

# AMSLS NEWS



## Australian MS Longitudinal Study (AMSLS)

October 2022

2022 brought another busy year for everyone involved with the AMSLS: our dedicated participants completed their regular surveys, along with specialised surveys on sleep and the impact of MS on their concept of self; MS Australia launched the MS Nurses report, highlighting the invaluable contribution of our MS Nurses; research continued in several key areas including employment, pain, and the impact of lifestyle; and several AMSLS-aligned projects took big steps towards their launch. We hope you enjoy reading more detail on the highlights of the AMSLS year!

### More results from the AMSLS Quality of Life Survey

Dr Julie Campbell recently led the first large-scale qualitative study that investigated the lived experience of the COVID-19 pandemic for people with MS. This involved analysis of responses to the free-text question "Would you like to provide any other information on your physical and emotional circumstances regarding the COVID-19 pandemic?" from the *2020 Quality of Life Survey*. One key finding was that if people were required to 'multitask' when working from home and caring for others during lockdowns, this substantially impacted on their quality of life. However, for some of those who did not need to multitask, working from home proved beneficial in managing fatigue levels.

For all levels of disability, not being able to see family and friends during the lockdowns had a substantial impact on well-being, and social isolation was particularly challenging for people with more severe disability. These results call for further research into working from home for people living with MS, increased resourcing for childcare and for interventions to reduce social isolation for people living with MS during future similar crises. A paper based on this study was presented at the recent ECTRIMS conference and will be submitted for publication soon.

The data from the *2020 Quality of Life Survey* has also led to a collaboration between AMSLS researcher Mr Glen Henson and Associate Professor Gang Chen from Monash University. With general population quality-of-life data collected by Monash University around the same time as the AMSLS *Quality of Life Survey*, the researchers were able to use the new EQ-5D-5L-Psychosocial instrument to compare the quality of life for people living with MS and the general population. Analysis showed that people living with MS were more impacted by the COVID-19 pandemic than the general population, including people with chronic diseases in the general population. This paper was recently presented at a seminar at the Centre for Health Economics at Monash University and will soon be submitted for publication.



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

We are always accepting new participants. To join, download the information sheet and consent forms from:

[www.msaustralia.org.au/AMSLS](http://www.msaustralia.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!

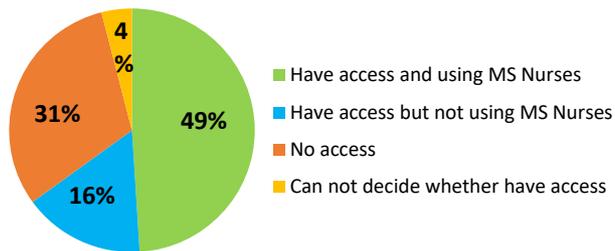
UNIVERSITY of TASMANIA

**MENZIES**

Institute for Medical Research

## MS Nurses – important contributors to long-term health for those with MS

Changes in traditional funding models have led to a reduction in the number of MS Nurses available in Australia. The *2020 MS Nurses Survey* aimed to examine how the MS Nurses are currently influencing the care of people with MS, and whether those who want the support of an MS Nurse are able to access them.



For the 49% of participants who actively access an MS Nurse, 78% reported that having an MS Nurse was helpful, with the most frequently reported beneficial services including advice on the management of MS symptoms (54%), advice on the management of treatment side effects (49%), providing education and information to assist with informed treatment decisions (47%) and providing education to assist with the use and monitoring of disease modifying therapies (42%).

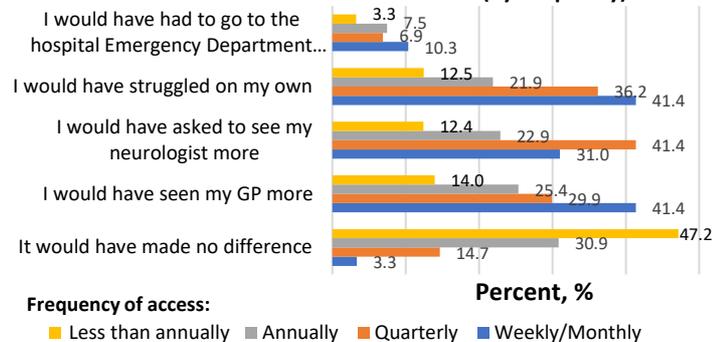
Interestingly, those who had access to an MS Nurse had consistently better health outcomes, including lower severity of symptoms, higher health-related quality of life and higher work productivity.

