such as disposable pads, pants, or other products. They will discuss the use and care of these products and help you to apply for financial assistance through the Continence Aids Payment Scheme which is a Federal Government Scheme paying up to \$650 per year. Financial assistance is also

provided through Department of Veterans Affairs, National Disability Insurance Scheme and My Aged Care higher level packages.

Changes such as adopting a healthier diet and lifestyle, incorporating regular exercise, and practising good toilet habits can all lead to improvements.

Five healthy habits for bladder and bowel

1. Drink well. Water is best. Caffeine and alcohol are irritants. Drinking less causes more problems.
Urine should be a pale straw colour, if urine is dark, you may already be dehydrated.
2. Eat well. Include more fruits, vegetables, and fibre in your diet.
3. Be active. Where possible do some gentle exercise, walking or gardening to keep muscles strong.
4. Work pelvic floor muscles. The pelvic floor is a band of muscle that holds organs in place and needs to be kept strong as possible. Check out the website at <https://www.pelvicfloorfirst.org.au/>
5. Follow good toilet tips:
 - Sit comfortably with feet on a small stool if necessary (but beware of falls hazard).
 - Lean forward with arms resting on your knees.
 - Don't get into the habit of going to the toilet "just in case". It's a bad habit and hard to break.

For further information and resources go to the Continence Foundation of Australia website at <https://www.continence.org.au/> There are a wide range of resources including booklets, factsheets, posters, brochures, and magazines that may be downloaded directly, or you can request any of these through the Helpline on 1800 33 00 66.

Other useful information:

- **National Public Toilet Map.** This is produced by the Federal Government and is available for all states and territories. It is a free website and app that shows the location of more than 22,000 public toilet facilities across Australia. This is a useful map for all Australians when they are moving around the community especially people with incontinence, travellers or young families.
- **Master Locksmiths Access Key (MLAK).** This is a key system that enables 24/7 access to public toilets for people with a disability, or bladder or bowel condition. The MLAK master key opens all toilet facilities equipped with an MLAK lock. There is a \$20 fee but this is a one-off charge. You can order a key from the Master Locksmith's website at <https://masterlocksmiths.com.au/mlak/>. The application must include a letter from your medical practitioner or you may use your State Disability Parking Permit.



Neuropathy and PPS

By Dr William M. DeMayo MD

Reprinted with permission by The PA Polio Survivors Network www.papolionetwork.org March 2023

Dr. DeMayo has had 30 plus years of clinical experience in the field of Physical Medicine and Rehabilitation. He has served as Medical Director for several comprehensive inpatient rehabilitation units and maintained an active outpatient practice. He recently returned from a temporary position in Abu Dhabi.

A number of Polio NSW members met Dr DeMayo in 2016 when he gave a Q & A talk before attending the Polio Australia's Australasian-Pacific Post-Polio International Conference, held in Sydney. His articles and videos are available for downloading and sharing, <https://www.papolionetwork.org/demayos-q-a-clinic.html>



Question: I had “bulbar” polio in 1952 when I was 7. Except for some difficulty swallowing, I recovered. (To this day, I must turn my neck slightly when I eat). I became a runner in my 30s but in my 50s started having a lot of muscle problems and huge fatigue. I was diagnosed with having the “late effects of polio” and I have been doing my best to manage the symptoms.

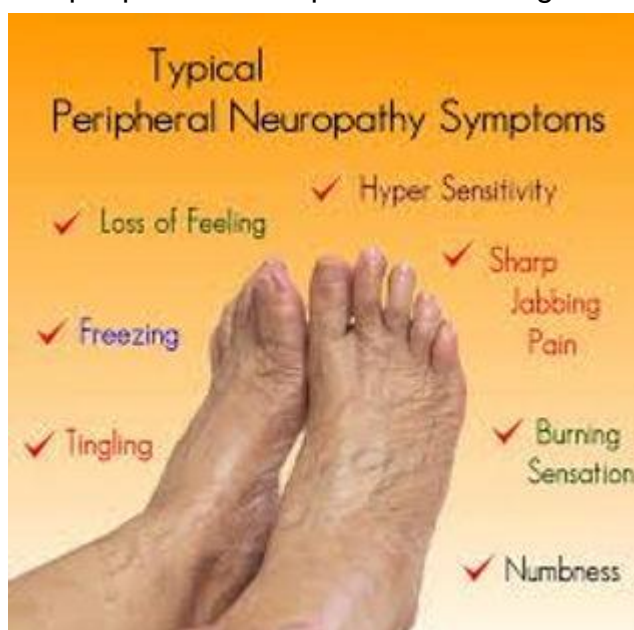
For the last 2 years I have been suffering constantly with burning pain in my limbs that is worse towards the end of the day and particularly during the night. This is having a terrible effect on my sleeping. Is this common for polio survivors? My doctors know very little about polio and cannot find out what is wrong. The burning pain episodes seem like it is nerve pain. Is this something that other polio survivors experience?

Dr. DeMayo's Response: First and foremost, you are not alone! There certainly are a good number of polio survivors with similar symptoms and many people in the general public with this issue. You are right in that this type of pain is typically associated with the nervous system serving as a pain generator. This does not necessarily mean that PPS is the cause. This type of symptom is also very common in peripheral neuropathies in the general population.

