

**POLIO NSW**

*formerly Post-Polio Network (NSW)*

# NETWORK NEWS

*Incorporating – Polio Oz News*

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## Editor's Report:

The Polio NSW Board held a planning meeting by ZOOM recently to discuss what is ahead for us in 2021. We have a number of new ideas on how to support our members in a more conducive way, taking into account our increasing fatigue and mobility issues.

COVID has opened up many options for staying connected to our family and friends e.g. video calls or ZOOM meetings. Perhaps we could still hold seminars, an AGM or support group meetings using different technology. Taking advantage of new technology will be more cost effective and fatigue effective. For our Board members not having to travel great distances to attend meetings is a perfect example of the benefits of using these new means of communication.

These changes will require some organising of course for both the Board and for members. Some members may not have access to a computer or the knowhow BUT using a family member or friend's PC or laptop could work. Once dates for 'events' are known members could arrange for their 'tech' person to be available to allow this to happen in the convenience of your home or theirs. This is how two of our Board members make it work for them – and it includes a lunch outing afterwards!

Communicating more regularly by email would be of great benefit as well, when the Board has items of interest to share with members, such as notifications from Polio Australia, Consumer Health Forum or of an interesting event. Similarly, for those who don't have email access perhaps they could supply a contact email address, i.e. a family member's email address. Provide your email contact details to the office by email address [office@polionsw.org.au](mailto:office@polionsw.org.au) or phone 9890 0946. A group email list will be setup to make this process as simple as possible for our Board to achieve.

Our newsletter, Network News, will continue to be mailed out as usual or emailed to those members who have selected this option.

This issue of Network News covers many topics that I hope will be of interest - from breathing issues, bracing (Callipers - AFOs, KAFOs), nerve pain and back issues and some advice from Dr DeMayo via Dubai. On page 5, Polio Australia's Community Program Manager, Stephanie Cantrill, announces ZOOM chat meetings for 2021 – they are conducted well and I encourage you to give it a go as a test run for when Polio NSW gets up and running with ZOOM!

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# PPS and a Glass of Water

Reprinted from PA Polio Survivors Network, January 2021 [www.papolionetwork.org](http://www.papolionetwork.org)



A psychologist walked around a room while teaching stress management to an audience. As she raised a glass of water, everyone expected they'd be asked the "half empty or half full" question. Instead, with a smile on her face, she inquired: "How heavy is this glass of water?"

Answers that were called out ranged from 8 oz. to 20 oz. She replied, "The absolute weight doesn't matter. It depends on how long I hold it. If I hold it for a minute, it's not a problem. If I hold it for an hour, I'll have an ache in my arm. If I hold it for a day, my arm will feel numb and paralyzed. In each case, the weight of

the glass doesn't change, but the longer I hold it, the heavier it becomes."

She continued, "The stresses and worries in life are like that glass of water. Think about them for a while and nothing happens. Think about them a bit longer and they begin to hurt. And if you think about them all day long, you will feel paralyzed –incapable of doing anything." Remember to put the glass down.

"This applies to PPS - Consider using power mobility outside and inside the house. One step at a time. But, don't wait until your legs and/or arms are not stable anymore."

A post from survivor Jann Hartmann From the 2018, PNNJ Conference.

## Regional Seniors Travel Card

The regional seniors travel card provides eligible seniors in regional, rural and remote areas with a \$250 prepaid card to help ease the cost of travel. You can use the travel card at certain retailers across Australia to pay for fuel, taxis and pre-booked NSW Trainlink Regional trains and coaches.

The regional seniors travel card program is available for a 2-year trial period (2020-2021). Application for eligible seniors for the 2021 card will open on 18 January 2021 and will close on 30 November 2021.

### Services Australia

You must be:

- receiving the Age Pension; or
- a Commonwealth Seniors Health Card holder
- 

### Department of Veterans' Affairs

You must be receiving one of the following:

- Age Pension
- Service Pension
- Disability Pension under the *Veterans' Entitlements Act 1986*
- War Widow(er) Pension

Or hold a Commonwealth Seniors Health Card.

