



EXTENDED MS CONNECT HOURS STARTING 1 JULY



Following feedback from the MS Community we are extending the hours of MS Connect as a 6 month trial. One of our team members will now be available from 8am until 6pm, Monday to Friday to respond to your phone calls, emails, live chats. If the line is busy please leave a message and one of the team will get back to you, and we have a commitment to respond to you within one working day. The team is here to answer your questions, provide you with support and ensure that you get the right advice. We have recently welcomed three new members to our team. Emily, Jessie and Amanda.

Pictured: Emily, Jessie and Amanda

They join Jenni and Katie to complete our team. Jessie has a passion for empowering people living with a disability and has experience in providing self-advocacy, education and community access. Emily has vast experience over varying roles including supporting people to access My Aged Care services as well as being a trainer in delivering certificates in disability services and transitions education to adults with disabilities. Amanda has come from the NDIA where she worked as a planner and has previous experience with DHS.

SAVE THE DATE!

Canberra MS Symposium 2019

When: **Tuesday, October 29**
9:30am-3:30pm

Where: **The John Curtin School of Medical Research**

The 2019 Symposium will focus on personalised and integrated management of MS and we are happy to announce that we secured an international keynote speaker on that topic.

We would like to invite you to come along and hear what kind of research is being done around this important aspect in Canberra and beyond. Appropriate parking, food and drink will be provided. **More information to follow.**

On behalf of the organising committee, Professor Robyn Lucas and Dr Anne Bruestle.

do it for **MS**

Let us help YOU to raise funds for MS!

Community fundraising is easier than you think! If you're interested in taking the plunge and running your own MS fundraising activity, support is just a phone call or email away.

Get in touch with Erin on 03 9845-2825 or communityfundraising@ms.org.au and she'll help you every step of the way.

Funds raised help MS continue to provide life changing services to people living with multiple sclerosis! Visit www.doitforms.org.au to see the great fundraising options available.

Upcoming MS Nurse Visit to Canberra

MS Nurse Advisor Jane Bridgman will be visiting Canberra on Tuesday 20 August 2019. To book an appointment, please contact MS Connect™ Freecall 1800 042 138 or email msconnect@ms.org.au.



National Volunteer Week

On Thursday 23 May to mark National Volunteer Week, MS celebrated the ongoing contribution of its tireless volunteers with a function at Gloria McKerrow House, Deakin, ACT.

With the valuable support of volunteers, MS has been able to offer more important services to the community such as one on one client support, wellness days, family events, peer support, ambassador talks and countless fundraising events.

John Blewonski (CEO, MS Limited) presented Ian Pennell AM, with his service pin for 20 years as a volunteer with MS.

A hearty thank you to our wonderful volunteers who make all the difference in many lives, and to MS staff who helped organise this event.

MS Research Australia Update

Head of Research Dr Lisa Melton who has been with MSRA since 2011 has left to take on a role as Institute Manager UNSW Ageing Futures Institute and has been replaced by the current Deputy Head of Research Dr Julia Morahan.



Ever wondered about attending a MS Wellness Dinner?Here are a couple of reviews from members who attended the Wellness Dinner held in June.

It was the first time I've attended anything MS have put on and being about diet I was reluctant to attend so went with my closest friend/carer and with an open mind. There were about 50 people who attended the program held at Raiders in Belconnen, I was surprised at the friendliness of people there and especially at the table I was seated on. It was good to be face to face with MSers for the first time, it was interesting hearing what they had to say about symptoms and meds, it was comforting to know so many others all go through what I do, so I'm not alone.

The speaker (MS' own Nicola Graham) wasn't boring, in fact quite the opposite and diet was actually interesting in the way it was presented. I guess we all tend to think our diet is healthy, but let's face facts, we aren't really winning the MS war, we are surviving in it, so we need every bit of help we can get. I walked away with several pointers, things I need to change, one of them being sugar. I'm a confirmed sweet tooth to the max, but it needs to change, I need to change and see if there is benefit for me. I have nothing to lose and everything to gain. Would I attend another MS function? Just try and keep me away! I enjoyed the dinner, got some pointers from it, met other friendly people. Don't think about attending, book in and attend, you won't regret it. - JR Mitchell, Canberra

I went along to the MS Wellness Dinner. And wow, it hit the nail on the head with the 'wellness' header! I came away with so many hot tips for health from the guest speaker Nicola Graham from MS. There was a strong focus on healthy eating, and as a lover of food I appreciated this! There is so many delicious and exciting options out there!

I sat at a table of new faces and loved connecting with them. Absurdly, there were three of us sitting next to each other sharing the same surname - unrelated and unknown to each other before the night. As a result of meeting new people on the night, I'm now part of a new peer support group.

