

# AMSLS NEWS



## Australian MS Longitudinal Study (AMSLS)

November 2023

**2023 saw us delve deeper into MS and sleep, gather critical information to improve family planning and MS, kick off the behemoth survey that underpins the Health Economic Impact of MS in Australia baseline study and much more. Read on for the highlights!**

### Improving working life quality

We know that more people with MS are staying at work, and staying for longer, which is likely to be because of improved treatments and other support programmes. However, this doesn't mean that people with MS are always able to fully participate at work and get all the benefits of employment. The goal of our research through the *Employment Survey* is to understand more about your experiences with work and the factors that help you stay employed or that cause you to choose to leave or force you to leave the workforce.

From the survey responses, we now know that disclosing your diagnosis at work means that you are more likely to remain employed and receive assistance to help you remain in work if you ask for it (e.g. assistive technologies or flexible work hours).

The COVID-19 lockdowns finally convinced many employers that working from home or flexible working hours are good for both employees and for business. But we still have much to learn about work experiences that increase your job satisfaction and confidence in your ability to perform work tasks, as well as what might undermine these.

Your participation in the *Employment Survey* is helping us develop resources for both organisations and employees with MS to help keep jobs. Our goal is to find ways to help people stay at work when they want to, be satisfied with the quality of their working lives or to leave on their own terms.

*"JobAccess is assisting me to further modify my home office to make working from home even easier for my wheelchair." — Shelly*



**AUSTRALIA**  
AUSTRALIAN MS  
LONGITUDINAL  
STUDY

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 are always happy to hear from you!

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**MENZIES**   
Institute for Medical Research

## Increasing prevalence of MS in Australia

In February 2023, MS Australia launched its interim [Health Economic Impact of MS in Australia in 2021](#) report based on the valuable data that AMSLS participants provide.

The report includes an updated estimate of MS prevalence in Australia calculated using our novel medications methodology. This draws on information you give us about your disease-modifying therapy (DMT) usage combined with data from the Australian Bureau of Statistics Census and the Pharmaceutical Benefits Scheme to estimate MS prevalence accurately and efficiently.

In 2010 and 2017, using this same method, we estimated that the number of people living with MS in Australia was 22,243 and 25,607, respectively. This number has now escalated to 33,335.

We also found that the number of people living with MS per 100,000 for each state and territory was climbing, particularly for states further away from the equator (such as Tasmania and Victoria).

Additionally, the proportion of MS prevalence was increasing at a faster rate than population growth in Australia. There could be several reasons for this including improved diagnosis, people living longer and the overall increase in population.

These prevalence estimates helped us calculate the cost of MS in Australia in 2021 to be \$2.45 billion. We expect that these costs will increase for 2024 due to inflation and cost of living pressures combined with escalating prevalence.

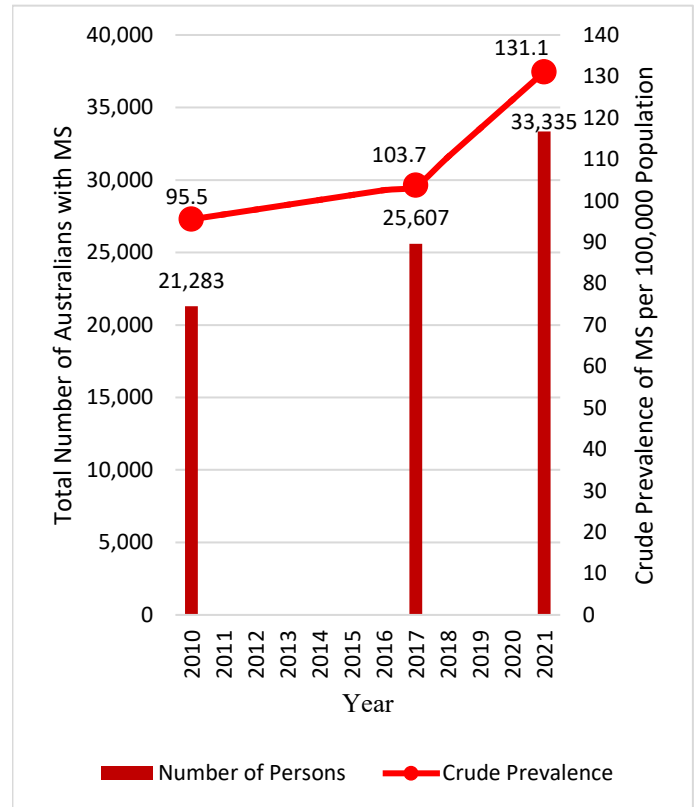
## Sleep, MS and other medical conditions

We previously reported that poor sleep substantially affects quality of life. PhD student Baye Dagnev has now conducted a deeper dive looking at the impact of sleep on the different aspects of quality of life and how symptoms fit into this picture.