- You must also have received your pension or have held your card for at least one month.

**Note:** Services Australia was formerly the Department of Human Services.

**How to apply:** Due to COVID restrictions we strongly advised you apply online at [service.nsw.gov.au](http://service.nsw.gov.au) or by phone [13 77 88](tel:137788), rather than visiting a service centre.

# NEWS FROM TRANSPORT NSW

Information provided by the Physical Disability Council of NSW

**The Taxi Transport Subsidy Scheme** is transitioning away from manual paper travel dockets to a digital Smartcard. This will happen over several months starting in NSW regional areas and concluding in Sydney Metro. If you're a current participant there's no need to apply for the Smartcard, you'll be contacted directly by Transport for NSW when it's being introduced in your area. Transport for NSW will issue you a Smartcard and instructions on how to use it. This will happen before your area transitions away from paper travel dockets. Find out more on the [Transport for NSW website](#).

**Have station upgrades changed your life?** As part of our involvement in Transport for NSW's Accessible Transport Advisory Committee, we have been approached by the Transport Access Program who want to hear from people with disability who have benefited from transport upgrades. If you have a story you are happy to share with Transport for NSW, register your interest via email to [admin@pdcnsw.org.au](mailto:admin@pdcnsw.org.au) and someone from the PDCN team will contact you in the new year.

## Dine and Discover Voucher Scheme

The following two articles are reprinted from IDEAS, Newsletter Jan/Feb 2021.  
IDEAS - Disability Information Free, Accurate & Independent [www.ideas.org.au](http://www.ideas.org.au)

The NSW Government launched the Dine & Discover NSW voucher scheme to encourage the community to get out and about and support dining, arts and tourism businesses and to stimulate spending in the economy.

In early December, the scheme invited customers to use their vouchers with participating COVID Safe businesses as part of a trial in The Rocks. This program will then be rolled out across NSW from March 2021.

### How does Dine & Discover NSW work?

Every NSW resident aged 18 and over will be eligible for four \$25 vouchers worth \$100 in total. The vouchers can be used at participating NSW businesses that are registered as COVID safe.

The Dine & Discover NSW vouchers will be divided into two categories:

- Two \$25 vouchers to be used for eating in at restaurants, cafes, bars, pubs and clubs from Monday to Thursday
- Two \$25 vouchers to be used for entertainment and recreation, including cultural institutions, live music and arts venues, available 7 days a week

### How do I apply for the vouchers?

To participate in Dine & Discover NSW, you must have a **MyServiceNSW** account. You can download the Service NSW app now and register for a MyServiceNSW account ahead of the vouchers becoming available from March 2021.

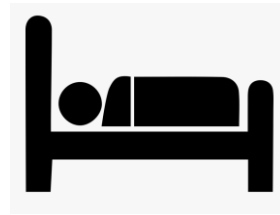
**SERVICE NSW** Contact Details: [www.service.nsw.gov.au](http://www.service.nsw.gov.au) Phone: 13 77 88

# Looking for an accessible classifieds website?

## Buy or Sell:



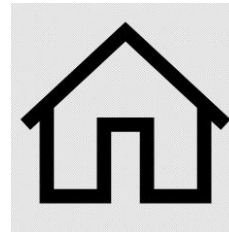
Cars



Beds and  
Equipment



Wheelchairs  
Scooters



Accessible  
Properties

Website: [www.ebility.com.au](http://www.ebility.com.au)

Phone: 1800 029 904

Email: [sales@e-bility.com](mailto:sales@e-bility.com)

## New Orthomotion Orthotics Clinic - Sydney South

ORTHOMOTION is opening a new orthotics clinic in Sydney's south:-  
**Suite 113, 59-63 Captain Cook Drive, Caringbah**

Orthomotion offer a comprehensive orthotic clinical service across two Sydney locations; their new clinic at Caringbah and at Advance Rehab Centre, 5 George Place, Artarmon. They offer clients access to technically advanced and innovative assistive devices to help achieve mobility goals.