As many as 45% had utilised MS Nurse care for more than 10 years, indicating that MS Nurses play a long-term role that is viewed as beneficial. In addition, those who utilised an MS Nurse more frequently were more likely to report that they otherwise would have had to see a GP, neurologist, go to the hospital or

emergency department, or would have struggled on their own. Even with conservative estimates on relative costs, MS Nurses prove to be a highly cost-effective model of care.

Unfortunately, however, 31% of respondents did not currently have access to an MS Nurse, even though more than a quarter of those would like to see one. The lack of access to an MS Nurse was not strongly linked to the remoteness of where someone lives.

### Perceived effect on care if access to an MS Nurse was not available for those who do use an MS Nurse (by frequency)



The official MS Nurses report was launched at the Progress in MS Research conference in April 2022, with important recommendations around raising awareness of the existence and value of MS Nurses, increasing the use of telehealth, and increasing the number and support of MS Nurses in the workforce. There is a strong case to be made that every Australian with MS should have the opportunity to access an MS Nurse as part of their ongoing care if they so choose, and MS Australia has assembled a working group to action the recommendations from the report.

## Sleep and MS

*“It’s really difficult to perform a whole day’s activities unless you sleep well ... Fatigue is the most difficult part of my MS ... I hate not having the energy to do things ...” – Carmel (NSW)*

In last year’s newsletter we reported that sleep difficulties are far more common among people with MS than in the general community. Poor sleep substantially affected quality of life, and for many people with MS, improving sleep could make a meaningful difference to their quality of life.

A recent investigation conducted by PhD student Jason Turner found that despite perceptions of a link between disease modifying therapies (DMTs) and poor sleep and, in turn, poor everyday functioning in people with MS, there is no objective evidence that the use of DMTs influences sleep quality. The results suggest that whatever the causes of poor sleep in people living with MS, the use of DMTs is not one of them.

We are now digging deeper into sleep patterns and will use the *2022 Sleep Survey* to look at how individual patterns may have changed over the two years since the previous survey, and what factors may be associated with improved or worsening sleep.

PhD student Baye Dagnev will also look into which other medical conditions on top of MS most greatly affect sleep, and which areas of quality of life are most impacted by disturbed sleep.

If you are one of the many who need help with sleep, the first step would be to ensure your sleep hygiene is maximised (<https://www.sleepfoundation.org/sleep-hygiene>), and the Understanding MS Massive Online Open Course (<https://ms.mooc.utas.edu.au>) now contains a section on sleep and MS, with enrolments now open for the next free course in March 2023.

Even with good sleep hygiene, those with MS may have many additional reasons for sleep difficulties, ranging from pain, trips to the toilet, and general fatigue. It is important to find the right GP who understands that poor sleep is common in people with MS, and the large impact that a lack of sleep can have on quality of life. Your GP should be able to tailor their advice to your particular circumstances, and be able to assess whether any reasons for poor sleep are treatable. Don’t be afraid to use the article on the MS Australia website to back up your request for help ([msaustralia.org.au](https://msaustralia.org.au)) and search for ‘sleep in MS’.

## Celebrating 20 years of the AMSLS

On 3 March 2002, the first AMSLS consent forms were signed, officially kicking off Dr Rex Simmons's vision of giving people a formal way to record the challenges of living with MS.

Twenty years of hard work later, and the AMSLS has become a pivotal platform for Australian MS researchers, medical teams and support services alike. We thank everyone involved over the years, and will continue to be there for those with MS as long as we are needed.

