

# AMSLS NEWS



## Australian MS Longitudinal Study (AMSLS)

October 2020

With the country barely breathing after the devastating summer bushfires, before being plunged into the challenges of a global pandemic, there wouldn't be many Australians who haven't faced significant challenges in 2020. Somehow, our AMSLS family has continued to contribute to MS research, despite the chaos. Thank you to each and every one of you, as we share the AMSLS highlights of 2020, and plans for 2021 and beyond.

### The challenges of MS and physical activity

In recent years, there has been increasing focus on non-pharmacological interventions to improve the quality of life for those with MS. Physical activity has long been recognised to assist with depression, cognition, mobility, fatigue and overall quality of life. Exercise training may also be associated with a slower rate of disability progression. To understand how much physical activity Australians with MS are getting, Dr Claudia Marck, Dr Yvonne Learmonth and the AMSLS team used data from the 2016 *Lifestyle and Environment Survey* to investigate physical activity and exercise. The researchers then looked at any links between these two factors, and personal characteristics such as age, gender and features of MS.

Encouragingly, 71.5% of participants with mild or no disability participated in moderate to high levels of physical activity on a weekly basis in line with the general Australian population. The level of physical activity dropped to 46.8% for those with moderate disability, and reduced further to 19.6% for higher disability.

In terms of exercise, almost 80% of people who answered the AMSLS survey did aerobic exercise (e.g. brisk walking, bicycling), while strength, balance and flexibility exercise was far less common. Only 16.4% performed the amount and type of exercise recommended for people with mild to moderate MS. The recommendations are: 2–3 days per week of moderate aerobic exercise (10–30 minutes per session), as well as 2–3 days per week of strength exercises for the whole body (e.g. 1–3 sets of 5–10 strength exercises, 8–15 repetitions).

This study also indicated factors associated with decreased physical activity include progressive onset MS, more severe cognitive impairment, depression, mobility impairment, fatigue and being male. Walking and balance difficulties were also associated with higher sitting times, followed by bowel and bladder problems.

To support those with MS, increased education and information for healthcare professionals may be required and the monitoring of physical activity is useful. A qualified physiotherapist, occupational therapist or exercise physiologist will be able to provide a suitable and individualised physical activity plan, taking into account individual symptom management.

Do you know someone with MS who is not part of the AMSLS family?

We are always accepting new participants – the more voices we have, the louder we can shout.

To join, download the information sheet and consent forms from:

[www.MSRA.org.au/AMSLS](http://www.MSRA.org.au/AMSLS)

Need to contact us?

[AMSLS.info@utas.edu.au](mailto:AMSLS.info@utas.edu.au)

(03) 6226 4739

We're always happy to hear from you!



## An overdue thank you to our incredible AMSLS volunteers



In an increasingly digital world, the AMSLS knows there are many people who still prefer, or in fact need, old-fashioned pen and paper to complete surveys.

What many may not realise is that much of the hard work involved in supporting the administration and data entry of our paper surveys is done by a small group of AMSLS volunteers.

When the University of Tasmania joined the rest of Australia with 'work from home' orders in mid-March, supporting our physical surveys and forms suddenly became very challenging. When restrictions started to lift, necessary updates to the way we work introduced significant numbers of new protocols, training and forms before being allowed to return to campus. It would have been more than understandable for someone donating their time to throw their hands in the air and declare the 'new world' too hard to navigate for no personal gain.

However, our wonderful volunteers have not only jumped every hurdle with a smile on their faces, but they have allowed the AMSLS administration to continue with barely a hiccup.

We would not be in a position to support the paper surveys without them. Carol Ingram, Ian Mace, Maree Richards and Mara O'Dea – we whole heartedly thank you for your unwavering and selfless dedication!



## Further research on other medical conditions in people with MS

Previously, PhD student Lara Lo examined the changes in the frequency of occurrence of other medical conditions (comorbidities) in people with MS. The data from the 2016 *Lifestyle and Environment Survey* showed that compared with the time of MS symptom onset, substantial increases in the frequency of depression, anxiety, hypertension, osteoarthritis, high cholesterol, eye diseases, osteoporosis and cancer were seen. In addition, compared with the general public, people with MS were more likely to have anaemia, cancer, anxiety, depression, migraine, psoriasis and epilepsy. Combining this information, the accumulation of other medical conditions seems to be beyond normal aging and may be due to changes in lifestyle behaviours, shared risk factors with MS and possibly side effects of treatments.