I'd never been to a Wellness Dinner before this one and was really glad I went along. If you've not been, I recommend trying the next one - it really was a great night. - Jacqui Bradley

MYTH – My application to the NDIS was not successful, which means I can never access the NDIS
FACT – You have the right to a review if you have been rejected. Alternatively, you can also reapply for access three months after your rejection

MYTH – I am 64 now which means I cannot access the NDIS

FACT – If you are under 65, you can apply for access to the NDIS. Call the NDIS on 1800 800 110 to ask for an access request form

MYTH – I don't have many visible physical symptoms. The NDIS is not for me

FACT – Eligibility is not limited to people with mobility issues. The NDIS want to know about the functional impact of your condition. This can include things like fatigue, heat sensitivity, brain fog, cognition changes, incontinence, numbness and any other of your MS symptoms that impact on your day to day life

MYTH – The NDIS will leave me out of pocket

FACT – The NDIS is fully funded by the federal government, meaning anything they deem reasonable and necessary can be covered in your NDIS plan

If you have an NDIS plan that has Support Coordination in it, did you know this is a service we can provide for you? Your Support Coordinator assists you to connect to supports and services relevant to you as per your NDIS plan. We understand that deciphering your NDIS plan can be difficult.

If you have support coordination in your plan and need assistance, please call MS Connect on 1800 042 138 with your plan and your NDIS number.

Power Wheelchairs - Invacare TDX & Jazzy 600



MSL has kindly been donated two Powerchairs - an Invacare TDX and Jazzy 600 by some of our members who are keen to see them be used by someone who needs them.

There is no charge associated with the chairs, but if you are interested in having a chair, you would need to organize an OT assessment to make sure it suits your needs.

The wheelchairs are at Gloria McKerrow House and if you would like further information or to inspect the Chairs, call Heather on 02 6234 7000.



We have had an assessments completed on the chairs which outline the servicing that is required prior to use and can provide that for your information.

MS Limited takes no responsibility for delivering the chair or making any repairs.

Generic Drug for Teriflunomide (Aubagio)

A generic version of Aubagio (teriflunomide) has come onto the market from 1 June 2019 and is covered by the PBS. It is called "Teriflunomide Sandoz" and may be offered to you when you next attend the pharmacy to collect your prescription for teriflunomide (Aubagio). You should make an informed choice about whether or not to accept the generic brand if offered to you at the time of dispensing.

People taking the original brand Aubagio (teriflunomide) can access Sanofi Genzyme's "MS one to One" patient support program and blood test service, those who choose the generic cannot. In the case of Aubagio and Teriflunomide Sandoz, both the packaging and the tablets themselves will look different. MS Australia has produced a fact sheet which can be found at www.msaustralia.org.au/about-ms/medications-treatments



National Gallery of Australia Assisted Tour Monet: Impression Sunrise

For people with a disability and their care partners.

Thursday 25 July 2019 9.30 am to 10.30 am

Bookings via email: access@nga.gov.au or phone: 02 6240 6519



Webinars For July

Working with Multiple Sclerosis

Tuesday 9 July - 7.00 pm - 8.00 pm

Sleep Well with Multiple Sclerosis

Wednesday 17 July - 11.00 am - 12.00 pm

Managing Fatigue in Multiple Sclerosis (Management Strategies)

Wednesday 7 August - 3.00 pm - 4.00 pm

Mindfulness by Webinar focusing on pain

(8 Weeks) Mondays 14 October to 2 December 1.00 pm - 2.00 pm

NDIS Information Sessions

Various Webinars and workshops

To register your interest, please contact MS Connect™ Freecall 1800 042 138 or email msconnect@ms.org.au.



Wednesday Evening Dru Yoga

Term 3 will commence on 24 July continuing through to 25 September for a total of 10 classes.

The term rate is \$200 or \$25 per class for casual attendance.

Wednesday evening Therapeutic Dru yoga classes (5:45 pm - 7:15 pm)

For further information please contact Karen Ivkovic on 0409662832 or email karen.ivkovic@gmail.com

Try your first class for free.

Mums with MS Telegroup: The power of connecting Mums with MS

In 2018 the MS Peer Support Program began a telegroup to connect Mums with MS. This has been very well received by mums with multiple sclerosis with up to 10 mums joining in on the phone once a month for an hour. Feedback from the program is that is the impact the program has made in reducing the isolation and fear often faced by Mums with MS. We are extremely grateful for the support Liz Bullock and Nikki Sampson the Peer Support Volunteers who facilitate this group have provided.

