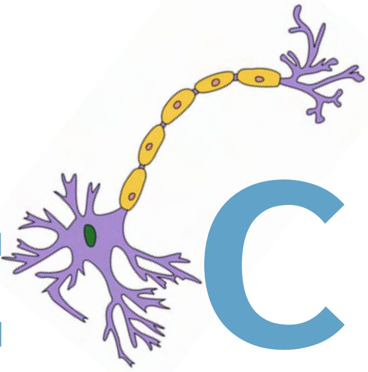
Autumn Edition 2022

Victoria

Short Circuit



PwMS Annual Conference 2022
LIVING BETTER WITH MS
Saturday May 7th -10.00am to 3.00pm
The Nerve Centre, Blackburn

Dr Lisa Grech

A person with MS and senior research Fellow, Medicine at Monash University -Living with and Researching the Reality of Living with MS-

Associate Prof Anneke van der Walt

Director MS and Neuroimmunology at Alfred Health and Head of MS and Neuro-ophthalmology Group at Monash University.-Current research and advances in treatment; for MS.-

Natalie Francis

Executive Manager Consumer Directed Care at MS+ -The role and importance of exercise in managing MS-

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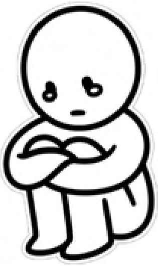
Let's talk about: Depression



While depression is a less obvious MS symptom, it is one of the most common symptoms of MS. In fact, it is two-three times more common in people with MS than in the general community.

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Power Saving Bonus HAS BEEN EXTENDED

WOW!

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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CONGRATULATIONS TO DYLAN ALCOTT O.A.M.

Dylan Alcott made history in January by becoming the first person with a visible disability to be made Australian of the Year.

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Victoria

People with Multiple
Sclerosis Victoria Inc.
ABN: 73 104 198 752
admin@pwmsv.org.au

Chairman's report February 2022

I hope you are coping with the extraordinary weather we have had recently with most un-Melbourne like high humidity. Fortunately; the weather was kind for Stevie and my celebration of the 50th anniversary of our arrival in Australia on Feb 4th 1972.We feel very lucky that we chose to come to Australia.

Of course: being white, Christian and English speaking; our adopted country welcomed us fairly warmly. Although I still remember being accused of being a “Pom” and of being ridiculed for carrying an umbrella! Unfortunately; many other migrants have a much less welcoming experience. Not that different perhaps to the reception some of us got when telling our families or employers that we’d been diagnosed with MS. Fortunately MS is much better and more widely understood these days, although the media still tends to portray in the worst possible light. If you or anyone you know is worried about their employment after being diagnosed with MS contact the MS Employment support service via MS-Connect: Email: msconnect@ms.org.au or Phone; 1800 042 138.

Now that COVID is a fact of life, a doctor friend in England has proposed having a plan for enjoying life with COVID. His plan is based on what he describes as medical common sense, and he urges us all to have similar personalised plans. His plan is;

- Get triple jabbed,
- Always wear a mask in supermarkets and shops and other indoor or crowded places;
- Also wear them on public transport;
- Carry an alcohol-based hand gel and use it when you have had to touch things you would rather not
- Try to meet friends outdoors, but if indoors choose somewhere well ventilated, and give everybody space; and
- If it’s too crowded, go away and try later;

Being triple jabbed means you’re unlikely to catch COVID and be seriously ill. So; you should not be frightened to go out and about. There is no longer a need to hibernate, you can enjoy yourself again but be cautious about shaking hands or hugging. We held the delayed PwMS 2021 AGM on Feb 7th. Because of COVID limitations it was held online and broadcast on the internet. The keynote speaker was Rohan Greenland, CEO of the combined MS Australia and MS Research Australia who spoke about the benefits of the amalgamation and what had already been achieved and what is planned. For further details see the report later in this newsletter

Our next major event is our annual conference “Living Better with MS” which will be held on Sat. May 7th at the Nerve Centre at Blackburn. We will have three excellent speakers on topics of importance.

