AMSLS NEWS

Australian MS Longitudinal Study (AMSLS)

October 2024

2024 saw us delve deeper into MS diagnosis, sleep, pain and family planning, develop a fancy cost diary, conduct a feasibility study, and prepare for the new year that is to come with InforMS and an NDIS survey.

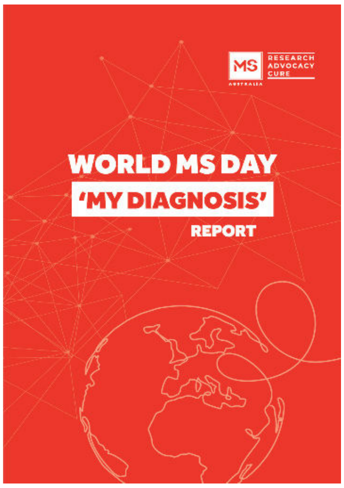
Read on for the highlights!

World MS Day ‘My Diagnosis’ report

In May 2024, MS Australia launched its World MS Day ‘My Diagnosis’ report based on the valuable data that AMSLS participants provide. Dr Laura Laslett and Professors Ingrid van der Mei and Bruce Taylor of the Menzies Institute for Medical Research reviewed AMSLS data to look at trends in MS diagnosis over the last 25 years, preparing a report for MS Australia.

Since the introduction of the first disease-modifying therapies (DMTs) for MS treatment in 1996, the average time to diagnosis has reduced from approximately five years and four months in 1997–2000 to almost three years and 11 months in 2017–21.

Earlier diagnosis allows DMTs to be started sooner, which can reduce the risk of permanent damage to the central nervous system and the accumulation of disability. This earlier intervention can improve quality of life for individuals with MS as well as their families and supporters.



WORLD MS DAY
‘MY DIAGNOSIS’
REPORT

The report also found that many people still go undiagnosed for many years, reflecting the complexity of MS.

Much progress has been made in reducing the time to diagnosis and improving long-term outcomes for people living with MS over the last 15 years. However, there remains a need for a prompter diagnosis for many people living with MS.

MS AUSTRALIA
AUSTRALIAN MS LONGITUDINAL STUDY

Our AMSLS community has decreased in recent years.

Can we call on you to recruit someone else?

For anyone to join, go to:

www.msaustralia.org.au/AMSLS

Need to contact us?

✉ **AMSLS.info@utas.edu.au**

☎ **(03) 6226 4739**

We are always happy to hear from you!

UNIVERSITY of TASMANIA
MENZIES
Institute for Medical Research

Understanding the role of pain in MS

In our previous work, we found that pain is the second most impactful symptom affecting the quality of life for people with MS. Funded by MS Australia, Menzies' postdoctoral researcher Dr Alice Saul, and PhD students Baye Dagnew Mekonnon and Mohammed Obsa have been working to better understand pain in MS. Their research, which utilises 2021 AMSLS Pain Survey data, looks at how common different types of pain are, how severe they can be, how predictable they are and their chronic nature. They are also exploring how people with MS manage their pain.

Of the survey participants, 52% reported experiencing regular pain, with 20% experiencing 5–10 different types of pain. The most common types were dysesthetic (unusual touch-based) extremity pain and spasticity-associated pain, which many experienced continuously, though the severity often fluctuated. Less frequent pain types were Lhermitte's phenomenon, optic neuritis and trigeminal neuralgia, which were unpredictable in occurrence. On average, participants used 2–3 pain relief medications and 4–5 other management strategies, such as consulting different health practitioners, using hot/cold packs, and rest or sleep.

Among those using medications, 62% reported 'much improvement' to 'complete pain relief', which was higher than expected. For other management strategies, 46% reported 'much improvement' to 'complete pain relief'. However, there was little evidence that disease-modifying therapies helped reduce pain.

We are working with people with MS, health professionals and MS Australia to develop two pain resources: one for people with MS and another for health professionals. These resources will include information on different pain types, and practical tools to help identify and locate the pain experienced by people with MS. The goal is to enhance understanding and improve communication about pain, leading to better management and care.

> *"I've been diagnosed over 40 years. But I can think back to when I was going to high school with the pain in my legs. I always get pain in my leg. I know for many years people said you don't get pain with MS. The disbelievers. But I tell you, we do." — Annette*

MS and family planning

The 2023 Economic Impact Baseline Survey included questions on family planning and how MS affects these decisions for people of reproductive age. The survey, completed by 270 participants (236 women and 34 men), explored the impact of MS on family planning, the information needs around this topic and preferred ways of receiving that information. The study was a collaboration with researchers at the Robinson Research Institute, the University of Adelaide and the South Australian Health and Medical Research Institute.

