



Canberra Region Newsletter

MS Nurse Advisor Visit - 25 - 27 February 2020



Jane will be in Canberra on **25-27 February 2020** for the **MS Nurse Advisor @ Deakin** face to face clinic. If you would like to book an appointment to see Jane on one of these days, please call **MS Connect on 1800 042 138**.

If you are unable to attend a face to face clinic, remember the MS Nurse Advisor service is available Monday to Friday - 9am to 5pm for anyone who may have queries about multiple sclerosis, symptoms, medications and general wellbeing. MS Nurse Advisor appointments are available over the phone, or via Skype or Facetime.

ACT Wellness Dinner Wednesday, 26 February 2020 6.30pm to 8.30pm

Please arrive at 6.00pm to check in

We invite you to attend our dinner with MS Nurse Advisor Jane Bridgman who will help you explore ways to live a healthy lifestyle and she'll also challenge you to make positive lifestyle choices to maximise health and wellness. Jane is an internationally certified MS Nurse and works as an MS Nurse Advisor with the MS Advisor Program.

Enjoy a wonderful 2-course dinner whilst hearing about wellness approaches and strategies. You will go home inspired to maintain a brain healthy lifestyle.

CO-CONTRIBUTION: \$10 per person You are welcome to bring one guest. Bursaries are available for those who find the cost prohibitive by contacting education@ms.org.au. Please note: As catering must be confirmed within 7 days of the program, we are unable to offer refunds outside of that time period (except in extenuating circumstances - please contact us if this applies education@ms.org.au).

VENUE: Gungahlin Lakes Golf & Community Club, 110 Gundaroo Drive, Nicholls ACT (*Venue is wheelchair friendly and parking is available onsite*)

REGISTRATION DETAILS: MS Connect 1800 042 138 or email education@ms.org.au or click here to book online: <https://www.trybooking.com/BHRR>

REGISTRATIONS CLOSE: Wednesday, 19 February 2020. Places are limited and a waitlist will be taken.

Get moving in Canberra at the 2020 MS Walk Run + Roll 29 March 2020

We are very excited to bring you the latest and greatest in the Fun Run experience, join us at the 2020 Canberra MS Walk Run + Roll!

The Canberra MS Walk Run + Roll, formerly known as the MS Walk + Fun Run has been rebranded to celebrate the diversity of our fantastic participants.

This year, the course is more friendly on feet and wheels, so we encourage people of every speed and style to participate, with 5km, 10km and 14.4km course options.

Join us on Sunday 29 March and help raise awareness and vital funds to support people living with Multiple Sclerosis.

Register now at mswalk.org.au – save up to 21% with the launch special, offer ends 12 February 2020.



MS EDUCATION

Webinars, Wellness and other Education Events



Fatigue Management in Multiple Sclerosis—General Overview

Tuesday 11 February—10:00am to 10:30am

Presented by MS Employment Consultant, Jacqueline Efthimiou, this webinar will help explain the experience of fatigue for people living with multiple sclerosis as well as provide some strategies managing fatigue.

Pilates by Webinar

Tuesdays 11 February to 17 March—3:00pm to 3:45pm

A six week program presented by Ella Wong, Director of Pilates Tasmania who has been practicing Pilates since 2004. Ella teaches Pilates to a range of people with various conditions, including multiple sclerosis and understands the limitations faced by those living with the condition and has tailored this program to ensure it is available to all, by either chair position or standing position.

Please email education@ms.org.au or for enquiries call Annie Sassin on 03 9845 2728

REGISTRATIONS CLOSE Tuesday 4 February 2020

Working with multiple sclerosis

Thursday 13 February—6:00pm to 7:00pm

Are you aware of your rights and responsibilities and your employer's obligations in your workplace? Led by MS Employment Consultants, Shannon Moyle and Harshi Franciscus, this program will include strategies for symptom management in the workplace, discussions about disclosure of multiple sclerosis at work, superannuation and insurance considerations and who to contact regarding work issues.

Preparing for your Neurologist Appointment

Tuesday 18 February—10:00am to 10:30am

Your appointments with your neurologist may be few and far between, and you may not have very long to ask a lot of questions. Join MS Nurse Advisor, Jane Bridgman as she provides an overview on how to prepare for your neurologist appointment. Jane will also provide some tips and tricks on how to get the most from your appointment.