- **A/Prof Anneke van der Walt** [Director MS and Neuroimmunology at Alfred Health and Head of MS and Neuro-ophthalmology Group at Monash University, speaking about current research and advances in treatment; for MS.
- **Natalie Francis**, Executive Manager Consumer Directed Care at MS+ who will talk about the role and importance of exercise in managing MS. and
- **Dr Lisa Grech**, a person with MS and senior research Fellow, Medicine at Monash University; who will speak about her journey with MS and her research into depression- medication adherence & healthcare services in people with MS.

Morning tea and a light lunch will be provided. So there will be time to chat with other people from the MS community. Booking details are provided later in this newsletter. Unfortunately; numbers may still be limited so if you are interested get your registration in early. It will also be broadcast via the internet, so if you can’t attend why not get your peer support group together and watch the broadcast.

I look forward to seeing many of you there.
Nigel Caswell O.A.M.

KEEP COOL with an ICE TOWEL

Have you heard of ICE TOWELS? They are a very cheap and very effective aid to keeping cool in hot weather and they don’t require electric power.
They cool by evaporation. They are a polyester scarf which you simply soak in water and then wave about for maybe ten seconds to start the evaporation process. Then put them around your neck, and voila cool relief! Of course, they do eventually warm up; at which point they can be reactivated by waving in the air again. If, and when, they dry out you simply re-wet them and hey-presto they are cool again.
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You can use the same one all day and all you need to carry with you is a water bottle. They are much better than things you cool down in the fridge which lose their cooling ability all too quickly and then have to go back in the fridge!
What is more they are cheap. Their most common name is Ice Towel, (sometimes called instant cooling towel) and you can get them at most chemists (see the picture) they cost between $5 and $15. I have several, I keep one in my wheelchair bag, one in the car, one in the caravan and one at home.
Carry them wet in the bottle they come in then they are ready to use. They can get a bit smelly after being used a few times and then you just put them in the washing machine with your laundry. Don't put the bottle in the dishwasher it will melt!
Note; there are also evaporative cooling vests advertised. These are also activated by soaking them in water, however, I have no first-hand experience of their performance

Nigel Caswell

VICTORIAN POWER BONUS PROGRAM HAS BEEN EXTENDED TO 30 JUNE 2022

Did you know that you can claim a “one-off” $250 Power bonus if you have a Victorian Residential Electricity Account, and are receiving Centrelink payments under one of the following concession programs:

- Centrelink Pensioner Concession
- Job Seeker, Youth Allowance, Austudy or Abstudy

Applications can be submitted online and will take approximately 5-10 minutes to complete. Have your electricity bill handy to reference the required information.
For more information and to check your eligibility, please refer to the Victorian State Government, Energy Compare Website: https://compare.energy.vic.gov.au
The “Energy Compare” website also has lots of useful information about comparing Energy Plans to help you to select the most cost-effective energy option.

CONGRATULATIONS TO DYLAN ALCOTT O.A.

(Compiled by Nigel Caswell from Dylan's acceptance speech)

Dylan Alcott made history in January by becoming the first person with a visible disability to be made Australian of the Year. The 31-year-old athlete, Paralympian, philanthropist, media commentator and advocate was recognised for both his sport and his **advocacy for people with disabilities**.

On receiving the award he said what an unbelievable honour it was to be named Australian of the Year and to get it for not just being good at tennis, but for the work he's done off the court.

Dylan said... His purpose in life 10 years ago, yesterday, today and as Australian of the Year, it's never changed... It has always been... not just to win tennis tournaments, but to change perceptions so people with disability (can) live the lives that they deserve to....To be given this honour, to stand on this platform to be able to do that, it's huge, and I'm just so grateful and thankful ... it's unbelievable.