Bernard Badorrek, MAOPA CPO, is a neuromuscular orthotist who specialises in the orthotic management of neuromuscular disorders such as poliomyelitis, cerebral palsy, stroke, brain and spinal injury, MS, neuropathy and MND. Bernard has presented at Polio Australia's International Conference and is orthotist to a number of our members. For reviews of their experiences visit ORTHOMOTION's website [www.orthomotion.com.au](http://www.orthomotion.com.au).

Bernard established ORTHOMOTION in 2012 as a clinical practice specialising in the treatment of people with mobility impairments. He has 20 years experience in the orthotics profession and has practised in Melbourne and Sydney in both private and public facilities, including Advance Rehab Centre, Prince of Wales Hospital, Royal North Shore Hospital and Orthotic Consultants.

To book an appointment for an assessment call: **(02) 9055 5300**

ORTHOMOTION  
Walk Your Way



(02) 9055 5300

CARINGBAH: Unit 13, 59-63 Captain Cook Drive, Caringbah NSW 2229

ARTARMON: 5 George Place, Artarmon NSW 2064

[www.orthomotion.com.au](http://www.orthomotion.com.au)

Stephanie Cantrill, Polio Australia's Community Programs Manager, sends this announcement. If you are interested in participating in one of these chat sessions contact Stephanie via Polio Australia's website. [www.polioaustralia.org.au/community-information-sessions](http://www.polioaustralia.org.au/community-information-sessions)

# Polio Australia

Improving health outcomes for Australia's polio survivors

## Monthly Zoom Chats

Many of you were able to join some of our Zoom chats with the polio community last year. It was great to connect with you, and great to provide an opportunity for you to connect with each other!

As requested, we've decided to continue these chats into 2021. We're starting with a monthly informal chat for anyone who would like to join us from across Australia.

The sessions will be held on the **first Monday of each month\* at 11.00am NSW/ACT/Vic/Tas time** (make sure you know the right time in your state!).

Over the course of the year, we'll be adding more sessions – webinars, focused sessions around specific topics, etc. As well as that, we want to keep these monthly chats open to anyone looking for connection, sharing and learning with the polio community in Australia. We'll try to send out a question or two in advance of each meeting, to get you thinking and sharing!

*\*The April meeting will be on the second Monday due to the Easter public holiday.*

**Editor:** I have participated in three of these meetings and found them to be informative and fun! A lot like an informal support group meeting really. To book in for a chat go to: [www.bit.ly/monthly-polio-chats](http://www.bit.ly/monthly-polio-chats) If you do not have access to a computer perhaps a family member or friend could set this up for you on their PC or laptop so you can participate.

## BRUNO BYTES

Reprinted from PA Polio Survivors Network [www.papolionetwork.org](http://www.papolionetwork.org) 2020



### A Bruno Byte

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

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

### Bracing for Polio Survivors:

**Question:** The knee on my polio leg kept bending further backward over the years. I was told to get a brace but didn't want one until I absolutely had to have it. After a while my knee hurt so much I've finally gotten a brace. My knee bends so far back now that the brace bites into my skin and is so painful I can't wear it. Even if I could wear the brace, it is so heavy I can't lift my leg. What can I do?

**Dr. Bruno's Response:** Unfortunately, it's too late for a brace to help. Braces are designed to support a weak leg, not to fix mechanical problems like recurvatum ("back knee"). We have seen many braces that hurt too much to wear because they were intended to "fix" recurvatum or to straighten a foot that has turned outward for 40 years. All braces should be designed to fit your leg just as it is, not to make it look the way other peoples' legs do, which leads to a Post-Polio Precept: *never brace to fix a deformity!*

Many polio survivors came to The Post-Polio Institute with braces that were unusable because they are too heavy, made with the 1940's vintage steel, aluminum metal uprights, contain way too much plastic or have ankle joints. The Post-Polio Institute patients do very well with the new lightweight braces that use plastic molded to the shape of your foot and leg to replace the metal uprights. The most common brace worn by polio survivors is the short leg brace, the molded ankle-foot orthosis (MAFO). It is made of a relatively thin plastic that slips into your shoe and goes up the back or front of your lower leg to stop foot drop, give a spring to your step if you have weak calf muscles, and even support a weakened thigh muscle to help prevent the knee from buckling.