FACETS by webinar - A Fatigue Management Program (6 classes)

Wednesdays, 19 February to 25 March 6.00pm to 7.30pm (8.00pm finish for first class)

FACETS (Fatigue: Applying Cognitive behavioural and Energy Effectiveness Techniques to LifeStyle) is an evidence-based group program for people living with multiple sclerosis to support self-management of fatigue.

The program was developed in the United Kingdom by researchers from Bournemouth University and clinical staff from Poole Hospital.

The FACETS program incorporates 'energy effectiveness' techniques and ways of working that maximise the energy people have – alongside cognitive behavioural strategies, helping participants learn helpful ways of thinking about fatigue.

CONTACT DETAILS: FACETS Team: facets@ms.org.au or msconnect@ms.org.au

The cost of the 6-week program, including workbook and all resources is \$80 per person. Participants are encouraged to have a family member or friend alongside them for the first session.*

**You may be eligible to access NDIS funding for this program. Speak with your Local Area Coordinator or your Support Coordinator.*

Opportunity to participate in research into healthcare for people living with multiple sclerosis

Researchers at the Australian National University (ANU) are investigating the healthcare experiences of people living MS, as well as their healthcare providers. Through one-on-one interviews, researchers will examine healthcare for people living with MS from multiple perspectives. The findings from this study may identify the areas in healthcare for people living with MS that are working well or could be changed'

What does participation involve?

Participants must be 18 years or over with a confirmed diagnosis of MS, or are MS healthcare professionals (including neurologists, GP's and MS nurses). Once you provide consent, people living with MS will be asked to conduct a 10 minute online questionnaire prior to the interview to provide background information. All participants will take part in a single one-on-one interview which may take up 40 minutes at ANU, over the phone or via skype. Participants will be asked about experiences of MS healthcare across different appointment types.

To find our more, please contact Eluned Price on 6125 1485 or email eluned.price@anu.edu.au



Many people with MS still experience ongoing difficulty accessing specialist MS Clinics which are typically concentrated in major cities and metropolitan areas, and their communication with neurologists is usually limited to once or twice a year, meaning that most of the time they may feel alone in dealing with the impacts of MS on daily life.

Treatment for those living with MS has however, advanced significantly over the years, with 12 disease modifying therapies now available on the PBS, advances in formal funding via the rollout of the NDIS and an abundance of information available on the internet.

These advances have also seen the need for those living with MS to be more self-reliant when it comes to reaping the benefits of all that is on offer.

This need of course, requires significant life administration and effort on the part of the patient, as evidenced in journal articles which state that patients are now seen as "engager" rather than "receiver," with the role of the healthcare professional changing from "provider" to "supporter."*

Whilst numerous studies (such as the *International Brain Health: Time Matters* initiative, authored by several specialists including Prof Gavin Giovannoni and Prof Helmut Butzkueven), have shown that, for a person living with MS, engagement in their own healthcare is actually beneficial, studies have also shown that telephone support and help lines can decrease social isolation, improve self-efficacy and satisfaction, increase decision-making confidence and may also decrease hospitalisations for some patient groups.

Simply picking up the phone and calling someone can also contribute to higher health status and quality of life, making it easier to discuss difficult topics such as bladder/bowel changes, sexual difficulties and cognitive changes.

In response to this changing landscape, our own MS Nurse Advisor Service is a phone and internet-based service designed to provide equal access for everyone to information, advice, support and referral from MS specialised nurses.

Making a call to our MS Nurse Advisor service can really help. We have a vast range of benefits to offer over the short and long term, so please feel confident in contacting MS to request to speak with one of our MS Nurse Advisors.

The service is available 5 days a week, with all enquiries welcome. Whether it's a quick question or a long chat, we're here for you.

Give us a call on 1800 042 138 today. Should you wish to read the full scientific article, it can be accessed via <https://doi.org/10.1016/j.msard.2015.02.005>



MATISSE PICASSO

All abilities Tour

A free tour of the Exhibition for people with a disability and their carers.

Wednesday 19 February
10.30 am to 11.30 am

The National Gallery has wheelchairs, walkers and mobility scooters available for use. If you have a mobility parking permit, take a photo of it on your phone and you get free parking. This applies at any visit to the NGA.

Peer Support & 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, Gloria McKerrow House, Deakin** Last Friday of Every Month (except December), 12.30 pm to approx. 2.00 pm
- **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

- **HSCT for MS Support Group, Deakin** 1st Monday of each month, 5.30pm-7pm
- **Taking Control of MS Group, Deakin** 2nd Saturday of each month, 2pm – 4pm
- **Art Group, Deakin**, 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

- **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.