Dylan said he'd been in a wheelchair his whole life, having been born with a tumor around his spinal cord..... That he'd known nothing but having a disability, and how much he used to hate himself. How he used to hate having a disability; being different.....and how the only times he ever saw anyone like him on the TV, or in a newspaper, was in road safety ads. Someone drink drives, has a car accident and what's the next scene? Someone like him in tears because their life was over!

But now he is a proud man with a disability because of the support he has received from family and friends. And because of the path that has been forged by paralympic giants like Louise Sauvage, Kurt Fearnley, and Danni Di Toro that are the reason he got into sport, and advocates like Stella Young, who paved the way. He said they should all share the honour of being Australian of the Year.

Dylan said he is proud to be the person he is; that his disability is the best thing that ever happened to him, he is so thankful for the life that he lives. But he recognises that the 4.5 million people in this country, that have a physical or non-physical disability, don't all feel the same way that he does and it's not their fault. And it's up to all Australians to do things so people living with a disability can get out ,and be proud of their disability as well, and be the people that they want to be.

We've got to fund the NDIS, first and foremost, and listen to people with lived experience and ask them what they need so they can get out and start living the lives they want to live and remind ourselves that it is an investment in people with disabilities, so they can get off pensions and start paying taxes, just like their carers and their family members.

As we reopen from this pandemic, we've got to think about and prioritise people with disability. They are among the most vulnerable people in our community. We've got to get them the vaccines and the tests and whatever else they need so they can get out there and start living their lives.

We've got to keep improving employment opportunities for people with a disability. Of those 4.5 million people, only 54 per cent of them participate in the workforce. "Their unemployment rate is double that of able-bodied people, a figure that hasn't moved in 30 years.

And lastly, we have to have greater representation of people with a disability everywhere. In our boardrooms, in our parliaments, in our mainstream schools, on our dating apps, on our sporting fields, in our universities, absolutely everywhere. And he promises this won't just enrich the lives of people with disabilities, but everybody's lives!

Dylan is a fantastic advocate for everyone with a disability!----------GO DYLAN----------------

“Supercharging the MS Research Agenda”

[Summary of presentation by Rohan Greenland to the PwMS 2021 AGM]

Rohan was appointed the Chief Executive Officer of the combined MS Australia and MS Research Australia in late 2020. He came from Palliative Care Australia where he had also been CEO. He had previously worked in senior advocacy roles at the National Heart Foundation, as Director Public Affairs at the A.M.A., and as political adviser to Australian national and territory ministers.
1. MS Australia was formed by integrating MS Research Australia with the previous MS Australia; consolidating their Research, Advocacy, Education & Awareness, & Governance activities.
2. Board Members; There are four independent skill-based Directors Ms Vicki Thompson, Ms Bronwyn Rout, Ms Sharlene Brown, & Mr George Pampacos; and there are five State/Territory Directors Mr Des Graham, Mr Gary Whatley, Mr Horst Bemmeri, Mr Shaun Treacy, & Miss Maureen Lawlor.
3. Key milestone achievements for 2021, included;
a. Consolidating the research arm into MS Australia, Directing strong funding growth into MS research
b. Enhanced advocacy particularly in relationship to NDIS & Aged Care
c. $5.2 million raised for research from the May 50k campaign
d. $275k funding provided for MS researchers affected by COVID-19
e. A new website introduced to provide information on vaccinations and medications.
f. A new guide for medical professionals and people with MS regarding managing health through diet, exercise, and vitamin supplements
4. Strategic Planning, included
a. Developing a five-year strategic plan
b. Surveying 3,000 people, more than half of whom were living with multiple sclerosis about what they believed the priorities should be for Research and Advocacy.
5. Questions asked of guest speaker Rohan Greenland
1. Q: What is happening about the suspension of the MS Brain Bank? A: The Victorian Brain Bank was suspended because funding from the NH&MRC ceased as a result a restructuring of its funding arrangements. The MS Brain Bank in Sydney is still operating and MSA is lobbying for the Victorian Bank to be re-funded.