### Here for the duration – 50 surveys and counting

Since its inception in 2002, the AMSLS has seen over 5500 Australians share their MS story. Amazingly, 560 people who joined the study in its first year are still actively completing AMSLS surveys 20 years later, with 10 having completed every one of the 50 surveys to date.

When we asked three of our participants who had signed their consent forms in the first two days of the study why they had remained so dedicated to the study, each of their responses reflected the selfless nature of so many in the study:

- **Pam M:** "I felt privileged to help out in some small way if it would help in gaining a better understanding of MS."
- **Yolanda H:** "I was diagnosed five months after the birth of my son back in 1999. When I heard about the study, I thought that would be my little way of helping out wherever I could. I feel very lucky and blessed as 23 years on I am very healthy and no-one would even know that I have MS."



**Carol Cooke**  
AMSLS participant  
and Paralympian  
*(photo credit: Alison McWhirter)*

**Carol Cooke's** name may be familiar as an inspirational top-level athlete and fierce MS advocate. Her commitment to do everything she can to help those with MS remains strong, and it is unsurprising she was one of the first to enrol in the AMSLS.

"I joined the AMSLS to help progress continuing education and research into MS and its effects on an individual. I'm certainly not a scientist or researcher so if I could help in my own small way then I was going to by filling out the surveys.

I didn't realise that I had been taking part for so long but every time one of the surveys popped up in my email I tried to make sure I did it so that the researchers would have long term information on someone. It certainly doesn't take long, so I just figured, why not! It has made me realise how my MS has changed over the years. Sometimes for the worst and sometimes for the best. It has given me an insight into my own journey, physically and emotionally."

### The power of data in achieving change

One of the primary aims of the AMSLS is to identify and address the biggest challenges those with MS are facing everyday.

The most familiar achievement backed by AMSLS data was the inclusion of MS as an eligible condition for electricity medical cooling rebates around Australia. Even in Tasmania, long-term AMSLS contributor Beth Muller requires the use of her air-conditioner year-round: 'My sensitivity is severe,' she says; 'I'm going to the dentist today, and the outside temperature is 16°C. I'm taking my ice vest and a small personal fan.' Not one to just accept the inevitably large electricity bills, Beth was part of the Tasmania campaign that took the findings of the *Keeping Cool* survey to the government and ensured that Tasmanians with MS were not overlooked for the rebates.

Other support efforts have been evolving with the changing landscape of MS in Australia. In the last 20 years, advances in the effectiveness of disease modifying therapies have led to longer-term workforce retention for those with MS. Consequently, employment support efforts have been redirected to optimise that time in the workforce. The *MS WorkSmart* program is due to enter the pilot phase in early 2023 and will allow those who participate to customise a work plan based on their own unique set of circumstances. Backed by findings from the AMSLS, the program has practical information and tools to identify and optimise personal work patterns, along with advice on disclosure, overcoming barriers and effective communication of MS in the workplace.

While the above represent two more public instances of the AMSLS data at work, other battles continue in the background. Recent examples include the push to include psychological wellbeing in funding decisions for MS treatments, and the long-term health and economic benefits of the MS Nurses. Having irrefutable facts is essential in the success of advocacy, and we will continue to provide this essential role to fight for those with MS.



**Dr Rex Simmons**  
Founder of the AMSLS

### SMS notifications and updates to survey reminders

The AMSLS now offers SMS notifications for those who complete online surveys. In addition, we have removed all postal survey reminders, with survey reminders now sent by email, or by SMS (by election only).

If you would like to update your survey notification or survey reminder preferences, please contact us:

