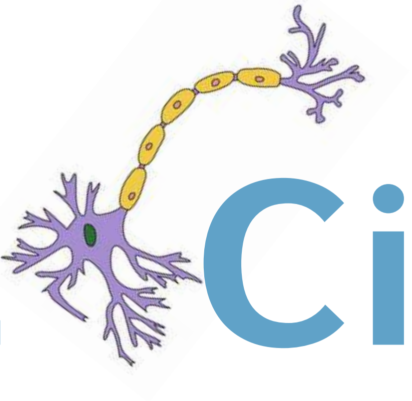
Autumn Edition 2024

PwMS Victoria

PEOPLE WITH MS

Short Circuit



People with MS Annual Conference Saturday May 4th

===============

Speakers

Helmut Butzkueven,

[Head, of Neuroscience, Monash University, and Director of Neurology, Alfred Health]

MS Treatment and Research

=====

Andrew Giles

Executive officer, the Neurological Alliance

&

Andrew Potter

Person with MS and

National Advocacy coordinator, MS Australia

Campaigning for people with MS

(Page 8)

Armchair Traveller Living with MS in Miena Tasmania

In this issue of Short Circuit, The Armchair Traveller takes you from the fjords and mountains of Norway back to Australia, where we visit the country's coldest inhabited town Miena, Tasmania.

(Page 3)

Benefits of Aquatic Exercise on Quality of Life in Patients with Multiple Sclerosis

A recent article on the National Library of Medicine site described research into the impact of aquatic exercise on the quality of life in individuals diagnosed with multiple sclerosis.

(Page 5)

What is Be Connected?

Be Connected is an Australian government initiative committed to building the confidence, digital skills and online safety.

(Page 6)

Letter from Nigel
Autumn 2024

President’s letter Feb 2024

Belated “Happy New Year” wishes to all our readers. May 2024 bring you good luck and good fun. And I hope you cope well with everything 2024 throws at you

I added that second sentence because it is becoming increasingly clear that we must expect our climate to present us with more frequent and more extreme challenges. I live in Melbourne, and we have had a most unusual summer (so far) without the heat we were warned about. But we have had some extraordinary rain events. Meanwhile, across Australia, January has presented us with bushfires. flooding and cyclonic winds!

So I ask; am I, and are you, prepared for an emergency? You may say you live in a city, safe from bushfires or floods, so there is nothing to worry about. But how would you cope if your power went off for a week(?) or you had to evacuate your home because of a building fire? Here are a few questions you should ask yourself;

About medications? Do you have a medication plan?

- Do you have your medications and scrips together so you can easily take them with you?
- Do you have a list of all your medications; name, dose, purpose and prescribing doctor?
- If some medications need to be refrigerated what will you do if there is no power.
- what would happen if you cannot access some medication.
- how long can you be without medications and are there any options?
- If you need regular infusions, ask about options for timing and alternative locations.
- You may be eligible for scripts that will provide longer term supply, say six months. (Discuss your plan with your pharmacist or GP. Ask what the options are). About communications? We may rely on our phones or computers to communicate and pay bills
- Do you have a portable power pack to recharge your phone or tablet?
- Do you have your passwords securely stored and accessible?
- Do you have a portable hard drive with critical information stored

Several bodies produce guides to help you prepare an emergency plan and kit. The Australian Red Cross in partnership with the Victorian SES has a tool to help you create your own home “Redi-Plan”; go to redcross.org.au/prepare/. The Australian government Business department has a template and guide to produce a “Business emergency recovery plan” at business.gov.au/tools-and-templates. Don’t be caught out by an emergency have a plan to cope.

==

And Don’t miss out on our next annual “Living with MS” conference
which is coming up on Saturday May 4th. We have invited three first class speakers on three important topics.

· Helmut Butzkueven [Head, of Neuroscience, at, Monash University, Managing Director, MSBase, and Foundation Director of Neurology, Alfred Health]

·Andrew Giles;, Executive Office, Neurological Alliance Australia

·Andrew Potter; National Advocacy Coordinator, MS Australia.

All three will talk about current progress in the management and treatment of MS and what is happening in Australia to advance this.

Conference bookings will open soon. Unfortunately we have had to put the entry fee up to $15. This still includes morning tea and light lunchtime refreshments, which is still very good value, but should anyone find this difficult all enquiries about the conference should be addressed to the PwMS Secretary at cplatford@gmail.com.