They have kindly offered their insights of the program:

Liz knows that No one knows better than a mum with MS what you might struggle with. It's a way to connect with those who understand you without having to worry about getting to an actual place first. So we can talk to mums in different cities, and different states from the comfort of our own surroundings"



If you are a Mum with MS and would like to share information and support with other Mums please call MS Connect on 1800 042 138 and ask to be connected.

We are always keen to add to our peer support team.

Ricochet Dance for All



**Belconnen Arts Centre,
118 Emu Bank, Belconnen
Fridays 12.00 pm – 1.00 pm**

**Amala Uniting Care,
200 Woodcock Drive, Gordon
Wednesdays 9.45 am – 10.45 am**

Ricochet is the focus of a weekly dance class held in north and south Canberra, designed for adults with physical challenges, who want to keep their body and brain active and healthy, regardless of mobility, skill or age. Please come and feed your body with music and movement, be physically and mentally stimulated, have fun, meet some new friends and feel good! People who experience Multiple Sclerosis, Chronic Pain, Chronic Fatigue, RSI, Arthritis or other various physical challenges, are especially welcome to attend, with carers if required.

No previous experience is necessary, and everyone - with and without walkers and wheel chairs, family members, friends - are all welcome to participate. Please note this is not a social dance class, and it does not require you to come with a partner.

Costs \$5/person, per class Pay on the day. Companion Card holders receive free admission.

More info Wear clothes comfortable to move in, wear light shoes, and bring a bottle of water.

Enquiries Creative Program Officer, Philip Piggini, email or (02) 6173 3300.

A daily cup of Cocoa to fight fatigue

"Daily cup of Flavonoid-rich Cocoa may help ease MS Fatigue" this was a trial published in the Journal of Neurology, Neurosurgery and Psychiatry, "A randomised double-blind placebo – controlled trial of flavonoid-rich cocoa for fatigue in people with relapsing-remitting multiple sclerosis.



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Six "Elephant feet bed raisers"

Mary has been gifted six 'elephant feet bed raisers' to pass on to anyone in the MS community who could use them.

They are designed to go under the legs of your bed, lounge chair, couch or table to increase the overall height, allowing you to ensure the height of your furniture is right for your needs. Please contact Mary on 0412 190 123 or denmar@netspeed.com.au if you're interested.



Peer Support and Self Help Groups

Please find below the ACT Peer Support and Self-Help Groups currently meeting in and around the ACT. Telegroups, that run over the phone are also listed. To register your interest, please contact MS Connect™ Freecall 1800 042 138 or email msconnect@ms.org.au.

MS Peer Support Groups

Young People Living With MS (under 35s)

Bi-monthly, first Saturday of the month.

People with MS Support Group, Deakin

Last Friday of Every Month, except December

Batemans Bay - Eurobodalla MS Peer Support Group

1st Thurs of month, 11.30am–1.30pm

Cooma/Berridale Peer Support Group

1st Wednesday of each month, time and venue varies



Self Help Groups

The MS Side Steppers Walking Group, Canberra (Please note - updated meeting place)

Weekly, every Wednesday Morning, 10 am at Carpark in Bowen Park on Bowen Drive, Kingston ACT

HSCT for MS Support Group, Deakin

1st Friday of each month, 5.30pm-7pm

MS Café Group

3rd Friday of each month, 10.30 am

Taking Control of MS Group, Deakin

2nd Saturday of each month, 2pm–4pm

Art Group, Deakin

Weekly, Every Second Friday Afternoon, 12.30pm – 2.30pm

Mindfulness Practice Meeting, Deakin

Monthly, Last Friday of Each Month, 10.30am – 12pm.



MS Peer Support Telegroups

Current Telegroups:

- **Men's support group** First Thursday of the month – 1.30pm to 2.30pm
- **Women's support group** Fourth Monday of the month – 12.30pm to 1.30pm
- **Women in 40 to 64 group** Third Tuesday of the month – 10am to 11am
- **Over 65's group** First Tuesday of the month – 10.30am – 11.30am
- **After hours group for working people** Second Wednesday night of the month – 7.00pm to 8.00pm
- **Family and friends telegroup** First Tuesday of the month – 7.30pm to 8.30pm
- **General support groups** First Monday of the month – 11am to 12pm Second Monday of the month – 7pm to 8pm Second Tuesday of the month – 7pm to 8pm
- **Mums with MS support group** Second Tuesday of the month – 1pm to 2pm
- **Greek Speaking Telegroups for People living with multiple sclerosis** Fourth Monday of the month – 11am to 12pm. Telegroup start date to be advised, please register interest with MS Connect.