

PWMS

Victoria

### **2021 Annual General Meeting** and **Briefing on the new MS Australia** Monday 7th February at 10.30am

This meeting will be held at the Nerve Centre, 54 Railway Rd Blackburn and will be livestreamed so that people who wish to can view it and take part online. Copies of the previous minutes, correspondence schedule, president's report and treasurer's report will be posted on our website prior to the meeting.

### **My MS Road Trip**

Paul Gallagher reflects on his experience of being diagnosed with MS, and why he prefers to think of it as a "road trip" rather than a "journey."

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### **Power Saving Bonus**

The Victorian Government is providing eligible households with a \$250 Power Saving Bonus to help offset the costs of their energy bills.

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### New Committee members needed for PwMS-Vic

People with MS Victoria is an entirely voluntary organisation run for and by people living with MS and their families and carers. It is run by a small committee of volunteers all of whom have MS or care for someone with MS.

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# **\$250** Power Saving Bonus

## Apply today



The Victorian Government is providing eligible households with a \$250 Power Saving Bonus to help offset the costs of their energy bills.

The easiest way to apply is online at: https://compare.energy.vic.gov.au

### Need help?

If you need assistance applying Uniting can help you apply. Interpreters are also available.

Register for help online or over the phone:



(C: 1800 313 126

### Eligibility

To be eligible, you must meet the following requirements

- You must be a Victorian residential energy consumer (i.e. have a residential electricity account).
- 2. You must be receiving payments under one of the following concession programs:
  - Centrelink Pensioner Concession
  - JobSeeker, Youth Allowance, Austudy or Abstudy
  - Department of Veterans Affairs Pensioner Concession; or
  - Hold a Department of Veterans Affairs Gold Card

Pension Concession Card holders who are not receiving payments, and Health Care Card holders who are not receiving Youth Allowance, JobSeeker, Austudy or Abstudy payments, are not eligible.

### What you will need to apply

When you apply for the Power Saving Bonus you will need to have:

- 1. Your electricity bill, either on paper or electronically.
- Your Centrelink Customer Reference Number (CRN), so the government can verify you. This is listed on your concession card and letters from Centrelink.
- Your bank details (BSB and account number), so the government can pay you via electronic funds transfer.

There is a limit of one \$250 Power Saving Bonus per residential address/household.



Brotherhood of St Laurence Working for an Australia free of poverty





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# What is Homeshare?

Homeshare offers a simple and effective way of meeting people's housing And support needs. The program is designed to be a mutually beneficial Arrangement with both parties valued for the exchange offered. Homeshare provides:

- An older person (the householder), with practical in-home support to they can stay living independently at home
- A mature adult (the homesharer) with free accommodation in exchange for u to 10 hours of practical in –home support.

How does it work?

Both householders and homesharers are carefully interviewed and screened before being accepted to the program. Care connect manage the matching process and provide ongoing support to all participants for the duration of the agreement.

The householder provides a bedroom and shared facilities. In exchange, the homesshare provides approximately 10 hours per week of low-level practical assistance such as cooking, cleaning shopping and gardening as well as providing company and the added security of having someone else sleeping in the home.

# A home away from home

### For an overseas student

Valerie has recently arrived from Zimbabwe to pursue further studies. She is working par-time to assist with her education costs, yet was struggling to find suitable long term accommodation. Plus she really wanted to be close to the city to reduce her travel costs and time.

Maria and Natalie are sisters living in the inner-north of Melbourne. They grew up in the home they're still living in, love the neighborhood, and the familiarity of their community. When they realized that they were struggling with housekeeping and shopping for their meals, they stared to look at home help options and came across Homeshare.

Valerie, Maria and Natalia are all quiet chatty and enjoy sharing their cultural histories and food. Maria and Natalia recall their memories of migrating to Australia when they were young, and can relate to Valerie's experience of settling down in a new country, the three women have formed a strong friendship and are content to continue the arrangement as long as needed.