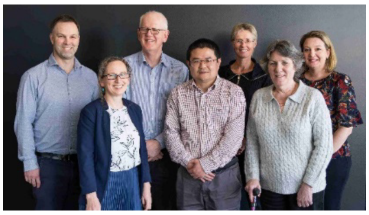
The data revealed that MS significantly influences family planning decisions. Almost half of the participants reported that MS affected their decisions about having children, with almost 15% deciding not to have children due to their condition. Many participants didn't seek or receive information on family planning, even though they considered it relevant. Half of the participants believed family planning discussions should begin at the time of MS diagnosis.

The neurologist was identified as the preferred source of information, although written handouts and online resources were also favoured.

The study's findings will be published and inform future work to develop family planning resources for people living with MS and health professionals. These resources, developed with input from people with MS, will aim to support informed reproductive decision-making and improve reproductive health outcomes.

> *"MS diagnosis was the deciding factor in not having children but it was not the only reason." — Anonymous*

> *"I found it difficult to find advice on risk / medication safety profiles with anecdotal studies regarding medication in pregnancy or breastfeeding. My medical team were fantastic but I would have loved a more central source"*
> *— Rachel*



Congratulations to AMSLS manager Professor Ingrid van der Mei, who is one of the chief investigators in the Menzies-led research team recently awarded $3m to establish the Multiple Sclerosis Centre of Research Excellence.

This large-scale collaboration between MS researchers, consumers, advocacy and resource organisations and industry will address the MS community's number one research priority: to identify and evaluate brain protection and repair treatments for progressive MS.

MS WorkSmart

Thank you to those who participated in the MS WorkSmart Feasibility Study. A randomly selected sub-group of the AMSLS was invited to take part. *MS WorkSmart* is a digital program with nine modules, designed to reduce the risk of job loss. Through videos, information, self-reflective quizzes and tasks, the program provides people with a deeper understanding of the effect of their symptoms on work, how to effectively manage their symptoms, and how to disclose and effectively communicate their MS at work. It also focuses on understanding the impact of thoughts on actions, beneficial strategies to reduce stress, understanding the practical changes that can be made to the workplace and how to plan for an uncertain future.

The development of the digital program was the culmination of many AMSLS findings over an eight-year period.

The feasibility study included 44 participants and showed that those who completed *MS WorkSmart* were highly satisfied with the program. Participants thought the program was easy to use, helped with turning information into action and provided skills that could be used immediately or which would be relevant in the future. There were also useful suggestions about how to further improve *MS WorkSmart*.

When we compared those who completed *MS WorkSmart* with those who did not, using a scale that measures the risk of job loss, we could see that the *MS WorkSmart* participants experienced improvements and substantially enhanced their confidence in managing their MS at work.

With these promising findings, we hope we will be successful in obtaining funding for a larger trial, to more definitively demonstrate that *MS WorkSmart* is effective in reducing job loss.

Quotes from participants in the feasibility study on *MS WorkSmart's* personal impact

"Yes, I learned so much extra and have implemented many into my work practice things I would never have thought of until it was too late, so thankyou thankyou to all who prepared and deliver this program, it has had a huge impact on my working life" ID 33

"Why wasn't this here 14-years ago, that could have alleviated a lot of years for me" ID 33

"Previously I didn't ask for help, now I request things more; feel it may be because of the modules" ID 179

"Downloadable PDFs I love; some [I] have put on the office wall" ID 146

"Course is amazing, love the self-reflective practices and quizzes" ID 146

"Nothing that was not helpful. Everything had its spot. [It is] very rare that I want to do more study, but this has been awesome" ID 230

MS Trial Screen

The AMSLS team has been asked by MS Australia to assist with recruiting participants for Australian MS clinical trials. This started through a collaboration with the United Kingdom, where researchers, led by Professor Jeremy Chataway, adopted a more efficient study trial design called a Multi-arm, Multi-stage Trial, specifically for progressive MS. This study is called OCTOPUS (https://www.mssociety.org.uk/research/explore-our-research/search-our-research-projects/octopus).

In Australia, a research group led by Professor Simon Broadley is contributing to that research through a study called PLATYPUS. You will hear more from MS Australia about this study later this year or early next year.