2. Q: Are Brain Banks State based? Shouldn’t we have a national BB scheme?
A: Yes, we should and MSA is supporting such an approach
3. Q: The 65y limit on the NDIS is unfair and discriminatory and affects many people with MS, and this is especially bad for PwMS in Aged-Care (as distinct from being cared for at home). Is MSA pushing for this to change?
A: Agreed the 65y/o age limit is totally arbitrary. This wouldn’t matter if the Aged Care support system was better, but as it is, the age limit results in huge inequity. A key finding of the Royal Commission into Aged Care was that the Aged Care system was in urgent need of fixing and improved funding. The worry is that the Commission’s report seems to have been forgotten!

MS Australia; 2021 Research & Advocacy Priorities Survey

In mid-2021 MS Australia invited the MS community to take part in an online survey about MS research and advocacy priorities. As part of the MS Australia strategic plan, feedback was sought as to which of the many different areas of MS research and advocacy are the most important to people directly and indirectly affected by MS including health professionals and researchers.

In January MS Australia announced the results of the survey. These are summarised below

- 3,000 people took part in the survey, including 1,544 people with MS.
- The top research priority was finding a cure via repair and regeneration.
- The top advocacy priority was additional funding for MS research.

The 1,544 people with MS who took part in the survey equates to approximately 1 in every 16 people in Australia with MS responding to the survey. Of the 1,544 , there were: 990 people with relapsing remitting MS; 284 people with secondary progressive MS, 128 people with primary progressive MS, and 16 people with clinically isolated syndrome The 1544 included people from remote areas, regional areas and urban areas. There were people recently diagnosed right through to those who have had MS for over 40 years. Therefore, this survey has been one of the most in-depth disease-specific surveys carried out by a disease organisation in Australia.

What are the priorities of the MS community?

The survey revealed some very clear messages. The top research priority was a cure via repair and regeneration. This was also reflected in the preferred research stream, neurobiology, which includes looking at ways to repair damage in the central nervous system (the brain and the spinal cord).

People were also asked what symptoms they thought should be prioritised for research and management. These results varied slightly when the respondents were separated into those with relapsing remitting MS or those with progressive MS. Overall, people living with MS thought the top five priority symptoms were:

1) Walking and mobility, 2) Cognitive function, 3) Fatigue, 4) Pain, and 5) Vision problems.

Another important area was the terminology by which people with MS preferred to be called. The options most favoured were either a ‘person living with MS’, or a ‘person with MS’. The options that ranked the lowest were ‘client’, ‘patient’ and ‘MSers’

Another core function of MS Australia’s work is advocacy on behalf of its Member Organisations, and the over 25,000 people in Australia diagnosed with MS as well as their families and carers. The results of this question were largely uniform across the different sections of the MS community with the top five priorities being:

1) Additional funding for MS research, 2) Approval of new MS medications, and inclusion on the Pharmaceutical Benefits Scheme, 3) Meeting the disability needs of people not eligible for the NDIS, 4) Better access to treatments, including disease modifying therapies, and 5) Better access to specialist neurologists.

People with MS have always played a key role in MS Australia, with people affected by MS involved at every level of the organisation. MS Australia will use the data gathered in this survey to shape its future strategic direction.

For more information go to www.msaustralia.org.au

Let’s talk about: Depression

While depression is a less obvious MS symptom, it is one of the most common symptoms of MS. In fact, it is two-three times more common in people with MS than in the general community. Indeed, depression can be a reaction to the diagnosis and symptoms of MS. But depression is also an MS symptom in its own right. This is thought to be caused by the changes that occur to the brain because of MS. For people with MS, depression can be more chronic and less likely to resolve without treatment. So it is important to identify depression, especially as there are effective treatments that can improve mood and mitigate the many negative outcomes that may occur when depression is not treated properly. This includes increased perception of pain and fatigue, poorer ability to look after yourself and take your medications as prescribed, and slower more foggy thinking. So depression may make your other MS symptoms worse

Some people who have symptoms of depression don’t realise it. This might be because the symptoms are different to what they think depression symptoms are like. For example, if you are feeling irritable and are getting annoyed with people more often, you might not realise it is because of your mood. Also, if symptoms creep up slowly it might be less obvious that your mood has changed. Some depression symptoms overlap with MS symptoms, for example sleep problems and fatigue can be symptoms of depression and symptoms of MS, or a combination of both..