## **Building a new life with Homeshare**

Bert has always been a busy and social person. He lives with his dog Wolfie and has strong relationship with his children and extended family and sees them regularly. Since his wife passed sway he's felt less confident socially and a bit less secure in his home. Through Homesgare, he was seeking to gain connection, security and some help with jobs around the home.

Jess recently moved to Melbourne to return to her studies as a mature age student. Her family and social networks remained interstate. She saw Homeshare as an opportunity to build connections and live affordably in a welcoming home.

Bert and Jess now live together in western Melbourne. They watch TV, grocery shop and walk Wolfie together, they also like to share meals, a cup of tea and a chat at the end of the day.

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# What can be expected?

Our hoomeshare coordinators work collaboratively with hoseholders and homesharers to determine individual needs and requirements.

Through the program the homeshare coordinator provides ongoing support and monitors the match.

The arrangement:

- The householder provides a private bedroom and shared facilities in their home.
- In exchange, the home share provides approximately 10 hours per week of practical support, Additional benefits include providing company and the added security of having someone else sleeping in the home
- The homesharer will contribute towards utility costs for example: electricity and Water.
- The exact nature of the arrangement will vary and be tailored to each individual's circumstances.
- Both householder and homesharer will agree to the arrangement prior to homesharing.

# What is practical support?

Practical support provided by the homesharer to the householder might include:



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Help with the computer





Household cleaning

Transport to appointments

Light gardening

Meal preparation

Practical support does not include personal care, manual handling or administering medication.

# Who is eligible?

### To become a householder you must:

- Live in Northern or Western Melbourne (the program is available in Banyule , Brimbank, Darebin, Hobsons Bay, Hume, Maribyrnong, Melbourne, Melton, Moonee Valley, Moreland, Nillumbik, Yarra, Whittlesea and Wyndham)
- Require practical assistance and support to remain living in your home
- Have a spare room available for a homesharer
- Be over 65 years of age.

### How do I get more information? Call 1800 692 464 and ask for the Homeshare team. homeshare@careconnect.org.au careconnect.org.au



### To become a homesharer you must:

- Be over 18 years old
- Be willing to live in Northern or Western Melbourne for at least six months (the program is available in Banyule, Brimbank, Darebin, Hobsons Bay, Hume, Maribyrnong, Melbourne, Melton, Moonee Valley, Moreland, Nillumbik, Yarra, Whittlesea and Wyndham)
- Commit approximately 10 hours per week to household task in exchange for free accommodation
- Contribute towards utilities
- Have an interest in supporting an older person to remain in their own home
- Be in stable study or employment with regular hours.

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# President's Letter Summer 2021 - 22

#### LUCKY OR UNLUCKY TO BE LIVING WITH MS

Someone asked me if I ever felt angry that life had dealt me a hand which included MS. I thought long and hard and my answer is an emphatic NO! In fact, I would say the reverse. I have been very lucky and in some ways my MS has been an advantage rather than a disadvantage.

The worst time of my MS life was before I was diagnosed; five years during which my condition deteriorated slowly but a galaxy of specialists expressed complete inability to determine what was wrong. Diagnosis for me came as a significant relief. I now had something I could research, try to understand, even fight. Fortunately, I had a supportive employer who was not at all phased by my slowly increasing disability.

It eventually dawned on me that a cure was not probable, and I started to think about what I could do and tried to forget about what I couldn't. I needed one and later two sticks for walking, so I made my own in the style of an old-fashioned thumb-stick (a "Y" with a very long stem).

Then two things happened I discovered that one of people in my work team also had MS but was suffering more than me from feelings of embarrassment and disapproval. I believe I helped her by showing she wasn't alone, and that I refused to be embarrassed by my disability. My view has always been that if someone thinks any the less of me because of my disability that is their problem not mine. Then soon after that my wife Stevie and I went to an MS conference in Melbourne, and I discovered the MS Ambassadors and People with MS Victoria. I joined both and so I began advocating for and working as a volunteer for people with MS.