The brace that you were prescribed: the long leg brace or knee-ankle-foot orthosis (KAFO), usually replaces the metal uprights with molded plastic that slips into your shoe, goes up the back of your lower leg and is attached to a plastic cuff behind your thigh with a metal hinge and lock at the knee. Uprights can be used in place of plastic but are now made of graphite -- a super-strong, ultra-lightweight but very expensive composite material used in airplanes -- if you need extra support or if your leg twists too much to be comfortable in a molded brace.

There are now two types of KAFO knee joints: the old, familiar joint with drop-locks ("Bale" locks) or a spring-loaded latch that prevents the knee from bending when you stand and walk. A newer development, the offset joint, can be used by those who have some strength in their quadriceps and whose knees bend backward at least a little. The offset joint doesn't lock, but it still prevents the knee from bending when your leg is straight. With the offset joint you can swing your leg normally when you walk but be secure when you're standing.

However, polio survivors should avoid ankle joints, be they plastic or metal, which prevent your foot from dropping but allow your ankle to bend upward. Hinged ankles add weight to the brace, take away support for weakened thigh muscles and prevent the brace from helping your leg to spring forward.

I'm sorry a brace can't help you. We have unsuccessfully tried to brace other polio survivors with severe recurvatum. They, too, couldn't wear a KAFO because it hurt too much. Instead, they needed to use crutches or a wheelchair, which raises two important points: waiting until you're ready" or until you "have to" before using an assistive device is waiting too long; and, even if you are willing and able to use a brace, you will also need to use a cane or crutches. How do you know which to use?

The rule of thumb is: if you use a MAFO, you also need a cane; if you use a KAFO, you need two forearm crutches.

If you have a brace on one leg, a cane in the hand on the opposite side shifts your weight away from the weaker, braced leg. Using two forearm crutches with a KAFO takes the load off your stronger leg as well as overused hip and lower back muscles on both sides. But there's a problem. Canes and crutches put a strain on your hands, arms and shoulders and can cause carpal tunnel syndrome and upper body pain and muscle weakness.

This is why we always recommend Polio survivors see a qualified Physiatrist. They are specially trained to manage these issues.

How do you save your arms? By using a wheelchair, especially outside the house.

*To walk is painful, to roll divine.*

#### **On the topic of Oxygen use vs. Bi-Pap:**

**Question:** What are your thoughts on using oxygen instead of bi-pap machines? Is anyone doing this? Because of "things" that occurred while I was hospitalized with Polio I am unable to have anything on my face.

**Dr. Bruno's Response:** Oxygen suppresses your brains urge to breathe but more importantly actually constricts blood vessels in your lungs effectively decreasing the size of your lungs. . Oxygen is no substitute for positive pressure ventilation with BiPAP or a volume ventilator. John Bach's website is full of information on breathing and polio survivors. [www.doctorbach.com](http://www.doctorbach.com)

#### **On the topic of CPAP and a Sleep Study:**

**Original post:** I had a sleep test and they say I have mild to moderate apnea and recommended I use a CPAP. But it seems that most polio survivors in the Post-Polio Coffee House [Editor: facebook group] have Bi-Pap. Should I be concerned about using CPAP?

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

**Dr. Bruno's Response:** Carbon Dioxide retention is as big a problem as is too little oxygen! So polio survivors should always talk to their pulmonologist about replacing their CPAP with BiPAP (or a volume ventilator).

#### **On the topic of Nerve Pain:**

**Question:** I am wondering about what I think is nerve pain in my ribs. The latest episode began when I lay sideways on my right shoulder, then spread to what felt like a spasm pain in my left rib area. Since I have a severe scoliosis and wear a plastic body jacket to sit up, I can't get comfortable sitting or lying. I end up taking a low, short-term dose of narcotic pills (which I hate to do) to try and break the spasms until hopefully it goes away.