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

(03) 6226 4739

## AMSLS Focus for 2023

Topic	Details	Supporting Survey(s)
<b>Sleep</b> – in collaboration with Dr Cynthia Honan (University of Tasmania)	Analysis from the 2020 and 2022 <i>Sleep Surveys</i> continues into how sleep changes over time, and people's confidence in their ability to make changes to improve sleep.	<i>2022 Sleep Survey</i> <i>2020 Sleep Survey</i>
<b>Concept of self</b> – led by Dr Cynthia Honan and Holly Emery (University of Tasmania)	Analysis of the 2022 <i>Concept of Self Survey</i> will continue into how MS impacts on changes to self-concept and other factors that may contribute to this change, e.g. changes in level of social support and employment.	<i>2022 Concept of Self Survey</i>
<b>Pain</b> – led by Dr Julie Campbell, Menzies Institute	To further contextualise and expand on the 2021 <i>Pain Survey</i> results, we will be conducting and analysing the data from focus groups and individual interviews about people's experiences with pain.	<i>2021 Pain Survey</i>
<b>The COVID-19 pandemic</b> – led by Dr Julie Campbell, Menzies Institute	Work assessing the impact of the COVID-19 pandemic using the 2020 <i>Quality of Life Survey</i> continues with a new collaboration with A/Professor Gang Chen from Monash.	<i>2020 Quality of Life Survey</i>
<b>Economic Impact Study</b> – led by Professor Andrew Palmer, Menzies Institute	Previous economic health studies have been of immense value to demonstrate in dollar figures the impact that MS has on individuals and society. With the previous study run in 2016, it's time to update the picture of MS in Australia.	<i>2023 Economic Impact Baseline Survey, and 2023 Cost Diary</i>

### Thank you from us

We wish to thank everyone for their ongoing support after a busy few years with the AMSLS. 2023 is set to be another important year, with the return of the *Economic Impact* study – the study used to monitor the overall personal and societal impact of MS in Australia.

In addition, we have three AMSLS-aligned projects we hope those who receive an invitation are willing to participate in:

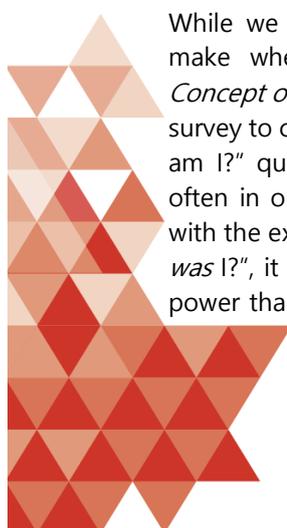
- **Pain focus groups** with Dr Julie Campbell (100 participants): November to December 2022
- **MS WorkSmart feasibility study** with Dr Alisée Huglo (40 participants), early 2023
- **MS Carergivers and People Providing Support (MS-CaPPS) pilot study** (100 AMSLS participants and their support network), early 2023.

#### 2022 Concept of Self Survey

*“Thank you for undertaking this research. I hope I am not alone in an improved self-concept since diagnosis but recognise this too has taken many years to reach.” – Kath (Vic)*

While we appreciate every effort our participants make when completing our surveys, the 2022 *Concept of Self Survey* has, by far, been our hardest survey to complete to date. The very personal “Who am I?” question is not one that we think of very often in our day to day lives, but when combined with the exponentially more difficult question “Who was I?”, it results in a survey that takes more brain power than any we have attempted in the past.

To all of you, a humble thank you. For those who tried, or wanted to help, but couldn't, please be assured we understand and knew not everyone would be able to or even want to complete this one.



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

### AMSLS Online

#### MS Australia Website

[msaustralia.org.au](https://msaustralia.org.au)

#### Recent AMSLS linked news articles:

- “Oh it's changed, it's changed 10-fold”: concept of self in MS
- Helping others by sharing the personal experience of MS
- Sleep in MS: more important than we thought
- The AMSLS: recognising twenty years of research into the lived experience of MS
- Landmark report on MS Nurse Care in Australia released

[msaustralia.org.au/AMSLS](https://msaustralia.org.au/AMSLS)

- All AMSLS scientific publications can be accessed from the ‘Publications’ tab.

#### Understanding Multiple Sclerosis Massive Online Open Course (MOOC)

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

- Enrolment is now open for the next course starting

**13 March 2023**

- Duration: 6 weeks; 2 hours per week

#### 2022 MS Research with Connections

Search in your browser for:

‘YouTube MS Research with Connections 2022’

AMSLS-aligned presentations include:

- The employment journey of people living with MS
- Self-concept and multiple sclerosis
- The impact of COVID-19 on people with multiple sclerosis