Further investigation was focused on the impacts of comorbidities on the health-related quality of life (HRQoL) and severity of common symptoms in MS. A higher total number of comorbidities was associated with a lower HRQoL and higher severity of symptoms. Importantly, mental health and musculoskeletal disorders were by far the largest contributors to the HRQoL and severity of symptoms in people with MS, and should, therefore, be targeted for early detection, prevention and optimal treatment.

Lara assisted with the development of recommendations for health professionals and people with MS (see *Adapting Your Lifestyle: A Guide for People with MS* from MS Research Australia). She

recommends that people with MS be informed about the risks and potential impacts of other medical conditions and live a healthy lifestyle in order to prevent the development of other conditions. She also suggests being proactive about self-monitoring and raising any new symptoms with the care team so that they can be optimally managed.

## Effects of natalizumab on patient-reported MS outcomes

In collaboration with Associate Professor Tomas Kalincik and Dr Ibrahima Diouf from the University of Melbourne, Jing Chen and Ingrid van der Mei developed a report where natalizumab (most commonly sold as Tysabri) was compared with other disease-modifying therapies (DMTs) with respect to changes in employment outcomes, MS symptom severity, quality of life, disability and self-assessed progression in the previous 12 months.

Compared with other DMTs, the use of natalizumab was associated with superior effects over two years in improving a number of MS symptoms (e.g. improving balance, vision symptoms, sensory symptoms, and feelings of anxiety) and reducing work productivity loss due to time absent from work. No differences were observed for quality of life or disability. These findings are useful for clinical practice in terms of treatment selection.

All AMSLS publications can be found on the MS Research Australia website:

<https://msra.org.au/australian-ms-longitudinal-study/publications/>

## Employment and MS

**Longitudinal trends in work productivity of Australians living with MS** – PhD student Barnabas Bessing looked at the longitudinal patterns between 2015 and 2019 of work productivity and the factors associated with annual change in work productivity for people with MS.

He identified three distinct groups: a group with a very high mean work productivity of 99.7% (36.3% of participants), a group with a 'mildly worsened' work productivity (mean of 86.3%; 46.7% of participants) and a group with a 'moderately worsened' productivity (mean of 47.6%, 17.0% of participants).

While there was individual fluctuation from year to year, at the group level the work productivity remained very stable over four years.

When examining what predicted annual change in work productivity, it was found that it is not the actual severity of symptoms, but the changes in symptom severity that are associated with a change to work productivity.

These findings specifically suggest that the prevention of worsening or fluctuation of symptom severity may benefit employment outcomes in people with MS.

**Changes in the risk of leaving employment due to MS over the past decades in Australia** – Using AMSLS employment data, Jing Chen assessed factors affecting leaving employment due to MS and whether the risk of leaving employment has changed over recent decades in Australia since the introduction of disease-modifying therapies (DMTs). Her work found that males, people

lower education level and people who had an older age at diagnosis were more likely to leave their employment due to MS. This suggests that providing tailored health information and guidance are likely to improve the efficacy of health interventions to help these people stay in work longer.

In terms of changes in employment retention, the AMSLS data showed that the risk of leaving employment due to MS was increasingly reduced since 2010 in people with relapsing–remitting MS (RRMS) while this pattern was not seen for people with PPMS or SPMS. This coincides with the increased usage of higher efficacy DMTs for RRMS in Australia.

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## The impact of symptoms on quality of life

With everyone experiencing MS differently, PhD student Yan Zhang examined which of the 13 common MS symptoms have the biggest influence on overall quality of life. By identifying these symptoms, health professionals can prioritise treatments that will have the largest impact on quality of life.

While fatigue and feelings of anxiety had significant impacts, it was feelings of depression, pain and walking difficulties that were the strongest predictors of decreased quality of life, regardless of MS type.

Targeting depression and pain together in treatments has been found in previous studies to be more effective than treating either symptom alone. Treatments shown to be effective in both pain and depression in those with MS include tricyclic antidepressants, mindfulness-based medication and telephone-delivered self-management intervention.

## Adapting Your Lifestyle A Guide for People with MS

There are many lifestyle choices that can influence MS disease progression and disability, such as diet, exercise, gut health and supplementation. However historically, it has been hard to find a single source of reliable, evidence-based information.

MS Research Australia has worked closely with clinicians, researchers, allied health professionals and people affected by MS to bring you the best practical guide to everyday choices to help minimise the impact of MS on your life.

Receive your free copy at:

[msra.org.au/news/australian-lifestyle-guide-for-ms](https://msra.org.au/news/australian-lifestyle-guide-for-ms)

## Impact of remoteness on the health outcomes of people with MS in Australia

It is often thought inequity in the availability and quality of health care may exist across geographical locations, but little is known about whether living in remote areas is associated with worse health outcomes in Australians with MS.

