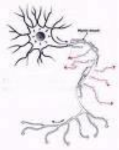
Short Circuit



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People with Multiple Sclerosis Victoria Inc. Spring 2019

PwMS Vic Inc. is endorsed as a deductible gift recipient and a registered charity. Gifts of $2 or more are tax deductible.

In This Issue

G'day Everyone,

This time I am speechless. I am looking to rent a disabled friendly house as my current one is going to be sold by the landlord and it seems to be mission impossible. However, I made it so read all about it in the next SC.

Editor

President's Letter

Stevie (my wife) and I are travelling again. As I write this we are in western Queensland near Carnarvon Gorge. As many of you know I have had MS for many many years and am unable to walk unaided so I thought it might interest you to hear how we manage.

We are travelling in a small motor home we call "Aphrodite". It is smaller than many caravans but for someone with MS like me it has a great many advantages over a caravan. First. It is incredibly easy to drive and much easier to park than having to back a caravan into a tight spot. Then there is much less setting up to do when you arrive somewhere; there is no unhitching and no lowering the legs, you just have to park it and connect it to power and water and you're done. Which is good if as is sometimes the case that I am just too tired to do anything much after travelling for a day.

Yes we normally stay in caravan parks where there is access to power in particular because I travel with a folding mobility scooter and it really needs charging most nights. Although we have an inverter fitted in the van so that we can charge a battery while we are travelling. This works well providing we are driving a few hours each day but of course is no good if we want stop somewhere for a few days. I also take a pair of elbow crutches and a very lightweight folding walker. The scooter is a *Supa-Scoota* which has pneumatic tyres which are a big advantage in that they are much more capable on rough or soft ground than are solid wheeled machines.

Aphrodite has also been modified so that I can drive it hands only and Stevie, my wife, can drive it as a conventional automatic. We share the driving religiously; I always do the first driving shift in the morning of one to one and a half hours when I am fresh. We try to limit our day's travel so that we arrive at our destination in time for lunch (sometimes a very late lunch). If the sun is very strong and shining straight in the windscreen on my chest that can cause me problems so I have a couple of mesh shades which I can stick in the side windows or low on the windscreen to reduce the suns heat.

We've had extra handles installed at several places in Aphrodite two in the entry, three in the shower & toilet and one above my side of the bed. I sit on a small folding stool to shower; importantly the shower is walk-in without a significant step.

I can thoroughly recommend caravanning even for someone who is physically disabled provided you are well enough prepared.

Now to something more serious future distribution of our newsletter Short Circuit. As I am sure you can imagine it is becoming more and more of a challenge to afford to print and mail out several hundred paper copies each quarter. We fear we will be forced to virtually limit ourselves to delivering it by Email from this time next year. We ask you to try and work out how you can access a copy by email directly to your own PC or iPad or via a friend or family member. When you've worked it out let us know what Email address to send it to and we will start sending it by email. And remember when you do let us know your name will go into the hat for a draw to win a $50 voucher.

Nigel Caswell

Telco can help

Telstra customers who have a disability can access the following products and services for the Hearing, Speech, Vision and Mobility & Dexterity categories. Click on the following link to see the products and/or services available: https://www.telstra.com.au/aboutus/community-environment/community-programs/disability/disability-products-services

Telstra can also help with identification of accessibility features of their customers' mobile and tablet devices and assist them with their needs. To learn more about mobile and tablet device accessibility please visit the IDEAS Accessible Telecoms website at http://www.ideas.org.au/telecom/category and the Global Accessibility Reporting Initiative website at https://www.gari.info. Find out more by contacting the Telstra Disability Enquiry Hotline1800 068 424 (Voice), 133 677 (TTY) or Email via web form here: https://say.telstra.com.au/customer/general/forms/disability-enquiry-hotline

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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.

***Last quarter winner is:* JOANNE CLAYWORTH**

Congratulations!

What to Expect After Your MS Diagnosis, from Someone Who's Been There

Dear Recently Diagnosed Multiple Sclerosis Warrior,

I'm sorry to hear of your recent multiple sclerosis (MS) diagnosis. I wouldn't wish this life on anyone, but I must reassure you, you're not alone. And as simple as it sounds, everything will be OK. I was diagnosed with MS seven years ago. One day, I woke up and couldn't feel my legs or walk. I went to the emergency room, convincing myself it was an infection and some antibiotics would fix it. I'd be back to "me" in just a few days.

An MRI from that day showed multiple lesions on my brain, neck, and spine. I was diagnosed with MS that night.

I was given a round of high-dose steroids for five days and then discharged with orders to move back in with my parents to heal. I packed a bag and went from DC to Pittsburgh for a few weeks. I told my boss I'd be back and left a list of how-to's with a co-worker.

I never returned. It sounds dramatic, but it's the truth.

I spent eight weeks in inpatient rehab where I learned how to eat with weighted utensils, learned a new way of talking that didn't sound like me, and relearned how to walk with arm crutches.

It was the most terrifying experience of my life. But looking back, that's not all that I remember.

MS is life-changing. If you've been diagnosed with MS, you have two choices: You can become victimized by it or you can become a warrior through it.

A warrior is a brave fighter. Living an adapted life in a world that isn't that adaptive-friendly is brave. It's brave to get up every day and fight against your own body with a condition that has no cure. You might not feel it now, but you're a warrior.

Since that first summer, I've experienced a road of ups and downs. I'd go through many more life-altering symptoms. I spent a full year in a wheelchair before relearning to walk — again — with arm crutches. I'd compete in a marathon in a recumbent tricycle.

I'd keep on fighting. I'd keep on adapting. And I would keep on living limitlessly while limited.