Two main thoughts arose in my head as I read your question:

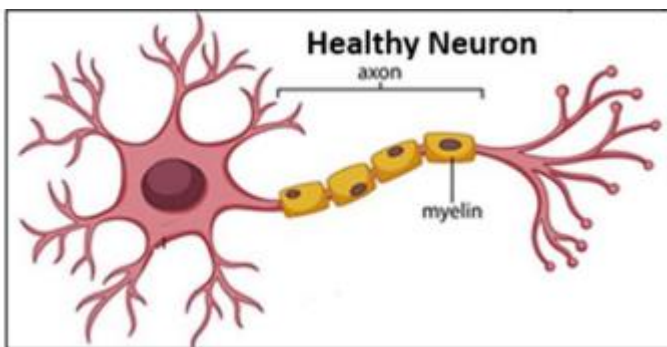
- Is anything being missed that could be causing or contributing to this pain?
- What can be done to minimize the pain moving forward?

With regard to the first question, there are many factors that could play a significant role. Of course, these may or may not apply to you but are worth considering and possibly discussing with your primary care doctor. It should be noted that NONE of these require any specific knowledge of PPS and it is important to not minimize the role of your primary care physician.



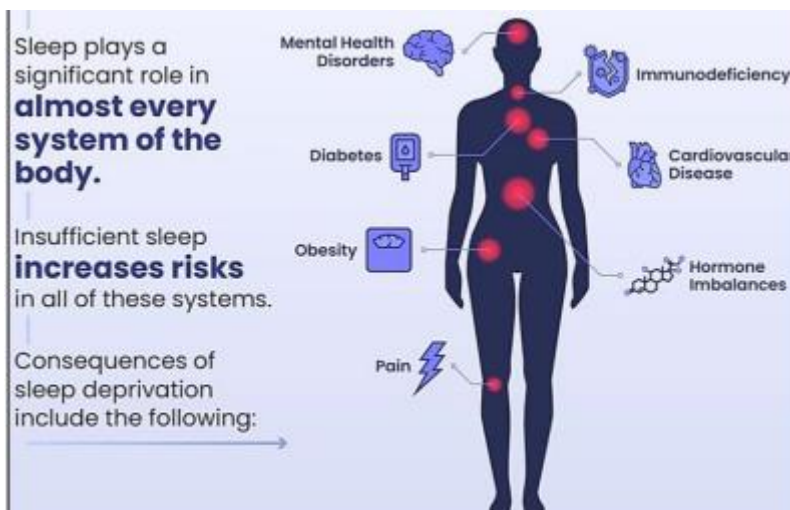
All causes for neuropathy should be considered as they could be having effects that add to the symptoms you experience as a result of possibly having PPS.

- Diabetes is by far the most common cause of neuropathy. Even though it is typically a late symptom, sometimes neuropathy comes quite early in the progression of symptoms. A specific test called a hemoglobin A1c is an excellent screen for diabetes as it gives you a type of "average" of what glucose levels in the blood have been over an extended time.
- B12 deficiency is certainly also another possibility. B12 levels can easily be checked, at the same time "low normal" levels may still be a problem since metabolism of B12 is very complex. Primary care physicians are very capable at evaluating and treating this. B12 can be taken orally or intramuscularly, however some patients simply do not absorb B12 properly. There is a sublingual (under the tongue) version that has increased absorption directly into the bloodstream.



Ask your primary care physician for a screening of the causes of neuropathy. Depending upon your history, the workup could include thyroid tests and possibly folate level, ANA, serum protein electrophoresis or other lab investigations. Most of the common causes of neuropathy can be screened for by a primary care doctor. A neurologist would likely screen for even

wider set of potential causes including heavy metal exposure, Lyme disease and other uncommon causes. If the initial screening does not result in a common cause of neuropathy, then a referral can be made for EMG/NCS (Electromyography and Nerve Conduction Studies). This is a test that involves placing thin needles in the muscle to look for changes. In addition, it will stimulate nerves electrically and watching how quickly they conduct the current. This cannot only definitively diagnose a peripheral neuropathy but also define if it is a problem with the axon (the nerve cell itself) or the myelin (the insulation around the axonal). These are typically done by both neurologists and rehabilitation physicians.



Contributing factors such as stress, anxiety, and sleep problems should also be considered. For example, lack of deep sleep alone can be like "gasoline on the fire" for any chronic pain but especially pain of neurologic origin. It is very common for patients to say that they are not sleeping because of nerve pain. As true as this is, it is also true that they may be having severe nerve pain because they are not sleeping. Diagnosis and

management of underlying sleep or stress related issues can be a significant factor.

Regardless of the actual source of the pain you describe, there are several approaches that can be helpful in neuropathic pain.

- Managing stress, anxiety and sleep can have a profound impact on this type of pain and is often underestimated. Since the pain is coming from within our nervous system, other factors within this system can “dial it up or down”. Yoga, relaxation techniques, counselling, improved sleep hygiene and medical management (if needed) are potential options to investigate.

Note: Caution should be exercised with medical management as most medicines that address these issues can actually decrease the amount of deep sleep, even if they increase the amount of total sleep. Deep sleep is what everyone needs.