**Dr. Bruno's Response:** You need a diagnosis regarding the cause of the pain. Is it "nerve pain" or muscle spasm or both? Scoliosis and wearing a body jacket are going to put pressure in different parts of your spine and joints that certainly can cause pain. Pain could be radiating from nerve entrapment in your right shoulder or pinching nerves in your neck. So talking to your doctor about an MRI of your neck would be the first place to look.

If spasm is the issue narcotics aren't the answer. Something like Valium would be more appropriate. A proper head pillow and a body pillow may be of help to take the load off your ribs and shoulder, give you some cushioning and better positioning in bed. You may need a new body jacket, but again, diagnosis is the issue. You don't need a post-polio specialist to diagnose and treat this. A local physical medicine (physiatrist) doctor would be of help.

## **Don't Let a Doctor Stone you or Stab you in the Back**

**By Dr Richard Bruno** [www.papolionetwork.org](http://www.papolionetwork.org) 2020

The following New York Times article is a good reminder that almost all of back pain is caused by muscle spasm. This is especially true in polio survivors who've endured decades of muscle overuse, muscle weakness, scoliosis, poor posture and have different leg lengths. So, if you develop back or neck pain without other symptoms (like pain radiating

into a leg or numbness) beware of doctors immediately referring you to a surgeon. Rest, heat, a non-steroidal anti-inflammatory drug like ibuprophen -- and maybe a few days of good old Valium -- could do the trick, followed by physical therapy to find ways to reduce back muscle overuse and to learn good posture. A bout of back pain should not lead to immediate epidural injections, prescriptions for narcotics or, God forbid, surgery.

This said, polio survivors are more prone to have acute or, more commonly, progressing chronic back pain caused by arthritic spurs, stenosis, scoliosis and possibly herniated disks pinching spinal nerves. Still, without pain radiating into your leg or numbness, although an MRI may be indicated for diagnosing the cause of chronic back pain, beware of doctors giving you narcotics or referring you to a surgeon. Oxycontin, fentanyl patches and methadone have been found not to be effective in treating chronic back pain but are great if you want to live life stoned and constipated. A decrease in back muscle overuse and learning good posture is often *the* treatment even for chronic back pain.

And if an MRI finds that you do have pinched nerves caused by arthritic spinal bone spurs or a herniated disc, six days of self-tapering oral steroids (a Medrol Dose pack) and then, if needed, epidural or facet joint steroid injections should be your first treatment options and typically are very effective.

Remember, a US study found that 99% of back surgeries were unnecessary. A larger Scandinavian study found that 99.9% of back surgeries were unnecessary. In 37 years of assessing thousands of polio survivors I have had a mere handful of patients who needed and were helped by back surgery but many dozen who had unnecessary surgery and had the same or more pain afterward.

If you are in that 0.1% who needs surgery, get at least three neurosurgical opinions. Just don't let yourself become one of the 99.9%.

## Back Pain Remains Overtreated

New York Times, August 2, 2013, 11:36 am

by **Nicholas Bakalar**

Well-established guidelines for the treatment of back pain require very conservative management — in most cases, no more than aspirin or acetaminophen (Tylenol) and physical therapy. Advanced imaging procedures, narcotics and referrals to other physicians are recommended only for the most refractory cases or those with serious other symptoms.

But a study published in JAMA Internal Medicine suggests that doctors are not following the guidelines.

Researchers studied 23,918 outpatient visits for back pain, a representative sample of an estimated 440 million visits made over 12 years in the United States. After controlling for age, sex, the nature of the pain and other factors, they found that during this time, NSAID and Tylenol use fell more than 50 percent. But prescriptions for opiates increased by 51 percent, and CT or M.R.I. scans by 57 percent. Referrals to other physicians increased by 106 percent, which the authors said is a likely contributor to recent increases in expensive and often ineffective spine surgeries.

The senior author, Dr. Bruce E. Landon, a professor of health care policy at Harvard, said that in most cases back pain improves by itself. But he added: "It's a long conversation for physicians to educate patients. Often it's easier just to order a test or give a narcotic rather than having a conversation. It's not always easy to do the right thing."