Sometimes I don't like sharing my journey to the newly diagnosed because I don't want it to intimidate you. I don't want you to be scared of the possibilities, the what-if's, and the frustrations.

What I hope comes across instead is the theme of whatever happens, it'll be OK. You may temporarily lose your ability to see, but your other senses will grow. You may experience mobility issues, but you'll work with a physical therapist who'll help determine if you need an aid and get you moving again. You may even have troubles with your bladder, but it makes for some funny stories after the fact.

You're not alone. There's a large community of other people with MS just like you. While every case of MS is different, we also get it because we have it. There's a lot of comfort in that.

There's also a lot of hope in the disease management therapies available. While MS has no cure, there are drugs to help slow progression. You may have just started one or you may be chatting with your neurologist still about which one is best. Hopefully you're able to find one that helps.

Whatever you're feeling right now, feel it. Take your time to adjust. There's no right way to tackle this disease. You just have to find what works for you and your journey.

You will be OK.

You're a warrior, remember?

Full text: https://www.healthline.com/health/multiple-sclerosis/what-to-expect-ms#3

Carers Gateway

Developed specifically for carers, Carer Gateway helps carers access practical information and advice and connect with services in their local area. From July 2019, new digital services will be available on the Carer Gateway website including:

- digital counselling services to help carers manage daily challenges, reduce stress and strain, and plan for the future
- online peer support, connecting carers with other carers for knowledge and experience sharing, emotional support and mentoring
- online coaching resources with simple techniques and strategies for goal-setting and future planning
- educational resources to increase skills and knowledge of carers relating to specific caring situations, to build confidence and improve wellbeing.

These new online services have been designed and tested in consultation with carers and the sector.

Carer Gateway includes a website and phone service to assist carers to locate their nearest support services.

Carers can visit carergateway.gov.au or call the professional, Australian based team on 1800 422 737 Monday to Friday 8am – 6pm.

Carer Gateway provides information about services and support available for people who care for someone with disability, chronic illness, dementia, mental illness or who **are frail aged.**

'Please offer me a seat': Why people with invisible disabilities are making their own badges

By Chloe Sargeant

I commute on public transport every day. Public transport in my city is fine (save for the run-of-the-mill infrastructure woes), but I am reaching the stage where I wish I had ‘please, please give me your seat’ tattooed on my forehead.

I don’t blame people for not noticing; there’s nothing to notice. I have fibromyalgia, and to anyone else, I look like a healthy 20-something woman with boundless energy and her whole life ahead of her.

Fibromyalgia is an incurable illness affecting the central nervous system; it malfunctions and sends incorrect pain signals to my brain, so I experience severe pain all across my body 24 hours a day, 7 days a week. In addition, I get severe fatigue, headaches, memory loss, brain fog, nausea, and more.

Days where I don’t get a seat are regular, and if I’m having a ‘good day’ (pain present but at a low; fatigue not visibly dragging me down), standing for 45+ minutes zaps most of my limited supply of energy that I was hoping to save for my normal day at work. Standing up for my commute on a ‘bad day’, where most of my symptoms are flaring up, I feel like I’m going to faint from the pain or fatigue. I have fainted in public once, and it was beyond terrifying.

I have in the past asked for a seat. Some will begrudgingly stand, some politely say no, others laugh in my face, and some ask why they should. It’s a fair question considering I look healthy enough, but the energy it takes to explain this - what fibromyalgia is, why I look ‘normal’, why disability isn’t always visible, and why they should therefore stand for me - is enormous. It’s traumatising having to validate your illness and body and person like that to a stranger, so instead I end up avoiding that situation, and standing and making myself sick.

I believe that a possible resolution for this is public transport badges for invisible disabilities. These simple badges have been requested around the world for years, including in Australia.

Sound like a very good idea for many people with neurological conditions. What do you think?

__Full text at: https://www.sbs.com.au/topics/life/culture/article/2019/08/13/please-offer-me-seat-why-people-invisible-disabilities-are-making-their-own__

People with Multiple Sclerosis Victoria Inc

NOMINATION FORM 2019

I/We…………………………………………………………………………………

Being members of People with Multiple Sclerosis (Vic) Inc. hereby nominate

A member of the said Association, for Election as:

President: ……………………………………………………………………………………………

Vice President: ……………………………………………………………………………………

Secretary: ……………………………………………………………………………………………

Treasurer: ……………………………………………………………………………………………

Ordinary Committee Members

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(Five Positions to be elected)

Signature of Nominator……………………………………………………….

DATED / / 2019

Nominations must be in the hands of: -
The Secretary PwMS-V Inc., no later than 08/11/2019
Christopher Platford, PO BOX 1035 CRAIGIEBURN VIC 3064;

or

Email to Chris Platford: ***cplatfor@bigpond.net.au***

Acceptance of Nominee

I……….

Accept the nomination & all responsibilities of the said position.

Signed……………………………………………… Date / / 2019

People with MS Victoria Inc

Spring Seminar and 2019 Annual General Meeting

Monday 18th of November 2019 at 10.30 – 12.30

The Nerve Centre, 54 Railway Road, Blackburn

The Keynote speaker will be: Esis Tawfik

(Senior Manager, Support Services, MSL)

Who will speak about and answer questions on:

MS Connect, Social work, Nurses, Education and Peer support services.

The year that was and what exciting things lie ahead.

A brief AGM will precede the Seminar and will include reports on the work of PwMS over the past year and election of the committee for 2019-2020.

All are welcome

Come along to find out the exciting work the team at MSL have been involved in.

RSVP: **Chris Platford** email: ***cplatfor@bigpond.net.au***

[light refreshments will be served after the meeting]

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