



Short Circuit

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People with Multiple Sclerosis Victoria Inc.

Winter 2019

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G'day Everyone,

Probably many of you still have withdrawal symptoms after the GoT finale. So, to cheer you up I have prepared some interesting reading about new developments in alternative treatments which can ease MS symptoms and a new study about our humble gut bacteria. Also, while we were busy with the election, we had the Global Accessibility Awareness Day to make digital developments accessible to everyone - I have pointed out some inspiring projects on page 6.



Do you have that nagging question about the Carer payment or Age pension? We have provided some information to help you make the right choice.

Moreover, we need your help. Please follow the instructions on the next page to subscribe to the online newsletter. You will help save some trees, save us some money, and you can win a \$50 gift card.

How good is that? 😊

Editor

***BECOME AN ON-LINE MEMBER,
HELP PwMS SAVE MONEY,
AND POSSIBLY WIN
\$50 COLES GIFT CARD!***

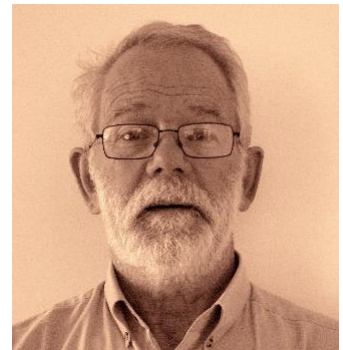
It is very expensive for PwMS to mail hard copies of Short Circuit to members, so we are keen to encourage new and existing members to receive their copy of Short Circuit electronically.

In each issue of Short Circuit until 10/2020, PwMS will announce the winning member who has agreed to receive Short Circuit electronically.

If you are willing to receive your copy of Short Circuit electronically please send an email to PwMS at admin@pwmsv.org.au, giving your name and the email address to which, you would like Short Circuit sent. Your name will then be entered in the lucky draw.

President's Letter

Did you get to this year's PwMS Vic conference, or did you watch it on the internet? If you didn't you missed a very interesting and informative event. We had three excellent speakers; John Blewonski, the new CEO of MS Ltd; A/Prof Anneke van der Walt, Head of MS and Neuro-ophthalmology at Alfred Health; and A/ Prof Catherine (Kate) Cherry, a person with MS & an infectious diseases physician at Alfred Health.



John Blewonski gave the audience an insight into the planning and thoughts for the future direction of MS Ltd. He started by talking about the challenges facing MSL and the extensive program of consulting MSL's customers and stakeholders, and the needs analysis being conducted with MS Australia. He spoke of what is needed including securing more income, being innovative and offering local services, and services outside 9am -5pm Monday to Friday. He said that MS is a strong and well regarded organisation but there are opportunities for growth and improvement and he then spoke of some of the products being considered such as an accreditation program, scaled up NDIS services and scaled up services for PwMS over 65 and potentially offering services to people with other chronic neurological conditions. We wish him every success.

Anneke van der Walt spoke about current MS treatments and research starting with a brief resume of what is MS and then what factors such as smoking, and childhood obesity increase a person's risk of contracting MS. She talked about work in the area of brain health which emphasises the need for disease management planning, and the importance of monitoring and participation. Anneke then discussed the relative efficacy and risks of the many treatments available, the long-term benefit of treatment, and changes in how the impact of MS is being measured. Finally, Anneke discussed recent updates regarding the performance of current MS drugs and potential drugs, and then answered questions.

Kate Cherry spoke about her journey with MS and the good and bad decisions she made regarding her MS. Kate is an infectious diseases physician at the Alfred, on the Board of the Peter MacCallum Cancer Centre and has a small research role at the Burnett Institute as well as teaching and mentoring. She spoke about her lifelong love of music and her early determination to become a doctor. She described her traumatic diagnosis of MS and the dramatic impact MS had until she was lucky enough to get on to Intragram which completely changed her life and enabled her to envisage life as a medical professional. Kate described how the MS Walk/Run in 2012 enabled her to exorcise the effect of her diagnosis, and she finished by describing what she says is her very enjoyable lifestyle.

It was a wonderful conference and it's not too late to watch it. You can watch the recording on the PwMS Vic website <http://www.pwmsv.net.au/portal>.

Finally let me remind you the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability was established on 4 April 2019. People with disability and their advocates have worked hard to get this Commission established and we hope that it will result in real improvement in the opportunities and services available to people with disabilities. For information about the royal commission go to <https://disability.royalcommission.gov.au>.