I am lucky to be happily married; we will have been married for 54 years in March and we have two sons and four granddaughters. Being disabled is a pain and so is having MS but it has given me insights into aspects of our society which might well have otherwise been hidden from me. I am fortunately still able to drive a modified vehicle and use a computer and I have had experience working as a professional in private enterprise and as a public servant. Luckily, I am able to use the skills that I have acquired and the experience I have gained for the benefit of other people with MS. This is very rewarding but importantly volunteering for people with MS also helps me cope with having MS. Moreover, it gives me a purpose which I can pursue despite being disabled and for which being visibly disabled is an advantage.

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Now a word or two about COVID vaccinations. Please note that if you are on one of the immune-suppressive medications, you should have a third dose of COVID-19 vaccine 2-6 months after your second dose. Please consult your doctor to see if you are eligible for this dose. These appointments can only be made after advice from your doctor.

Even if you are not on an immunosuppressive medication then you should be aware that the government has recently announced that COVID-19 vaccine boosters are now available for all people aged 18 or over if you have had your second dose of a COVID-19 vaccination at least 4 months ago. These booster doses are not mandatory. However, they are recommended to maintain immunity against COVID-19 and increase your protection against infection with the virus that causes COVID-19. Booster doses will be bulk billed and there should be no out of pocket cost to you.

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And finally, a reminder about our AGM; this year we have as our keynote speaker Rohan Greenland the CEO of the new MS Australia. This was formed by the merging of the previous MS Australia and MS Research Australia. He will brief us on the changes involved and the new initiatives being pursued. This is the 2021 AGM which because of COVID we had to delay until February 7th this year. It will as usual be held at the Nerve Centre Blackburn. For more details see the advert later in this Shortcircuit.

I hope you all had the best possible festive season and I wish you all the best for 2022.

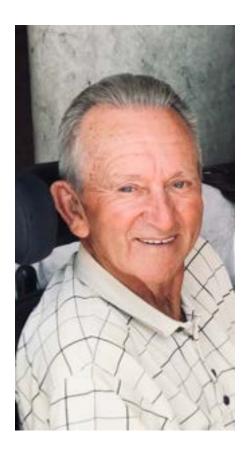
Nigel Caswell O.A.M.

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## ALLEN MAHER R.I.P.



It is with very great sadness that I report the death of Allen Maher, a long-serving and valued member of the Executive Committee of People with MS Victoria. Allen was a very effective committee member, responsible for fund raising for almost 12 years.

Although Allen's MS had confined him to a wheelchair for many years, he seemed indestructible. He was a keen bowls player who used a specially adapted wheelchair in which to play. He was a keen singer and Bulldogs supporter, and was committed to helping others through PwMS, Rotary and the Masons. Allen was a proud and loving father to three girls, grandfather to six grandchildren and foster parent to another six children. His motto was something like, "Always say yes to life and do everything with a full heart."

Allen will be sadly missed by his colleagues at PwMS-Vic and by his wife Dorothy, daughters, foster children and grandchildren.

Nigel Caswell President PwMS-Vic

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## **My MS Road Trip**

The MS Community Engagement Council Victoria is comprised of people with MS and carers who advise MSplus on the needs and expectations of PwMS. The Council recently had a discussion about the words used to describe our individual history with MS including the term "My MS Journey". This story was provided by a member, Paul Gallagher.

### What about an alternative?

I am not a fan of the word 'journey' ever since it was used for about the 50th time during the first season of Australian Idol! Overuse has surrendered the word to the inbox of jargon, and – by definition – diminished it as a metaphorical explanation for experiences gained through time and space. So, what about an alternative?

Well...MS has been less a 'journey' for me than a 'road trip'.

Picture this: You're driving out of the garage for a very long drive in the family car after hearing a loved relative has passed away. The boot is packed and your kids are barely visible among the additional devices, pillows and blankets piled on and around them in the back seat. That's like when MS begins – first, receiving news I didn't want to hear despite the fact I had already noticed a decline. Then, after packing the car (ie my mind) with way too much information, I headed off on a trip that had an air of grief associated with the distance to, and prospect of, a destination I hadn't imagined.

