Spring Edition 2023

PwMS Victoria

PEOPLE WITH MS

Short Circuit

Lets get care

If you know someone who either has a new package, is thinking about switching providers or is waiting for their Home Care Package (HCP), why not give them the gift of extra support?

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People with MS supporting People with MS

PwMS Victoria is a not for profit organisation of volunteers living with MS supporting people, of all ages, with MS, their families and carers.

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Using dictation software on the computer and iphone

Based on personal experience This message dictated hands free on the computer using the windows built in software.

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PwMS Victoria

People with Multiple Sclerosis Victoria Inc.
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Letter from Nigel Spring 2023

Have you heard COVID is over, finished? At least you would think so from the fact that most people have stopped wearing masks. Life is back to normal. However, that is not true.

For those of us who are immunocompromised, the post-COVID-19 path is unclear. Many people with MS take immune system modifying drugs or drugs which may diminish the effectiveness of COVID vaccines. I hope being fully vaccinated and taking anti-virals will enable me to fight COVID-19 if I get it.

It feels weird to be one of the few people still wearing a mask indoors and at busy places like the super-market or department store. I worry that others will think I'm out of touch — or worse, that I'm paranoid. But even if it is only protecting me a bit….Well every little bit helps.

Earlier in the pandemic I was critical of people who flaunted mask mandates, I disapproved of people who wore masks below their noses or used them as chin warmers. But now I try to ignore them. I'm only taking responsibility for myself and not worrying about others' choices.

MS Australia recommends wearing a face mask in public, avoiding public gatherings and crowds, and avoiding public transport where possible. My wife and I have some basic rules we follow based on these MS Australia guidelines. The rules we follow in this "Let's pretend COVID is over" world include

·We wear a mask at public events indoors.

·We try to avoid large, crowded spaces.

·We wear masks on public transport. But

·We don't bother with masks when we dine out with friends or see friends at home.

Rules like these mean our COVID-19-related decisions are automatic, I don't have to decide the health risk of each situation but merely stick to my plan. I don't suppose these rules are perfect, and I don't practice them perfectly, either. At the same time, they help me feel I'm doing what I can to protect myself while still living in the larger world.

As someone who's immunocompromised, I often feel like others are so focused on resuming life as they knew it before COVID-19 that they've lost sight of people like me.

Sometimes I think self-isolation might be the only way to stay healthy. But as disease severity lessens, and I consider how to live with MS in a world which likes to pretend COVID-19 no longer exists, I have not given up, nor have I given in. I've tried to weigh up my risk of infection from being with others against the risks of loneliness and depression from spending too much time alone.

I encourage you to do the same. Don't pretend that COVID-19 no longer exists and do take sensible precautions.

To finish may I remind you that everything People with MS Victoria does is aimed to help or inform people living with MS. This includes our conferences and seminars, our newsletter and website and Facebook page.And PwMS-V is run entirely by volunteers. And we need more volunteers to help us continue what we do and enable us to do more. If you feel inclined to help us, send a note to admin@pwmsv.net.au.

Keep Fighting and never give in.

Nigel Caswell O.A.M.

President PwMS-V

PwMS conference 6 May 2023

It was wonderful to have so many people attend our conference; back after the years of ZOOM imposed on us by COVID. We had three excellent speakers. Paul Gallagher, Matthew Ligtermoet and Sally Shaw.

Paul Gallagher, published author, journalist, book editor and person with MS spoke first. Paul's talk was entitled "Finding hope when life is overwhelming". Paul talked about what he does, who he is and how his MS has influenced these. He described how important his writing has been and still is. His biography of the former Deputy Prime Minister, John Anderson, won a Book of the Year prize in 2006; and as a journalist and freelance writer, Paul's articles have been published in Australia, the US and United Kingdom. He was diagnosed with MS in 2016, and is one of four in his extended family to have MS. He also talked about the inspiration he gets from the TV series "Survivor"; how important fire is to survivors and how hope like a fire requires regular attention and fuel to keep it burning.

Dr Matthew Ligtermoet spoke next about current treatment of MS and where research might be heading. Matthew is a consultant Neurologist at Northern Health where he runs the Multiple Sclerosis clinic. His specialty interests include neuroimmunology including the diagnosis and management of multiple sclerosis (MS) and related conditions. He talked about the enormous progress which has been made in the treatment of Relapsing/Remitting MS. Whereas there is a great deal the medical profession does not yet understand about Progressive MS. He also spoke about the important research being done on the Epstein Barr Virus and answered many questions from the audience.

The final speaker was Sally Shaw; Melbourne based psychologist who heads Focussed Health Psychology, a group of psychologists and health professionals, with a particular focus on the provision of information, education and support to people with neurological conditions and chronic illnesses such as Multiple Sclerosis. Sally spoke about the importance of recognising symptoms of poor mental health in yourself or someone close to you. Depression and Anxiety are 3 times more common in PwMS than in general population. Sally emphasized that emotional, psychological, social and physical well-being are all intertwined and she described some of the common symptoms of depression and anxiety. She finished by leaving the audience with list of things we could do to maintain our mental well-being including;

• Going to bed and getting up at the same time each day, and Exercising:
• Engaging in your community, reaching out to someone who is lonely or struggling,.
• Set yourself some goals, plan for joy. Set yourself up for positive experiences, do things that interest you. And
• Talk to your friends and family, or your GP, or call MS Connect.

Overall the day was very successful. The audience were thoroughly engaged by each speaker. Many identified closely with the examples given and numerous questions were raised.