- TENS (Transcutaneous Electrical Nerve Stimulation) can be helpful in some situations. Typically, this is obtained through physical therapists.
- Medication certainly has a role, especially if the pain is severe.
 - o It is Important to Note: Prescription and dosage adjustments should always be coordinated with a physician experienced with these medications - never adjust dosages on your own.
 - o Amitriptyline (Elavil) is an old medication which can be very effective in both decreasing pain as well as improving sleep (without the loss of deep sleep). Dosing can be highly individualized and physicians who are not comfortable in using it may prescribe a simple flat dose with a "pass/fail" approach. In my experience, it is much better to start at a low dose, increase each evening until there are side effects in the morning (typically a "hangover type feeling") and then back off immediately to be sure that the patient is within the "therapeutic window". This is the dose that gives us the maximum benefit with no side effects.
 - o Neuroleptic medications: These include Gabapentin (Neurontin) or Pregabalin (Lyrica). Most primary care physicians are familiar with these. At the same time many are not used to the higher doses that are sometimes needed. Both can be quite effective, however, Pregabalin tends to work more quickly and dosing is much easier. Gabapentin needs to be increased slowly and can take several weeks to reach the maximum dose of 1200 mg 3 times per day. Typically, the primary side effect is sedation. If sleep is a problem, then taking a higher dose in the evening and lower dose during the day can help with both pain and sleep.
 - o Medications that treat underlying issues of neuropathy, that may be contributing to the pain, should always be considered. As mentioned previously, these may include thyroid medications or B12.

This is an overview that I hope helps provide a foundation for understanding neuropathy and neuropathy pain. The basic message is to work with your primary care physician on all factors that might be contributing to your symptoms, and then look for the approaches or medical management that can help you.

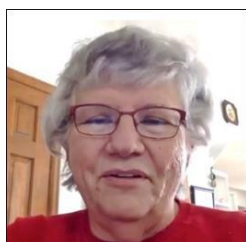


The COVID Pandemic has been a great Reminder.

Immunizations are for Everyone: Not just for COVID and Not Just for Kids

by Marny K. Eulberg, MD Primary Care Perspective

Reprinted with permission by The PA Polio Survivors Network www.papolionetwork.org April 2023



World Immunization Week is celebrated every year during the last week of April. In 2023 that will be April 24-29. The purpose is to highlight the collective action that is needed to emphasize the critical need for vaccination and to promote the use of vaccines (immunizations) to protect people of all ages against serious disease. The ultimate goal is for community acceptance so that more people will be protected from vaccine preventable diseases.

We, polio survivors, have seen first-hand the value of polio vaccines that were first released to the public in the U.S. in 1955 (killed virus - Salk/injectable) and in the early 1960s (live, attenuated - Sabin/oral) and the subsequent sharp decline in the number of people paralyzed by polio. And, we have seen a significant drop in the number of people who have gotten seriously ill, possibly needing a ventilator to help them breathe, or have died since COVID vaccines became available.

Smallpox was the first human infectious disease ever eradicated and that was a direct result of one thing - Vaccination.

How many of us have known a child who has died of tetanus or diphtheria? I suspect none! Those of us in our 50s or older do remember getting sick with measles, mumps, and/or chickenpox. But young people today hardly ever get sick or miss days/weeks of school because they have one of these diseases. This is because, since the 1970s, the majority of children are protected from these diseases by immunizations. In fact, if children are fully immunized by the time they start first grade, they will have received between 17 and 29 immunization shots. The number of injections depends on how many of the immunizations combined 2 to 4 vaccines into one injection. Some health insurances will cover the cost of combo vaccines and some will not; some facilities stock the combo vaccines and some do not.



Once individuals finish attending school, and hence have no school nurse monitoring immunization records, immunizations tend to be forgotten and neglected. There are no regular immunizations recommended for adults aged 26 through 50, other than once every 5 to 10 year boosters against tetanus and recommendations for annual flu vaccines (and whatever the COVID vaccine schedule is going to be).

However, as a person approaches their 50th birthday and beyond, recommendations for vaccines again appear. Certain health conditions, occupational exposures, or travel overseas may also dictate the need for certain vaccinations or a different vaccination schedule.

The current vaccines recommended for adults over age 50 are:

- Annual flu vaccines and what may likely be annual COVID vaccines.
- One dose of Tdap (Tetanus, diphtheria, activated pertussis/whooping cough) and then Tetanus/Diphtheria or Tdap booster every 10 years

- o People often call tetanus “lockjaw” because one of the most common signs of this infection is tightening of the jaw muscles.
- o Tetanus infection can lead to serious health problems, including being unable to open the mouth and having trouble swallowing and breathing. (2)
- o Diphtheria is a serious illness that spreads easily. Doctors treat it immediately and aggressively. Doctors first ensure that the airway isn't blocked or reduced. In some cases, they may need to place a breathing tube in the throat to keep the airway open until the airway is less inflamed. (1)
- Shingles vaccine - series of two injections of Shingrix once in lifetime.

The current vaccines recommended for those age 65 or older (or younger with certain risk factors).