# CPAP, BiPAP and oxygenation - What does it all mean?

By Dr. Marny Eulberg, MD [www.papolionetwork.org](http://www.papolionetwork.org) 2020

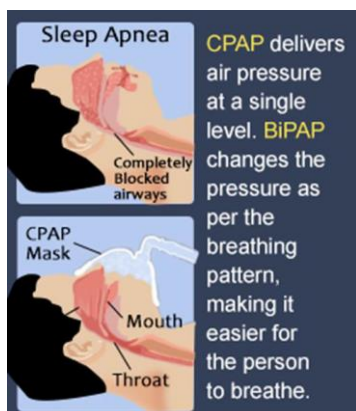


**Question:** I had polio when I was 18 months old. I worked extremely hard for almost 30 years in a factory, 10 and 12 hours a day. I had to retire on disability at 42. Now, at 61 things are getting worse. I'm so tired; I can't do anything longer than 15 minutes. I've been on a CPAP for a long time. I had a new sleep study done and was diagnosed with both obstructive sleep apnea and central apnea. My CPAP was set on 14. Now they want me on a BiPAP that is set at 18/13.

The question I'm asking is - will this make me dependent on the BiPAP? My muscles are getting weaker. I feel like I have real muscle pain right now and I feel like I'm in a fog. I'm very tired.

## Dr. Eulberg's Response:

Your situation, as you know, is complicated because of so many different medical problems that affect diverse parts of your body. As I understand your email, one of your major concerns is your breathing and the recommendation for BiPAP and the settings, which seem to you, to be quite high. Since we have limited space in this newsletter, I will limit my response to the issues of breathing and possible treatments and also try to provide some basic education to individuals who also may be using CPAP or BiPAP.



It is important that all people with breathing challenges understand the difference between oxygenation and ventilation. Oxygenation is how much oxygen is absorbed by the lungs and is then carried around the body by the blood. Ventilation is the amount of air that is moved into and out of the lungs with each breath or within one minute. So, ventilation includes the oxygen that is brought in with each breath and the carbon dioxide that is expelled with those breaths. It is possible to have normal ventilation but low oxygenation, such as when a person with normal lungs and normal breathing muscle function is in a low oxygen environment at a high altitude, like that of Mount Everest.

It is also possible to have normal oxygenation with decreased ventilation especially if someone is receiving supplemental oxygen, but at the same time they can suffer from build-up of excess carbon dioxide. Of course, if someone is taking less breaths per minutes than is needed, they likely will have decreased oxygenation and decreased ventilation.

Oxygenation is usually measured by the "pulse oximeter" that clips on a person's finger. Oxygen levels in the blood is most precisely measured by testing a sample of blood taken from an artery. High carbon dioxide levels are suggested by high levels of bicarbonate (HCO<sub>3</sub>) in the blood (venous blood); carbon dioxide (CO<sub>2</sub>) can only be measured from an arterial blood sample (ABGs = arterial blood gases).

Hypoxia (less oxygen in the blood than normal) can be due to muscle weakness of the respiratory muscles, taking less breaths per minute than is needed or taking very shallow breaths, or various disorders of the lungs themselves so that oxygen is not absorbed into the lung tissue and then transferred to the blood. Decreased ventilation can be due to messages not getting from the brain to tell the body to take a breath (central apnea); partial or intermittent blockage of the airway (such as in obstructive sleep apnea), decreased depth of each breath which can be due to weakness of respiratory muscles (diaphragm,

chest muscles, some abdominal muscles, and some neck muscles); the effects of significant obesity (one form of restrictive lung disease); or the effects of medications/drugs/large doses of alcohol that are respiratory depressants. This is not a complete list of all possible causes but includes the more common causes.

For those less familiar with some of the terms/acronyms--CPAP stands for Continuous Positive Airway Pressure, which means a certain amount of air pressure is continuously supplied by a machine to keep tissues in the throat and upper airway from collapsing and acting as a one-way valve to block air going out the lungs. The person using CPAP actually has to exert slightly more force than usual to breathe out (exhale) against the constant pressure coming in.