Let's Get Care

A Revolution in Home Care Packages

If you know someone who either has a new package, is thinking about switching providers or is waiting for their Home Care Package (HCP), why not give them the gift of extra support?

You can do this by Referring a Friend to Let's Get Care and when they sign up with us, we will gift you both extra care. We have even increased our referral bonus to $150 for both you and your friend into both of your HCP funds.

Our mission is to give every Home Care Package holder more freedom and control to choose the care services they want and when they want them. We appreciate you helping us do just that.

If you know someone who would benefit from Let's Get Care, call us today on 1300 497 442 to refer your friend!

Kind regards,

The Let's Get Care Team

1300 497 442

Using dictation software on the computer and iphone

Based on personal experience
This message dictated hands free on the computer using the windows built in software.

Summary

- Over a decade ago Dragon Dictate appeared to be the best software and it worked
- Now dictation software is built into both the windows and Apple operating systems and while not perfect it works.
- I can recommend dictation software as vital if your hand function is compromised.
- Professional training programs to use hands-free software would be welcome.
- The features that you need depend on your level of disability. You need not activate all the features at the beginning. Only activate only those features you need now and progressively activate more features as necessary.

I have had multiple sclerosis for many years. My legs have been less affected by the disease, but my hands have been more affected making It difficult to manage shoes, buttons, writing, typing and other activities which require the use of my hands.
Over the years I have used voice technology to varying degrees. Basically, if I need to do it, I will find a way to make it work through reading instruction manuals and watching online tutorials using the voice features built into the Windows operating system and the Apple software on the iPhone. The process is more trial and error and then testing the outcome rather than by following specific instructions.
Over a decade ago when I was typing long meeting notes, I found it handy to use Dragon Dictation software. That software worked well. It did what I needed it to do and only required a review after dictating. I can only imagine today's version is an improvement on that. My subjective view for users of non-Apple computers is that Dragon Dictate is still the gold standard. However, the versions I used in the past are now out of date. They will not work with my current version of windows nor are they supported by the organization that makes the software.
When I used the Dragon Dictate software a decade ago my hands did work but typing was very slow, frustrating, and error prone. Over the last few years, I have completely stopped using my right hand with the computer. I am now very dependent on dictation software and use it every day on both my mobile phone and my desktop computer.
But now - unlike a decade ago - I find the dictation software built into the iPhone very adequate for my needs. Also there are other hands free features that you can set up for the iPhone; an example of this is when I receive a call it automatically goes to speaker. Similarly with the desktop I have activated half of the hands-free features and I am able to operate the computer quite effectively with my voice.
I do not have a background in information technology. So it has been a matter of trial and error what works what doesn't? Can I get the job done with what I've got? If you are like me, you do not need the full hand free features on the technology however with partial activation of these features you can use technology far more effectively than would otherwise be the case.
I suspect there is a market available in Australia to set up computer systems and train people to make use of technology. I would be happy to attend professional training in the use of hand free software. I know there are instruction manuals, but professional training would be welcome.

Chris Platford PwMS

People with MS supporting People with MS

A registered charity
ABN: 73 104 198 752

www.pwms.net.au
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facebook.com/pwmsv

PwMS Victoria is a not for profit organisation of volunteers living with MS supporting people, of all ages, with MS, their families and carers. We provide;

- Annual Conference with expert speakers, and regular newsletters.
- Lobbying of government and service providers to achieve improved support services and affordable MS treatments.
- Up-to-date news and developments in research and medication via our Facebook page.
- Information about concessions and aid schemes, accessible holiday locations, members' stories and much more via our website.

We need more volunteers to help us continue to provide these services. If you might be willing to join our small committee send contact details to admin@pwmsv.net.au

Our Armchair traveller visits the Loen Skylift, Norway

Your armchair traveller has been to fascinating places from the deserts of America to frozen Svalbard. Now we travel to Norway, which is an amazing place of rugged rocky towering mountains and fjords.

At certain times in Norway the sun never sets in summer and in winter the sun never rises. It strikes me as a great destination suited to both hiking and sightseeing.

Occasionally I see something magnificent that takes my breath away. The Skylift at Loen in Norway is one such place. Loen at the head of the Nordfjorden (Fjord) and surrounded by mountains is approximately 500km NW of Oslo.

The town has two reasonable sized Hotels for guest accommodation, as well as a camping ground. The warmest month is July where it will reach an average of 22'C during the day and 12'C at night. In the winter months it will reach a high of 3'C during the day. In summer you can hike the mountains and in winter, snow sports are popular pursuits.

Cruise ships frequent the village and will include day trips to the Skylift and the restaurant at the top. For those of us with walking disabilities the Skylift and restaurant are wheelchair friendly.

The Skylift climbs 1,011 metres to the top of Mount Hoven and is a breathtaking way to see the magnificent mountain, and fjord land scenery. When you ascend the mountain there is a restaurant with the most spectacular views from the tables and from the lookout outside the restaurant. For more information go to https://www.loenskylift.com.

The Loen Skylift must be on the to do list of anyone visiting the country.

Skylift cable car above Loen & the fjord

The location of the Loen Skylift

By Susan and Chris Platford

People with MS Vic Inc Spring Seminar and ANNUAL GENERAL MEETING

Monday 20th November 2023, 10.30am.

At the Nerve Centre 54 Railway Rd Blackburn

Enquiries to; cplatfor@bigpond.net.au

PEER SUPPORT

WHAT IS IT? HOW DOES IT WORK?

COULD YOU BENEFIT FROM IT?

The keynote presentation at this year's PwMS Spring Seminar will be about the Peer Support programmes run by MS Plus