- Pneumococcal vaccines (PCV 15, PCV 20, or PPSV23). The vaccination schedule has changed several times since 2000.
 - o In 2023 the recommendation is one dose of PCV15 (Vaxneuvance) followed by PPSV23 (Pneumovax)
 - o Or a single dose of PCV 20 (Prevnar 20)

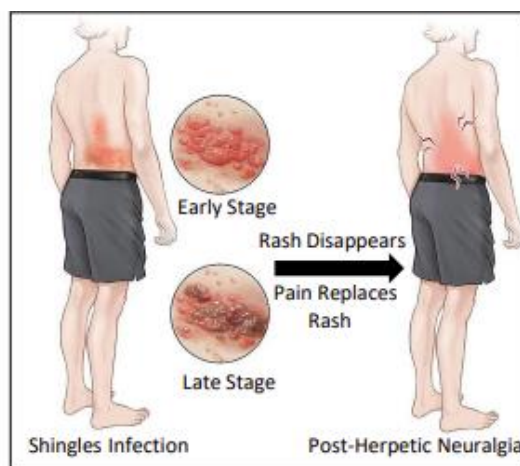
The vaccines for COVID, Flu, Shingles and Whooping Cough do decrease your risk of getting these diseases but do not prevent you from getting it. The purpose of these recommended immunizations is:

- To prevent serious disease, hospitalization (and death from Flu and COVID);
- To minimize the risk of adults becoming ill from whooping cough when exposed to it, and to lessen the transmission of the whooping cough bacteria to infants/young children who are too young to be fully protected by immunizations;
- To prevent the pain and suffering that comes with an episode of herpes zoster, known commonly as “shingles”,
- To decrease the number of episodes and risk of hospitalization from pneumonia, and minimize the damaging effects caused by the pneumococcal bacteria.

Shingles (medical term: herpes zoster) is produced by a reactivation of the varicella-zoster virus that causes chickenpox. It happens most often in people over 50 and in those who experienced the painful, itchy skin lesions from having had the disease chickenpox.

The CDC describes what it feels like to have shingles:

“The rash is usually painful, itchy, or tingly. These symptoms may precede rash onset by several days. Some people may also have headache, photophobia (sensitivity to bright light), and malaise in the prodromal phase. The rash develops into clusters of vesicles (small blisters). New vesicles continue to form over three to five days and progressively dry and crust over. They usually heal in two to four weeks. There may be permanent pigmentation changes and scarring on the skin.” (2)



The Shingles rash is usually along the course of one or two adjacent paths of the involved nerves anywhere on the body, is seen most often on the trunk and characteristically does not cross the midline of the body.

- It's important to note: this virus is NOT the same as the virus causing genital herpes!
- Some people develop post-herpetic neuralgia that can cause unrelenting pain in the area that showed the outbreak of skin lesions. This can last for months, years and in

the worst cases, become permanent. There are some medications that can help but they are not 100% effective and are not curative.

- Ophthalmic shingles (Shingles in the eye) is one particular version of the disease that can have some serious side effects that ultimately can cause permanent damage to your vision. (1)
- Shingles can affect the facial nerve near one of your ears (Ramsay Hunt Syndrome). In addition to the painful shingles rash, Ramsay Hunt Syndrome can cause facial paralysis and hearing loss in the affected ear.

Many people complain about a sore arm after the 2 dose shingles vaccine. That's minor compared to the pain this virus can bring.

Pneumonia is a generic term for any infection that inflames the air sacs in the lungs. Pneumonia can be caused by viruses (such as influenza and COVID) along with many different bacteria, and fungi.

Symptoms can range from relatively mild to life-threatening. It is most serious for infants and young children, people over 65, and individuals with various health problems and immune system disorders.

Pneumonia is often classified depending on the likely place where/how the person got the infection. Thus, you can hear these terms to describe it:

- “community-acquired pneumonia (CAP)” and “healthcare-acquired pneumonia” (HCAP). CAP generally affects relatively healthy people and is usually treated with common antibiotics: HCAP is more likely to be resistant to one or more antibiotics and the people who get it are usually already sick with other conditions.
- Aspiration pneumonia occurs when food, drink, and/or saliva or vomit is inhaled into the lungs.

The vaccines that can decrease a person's risk of getting pneumonia are the flu shot, the COVID vaccine, and the various pneumococcal vaccines. However, getting one of the pneumococcal vaccines will NOT prevent all pneumonias.

- It will not prevent pneumonia from bacteria that are not pneumococci (streptococcus pneumonia) such as the bacteria causing Legionnaires' disease, or bacteria-like organisms such as Mycoplasma, viruses, or fungi.
- And it will not prevent the damage caused to lung tissue caused by aspiration of bacteria that are present in the mouth or stomach acid.

Please talk to your primary care physician about staying up to date on the vaccines you may want or need.

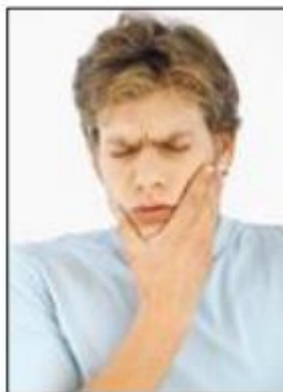
Sources: (1) www.mayoclinic.org (2) www.CDC.org (3) Cleveland Clinic



Smallpox



Measles



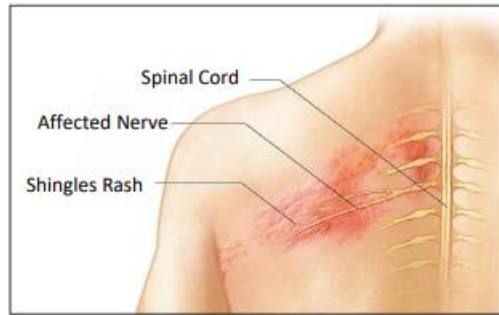
Tetanus (Lockjaw)