Sometimes when people with MS realise their mood isn’t great they will choose not to seek help. This might be because they hope that things will get better on their own or because they are too exhausted by life (a symptom of depression, but also compounded by MS). Even when people do seek treatment, whether it is medication or psychotherapy, it might help a bit but not fully resolve emotional difficulties. You may need a greater amount of support or an increase in medication dose. This is why it is important that depression symptoms are monitored once identified.

What to do?

The first step is identifying symptoms of depression. If you have concerns about your mood, speak to someone. Ask your GP, neurologist or MS nurse for a mood assessment. Even if you are being treated for depression you can ask for your depression symptoms to be assessed. Depression is treatable, even if it is a symptom of MS, so it is ok to ask for help. MS has many things about it you can’t change, but the way you feel is something that you can change.

Here are two questions that are helpful to identify if your mood could do with a more thorough assessment. If you answer yes to either one of them it is worth a trip to the doctor.

1. During the last month, have you often been bothered by feeling down, depressed or hopeless?
2. During the last month, have you often been bothered by having little interest or pleasure in doing things?

If you didn’t answer yes to either of the above questions, but have been feeling more anxious, irritable or angry than usual, then it is worth a discussion with your doctor. MS has a lot of layers that require emotional processing, so it’s ok to ask your doctor for a referral to a psychologist if you think that would be helpful. Other ways to improve your mood, might include a mood lifestyle review. Healthy eating, regular exercise, good sleep habits, balance and socialisation have all been shown to improve mood. A psychologist or other suitable counsellor may be helpful with this, but other allied health specialists such as a physiotherapist for exercise or dietitian for healthy eating are good options too. However, if your mood difficulties are severe and persistent it is likely that medication will be required.

The take home message:

Depression is a symptom of MS and should be identified and treated as such. Other emotional issues are also highly prevalent, including anxiety, irritability, grief and loss. It is important to seek help. Depression, and the way you feel more broadly, is one of the things you can change about MS and appropriate treatment has the ability to positively change a range of other areas.

PEOPLE WITH MS

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LIVING BETTER WITH MS
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This conference proudly brought to you by **People with MS Victoria Inc;**
with support from **MS Limited, and the National Disability Conference Initiative**
Enquiries; rogerreece@optusnet.com.au **Mobile: 0404 01 54 54**

----SPEAKERS----

Dr Lisa Grech,

A person with MS and senior research Fellow, Medicine at Monash University

-Living with and Researching the Reality of Living with MS-

Associate Prof Anneke van der Walt

Director MS and Neuroimmunology at Alfred Health and
Head of MS and Neuro-ophthalmology Group at Monash University.

-Current research and advances in treatment; for MS.-

Natalie Francis,

Executive Manager Consumer Directed Care at MS+

-The role and importance of exercise in managing MS-

Morning tea and light lunch are included
The cost is only $10.

Some assistance with transport and accommodation, is available for information call Mob: 0435 085 827

NUMBERS ARE LIMITED - REGISTRATION IS ESSENTIAL

To register complete this form and return to:
PwMS Conf22, PO Box 1035, CRAIGIEBURN NORTH VIC. 3064
Or by email to; admin@pwmsv.org.au

Names of attendees			
Phone:	**Email:**		
Dietary needs [if any]	Vegetarian	Vegan	Gluten Free
Access needs [if any]	Wheelchair	Walker	Scooter

Enclose payment of $10 per attendee (Please tick payment method)
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