Nigel Caswell, O.A.M. President.

Armchair Traveller: Living with MS in Miena Tasmania

In this issue of Short Circuit, The Armchair Traveller takes you from the fjords and mountains of Norway back to Australia, where we visit the country's coldest inhabited town Miena, Tasmania.

The township of Miena by all appearances can look unremarkable. Located on the Great Lake in the Central Highlands, the permanent population in the 2016 census was under 100. The elevation is 1,000 metres above sea level, and it is 120 km from Hobart. Accommodation is found at a lakeside hotel, self-contained lodges, and fishing huts. The township itself is favoured by anglers, famous for its trout fishing and the hydroelectric dam.

Although the area can be subject to bushfires, Miena, is one of the coldest non alpine townships in Australia. When we say cold, snow is common year-round being both frequent and deep with the average low temperature in July at -1.8'C. There have been reports of the temperature dropping to -10'C, and pictures of the area remind you of winter in Europe.

February is typically quite a warm month in Melbourne. People with MS are reaching for their cooling jackets, seeking shaded areas and air conditioners. Some of us (me included) who are very sensitive to heat, look with amazement at the average high temperature down in Miena only being 16.3'C. If you prefer cool temperatures, remote locations, this is the place to be. Things work again when it's cool.

Back in April 2019 the ABC produced an article "Trout, family and isolation: What it's like living with multiple sclerosis in Australia's coldest town" – Jess Davis. The article features Mr Peter Glowacki and mentions that following his diagnosis of multiple sclerosis, Peter, under medical advice decided to remain living in the cooler climate. Peter spends much of his time fishing, along with his six children, on a boat that has been modified for mobility. Peter, like many of us finds that his multiple sclerosis is much more manageable in the cool.

As the article by the ABC was written in 2019, I contacted Peter to see if he was still in the same place and how life with multiple sclerosis was traveling.

In a telephone conversation, I found Peter was indeed still located in Miena. He explained that after his diagnosis, he was treated by the doctors with new medications and that treatment combined with living in a cold environment, led him to feel multiple sclerosis has been very stable when he compares himself to some of his peers. Peter has been mostly impacted by mobility, balance, and fatigue. Peter advises that the distance he feels he can walk has improved slightly over the last few years which is encouraging for those of us reacting well to cutting edge medications.

Strongly supportive of medical cannabis, Peter feels that it helps him to control his symptoms. As mentioned, Peter is still very keen on fishing, and he replied that he will accompany his growing children to fishing tournaments around inland Tasmania. When asked if living in a very cold area of Tasmania impacts him negatively regarding MS, Peter responded that he is OK living in a cool environment.

Of course, the NDIS Is available for Peter, and he has been approached in the past about joining the scheme. Peter wryly states that he has commenced the application process, however, generally gets sidetracked by questions about fishing and the curiosity of living remotely in the wilds of Tasmania and will return to the process in the future. Peter is coping well with multiple sclerosis and has further support available when he needs it.

Peter's occupation was a commercial painter, and whilst at a painting job at a hospital, he ironically had an MS episode resulting in a fall. If you're going to have an accident, having it at a hospital is, I guess, the best place to have it. Following his accident, the doctors advised Peter that he was no longer able to follow his occupation. Multiple sclerosis can have devastating impacts for the person and their family. Many of us are negatively affected in terms of our career and relationships. For Peter, the diagnosis robbed him of both his career and contributed towards marriage difficulties. It is a credit to Peter that he is in good spirits recanting humorous tales of eccentric personalities and events in the hills of Tasmania.While the lake can look rocky and barren, the area itself when covered in snow is spectacular. At times residents are snowed in and will gather at the local hotel or with neighbours.

Living in a large city, it's easy to feel envious when hearing about some of the remote areas of Australia. I am sure that there are specific challenges, but it is otherworldly, yet only a couple of hours away. Challenges aside, Peter is enjoying the good life, and we thank him for sharing his experiences with the Armchair Traveller.