Ramsay Hunt



Flu



Shingles

[Editor: For information on current vaccines for adults in Australia visit:

<https://www.health.gov.au/topics/immunisation/when-to-get-vaccinated/immunisation-for-adults>]

Travel Webinar Report

by Gail Hassall, Webinar Co-ordinator

Polio NSW held a webinar on “Travel Without Limits” on Monday 8 May with guest presenter, Julie Jones. Following that webinar Julie provided a list of links to information that may help answer participant’s questions. These links are to articles she has written for her publications, the articles are quite detailed and it’s better you are able to read the aspects of travel that interest you rather than me extracting information of a more general nature.

I have also included some extra information that may help your travel planning. Julie Jones websites <https://havewheelchairwilltravel.net/> and <https://www.travelwithoutlimits.com.au/> are packed with additional information to give anyone, with or without a disability, confidence to travel without limits.

The links below take you to pages of the website and gives information on topics Julie has researched, or with which she has had direct experience. The information covers many topics that were discussed in the webinar.

For those who were unable to join us for the webinar I hope you find the information useful.

Best Practice in a Holiday Park

<https://havewheelchairwilltravel.net/belmont-lakeside-holiday-park-accessible-lake-macquarie-accommodation/>

<http://havewheelchairwilltravel.net/swansea-lakeside-holiday-park-accessible-lakemacquarie-accommodation/>

Cruise tips

<https://havewheelchairwilltravel.net/royal-caribbean-ovation-seas-wheelchair-accessible-cruising/>

<https://havewheelchairwilltravel.net/royal-caribbean-explorer-of-the-seas-wheelchair-accessible-cruising/>

Air Travel

<https://havewheelchairwilltravel.net/tips-making-air-travel-comfortable-wheelchair-accessible-travel/>

Travel Insurance

<https://havewheelchairwilltravel.net/travel-insurance-existing-medical-conditions-disability/>

<https://havewheelchairwilltravel.net/what-you-to-know-about-travel-insurance/>

Sydney Harbour YHA

<http://havewheelchairwilltravel.net/sydney-harbour-yha-accessible-budget-sydney-accommodation/>

Ridges Airport Hotel accessible accommodation

<https://havewheelchairwilltravel.net/rydges-sydney-airport-hotel-wheelchair-accessible-accommodation-sydney-airport/>

Exceptional AirBnB accommodation

<https://havewheelchairwilltravel.net/mt-warning-estate-two-bedroom-accessible-accommodation-murwillumbah/>

Tips on booking an accessible hotel

<https://havewheelchairwilltravel.net/booking-an-accessible-hotel-2/>

Information on MLAK key and other bits

<https://havewheelchairwilltravel.net/7-things-that-make-travelling-with-a-disability-in-australia-easier/>

Beach wheelchairs

<https://havewheelchairwilltravel.net/beach-wheelchairs-walkers-surfers-paradise-beach-gold-cost/>

TrailRider (may be of interest to any outdoorsy members)

<https://havewheelchairwilltravel.net/dorrigo-national-park-trailrider-wheelchair-access/>

Additional Resources:

These websites may help you on the way to planning your next holiday.

ACCESSIBLE ACCOMMODATION

<https://www.accessibleaccommodation.com>

CLUBMATES

<https://www.clubmatestravel.com>

SUPPORTED TRAVEL EXPERIENCES

<https://www.supportedtravelx.com.au>

GETABOUTABLE

<https://www.getaboutable.com/>

HAVE WHEELCHAIR WILL TRAVEL

<https://havewheelchairwilltravel.net>

HIDDEN DISABILITIES

<https://hiddendisabilitiesshop.com.au>

PUSH ADVENTURE

<https://www.pushadventures.com.au>

THE ACCESS AGENCY

<https://www.theaccessagency.com.au/>

ACCESSIBLE GO


<https://accessiblego.com/>

AIRBNB

<https://www.airbnb.com.au/accessibility>

[Editor: Julie Jones spoke of a service she uses, Ladies running errands. They do airport transfers, school pickups, collect mail or water garden when you are away, transport you to doctor appointments, take pets to vet, do shopping for you and more.

Contact: 1300 807 031 Mobile: Maria 0412 438 635 Email: maria@lre.com.au
Website: www.ladiesrunningerrands.com.au]



Travelling with Incontinence: Tips for stress-free holidays

By Sonya Meyer, Consultant for Confidence Club, a provider of continence management products. (<https://confidenceclub.com.au/>)

Travel is one of the biggest joys in life, but for people who experience incontinence, an enjoyable experience can quickly turn into a headache. Lost luggage, badly stocked stores, and simply an unfamiliar location can all spell disaster for someone with continence issues.

Even if relatively mild, a long-distance plane or car trip can present a whole world of problems that you simply wouldn't have to worry about in the comfort of familiar surrounds.

On a plane, the worries can pile up fast. "What if I need to go while standing in line at the airport security?", "Will I be able to get to the toilet fast enough?" "What happens if there's a big queue to get onto the flight?" "What if the seat belt sign comes on?"