PhD student Jing Chen's work thankfully revealed that living in more remote areas of Australia was not associated with substantially worse health or employment outcomes, or higher MS costs.

There was a consistent pattern of those living in inner regional areas having slightly worse health outcomes and higher costs, but the effects were relatively small compared with those living in major cities. The finding suggests that there is not a large inequity in the Australian MS population as a result of remoteness.

## Understanding Multiple Sclerosis free online course

The *Understanding Multiple Sclerosis* online course continues to gain popularity, providing understanding and awareness to anyone touched by MS. Enrol now for the next free course, starting in March 2021:

[ms.mooc.utas.edu.au](https://ms.mooc.utas.edu.au)

## AMSLS focus for 2021

Topic	Details	Supporting Survey(s)
<b>Pain</b>	The MS Research Australia Priorities Survey identified pain as a priority for research. A workshop was held in 2019. In 2020, the AMSLS will analyse existing pain data and develop a pain survey to address gaps in knowledge.	<i>2021 Pain Survey</i>
<b>Sleep</b> – in collaboration with Dr Cynthia Honan (University of Tasmania)	Sleep is essential to our functioning, but MS can adversely impact sleep. We will quantify how many people have issues with sleep, examine factors that might influence sleep, and assess how sleep has an impact, e.g. on quality of life and daily functioning.	<i>2020 MS Nurses and Sleep Survey</i>
<b>MS Nurses</b> – in collaboration with MS Australia and MS Nurses Belinda Bardsley and Sue Shapland	To gain insight into the availability and value of MS Nurses, we will map the accessibility by people to an MS Nurse and examine how an MS Nurse influences the health care of people with MS.	<i>2020 MS Nurses and Sleep Survey</i>
<b>Quality of life instrument</b> – led by Dr Julie Campbell, Menzies Institute	Decisions on government funding for many treatments are supported by quality of life instruments. This work will assess the best type of quality of life questionnaire to use for making informed healthcare decisions.	<i>2020 Quality of Life Survey</i>
<b>Crisis resilience</b> – in collaboration with Dr Yvonne Learmonth, Murdoch University, and Dr Claudia Marck, University of Melbourne	This work will examine the impact of COVID-19 on health behaviours and medical care and how to minimise that the impact of a crisis.	<i>2020 Lifestyle and Environment Survey</i>

## General AMSLS updates

**AMSLS staff updates** – A big congratulations to **Yan Zhang** and **Jing Chen** who successfully obtained their PhD title and have taken up research positions in China. We also said farewell to **Lara Lo**, who has just submitted her PhD thesis and made a much-anticipated journey to the US to join her fiancé. They have all made a significant contribution to the AMSLS in their time at Menzies and will be missed.

In other significant news, the dedication, hard work and vision of our AMSLS Managing Director has been recently recognised with a well-deserved promotion. Congratulations to Professor Ingrid van der Mei!



**2020 survey updates** – 2020 was expected to be a busy year for the AMSLS, with scheduling of the *Sleep and Nurses Survey* from March to April, the *Quality of Life Survey* from June to July, and the regular *Disease Course* and *Lifestyle and Environment* tracking surveys from October to November.

When the COVID-19 virus was officially declared a pandemic, it rapidly became clear people with MS were very concerned about how their MS, and MS related treatments, may impact not only their susceptibility to contracting coronavirus, but whether it may also affect the outcome should infection occur.

The AMSLS was fortunate to be in a position to help answer these questions, and joined a global collaboration headed by the **MS Data Alliance** and the **MS International Federation**.

The support for the alliance was staggering, with 75% of our online participants helping out. Together

with other people with MS, and their neurologists, the alliance was able to provide rapid answers and advice, with details available on the MS International Federation's website ([www.msif.org](http://www.msif.org)).

Even more amazing than the response to the *COVID-19 and MS Survey* has been the ongoing support for our planned surveys. With a continued response rate in excess of 65%, despite the workload and the year that it has been, we are grateful for such a dedicated and generous AMSLS family. In return, the 2020 surveys have included several in-depth topics that will provide vital data in how we can better support those with MS, including sleep, access to healthcare services, and support in times of crisis.

Menzies is also investigating the potential of setting up a longitudinal study focusing on the needs of partners, carers and other support people of people with MS. Stay tuned!

For now, we hope you have managed to survive 2020 relatively intact and wish you all a far more boring 2021.

**The AMSLS team thanks you for your ongoing support. Together we can make a difference.**