Baye found that sleep affected all aspects of health-related quality of life. It had the strongest effect on mental health and pain, while the effect was smaller for independent living and senses. He also found that a considerable proportion of the effect was the result of sleep affecting MS-related symptoms such as anxiety, depression and pain, which in turn affected quality of life. This suggests that sleep interventions for those with sleep problems may substantially improve MS-related symptoms as well as overall quality of life.

Baye also assessed how medical conditions other than MS affected sleep. Maybe not surprisingly, he found that having more medical conditions was linked to worse sleep quality.

We ask once more for your assistance by completing our 2024 cost diary to ensure that we accurately capture these costs. Ultimately, this work is used to advocate to government for improved resourcing for people living with MS, their families and carers.



**Figure:** The total number of Australians with MS (left axis) and the crude prevalence of MS in Australia (right axis) by year, demonstrating an acceleration in the increase in MS prevalence.

The 28 medical conditions that were measured explained 12.9% of why some people with MS don't sleep well. Mental health conditions, such as diagnosed depression and anxiety, affected sleep quality the most.

Baye concluded that many different health problems, especially mental health conditions, can make it harder for people with MS to get a good night's sleep. Managing those other medical conditions well could make a real difference in helping people with MS sleep better.

*"Sleep deprivation due to MS symptoms has a huge impact on MS fatigue only making it worse which then impacts on performing daily activities. It also has a huge impact on mental health when it occurs on a regular basis."*

— Sandra

## The impact of COVID-19

We've previously demonstrated that the quality of life of people living with MS was substantively and negatively impacted by the COVID-19 pandemic particularly people with MS exposed to the Victorian lockdown and with severe disability.

Our latest study based on your survey responses investigated whether the pandemic's effect on people with MS was different from its effect on the general population.

As a group, people living with MS were 20% more likely to report a reduction in quality of life due to the COVID-19 pandemic than members of the general population, and 12% more likely than people with other chronic diseases. However, the magnitude of the impact on affected individuals was similar regardless of whether they had MS or another chronic disease.

## MS and self-concept

The 2022 *Concept of Self Survey* explored challenging questions related to self-concept. The questions "Who am I?" and "How have I changed?" were posed to AMSLS participants to help us gain understanding of how MS may impact this very personal facet of one's life.

For the 94% of participants who indicated that their self-concept had changed since diagnosis, 44% indicated that their self-concept had changed a lot or completely.

Interestingly, how this change looked was complex. While some participants reported multiple changes across different parts of their self-concept (e.g. how they defined themselves at home, work and socially), others reported change occurring only in specific areas of their life.

Change to self-concept wasn't always negative, as some participants reported positive changes or improvements to their self-concept. While some participants reported they were less outgoing and more dependent, others reported being more kind, loyal and caring since their MS diagnosis.

For those participants who did report experiencing changes to their self-concept, factors such as greater severity of difficulties was related to more negative self-concept change. However, the ability to maintain and engage with meaningful relationships, and self-perceived coping ability both contributed to positive self-concept change.

Overall, 44% of people living with MS reported that they were substantially impacted by the COVID-19 pandemic, evidencing that people living with MS require more assistance during future pandemics (and other national crises) compared with members of the general public.

*"The social changes imposed by the COVID second wave and the state of emergency in Victoria has had the most emotional impact on me. Not being able to see grandchildren or to give help in person to them is very difficult."*

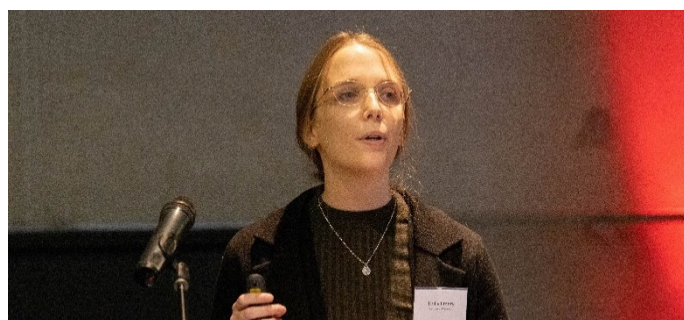
— Di

Importantly, no two participants reported exactly the same changes in self-concept. This tells us that more needs to be done to understand how to best support people living with MS who are transitioning to a new or redefined self. A 'one size fits all' approach is unlikely to be suitable.