Nigel Caswell

Government announces first ever national plan to keep young adults out of residential aged care

On March 22nd, 2019 the (previous) government announced what it claimed is the country's first ever national plan to keep young adults out of residential aged care. The stated aims of the plan are to;

- Support those, aged under 45, already living in aged care to find alternative, age appropriate housing and supports by 2022,

- Support those, aged under 65, already living in aged care to find alternative, age appropriate housing by 2025, and
- Halve the number of people aged under 65 years entering aged care by 2025.

When announcing the plan, the Minister did not offer extensive detail on how the government's targets will be met, nevertheless the commitment is welcome.

Younger people with disability who have not been able to secure appropriate housing have historically moved into residential aged care as a last resort. This is not fair on the young people nor on the staff in the aged care venues. The aged care system is designed to support the needs of older people and is not designed or equipped to meet all of the needs of younger people with disability. As at 30 September 2018, the Department of Health reported there were 5,905 people aged under 65 living in residential aged care facilities across Australia. Of these 188 were aged under 45 and on average, 50 young adults enter aged care every week.

The Plan appears to depend heavily on the NDIS enabling younger people with disability who have high support needs to be adequately funded to get the support they need in the community, rather than entering aged care. It is claimed this will be achieved by giving all NDIS participants in aged care, or currently in hospital settings who are at risk of entering aged care access to “Faster access, better planning and integrated supports”.

A key reason younger people are entering aged care is the lack of suitable housing. There is a significant gap in the market for highly specialized disability accommodation. As at 31 December 2018, there were almost 2,600 Specialist Disability Accommodation (SDA) properties enrolled in the National Disability Insurance Scheme (NDIS), compared to almost 11,000 NDIS participants with “SDA support” in their plans. Moreover, it is estimated that approximately 28,000 participants will require SDA when the NDIS is fully rolled out.

The plan includes a commitment to conduct an analysis of the characteristics of younger people in aged care to understand their needs and what works. The plan also acknowledges that it will need the collaborative engagement and positive contribution from all people with disability, their families, carers and supporters; the Australian and state and territory Governments, providers and investors in the SDA market; and other stakeholders.

However, unfortunately, the plan does not appear to include funding specifically aimed at increasing the supply of Specialist Disability Accommodation (SDA) other than through introducing changes to building approval processes to improve market confidence and drive stronger investment to grow the supply of SDA.

Never-the-less PwMS welcomes this commitment; it is long overdue recognition of the dire need for a solution to this national failure. We hope that this was not just an empty election promise.

Nigel Caswell

President PwMS Vic. Inc.

Treatment with Gut Bacteria Shows Benefits in New Study

Many people living with multiple sclerosis say they have experienced benefits from using diet to manage their disease. In more recent years, this has led to a greater focus being placed on research in this area. Gut health is one topic that has generated significant amounts of interest. In particular, there has been a number of exciting studies that have suggested a potential role for gut bacteria (or the gut microbiome) in multiple sclerosis.

A couple of major pieces of information have led to excitement that this may be a potential avenue for treating multiple sclerosis.

Firstly, it has been shown that the gut bacteria in people living with MS are different to healthy controls. This is both in terms of the types of bacteria present and the abundance of them.

Secondly, it has been observed that receiving some multiple sclerosis treatments actually reverses these differences.

An example of this is with a bacteria called *Prevotella*. People living with multiple sclerosis tend to have fewer numbers of this bacteria compared to healthy individuals. However, for those taking Copaxone, it was found that the abundance of *Prevotella* was increased.

This finding has led researchers from the University of Iowa to investigate whether treatment with the bacteria itself could be a useful therapy for multiple sclerosis.

Using a mouse model of multiple sclerosis, they found that treatment with the bacteria (*Prevotella histicola*) was just as effective at reducing the symptoms of the disease as treating it with Copaxone. They found that treatment with both the bacteria and Copaxone in combination did not increase the benefits seen for either therapy alone.

These results were observed in both preventative and therapeutic settings. This means that benefits were seen whether the treatments were given before the disease had started or after symptoms had developed.

It was found that the treatment with *Prevotella histicola* had a greater impact on reversing the gut microbiome of the mice with disease back to the 'normal' state compared to Copaxone.

This study provides some really interesting evidence that suggests that not only might gut bacteria be playing a role in multiple sclerosis, but they could also be a potential new avenue for treatment.

Whilst this has only been shown in a small mouse study so far, it will be exciting to see how it progresses and we will make sure to keep you updated as the research develops!

Source: MStranlate May 2, 2019.

Global Accessibility Awareness Day (16 May 2019)

In a world of rapidly advancing technology it's crucial to ensure companies and organizations are doing their best to make digital developments accessible to everyone.