Images Peter Glowacki

By Chris & Susan Platford

Referred to article https://www.abc.net.au/news/2019-04-12/living-and-fishing-with-multiple-sclerosis/10989574 12 of April 2019

Report on the 2022-23 Annual General Meeting and Spring Seminar

The AGM was held on Monday 20th November followed by the spring seminar. Reports on the year's activities and the end of year accounts were presented and approved. Copies will be posted on the PwMS-Vic website. The committee was elected for the 2023 to 2025. Retiring treasurer Michelle Raymond was thanked for her long and valuable service and voted a Life Member in recognition. The members of the committee for 2023-25 are;

- President, Nigel Caswell O.A.M.
- Secretary, Chris Platford
- Treasurer, Anne Rigg
- Newsletter Editor, Zsolt Kovacs
- Vice President, Roger Reece

- Committee members
    - Andrea Badlee
    - Trish Mifsud
    - Martin Skoneczko

Volunteers;
- Aldo Gianni, Website admin
- Harpreet Dhingra,
- Alison Reece, Meetings assistance
- Michelle Raymond

It is an excellent committee, and I am pleased to welcome the new members Trish Mifsud, and Martin Skoneczko, and volunteer Harpreet Dhingra. I am sure this new committee will continue to provide an excellent program of information to people living with MS in Victoria, and be an important voice lobbying government and authorities on behalf of people with MS.

Nigel Caswell O.A.M; President.

The Spring Seminar followed the AGM. Two Speakers Kylie Osborne, (Senior Manager Community and Partnerships, MS Plus), and Kim Repcak, (Peer Support Coordinator, MS Plus) spoke.

Kylie Osborne spoke about the range of programs offered by MS Plus; with a Key contact to help each client navigate the system

- Wellbeing services; Social Workers, Health promotion and education, and MS Nurses Connection and Community Services incl:- Peer Support program, Community (Aged Care)
Visitors Scheme, and Family camps,
- Allied Health Services, Exercise Physiology, Physiotherapy, Occupational Therapy and Continence and diet and nutrition advice
- NDIS Services including Support to access the NDIS, and Plan management, and
- Employment Support including help finding work, work strategies and equipment; and helping employers understand how to support their employees living with MS

Kim Repcak then spoke about the MS Plus Peer Support Program which

- provides people with MS the opportunity to share experience of living with multiple sclerosis and build connections with people who have walked in similar shoes
- sharing information about MS Plus services and empowering the person to utilise services; and reducing isolation;
- **The types of Peer Support offered**;
    - Individual Phone support; Face-to-Face Group support & Telegroup support
    - Clients and supports matched by their needs, age, gender, and background.
    - Ongoing training, support and mentoring of facilitators.
- **The Program's demographics**
    - About 125 phone matches per year, 71 face to face groups across ACT, NSW, Vic & Tas;
    - Telegroups; Men's, women's, mum's, day and evening, Open age, Over 65 & Under 30
    - Currently: 70% women, ages range from 24 to 85, wide variety of ethnicities
- **Currently recruiting;** Younger women & men including carers: partners, husbands, wives,

---

Following the seminar all present were invited to join the committee for refreshments

Benefits of Aquatic Exercise on Quality of Life in Patients with Multiple Sclerosis

A recent article on the National Library of Medicine site described research into the impact of aquatic exercise on the quality of life in individuals diagnosed with multiple sclerosis. The abstract from the project is reproduced below.

==================================

This medical article investigates the impact of aquatic exercise on the quality of life (QOL) in individuals diagnosed with multiple sclerosis (MS). MS is a central nervous system disease that affects both physical and spiritual well-being, with a significant prevalence globally. The study aims to explore the potential benefits of aquatic exercise, a relatively new innovation in medical science, on the QOL of MS patients.

The semi-experimental research involved 22 MS patients selected through simple random sampling. Participants, with an average age of 32.86 years, underwent aquatic exercise sessions three times a week for one month. The researchers utilized the standard SF-36 questionnaire to assess various aspects of QOL before and after the aquatic exercise intervention. Statistical analysis was conducted using paired t-tests through SPSS software version 10.

The results demonstrated significant improvements in different dimensions of QOL, including spiritual well-being, mental health, social function, physical pain, general health, physical efficiency, limitation of roles due to mental and physical issues, and health status over the study period.

The findings support the hypothesis that aquatic exercise positively enhances the QOL of MS patients. The research aligns with previous studies that have shown the benefits of physical exercise, contradicting earlier recommendations for MS patients to conserve energy. Aquatic exercise, performed in warm water, offers advantages such as reduced muscle stiffness, increased ease of movement, and lower impact on joints and spinal cords due to buoyancy.

Comparison with other research studies, including those in France, Germany, and England, reinforces the positive impact of exercise programs on MS patients' QOL. The article suggests that the incorporation of aquatic exercise into treatment programs for MS patients, alongside existing approaches, can significantly contribute to improving their overall QOL. The study concludes by recommending the integration of aquatic exercise programs into the practices of neurologists, MS societies, and swimming facilities, emphasizing the potential benefits of this therapeutic intervention for MS patients.