The good news is that with the right preparation and planning, travelling with incontinence can be a lot easier. SO, if you have a long trip ahead of you and you're already worrying about how you'll cope, here are five quick tips to make the journey a whole lot more comfortable.

Pack enough products:

This might sound straightforward, but it can be easily overlooked. Ensure you have enough products for your normal wear and add an additional one for every day you are away. This will prevent you from running out of supplies and needing to buy more while on your trip.

If travelling by plane, ensure you pack your continence products in two different cases and in your carry-on. Allow at least one day's worth in your carry-on in case your main luggage is lost in transit. If travelling longer distances, consider upping your absorbency for extra protection while in transit. Pack some large zip-lock bags so when you go on day trips you

can pack everything you will need for each change into one bag. If you do leak occasionally at night, consider taking bed pads to protect the hotel's bedding and prevent embarrassment. If you use wipes, remember to pack those as well.

Choose your seat wisely:

If travelling by plane, try to book an aisle seat to allow for access to the bathroom. This will prevent you from disturbing other passengers and make your trip more comfortable.

If embarking on a long train journey, try to book a seat in a carriage with a bathroom, since many trains can require passengers to walk through several carriages before they find the facilities.

Prepare, prepare, prepare:

As with the best-laid travel plans, preparation is critical. When travelling to a new destination, research maps of public toilet facilities so you know where they are ahead of your day trips. This will save you time and reduce any potential anxiety about finding a bathroom when you need it.

If you're travelling in Australia, check out the National Public Toilet Map which has been designed as part of the Federal Government's National Continence Program.

If travelling internationally for a longer period, contact your continence provider and see if they distribute to the country you are visiting. If they do, get them to ship your products from there to the address you are staying at. This means you don't have to carry a case full of your aids, and you'll have more room for souvenirs!

Take a good quality protection cream:

If you experience incontinence, your skin is classed as being compromised. Sometimes a different water pH in a new place can irritate compromised skin, so it's important to pack a good quality protection cream. Always use according to the manufacturer's instructions and try to avoid using anything you haven't thoroughly tested in the comfort of your own home beforehand.

Stay hydrated:

It is important to stay hydrated when travelling, as a dehydrated body can lead to bladder irritation, making incontinence worse. Drink plenty of water and avoid beverages that can cause dehydration, such as caffeine and alcohol. This is especially important if you're travelling to a hot place, or if the location doesn't have public water fountains readily available.

Travelling with incontinence can present some challenges, but with the right planning and preparation, your trip can be enjoyable and stress-free and you can focus on making some amazing memories.

Did you know?

While sourcing the right continence products is a top priority, many people are reluctant to seek advice... even from medical professionals. According to the Continence Foundation of Australia, 69 per cent of surveyed GPs revealed men never or rarely speak about continence issues, making it difficult to assist in treating the condition.

A Confidence Club survey of 1691 respondents (male and female) show 73 per cent received no help in choosing the right product, and only 6 per cent sought advice from a health professional.



The Vagus Nerve: Everything you need to know

By Hayley Bennett

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It's the body's information superhighway that tells your organs how to rest.

What is the vagus nerve?

Your [brain](#) is connected to your body through a set of 12 crucial nerve networks that descend through your spine and branch out into your body. Of these, the vagus nerve is probably one of the most important. Its tendrils influence digestion, your [heart](#), your reflexes and your breathing.

So you can see why scientists are so interested in what the vagus nerve does – especially when you consider how all of the above affects your mood. You could call it a superhighway between our brains and bodies.

Vagus nerve function

In contrast to the rapid 'fight or flight' responses that are under the control of the sympathetic arm of the nervous system, the vagus nerve is responsible for many of the slower, 'rest and digest' responses that we collectively call the parasympathetic arm. The nerve itself is actually two thick bundles of individual neurons (nerve cells) that originate in the brain and pass out to the rest of the body through left- and right-sided openings at the bottom of the skull.

Most of the individual neurons that make up the vagus nerve are sensory ones – about 100,000 on each side of the body in humans – which pass messages from the organs to the brain, and are activated by sensory input from the environment. The remainder are motor neurons, which send messages in the opposite direction, from the brain to organs, and directly control all of our muscle movements.

Why is the vagus nerve so important?

The vagus nerve is a sort of polymath of the parasympathetic nervous system, getting involved in everything from breathing, heart rate, swallowing, sneezing, digestion, appetite, immune responses and even orgasm.

The vagus nerve's wide-ranging skill set comes from having a diverse array of neuron cell types at its disposal. These allow the nerve to pick up [different types of sensory signals](#) from different organs. Some, for instance, sense chemical signals like oxygen levels in the blood or the secretions of bacteria in the intestine, while others sense mechanical signals like stretching of the blood vessels and gut.

Therefore, the neurons in the vagus nerve mostly give the brain information about what is going on in the rest of the body. The brain interprets this information and acts upon it to help maintain the internal status quo. But there are also important functions associated with the less numerous neurons that send signals the opposite way, including in communications between the brain and gut, and in select muscles in the mouth and throat that are responsible for speech and the gag reflex.