BiPAP is a term used for Bi-level Positive airway Pressure which means that pressure is used to push air in as the person begins to inhale and there also is some positive pressure applied to the airway as the person exhales. The settings for BiPap are expressed as two numbers: the first number is the pressure used during inhalation and the second number is the pressure that is maintained during exhalation. Settings may seem to be higher than "normal" for several reasons including leaks around the mask (difficulty getting a good snug fit of the mask/interface), stiffness of the person's airway including the lungs (example scarring of lung tissue from prior infections, COPD, interstitial lung diseases, pulmonary fibrosis), or significant weight/bulk of the person's chest.

In your specific case, you said your doctors want the new settings on your BiPAP to be 18/13. This means the pressure against which you would be breathing out would be slightly lower (13 cm) than it was with your CPAP which had a pressure of 14 cm.

You cannot get "dependent" on oxygen or breathing machines by using them; it is not like becoming physically dependent on narcotics. If you find that, in the future, you cannot function without use of these devices, it is because you need them and you have learned to appreciate the benefits. Your breathing muscles may become weaker over time, simply because they have overworked for years and are "wearing out" or your condition is getting worse. It has been found that for most polio survivors with breathing problems using some form of respiratory assistance at night actually allows them to breathe better in the daytime because the respiratory muscles have had a chance to rest, get their nutrients restored, have the waste products that have built up expelled, and get a "second wind" (pun intended)!

It is unlikely that any changes to your breathing equipment will help with your pain, although if you do indeed start sleeping better that can make dealing with the pain a bit easier.

Full Face Masks



Nasal Pillow Masks



Nasal Masks



Mask Kits



Different Styles of CPAP/BiPAP Masks [www.thecpapshop.com/all-cpap-masks](http://www.thecpapshop.com/all-cpap-masks)

Dr. Eulberg's inventory of informative Articles and Videos are available in the Living with Post-Polio Syndrome section of our website. [www.papolionetwork.org](http://www.papolionetwork.org)



# BiPaps, Ventilators and Masks - A Personal Note

By Daniel J. Wilson, PhD [www.papolionetwork.org](http://www.papolionetwork.org) 2020



I have been wearing masks for assisted breathing for some 20 years. I had polio in 1955 when I was five. I developed scoliosis and had a spinal fusion in 1960, but over the decades my spine curved above and below the fusion. In 2000 I was diagnosed with sleep apnea and put on a BiPAP. I initially found it difficult to adjust to the mask. The first night, my Wheaten Terrier, Abbey fled the bed thinking I had turned on a vacuum machine! She eventually got used to it and returned to our bed. I, too, initially found it difficult to adjust to wearing a nasal mask at night. For the first several nights, I didn't make it all the way through the night before I took it off. But I persisted. After a week or ten days, I discovered that I was sleeping through the night and waking up much more rested. After a few years, supplemental oxygen was added to the Bi-PAP.

After I was hospitalized with pneumonia in 2013, I was switched to a Trilogy ventilator at night which provided more support, with its supplemental oxygen. Following the pneumonia, I found myself short of breath during the day, and with the support of my pulmonologist, began to use an old Bi-PAP during the day while sitting in my usual chair. However, I had to switch to a nasal pillow mask so that I could wear my glasses (which wasn't a problem when I was sleeping). Since then, I have used a ventilator every night, the Bi-PAP during the day at home, and oxygen when I go out of the house. (For example, to a restaurant in pre-COVID days.)

I don't particularly like wearing a mask most of the day and night, but I like breathing comfortably even more. The machines mean that I don't have to struggle to breathe, and that is comforting. For me, a key is finding comfortable masks. Recently I was in the hospital with kidney stones and the nasal mask the hospital provided was a disaster. It was cheap, didn't fit well, and leaked. I went back to the nasal pillows I had brought with me and then had my wife bring my nasal mask from home. The lesson I took from this was the importance of a well-fitting, comfortable mask.

Several different companies make masks and many masks come in different sizes. My nasal pillow mask comes with three different size nasal pillows to fit different nostrils. If one doesn't work, ask your therapist to try another until you find one you can live with comfortably. When you find a comfortable one, persist in wearing it until it becomes second nature. You will breathe more easily, be more rested, and healthier.