Meanwhile, Dr Laura Laslett and Professor Ingrid van der Mei of the AMSLS are developing an online tool called MS Trial Screen. This tool allows people with MS to register their interest in clinical trials and complete a survey that will screen for key eligibility criteria. MS Trial Screen will not only support PLATYPUS but also other Australian clinical trials. When new clinical trials are available, registered people who may be eligible will be notified, to update their information if needed and decide whether they want to participate.

So ... watch this space!

SMS notifications and updates to survey reminders

The AMSLS now offers SMS notifications for those who complete online surveys. In addition, we have stopped 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** ☎ **(03) 6226 4739**

How workplace factors impact people with MS

Research Fellow Dr Ting Zhao conducted a study using data from the AMSLS 2016 Economic Impact Survey to explore how workplace factors influence employment outcomes for people with MS. Since there is limited information on how these factors affect employment, the study aimed to produce evidence to inform and guide future workplace programs to improve the employment situation for people with MS.

The study looked at two groups: retired individuals and those still working. For retirees, it examined whether workplace factors influenced their decision to stop working. For people who were still working, the survey asked whether their job was at risk and if workplace factors contributed to that risk. The study classified 15 workplace factors into four categories: organisational factors (e.g. flexible working arrangements, running out of sick leave), factors around getting to and from work, factors related to moving around at work (e.g. inaccessible spaces) and having suitable equipment at work.

For retirees, the most common factor influencing their decision to stop working was prolonged standing with equipment. Among those still working but feeling their job was at risk, transportation difficulties were the most frequently mentioned issue. Additionally, professionals, 'blue-collar' workers and people with moderate or severe disability felt that a higher number of workplace factors impacted their employment.

The main conclusion from the study was that workplace factors play an important role in maintaining employment for people with MS, and understanding these and finding suitable supports may assist them to remain in the workforce.

The study results have recently been published in the journal Multiple Sclerosis and Related Disorders.

MS and sleep

PhD student Tadeg Amare (primary supervisor Dr Laura Laslett) is using data from the 2022 Sleep Survey, plus data from those who agreed to let us access Pharmaceutical Benefits Scheme data, to assess the treatments and strategies AMSLS participants use to improve sleep (e.g. medications, sleep hygiene, exercise, meditation) and how these affect sleep quality and daytime sleepiness.

Early results show that 72% of participants used one or more treatments to help them fall or stay asleep.

Surprisingly, most medicines that might impact sleep had little to no effect on sleep quality or daytime sleepiness, after accounting for the reasons why people might be prescribed these medicines.

MS Cost Diary

In mid-July we sent the second part of the Economic Impact Study – the 2024 Cost Diary – to AMSLS participants who completed the 2023 Baseline Survey. We are asking participants to record all items and services they purchase or receive that may be linked to their MS for a six-month period. The development of the Cost Diary was a huge undertaking, and participants can choose to complete it either digitally or on paper.

We appreciate that participating in this survey requires significant time and effort; however, previous economic health studies have been incredibly valuable in demonstrating the financial impact of MS on individuals and society.

If you have any questions about the Cost Diary, don't hesitate to contact the AMSLS team on (03) 6226 4739 or at AMSLS.info@utas.edu.au.

The AMSLS team preparing the mail out of the paper Cost Diaries: Dr Kirsty Hawkes, Carol Ingram, Anne Warby, Ian Mace and Carol Hurst.

Coming soon

InforMS – your new MS health app – is almost here!

We are excited to share that *InforMS*, our new MS health app, is nearing its launch. Developed by a team at Menzies in collaboration with MS experts across Australia, including people with MS, *InforMS* will soon be available to all AMSLS participants.

Led by AMSLS manager Professor Ingrid van der Mei, *InforMS* is set to be your 'one-stop shop' to view and track your MS health information. Data can be imported from the AMSLS, health and fitness trackers, My Health Record, your neurologist and more. There are also functions for document storage, goal setting and resources to help keep you up to date with the latest treatments and research. *InforMS* keeps everything in one secure place for you to access and share with your healthcare team.

We are launching *InforMS* to AMSLS participants first, to trial it as part of our research study. We want to find out whether *InforMS* is useful for people with MS and if it contributes to an improvement in their health. It will be rolled out Australia-wide after two years.

Stay tuned for your invitation to trial *InforMS*. In the meantime, if you have any questions, you can email us at informs.info@utas.edu.au.

This work is jointly funded by the National Health and Medical Research Council (NHMRC) and MS Australia, Grant ID 1193008. The views expressed may not reflect those of the NHMRC or MS Australia.