Source: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3093029/?fbclid=IwAR2yji-XnfFTWWu8h0x4q0tC7xa0ZwfVe5SGDcLOL1hyjHz9NHMPVlbbeoY

Australian Government | Be Connected Every Australian online.

https://beconnected.esafety.gov.au

Home **Browse content** **More ways to learn** **Free classes** **Help**

Free online learning

Build your digital skills, confidence and safety online with our free learning content and computer classes.

Listen to podcasts

Dive into conversations that unpack topics such as crypto, scams, and more.

Free presentations

Join our free live presentations to learn more about online safety and the digital world.

Games

Our games centre will keep you entertained with favourites like Jewel Match and Word Up!

Free scams guide

Subscribe to the Be Connected newsletter to receive our Top 10 tips to protect yourself against impersonation

What is Be Connected?

Be Connected is an Australian government initiative committed to building the confidence, digital skills and online safety of older Australians. Whether you want to pick up new skills or dive into a new topic, you can access our free learning resources online or join one of the thousands of community organisations running free computer classes across Australia.

HOW TO SEARCH LIKE A PRO

Avoiding impersonation scams

Setting up and using email

PayID: what is it and how does it work?

What our learners are saying about us

“I have found Be Connected information easy to understand and covers everyday issues e.g. planning travel/holidays."

Sue, Frankston South VIC

“The best way to learn everything about computing, (the) internet and other technology in (the) privacy of your home."

Darina, Payneham SA

“The website is easy to follow and simple to understand ... it is currently my go-to source for advice and information."

Robin, Waurn Ponds VIC

https://beconnected.esafety.gov.au

MS CLINICS IN AUSTRALIA

MS Clinics exist across Australia to provide expertise in the diagnosis and management of multiple sclerosis and many have a range of neurological services available. Some are called MS Clinics whilst others are neurology or neuroimmunology clinics.

MS Australia publishes a list of MS Clinics on its website. All listed will have specialist experience with multiple sclerosis. Some are large, tertiary referral, multidisciplinary, bulk-billing clinics, others are smaller, private or visiting specialist clinics. Most clinics require a referral from your GP.

To find the list go to www.msaustralia.org.au and then search for “MS Clinics in Australia”

Nigel Caswell
caswellnigelp13@gmail.com
61 418 323 873

MS Identity Card

Nigel Caswell
[redacted]
Date Issued: 6 December 2021

Do you need an ID card to show, to prove your age or identity? Or maybe to show when you are asking for assistance. Well you can get one issued by MS Plus.
The MS-ID Card is available free of charge to any registered client of MS Plus who has a confirmed diagnosis of multiple sclerosis.
The card has your photo, name, and age on the front and verification by MS-Plus on the back.
You can obtain an application form by contacting MS Plus Connect at 1800-042-138, or going to the MS Plus website at msplus.org.au. Then go to “Support Services”, then” Information and Advice” and scroll down.
Once you have submitted the application, the MS ID Card will be mailed to you.
I have one which I can use if ever anyone doubts that I have MS or challenges my disability. Or wants me to prove my identity.
I encourage you to get one. You never know when it might prove useful.
Nigel Caswell

People with MS Victoria 2024 conference

Sat 4th May, 2024

Only $15 Including Light lunch

Featuring

Helmut Butzkueven
Head, of Neuroscience at Monash University,
Foundation Director of Neurology, Alfred Health.

Andrew Potter;
Person with MS &
National Advocacy Coordinator,
MS Australia.

Andrew Giles
Executive Officer,
Neurological Alliance Australia

Enquiries to; cplatfor@bigpond.net.au; **Mobile: 0405 755 113**

To book your seat please complete and return this form

by email to: cplatfor@bigpond.net.au or by post to; PO Box 658 Eltham 3095;

Name(s)						
Dietary needs *[if any]*	*Vegetarian*		*Vegan*		*Gluten Free*	
Access needs *[if any]*	*Wheelchair*		*Walker*		*Scooter*	

Enclose payment of $15 per attendee (Please tick payment method)

[ ] Cheque payable to PwMS Victoria, Inc.(enclosed) or

[ ] Direct payment to PwMS Vic Inc, BSB 083-004, Acct 04-636-6841(include name)