The functions of the vagus nerve are so numerous and varied that it's very likely there are roles that we have yet to uncover. We do know, however, how we can tap into it. Doctors sometimes prescribe '[Valsalva manoeuvres](#)' to activate the vagus nerve and slow a fast-beating heart or calm heart palpitations. These might involve activities like coughing, straining like you're on the toilet or, perhaps most bizarrely, doing a handstand.

The long and winding nerve

The word, 'vagus' means 'wandering' in Latin, and the vagus nerve truly is. The nerve bundles reach as far as the base of the spine and colon, branching off to the vital organs, including the heart, lungs, liver and gut, along the way.

As the longest cranial nerve in the body, it's the main component of the parasympathetic nervous system, which controls automatic bodily functions such as digestion, when the body is at rest. Historically, the vagus nerve was known as the pneumogastric nerve, because it supplies both the lungs and stomach with nerves.

How is the vagus nerve connected to our wellbeing?

When we're in a high-stress situation, our sympathetic nervous system's fight or flight responses kick in, enabling us to deal with it quickly. The parasympathetic nervous system, meanwhile, comes into play more slowly to promote a more restful state, so it is crucial for helping us relax and calm down after experiencing stress.

With help from the vagus nerve, our brain recognises that, for example, our breathing and heart rate have accelerated and puts the brakes on. While the sympathetic and parasympathetic arms aren't always in sync – they can operate separately or in a more coordinated way – in theory, there is a balance to their activities that can be upset in certain circumstances. These include bowel disorders and mental health conditions. Persistent stress is thought to be a cause of sympathetic overdrive and researchers say they can detect this in people with depression, for example.

The vagus nerve and the heart

One key metric that is often used is [heart rate variability](#) – the variation in the gaps between consecutive heartbeats. A healthy heartbeat is slightly more chaotic in its rhythm, so low variation is said to be associated with a jacked-up sympathetic system, where the body is in constant fight or flight mode, with the vagus nerve and parasympathetic response struggling to keep up.

Despite its widespread use, however, there are still some questions about how useful heart rate variability can be as an indicator of balance between the parasympathetic and sympathetic systems. Although heart rate monitors can give us this information, we shouldn't obsess about the numbers.

What happens if the vagus nerve is damaged?

In the past, stomach ulcers were often treated by cutting the fibres of the vagus nerve below the rib cage. The thinking was that the vagus nerve plays a central role in producing the stomach acid that causes the sores. With modern drugs, the need for this type of surgery has decreased, but it demonstrates what can happen when a nerve with so many branches is compromised.

Indeed, 'vagatomies' cut off the vagal nerve supply to the stomach, pancreas, small intestine and part of the colon, meaning that without further surgery to the gut, the patient may be unable to pass solid waste. People with gastroparesis suffer from a similar problem, but in this case, the symptoms are usually due to vagus nerve damage caused by diabetes, drugs or infection.

However, when the vagus nerve is damaged higher up, the effects can be completely different. The chickenpox virus, for example, attacks the nervous system and though rare, it has been known for the virus to cause [vagus nerve lesions](#) that result in a patient losing their ability to swallow – they may also get a headache and an inflamed ear. Early data collected by Spanish researchers also suggests that some of the symptoms of [long COVID](#) may be related to vagus nerve damage, including breathing, voice and bowel issues.

Do I need to get myself a vagus nerve stimulator?

The evidence we have so far suggests devices for [vagus nerve stimulation](#) are safe.

However, researchers are still concerned about the increase in at-home use of nerve stimulators, which may come with risks that we're not yet aware of.

Those who prefer mindfulness to being hooked up to machines are turning to activities such as yoga, meditation, hypnotherapy and deep breathing, all of which are thought to boost the functioning of the parasympathetic nervous system and vagus nerve. There is also evidence to suggest that [cold water swimming](#) or bathing, or even just [splashing your face with cold water](#), can stimulate the vagus nerve and activate the parasympathetic system.

Of course, buying a cheap device to attach to your ear, or signing up to take part in [yoga](#) retreat, may seem like an appealing fix when you're not feeling quite right, but it's always best to get serious health complaints checked by a doctor.

What is vagus nerve stimulation?

The concept of vagus nerve stimulation goes back as far as the late 19th Century, when the neurologist James Leonard Corning developed an electrical stimulator to treat epileptic patients. Although it was discarded as a treatment back then, over 100,000 people have now had vagus nerve stimulation – by implant in the chest or, less often, brain – to treat epilepsy when the drugs they've tried haven't worked.

Some people are able to get as much as a 75 per cent reduction in their seizures with an implant; with multiple studies showing the benefits increase the longer the implant has been installed. An implantable device made by the US medical technology company Cyberonics is also approved for severe depression and headaches.

Nerve stimulation doesn't have to mean surgery, though. It's possible to access the vagus nerve [through its branches in the ear and neck](#), for example, using devices similar to the inexpensive TENS machines more commonly used for quelling labour [pain](#). Ear clips are widely sold as TENS attachments, while companies like [Nurosyl](#) make stylish neuro-modulators targeted at people who want to try the approach for anxiety, depression or fatigue.

Scientific research on vagus nerve stimulation is exploding currently, with trials covering burns, obesity, high blood pressure, rheumatoid arthritis, Alzheimer's, [tinnitus](#)... the list goes on. Due to the [close connection between the vagus nerve and gut function](#), it's also touted as a potential treatment for common bowel disorders like IBS. Although, as with other conditions, the process of gathering evidence from trials to support its use will take time.