We wish to thank all AMSLS participants who completed this survey. It was a difficult topic to think about and the nature of the questions was challenging for some. Thank you for your continuing support and willingness to share such a personal experience with us.

*"I have a new life now, very unlike the one I had planned ... It is like two different books in a series, same place, similar people, but a whole new storyline."*

— Pam



Holly Emery presenting on 'Concept of Self' at *Research with Connections 2022*

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

☎ (03) 6226 4739

## Preparing for a crisis

With increasing prevalence of crises such as floods, fires and heatwaves globally, people with disabilities are disproportionately at risk of short- and long-term consequences. Through the AMSLS, we surveyed 1,479 people with MS living in Australia to understand their needs for a crisis preparation plan.

Only 17.4% of survey respondents indicated that they already had a crisis preparation plan that met their needs, with a further 6.5% indicating they had a plan, but it needed updating. Equal numbers of respondents indicated they would (31.0%) or wouldn't (31.0%) find creating a crisis preparation plan useful, and 14.1% were unsure.

Of those who indicated they would find creating or updating a plan useful or were unsure, about a third said they'd need professional assistance to do this, preferably from MS healthcare providers (60.4%), MS nurses (46.9%) or support workers (41.5%).

The plan types considered to be most helpful were general emergency (45.1%), fire (26.3%), self-isolation (25.0%) and flood (8.1%).

Nearly a third of respondents indicated they'd want support with health behaviours during a crisis – most commonly managing stress (65.9%), exercise (57.4%), sleep (56.3%) and diet (46.9%). Less than 15% were interested in support for medication adherence, or for reducing alcohol use or tobacco smoking.

Our study showed that people with MS want and need better crisis preparation plans which should be inclusive and co-designed with consumers.

*"I think a crisis response plan would be generally useful for me, mainly to help me if any of my symptoms changed."*

— Dave



Congratulations to AMSLS manager Professor Ingrid van der Mei on winning the 2022 Research Impact Award at the Menzies Institute for Medical Research for the MS Nurse Care in Australia report, which is based on AMSLS data.

MS Australia is using the report as part of its extensive advocacy efforts to address the MS Nurse care crisis in Australia so that every person living with MS can access MS Nurse care.

## Improving the telehealth experience

From previous research, we know that the COVID-19 pandemic impacted healthcare delivery, especially for people with a chronic disease, and that the role played by telehealth services during the pandemic was critical.

In the *2020 Lifestyle and Environment Survey* we investigated telehealth use during the pandemic by people living with MS and their suggestions to improve their telehealth experience.

We collected data from 1,485 survey participants on demographic, disease-related and social health determinants, telehealth use during the pandemic and satisfaction with telehealth, and asked participants if they had suggestions to improve telehealth. We then analysed this data to establish the factors associated with telehealth use versus no use, and summarised experiences and suggestions for improvement.

We found that telehealth use was common, with 70% of survey participants using telehealth during the first phase of the COVID-19 pandemic.

Only small differences were observed for demographic, disease and social health determinants between telehealth users and non-

users. Most participants who used telehealth (74.3% with new providers and 78.6% with existing providers) had good or very good experiences.

The most common suggestion for improving the telehealth experience was "guidance on preparing for telehealth sessions". Participants also wanted expansion of telehealth availability and utility, predominantly expansion of telehealth to other clinical specialties, a wider range of technology options (e.g. video or phone tailored to the client and provider needs) and longer appointments to discuss needs.

Our study concluded that implementing the suggested improvements will help optimise telehealth for people living with MS.

*"Telehealth has made things so much easier for me. MS symptoms, particularly fatigue and inability to regulate temperature, mean going to a doctor is so difficult that I don't go unless it's absolutely essential."*

— Emma

**Coming soon**

## InforMS: a new MS health app

A new MS health app called InforMS is being developed by the University of Tasmania in collaboration with MS experts across Australia, including people with MS. Our very own AMSLS manager, Professor Ingrid van der Mei, is leading the project.

