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Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

By email to: community.affairs.sen@aph.gov.au

Dear Committee

Re: Senate Standing Committee on Community Affairs Inquiry into Issues related to menopause and perimenopause

I am writing on behalf of MS Australia in relation to menopause and perimenopause for women living with multiple sclerosis (MS).

Multiple Sclerosis (MS) is the most commonly acquired neurological disease in younger adults around the world with over 2.8 million people affected. More than 33,300 Australians live with MS and over 7.6 million Australians know someone or have a loved one with this potentially debilitating disease.

Menopause and MS

Three out of four people diagnosed with MS in Australia are women. About 3 in every 10 women with MS is going through menopause currently or has finished menopause¹.

There are mixed reports on the impact of menopause on MS. In surveys, some women say their MS symptoms and level of disability got worse after menopause. Feedback from members of MS Australia's Lived Experience Expert Panel (LEEP) shows a variety of experiences with menopause and MS from no effect to significantly increased MS symptoms and early onset menopause.

Amanda, a member of the MS Australia LEEP, lives with MS and has been going through menopause for the last eight years. Prior to menopause Amanda experienced heat sensitivity, a common symptom for people living with MS. Since menopause Amanda's heat sensitivity has increased dramatically and this has a significant impact on her daily life. Excessive sweating, fatigue, dizziness and weakness mean she can no longer undertake cleaning, cooking and other household responsibilities. It has also dramatically decreased her social activities and ability to leave her house to socialise with family and friends and limited her employment opportunities. She is heavily reliant on her family to undertake a caring role for her.

As outlined in the above case study, some of the effects of menopause overlap with the symptoms of MS making it difficult to separate their cause. This includes fatigue, cognitive impairment, depression and anxiety, sleep disturbance, bladder impairment and heat sensitivity/hot flushes. Additionally, MS can worsen with age and people with relapsing remitting MS may have fewer periods of time between relapses.

Research Gaps

There is currently a gap in the knowledge and understanding of menopause and MS, with further research needed in this area.

The International Advisory Committee on Clinical Trials in MS women's health working group recently completed a review of the literature relevant to women's health in MS². The review found considerable 'knowledge gaps' in a number of areas including menopause, with only three studies focusing on menopause and symptoms in women with MS.

In addition, the majority of studies focused on relapsing-remitting MS. Even among the studies that focused on menopause, which typically occurs around the age of 50 when many women with MS will have progressive forms of the disease, fewer than one in five participants enrolled had progressive MS.

The literature review was complemented by a global survey of women's health to determine the most important research priorities in women's health for women living with MS. Through this work menopause was identified as a top research priority. In late 2023, the working group undertook a further survey³ to prioritise the research questions within these priority research areas.

Women with Disability

When exploring the issues related to menopause and perimenopause for Australian women, it is important to note the factors that further impact on the experiences of women living with disability. These factors include:

- *Poor health outcomes:* People living with disability in Australia experience poorer health outcomes with only 24 per cent of people with a disability in Australia rating their health as excellent or good, compared with 65 per cent of Australians living without a disability⁴.
- *Co-morbidities:* Many women with disability experience a range of comorbid conditions that can significantly impact on their health, mental wellbeing and experience of menopause. The majority of people living MS have comorbidities including depression, anxiety, allergies, migraines and high blood pressure.
- *Poverty:* People with disabilities are more likely to live in poverty which impacts their health and wellbeing, ability to live safely, access the healthcare, supports and services they need and engage in their local community. For people living with MS and their families the main drivers of poverty are high living and health care costs and reduced employment and economic opportunities⁵. Analysis of MS Australia's *Australian MS Longitudinal Study (AMSLS)*⁶ shows that the annual cost of a person living

with MS is \$68,382. This represents a 17 per cent increase in costs from 2010 (\$58,652 per person). For those with 'severe disability', the costs are more than triple at \$114,813 compared with those living with low or no disability (\$30,561).

Universal access to perimenopause and menopause care is essential. A gendered approach must be embedded in national health policy in order to achieve equity in health and health care.

If you have any questions regarding the issues outlined above, please feel free to contact our National Policy Manager Katie Snell on _____ or _____

Thank you for your time.

Yours sincerely,

Mr Rohan Greenland
Chief Executive Officer
MS Australia

¹ MS International Federation. *MS and Menopause*. Retrieved from: <https://www.msif.org/living-with-ms/ms-and-menopause/>

² Ross, L., Ng, H. S., O'Mahony, J., Amato, M. P., Cohen, J. A., Harnegie, M. P., Hellwig, K., Tintore, M., Vukusic, S., & Marrie, R. A. (2022). Women's Health in Multiple Sclerosis: A Scoping Review. *Frontiers in neurology*, 12, 812147. <https://doi.org/10.3389/fneur.2021.812147>

³ The European Committee for Treatment and Research in Multiple Sclerosis (2023). *Have your say on the future of women's health in MS research*. Retrieved from: <https://ectrims.eu/have-your-say-on-the-future-of-womens-health-in-ms-research/>

⁴ Australian Institute of Health and Welfare (5 July 2022). *People with disability in Australia*. Retrieved from: <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/about>

⁵ Finney, A. (2020). *Poverty and Multiple Sclerosis: A Rapid Evidence Assessment*. Retrieved from: <https://www.mssociety.org.uk/sites/default/files/2020-11/Poverty%20and%20MS.pdf>

⁶ Menzies Health Economics Research Group (2018). *Health Economic Impact of Multiple Sclerosis in Australia in 2017: An analysis of MS Research Australia's platform – the Australian MS Longitudinal Study (AMSLS)*. Retrieved from: https://www.msaustralia.org.au/wp-content/uploads/2018/08/health-economic-impact-of-ms-in-australia-in-2017_ms-research-australia_web.pdf