Five facts you need to know about the vagus nerve

1. It's the longest cranial nerve, running from the brain to the large intestine, and sends signals in both directions via neurotransmitters and gut hormones.
2. The fibres of the vagus nerve contain 200,000 sensory nerve cells. Our ears are the only place where sensory vagus nerve fibres reach the surface of our bodies.
3. A vagus nerve 'bypass' that carries impulses directly between the uterus and brain is thought to allow women with spinal cord injuries to have orgasms.
4. Vagus nerve stimulation affects the gamma-aminobutyric acid neurotransmitter associated with ADHD, leading scientists to propose it as a potential treatment.
5. The scientific name for fainting is vasovagal syncope, which occurs when the vagus nerve is overstimulated, causing a sudden drop in heart rate and blood pressure.



LAZINESS...AYE OR NAY?

By Millie Malone Lill, Editor, Polio Perspective

Reprinted from Polio Perspectives, April 2023

Like most polio survivors, I have often been accused of laziness. In the Good Old Days, no one knew a thing about PPS, so usually their criticism was well meant. "You need to exercise to rebuild your strength." To be fair, no one really understood the fact that the polio virus had destroyed so many motor neurons. During the recovery period from the acute onset of the virus, these neurons grew sprouts and revived the muscles that were left without a connection to the brain. This led doctors to think that we were cured. Further research discovered the sprouting was a temporary fix. Those sprouts were overworked and eventually they also quit working.

During this recovery period, we polio survivors were left with the idea that we could just work harder and we'd be fine. Unfortunately, that was not true. Our hard work caused more damage. You can no more strengthen a muscle with no working motor neuron than you can tune a radio that has been unplugged. What you can do, and this is the sad part, is that by overworking that sprouted neuron you will kill it entirely.

A polio survivor has to work 3 times as hard as a non-polio affected person to do the same amount of work. So are we lazy? Nope. However, another polio residual is that we often become Type A people. We don't want to appear vulnerable or in any way "less than". So we push. And we push harder. We want to prove to the world that we are just as able as anyone else. In the end, we pay for it by becoming more and more disabled.

If only we had known that earlier. Maybe, had we not tried so hard to be normal, we would have more motor neurons that still worked. Maybe. It's too late to worry about that now, though, isn't it? As Garth Brooks sang, "I could have escaped the pain, but I'd have missed the dance." Now is the time to embrace your inner lazy slob.

I've recently become aware of the fact that people sometimes get a good feeling when they can help someone. I know, that is totally not the polio survivor's creed. No. We don't want to ask for help. What if someone saw us struggling to open a door while balancing on crutches and wearing a brace or two and thought we were disabled? Spoiler alert: we are. You will not get to heaven any sooner if you suffer more. Let other people help. We all know the glow we get when we help someone, even in a small way. Share that feeling. Ask some politely if they would mind helping you. Start small. We don't want to get giddy here. Maybe just ask some to reach something that is on too high a grocer shelf, or open a door for you. Don't forget to smile and thank them.

For year, I hosted my family at potlucks here in my building for various holiday meals. I would spend a week ahead of time, baking, cooking, getting thing ready. All by myself, of course! Then, when it took me a couple of weeks to recuperate from one such meal, I told my kids that I was done. If you want a Thanksgiving meal, I will supply the venue, but you will have to do the actual work. Whatever you bring, that's what we'll eat, I told them.

I could not believe the response. They pitched in, did almost all the cooking, all the setup and all the cleaning up afterward and we had such a great time that they offered to do

Christmas, too. I actually enjoyed both of those gatherings instead of merely enduring them because of my exhaustion. Light bulb moment.

I have reached the conclusion that laziness is our friend. I won't lie, I still feel guilty when I am sitting in my power chair just visiting with people while someone else is putting on the tablecloths, setting the table, putting out the food, cleaning up afterward but I'm getting over it. I've worked hard in my life and understanding that I worked harder with my few motor neurons than I gave myself credit for has made my life much more pleasant.

So my vote on this subject is AYE! All opposed, suffer the consequences.



Post-Polio Post



[Editor: Email from Bernard Badorrek, Orthotist]

We wanted to let you all know that Orthomotion is closing our Artarmon clinic at the end of **September 2023**.

This is the end of an era. Orthomotion has been providing orthotic services to our clients from our satellite Artarmon clinic at Advance Rehab Centre for 12 consecutive years.

We will continue to collaborate with ARC therapists and other health professionals that form part of our client's multidisciplinary care team to deliver the highest level of orthotic services and supports from our purpose-designed, primary clinic in Caringbah.

Our Caringbah clinic is located at Suite 13, 59-63 Captain Cook Drive.

Caringbah is located to the south of the Sydney CBD and easily accessible via car and public transport. Dedicated parking is available onsite and free, unlimited street parking is available close to the clinic.

Our orthotists are available to offer Telehealth appointments (video and telephone) to our clients, when appropriate for their case.

We are looking forward to continuing to deliver innovative orthotic services and supports to you to meet your ongoing mobility requirements and goals.

Please contact our team at office@orthomotion.com.au or (02) 9055 5300 to schedule your next appointment at our Caringbah clinic or if you wish to request to be removed from our client database.

Warmest Regards,

Orthomotion team