InforMS is a '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.

After a busy period of creating the InforMS app, we are almost ready for it to be tested. Early next year, we will invite all AMSLS participants to try 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.

Stay tuned for the invitation.

In the meantime, if you have any questions, you can email us at [informs.info@utas.edu.au](mailto: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 Institute for Medical Research's 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 among Australians with MS, and the research will be based in part on information provided by AMSLS participants.

Keep an eye out for the 2024 NDIS Survey, coming your way soon.



## AMSLS Online

**MS Australia**

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

Recent AMSLS-linked content:

[A powerful voice for MS: how an Australia-wide study is influencing policymakers](#)

[Multiple sclerosis rising and accelerating in Australia, new data shows](#)

MS Nurses content:

[MS Nurses: Life-changing care](#)

[Parliamentary Friends of MS Breakfast – World MS Day 2023](#)

MS Australia's advocacy work around MS Nurses leverages the [MS Nurse Care in Australia](#) report, which was based on AMSLS data

AMSLS scientific publications:

[msaustralia.org.au/AMSLS/key-findings](http://msaustralia.org.au/AMSLS/key-findings)

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

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

Enrolment is now open for the next online course.

Starts: 11 March 2024

Duration: 6 weeks; 2 hours per week

Cost: FREE

## Menzies Institute for Medical Research MS Research Flagship's Research with Connections 2023

[youtube.com/c/MenziesInstituteForMedicalResearch](https://youtube.com/c/MenziesInstituteForMedicalResearch)

AMSLS-aligned presentation:

[Cost of illness of MS: what did we find and how is the information used](#)

**Volunteers needed**

## Changing behaviour towards aerobic and exercise study

Researchers from Murdoch University, who partner with us on AMSLS projects, are recruiting people living with MS to take part in a home-based four-month exercise program as part of their latest MS Australia research study.

Find out more at [bit.ly/BASE\\_W4](https://bit.ly/BASE_W4) or contact the study via email [mshealthstudy@murdoch.edu.au](mailto:mshealthstudy@murdoch.edu.au) or phone (08) 9360 2435.

## AMSLS focus for 2024

Topic	Details	Supporting survey(s)
<b>Pain</b> In collaboration with Dr Kristen Lefever, Queensland Health	This survey is analysed by research fellow Dr Alice Saul and PhD students Baye Dagnev and Mohammed Obsa. The findings are used to develop a pain resource with fact sheets for people with MS and health practitioners.	<b>2021 Pain Survey</b>
<b>Sleep</b> In collaboration with Dr Cynthia Honan, University of Tasmania	Analysis from recent <i>Sleep Surveys</i> continues into how sleep changes over time, and people's confidence in their ability to make changes to improve sleep.	<b>2020 Sleep Survey</b> <b>2022 Sleep Survey</b>
<b>Family Planning</b> Led by Anna Fragoudi, University of Adelaide	A total of 270 people completed the family planning survey which included questions about family planning information and service needs. The researchers aim to improve approaches to family planning, such as contraception and pregnancy care, in people of reproductive age who live with MS. Findings will be shared in early 2024.	<b>2023 Economic Impact Baseline Survey, with a section on Family Planning</b>
<b>MS and the NDIS</b> 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).	<b>2024 NDIS Survey</b>
<b>Economic Impact Study</b> Led by Professor Andrew Palmer & 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, it's time to update the picture of MS in Australia.	<b>2023 Economic Impact Baseline Survey</b> <b>2024 Cost Diary</b>

### In your own words

*"I have been doing these surveys since inception and think the process is very worthwhile." — Meg*

*"Thank you for the opportunity to do this survey. I think it is really valuable to contribute and give you the information to better advocate for people with MS." — Jules*

*"I am delighted that these answers can be used to improve others' life quality. It is great also to be 'forced' to take stock and assess how I feel and how I'm coping with pain." — Sue*

*"I appreciate the opportunity to participate in the Australian MS Longitudinal Study. To me there is no doubt that the results of this study will be beneficial in many ways to sufferers from MS." — John*

*"I love reading your updates. It's great to see my little journey is helping provide insight into a bigger community experience. MS can be so isolating - me vs the world. This research changes this a little." — Jude*

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