> *"I am very interested in keeping track of my symptoms and being able to recognise any new symptoms should they occur. I am also wanting any help to relieve symptoms if possible. Any information that helps me manage MS would be well worth it."* — Lee

Is the NDIS working for you?

A new research project led by Menzies' Professor Bruce Taylor is putting the National Disability Insurance Scheme (NDIS) under the microscope to see how well it supports people who live with MS.

Among other things, the team will evaluate the factors influencing NDIS participation and its impact on Australians with MS. The research will be based, in part, on information provided by AMSLS participants.

Keep an eye out for the 2025 NDIS Survey, coming your way early next year.

AMSLS Online

MS Australia
msaustralia.org.au

Recent AMSLS-linked content:
🔗 Adjusting workplace factors may improve employment outcomes for people with MS

🔗 Improving sleep quality in Australians with MS by managing comorbidities

🔗 New report calls for faster MS diagnosis in Australia on World MS Day

AMSLS scientific publications:
🔗 msaustralia.org.au/AMSLS/key-findings

MS MASSIVE OPEN ONLINE COURSES (MOOCs)
ms.mooc.utas.edu.au

Understanding Multiple Sclerosis
Enrolment is now open for the next online course.
Starts: March 2025
Duration: 6 weeks; 2 hours per week
Cost: FREE

UPCOMING: TWO NEW ONLINE MOOCs (FREE)
- **Deciding about DMTs for MS**
- **Mental Health and MS**

No set enrolment time
Starts: TBA
Duration: Self-paced, 1.5–2 hours per module

Menzies Institute for Medical Research
MS Research Flagship's
Research with Connections 2024
youtube.com/c/MenziesInstituteforMedicalResearch

AMSLS-aligned presentation:
🔗 **Enhancing workplace empowerment for people with MS via MS WorkSmart: Findings from a feasibility study**

Participants needed

Telehealth study focusing on weight management in people with MS

Researchers at the University of Wollongong, who partner with us on AMSLS projects, are recruiting people with relapsing remitting MS diagnosed at least 12 months ago to take part in a weight management clinical trial in 2025. For more information, please email: HALT-MS@uow.edu.au.

AMSLS focus for 2025

Topic	Details	Supporting survey(s)
InforMS	We will launch InforMS and obtain feedback from users and non-users.	**InforMS surveys**
MS and the NDIS Led by Professor Bruce Taylor, Menzies Institute for Medical Research	This project aims to evaluate the impact of the National Disability Insurance Scheme (NDIS) among people with MS and then share what we have learned via a Massive Open Online Course (MOOC).	**2025 NDIS Survey (Feb–Mar)**
Economic Impact Study Led by Dr Julie Campbell, Menzies Institute for Medical Research	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, we are now updating the picture of MS in Australia.	**2023 Economic Impact Baseline Survey** **2024 Cost Diary**
MS WorkSmart scales and health literacy	We will assess whether two bespoke scales, developed to measure the effectiveness of MS WorkSmart, are fit for purpose. We will also measure the concept of 'health literacy', to assess the effects of health literacy on outcomes and how to improve it.	**2025 MS WorkSmart and Health Literacy Survey (Apr–May)**
Pain In collaboration with Dr Kristen Lefever, Queensland Health	This survey is being analysed by research fellow Dr Alice Saul and PhD students Baye Dagnew Mekonnon and Mohammed Obsa. The findings are being used to develop a pain resource with fact sheets for people with MS and health practitioners.	**2021 Pain Survey**
Sleep In collaboration with Dr Cynthia Honan, University of Tasmania	Analysis from recent Sleep Surveys continues into how sleep changes over time, and people's confidence in their ability to make changes to improve sleep.	**2020 Sleep Survey** **2022 Sleep Survey**

AMSLS staff update

After many years of dedicated work with the AMSLS, staff member Hilary Waugh retired earlier in 2024. The heartfelt accolades Hilary received from many AMSLS participants over the years reflect how highly she was regarded, and the significant contribution she made to the study.

Hilary's position has been filled by new staff member Anne Warby, who started in the role in June 2024. Anne takes on Hilary's previous responsibilities, such as conducting telephone surveys with AMSLS participants, as well as assisting with general AMSLS administration.

Anne has extensive administrative experience as a research study coordinator and executive assistant. She worked at the University of Sydney for many years supporting psycho-oncology and geriatric studies. Anne is looking forward to contributing to the ongoing success of the AMSLS and getting to know the people who participate in the study.


Anne Warby

We know you will join us in wishing Hilary a wonderful retirement and welcoming Anne to the AMSLS team.

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