We start driving, and debating what playlist the family can agree on. The kids and Karen, ever loving and just a little concerned for my welfare as the driver, reckon it's probably fair to let Dad pick the songs for the start of the trip. It reminds me how loving my wife and immediate family are. They didn't plan for this 'road trip' of MS either. They had plenty of other appointments and ideas that had to be shelved when I received the diagnosis. Anger and frustration must have been in them somewhere at the impost of my disease, but they put it all aside in favour of squeezing into the car and heading north.

Along the way, everyone gets a little more tired and uncomfortable, but my wife is more worried about me than herself. Karen notices my tired eyes getting heavier. That's when the analogy of a road trip highlights the love and work of carers, especially those from within our family. They see us fatigue and falter, and offer anything they can to remind us we are not alone, and we certainly don't need to occupy the driver's seat every kilometre we travel.

'Just pull over and rest,' she says, 'and I'll drive this next part.'

### Are we there yet?

At some point on this MS 'road trip', I hear the kids asking if we are there yet. It's a question I have in my head, earlier than the kids verbalise it. 'Not for a while yet,' I answer, passing some lollies into the back seat and saying, 'I love you'.

In truth, the road trip feels endless, and the car I drive in seems to be running out of juice. Beside me, however, is my co-driver and best friend, Karen. And so close I can touch them are my kids (son-in-law and now grandkids included) – wanting to be where I am, travel where I'm going, and laughing when I giggle so much at a joke that Karen has to grab the steering wheel momentarily.

So no, I do not prefer 'journey'.

Now back to the drive after that meal break.

Paul Gallagher www.Paul-Gallagher.com

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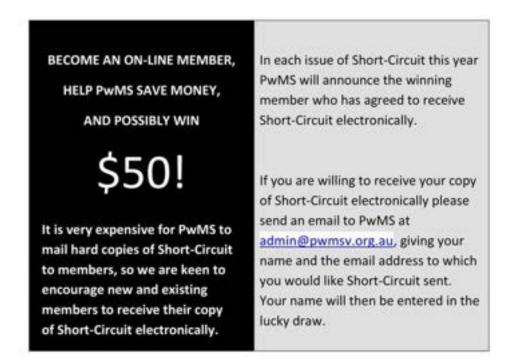
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## New Committee members needed for PwMS-Vic

People with MS Victoria is an entirely voluntary organisation run for and by people living with MS and their families and carers. It is run by a small committee of volunteers, all of whom have MS or care for someone with MS. It provides information for people with MS through its website, Facebook page, newsletter, and annual conferences. It also lobbies government and support agencies to improve services to people with MS.

We would dearly like to hear from anyone who would be interested in joining the committee. It is a very friendly team and the work is rewarding and is shared. If you are interested, please contact admin@pwmsv.org.au

Nigel Caswell President PwMS-Vic



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We are a team of continence practitioner nurses, technology experts, product specialists, care managers, home delivery professionals, and other health and business focused people. Over 4.5m Australians use continence support aids in managing their bladder and bowel functions.



### **Never Run Out**

An automated reorder option with a delivery schedule that perfectly matches your needs.

We offer this because we know running out is a constant concern and it can be quite difficult if you ever do run out. Tell us how many pieces you need each day and we'll do the rest, and save you and extra 10%



### **Bulk Discounts**

Pay less when you buy full cartons of your products.

We offer this because it costs less to send you a full carton in one delivery than across several smaller deliveries. We also offer free delivery on these orders where the price is \$50 or more



### **Personal Service**

We are an Aussie team, here to help you no matter what.

We offer this because you have questions about products, deliveries, and so much more. We also know that most of our customers are more comfortable discussing their product needs with us than with their doctor.



### **Discreet Parcels**

Deliveries without obvious product markings on the outside of the parcels. We offer this because only you need to know what is in the box; it's none of your neighbour's business.



### **Focused Range**

Our range covers all levels of need without confusion. We offer this because the market can be so confusing. It's nearly impossible to compare two similar products in different brands - does anyone know how 6 out of 8 "drops" in one brand compares to 8 out of 12 drops in a different brand?