Wearing a mask attached to a machine 24/7 is not what I would have chosen 20 years ago, but today I wouldn't give up either the masks or the machines.

Dr. Wilson's Complete Inventory of work is available on the website

[www.papolionetwork.org](http://www.papolionetwork.org)

Dr. Daniel J. Wilson, PhD –Putting the Pieces of Polio History Together





With **Dr. William DeMayo, MD.**

## Winter Wellness in a Time of Uncertainty

"Winter Wellness" begins with "Deciding what you really **Want** to do and holding off of the things that you want to do (w = impulse or desire, but not a decision).

"I believe that words that we use in our head have power over us and so deciding what we **Want** vs what we want can be an important factor in changing our decisions. Many people do this already with their finances and purchases but have not thought to apply the same language to their activity and health.

Another set of similar words that can have power in influencing our behavior and health include: "**need to**", "**have to**", and "**should**". The holidays are a particularly difficult time when it comes to these activity decisions. In order to avoid chronic overuse activities, some helpful questions to consider this holiday season may include:

- Do I want to continue to push myself to prepare the big family dinner (and risk creating pain and exhaustion) or do I **Want** to put my relationships with family first and preserve my energy by asking for help?
- Do I need to climb that ladder to put up decorations despite the obvious risk?
- Do I have to bake 12 dozen cookies or do I **Want** to avoid overdoing it and dial it back a bit and ask for help?
- Should I "shop 'til I drop" or do I **Want** to be a better example to my kids and grandkids by purchasing or even making one special gift.

All these questions center around individual values, desires, and goals. It is my hope, especially during the holiday season, and the cold winter months, that we can all focus on our real **Wants** and be less driven by passing desires/wants, "have to", "need to", and a "should" mentality. The holistic model of wellness applies to us all, especially during this time of year.

Dr. William DeMayo, MD - Complete list of articles and videos are available on PA Polio Survivors Network website: [www.papolionetwork.org](http://www.papolionetwork.org)

**Dr DeMayo sends a message from Dubai where he works in a rehabilitation hospital.**



### **A Message from Dr. DeMayo:**

In general, access for individuals with disabilities is very difficult here in the UAE. Even so, I saw this sign and I thought very determined Polio Survivors might enjoy it.

**"Beach access for people of determination"**



Nola Buck received this email from Diana Palmer, Executive Officer of IDEAS. We have benefited from information supplied to us by IDEAS over many years. I encourage members to register for their eNews subscription.

I write to thank you for your committed support of the IDEAS newsletter, our bi-monthly publication of information and news specifically for people with disability and their families, carers, and supporters. Thank you too for generously sharing the newsletter with your neighbours, libraries, and support groups, to help others who may be just starting on their different life with a disability.

IDEAS has dispatched the January/February issue to our print copy and digital subscribers. We are proud to have distributed accurate, fact-checked news to you for more than three decades. Feedback and contributions from all of you during this time has been a joy for our production team of writers, researchers, printers, and packers. We also thank our tireless and committed volunteers, without whom our newsletters would never have reached you.

The 2021 January/February edition of the IDEAS newsletter is the last one we shall publish.

The Federal Government has funded the Disability Gateway as the national disability information service, meaning we must make some changes to our service delivery. As of 27th January, our IDEAS Infoline will not be available. We suggest that people access the Disability Gateway, available on **1800 643 787** or at **www.disabilitygateway.gov.au**.

You can subscribe to our eNews (an electronic newsletter emailed regularly) which will be maintained to keep people up to date with disability issues and news. The website will continue to be available with information curated by our information and content team, as will information be disseminated through our social media channels.

If you know anyone who would like to subscribe to the IDEAS eNews, please email **ideas@ideas.org.au** and ask for them to be added to the eNews subscription list or visit the **link here on our website**.

IDEAS is a strong organisation and remains committed to providing information and assistance to people with disability. Please check our website for news about our products and services' redevelopment.