While browsing the internet, catching up on social media, or texting on mobile devices might seem like second nature to some, accessibility-related barriers prevent millions of people with disabilities from easily using basic forms of technology and, in some cases, even discourage them from going online.

In 2012, Global Accessibility Awareness Day was launched to help highlight the need for increased digital accessibility.

This is the eighth annual Global Accessibility Awareness Day, and for the second year, Microsoft is awarding grants to AI projects meant to make the world more inclusive.

Over the next year, the recipients will work on things like a nerve-sensing wearable wristband. That device detects micro-movements of the hands and arms and translates them into actions like a mouse click. Another project seeks to develop a wearable cap that reads a person's EEG data and communicates it to the cloud to provide seizure warnings and alerts. Other tools will rely on speech recognition, AI-powered chatbots and apps for people with vision impairment.

A day after Microsoft talked about AI and accessibility, Google is doing the same at 2019 developer conference. The Mountain View company unveiled three separate efforts: Project Euphonia (to help people with speech impairments), Live Relay (to help people who are deaf or hard of hearing), and Project Diva (to give people some independence and autonomy via Google Assistant).

Project Euphonia, which is in the early research stages, aims to help people with speech impairments communicate more easily. Speech impairments can be caused by developmental disorders such as cerebral palsy and autism, or neurologic conditions such as stroke, ALS (amyotrophic lateral sclerosis), MS (multiple sclerosis), TBI (traumatic brain injuries), and Parkinson's. With Project Euphonia, Google is hoping AI can improve computers' ability to understand impaired speech. And in turn, computers can help ensure everyone is understood.

Project Live Relay aims to help people who are deaf or hard of hearing often communicate via sign language or chat. But what about when they can't see the person they are talking to and texting isn't available? Voice calls aren't an option, until Google software engineer Sapir Caduri decided they are.

Live Relay uses on-device speech recognition and text-to-speech to let your phone listen and speak on your behalf. The research project makes it possible for a person who is speaking to call someone

who is deaf or hard of hearing. The tool converts speech into text in real time and sends back written messages as spoken voice. The person who is speaking can simply talk on the phone, and the person who is deaf or hard of hearing can text on their phone.

Project Diva, which stands for DIVERsely Assisted, helps people give the Google Assistant commands without using their voice. A person who is nonverbal or has limited mobility can use an external switch device to trigger Google Assistant commands.

There are many more projects recently coming out, so this seems to be a good start to more inclusive digital world for everyone.

Editor

CARER PAYMENT or AGE PENSION?

If you are over age pension age and you are caring for someone, you may choose to receive either Carer Payment or Age Pension. There can be advantages to receiving either Carer Payment or Age Pension depending on your circumstances.

For example, if you are getting Carer Payment because you are caring for someone who is not your partner, and that person dies, you may be entitled to receive a bereavement payment. You would not be entitled to the bereavement payment if you were getting Age Pension.

However, if you intend to travel outside Australia, receiving Age Pension during an absence from Australia may be more beneficial than receiving Carer Payment.

While there are several differences between Carer Payment and Age Pension, there are also several areas that are the same for both payments.

Carer Payment and Age Pension:

- 1) have the same rate of payment
- 2) have the same **income and assets tests** (for Carer Payment a special income test may apply to the care receiver)
- 3) are taxable (Carer Payment is taxable once the carer, or the person being cared for, reaches age pension age), and
- 4) entitle the customer to a Pensioner Concessioner Card.

Additional payments if you are on Carer Payment or Age Pension

CARER ALLOWANCE Rate of payment \$130.00 p/f

There is no asset test for Carer Allowance but there is an income test.

You and your partner's combined adjusted taxable income must be under \$250,000 a year.

The Carer and the person you are providing care for must both be eligible, and both be Australian residents.

Carer Allowance can also be applied for as a separate payment if you are caring for a person with disability or a medical condition and you are not receiving the Carer Payment or Age Pension. Check with Centrelink.

CARER SUPPLEMENT

Is an annual lump sum payment on 1st July each year of \$600. It helps with the cost of caring for a person with disability or a medical condition. You will receive Carer Supplement if you are receiving Carer Payment or Carer Allowance.

To find out more about claiming Carer Payment or Age Pension, see the Centrelink factsheet titled 'Carer Payment or Age Pension'.

Visit www.centrelink.gov.au or phone Centrelink on **13 27 17** or **132 300**

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Editor: Martin Skoneczko. Email: pwmsv1@outlook.com

Enquiries and articles should be addressed to: The Editor, PO Box 1035, Craigieburn Vic. 3064

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