### **Real Rewards**

Be rewarded on every order - redeem as discounts.

We offer this because we believe that customers that continue to order from us should benefit from their loyalty to our products and services.

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## Land of Fire and Ice

Where would you see road signs like this?

Where will you be packing both your swimming and snow gear?

Where could you find enormous factory complexes

mining cryptocurrency? What country has breathtaking scenery, active volcanoes, and amazing heated thermal water pools? Yes, this quarter we are off to Iceland, also known as the Land of Fire and Ice.

Iceland is a Nordic country, the most sparsely populated in Europe. The capital of Iceland is Reykjavík, home to two-thirds of the country's population. What struck me about Reykjavík was just how flat the capital appeared, perfect for wheelchair access. The weather was cool and overcast. The climate of the country, often described as polar, is due to its elevation and location. In the capital, the average temperatures are

around 2'C in winter and 12'C in summer.

Iceland was settled in 874AD by the Vikings, although Irish monks had previously inhabited the island; they gave up due to the extremes and without even naming the land. Until the 20th century, Iceland's economy was primarily fishing and agriculture. Following World War 2, Iceland became one of the wealthiest and most developed nations in the world. It is regarded as having an excellent standard of living, typical of many Nordic countries now. It has a universal healthcare system, provides tertiary education for all it is residents and





Icelandic volcanic activity

Thermal bathing

is noted for its relatively low taxes. Iceland runs mostly on renewable energy. The United Nations Human Development Index rates Iceland as the fourth most developed country in the world.

Iceland's landscape is largely the product of the impact of the Ice Age and volcanic activity. It now seems remarkably similar to the Faroe Islands. When it was first settled, Iceland was forested, with about 30% of the island being covered in trees, mostly Birch. However, the island was extensively logged for timber and firewood, contributing over time to a loss of topsoil. Other factors also contributed to a changing ecosystem, including over-grazing by sheep.

Cryptocurrency - what on earth is it, I wonder? When researching Iceland, I was astounded by the size of the factories, with row after row of computers 'mining' for cryptocurrency. Iceland is at the forefront of cryptocurrency mining, the term used for collecting Bitcoins and other tokens. It has been reported that 8% of all Bitcoins have been mined there. The very cold climate is perfect for data centres and the power is generally green (hydroelectric and geothermal). The Government is also supportive of the industry. While Cryptocurrency is not legal tender in Iceland, it is not illegal to trade in them.



Icelandic cryptocurrency data mining factory

So, if you have a passion for innovative social programs, freezing weather, fish, swimming, skiing, volcano watching and cryptocurrency, then Iceland is your "go-to destination" for 2022. Researched and written by Chris & Susan Platford

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## People with MS - Victoria 2021 Annual General Meeting

and

### Briefing on the new MS Australia

Monday 7<sup>th</sup> February; 10.30am

The Nerve Centre, 54 Railway Rd, Blackburn, 3183

### AGM

1. Welcome

2. Apologies

- 3. Minutes of previous AGM (Nov 2020)
- 4. Correspondence
- 5. President's Report
- 6. Treasurer's report
- 7. Appointment of Auditor for 2021-22

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### PRESENTATION FROM ROHAN GREENLAND THE NEW CEO OF THE COMBINED

### MS AUSTRALIA & MS RESEARCH AUSTRALIA

Light refreshments will be served after the meeting

### Attendance on-line

This meeting will be held at the Nerve Centre, 54 Railway Rd Blackburn. and will be livestreamed so that people who wish to can view it and take part on-line. Copies of the previous minutes, correspondence schedule, president's report, and treasurer's report will be posted on our website prior to the meeting.

Anyone living with MS in Victoria is welcome to attend. To attend online register your interest at <u>admin@pwmsv.org.au</u> by Monday February 1<sup>st</sup>.

Register by Monday February 1<sup>st</sup> and watch the AGM ONLINE!!

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## Providing information, referral and support to people with Multiple Sclerosis.

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