

MULTIPLE SCLEROSIS AUSTRALIA

Submission to the Productivity Commission's Carer Leave inquiry

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About MS Australia

MS Australia (MSA) is pleased to provide a submission to the Productivity Commission's inquiry into the provisions for Carer's leave against the following terms:

- The potential impact of amending the National Employment Standards (NES) in Part 2-2 of the *Fair Work Act 2009* (Cth) to provide for a minimum statutory entitlement to extended unpaid carer's leave for national system employees providing informal care to older people who are frail and living at home.
- The social and economic costs and benefits from any change to the NES, including the impact on residential aged care services, and the broader net impact on the economy.

The focus of the comments provided in this submission are on key areas that will impact on people affected by multiple sclerosis (MS) and other neurological conditions for which our state organisations provide services and support. Included are comments provided by representatives of our state organisations and, in some instances, directly from people living with MS. MS Australia's role is to work on behalf of our state and territory-based member organisations to provide a voice for people living with MS across the country.

MS Australia's member organisations are:

- MSWA (providing services and support in Western Australia)
- MS SA/NT (providing services and support in South Australia and the Northern Territory)
- MS QLD (providing services and support in Queensland)
- MS Plus (providing services and support in Victoria, NSW, ACT and Tasmania)

Each of these state-based organisations operates independently to provide a range of services and advice to people living with MS regardless of age, and, in some cases, to a broader group of people with other progressive neurological diseases. These services vary from state to state and include: phone information support and advice, online resources, MS clinics, specialist MS nursing, physiotherapy, allied health services, education and information workshops, seminars and webinars, psychology, financial support, supported accommodation, residential and in home respite, peer support co-ordination and employment services.

Key Facts
According to a 2019 study commissioned by MS Australia and undertaken by KPMG that surveyed 2,261 people living with MS and 135 family members and carers: ¹
<ul style="list-style-type: none"> • There are approximately 22,272 MS carers across Australia
<ul style="list-style-type: none"> • 87% of people living with MS have someone (unpaid or informal) who is their main source of support
<ul style="list-style-type: none"> • 69% of carers provide daily emotional support, rather than physical assistance
<ul style="list-style-type: none"> • 69% of carers report that caring has an impact on their emotional wellbeing
<ul style="list-style-type: none"> • 45% of carers are paying for health professional supports
<ul style="list-style-type: none"> • 61% of were employed full time before they started to provide care for someone with MS
<ul style="list-style-type: none"> • 30% of carers are employed full time while caring for someone with MS

Summary of recommendations

Recommendation 1:

MS Australia calls for increased funding for seniors and their carers who choose to remain at home. A national needs analysis should be commissioned to support and inform this increase.

Recommendation 2:

Flexibility in employment and workplace options, including the ability to request extended unpaid carer's leave is supported by MS Australia but should not be used as a means to negate the need for community and in-home supports for those wanting to remain at home for as long as possible.

Introduction

MS Australia acknowledges the importance and valuable contribution of informal carers in the care economy in Australia. There is great demand to better meet the needs of those caring for people living with MS; supporting family, friends and carers of people with MS is one of our key advocacy aims.

We strongly support efforts to improve the supports and recognition for informal carers in general, and the recognition they rightly deserve whilst in paid employment.

We commend the increased funding commitments through the 2021-22 Federal Budget, as a result of the Government's response to the Royal Commission into Aged Care Quality and Safety's recommendations², to early referrals to the Carer Gateway, community respite, increased quality outcomes for people using respite, enhanced support for informal carers of those living with dementia and to the aged care accommodation framework.

¹ <https://www.msaustralia.org.au/for-family-friends-and-other-carers/>

² <https://agedcare.royalcommission.gov.au/publications/final-report>

MS Australia believes that more is needed however to address the decades of underfunding and current state of quality and care in this sector.

We also commend the government's commitments to address the aged care crisis, delivering '*more staff and better support to the sector, whilst improving transparency and accountability*'³.

MS Australia encourages further consideration of commissioning a national needs analysis to increase the funding allocation towards seniors and their carers who choose to remain at home – to increase equity in access and more timely support. We also strongly advocate to abolish the current capped provisions and means testing to access aged care services, in line with the needs-based approach of the NDIS.

MS Australia encourages the Commission to consider the findings and recommendations of the Carers Australia report, *Analysis of the Australia Government response to the Royal Commission into Aged Care Quality and Safety Final Report: Care, Dignity and Respect* (July 2021).⁴

This Report included commentary comparing carers leave entitlements in Australia to overseas jurisdictions and these might provide models of best practice for adoption in Australia.

A number of recommendations in the recent Aged Care Royal Commission (RC) relate to workforce issues. Workforce shortages and future demand modelling in the whole Australian care economy will also hopefully be a key focus and discussion in the Jobs and Skills Summit planned for September 2022.

Recommendation 1:

MS Australia calls for increased funding for seniors and their carers who choose to remain at home. A national needs analysis should be commissioned to support and inform this increase.

Extended unpaid Carers leave entitlement

Informal carers who can sustain some form of paid employment in addition to their caring responsibilities, should not be seen as a solution for the current deficit in aged care quality, workforce or funding allocation.

The introduction of additional provisions for carers to access unpaid leave has been an advocacy issue for many years and has been the subject of previous parliamentary enquiries, including the House of Representatives Standing Committee inquiry into better support for carers in 2008⁵. The Family, Community, Housing and Youth Committee launched its report on the inquiry into better support for carers entitled *Who Cares ...?*, then

³ <https://www.pm.gov.au/media/delivering-labors-plan-fix-aged-care>

⁴ <https://www.carersaustralia.com.au/wp-content/uploads/2021/07/Carers-Australia-discussion-paper-Governments-Response-to-ACRC.pdf>

⁵ https://www.aph.gov.au/parliamentary_business/committees/house_of_representatives_committees?url=fchy/carers/index.htm

recommending to address barriers to participation in paid employment for carers.⁶

MS Australia supports flexibility in employment and workplace options, including the ability to request extended unpaid carer's leave.. This should be balanced with the legal rights of carers in the workplace, including the right to request flexible working arrangements and protection from discrimination or harassment should they disclose their carer responsibilities to their employer.

Extended unpaid leave should form part of a range of policy and financial settings and supports and must not be used as a means to negate or make up for community and in-home supports for those wanting to remain at home for as long as they can.

MS Australia would like to see further evidence-based, holistic models of support for carers in paid employment. This should be a key area for further government funding, support and policy development.

Recommendation 2:

Flexibility in employment and workplace options, including the ability to request extended unpaid carer's leave is supported by MS Australia but should not be used as a means to negate or make up for community and in-home supports for those wanting to remain at home for as long as possible.

Social and economic costs and benefits

Research indicates that for those who are frail and ageing at home whilst living with MS, the vast majority of personal support and home-care services are provided by family members and friends or informal unpaid carers. Understanding the experiences, needs and challenges of carers is necessary to create a systemic response within Australia's aged care system and to create effective and appropriate supports for carers.

MS⁷ impacts everyone differently, depending on where damage occurs within a person's central nervous system (CNS). The resulting symptoms from this auto-immune response and inflammation therefore presents differently too – often episodic – with periods of active disease and inactive disease. Symptoms (and their interactions) include variations in severity, interaction with medication and other diagnosis and the resulting functional impacts.

As such, caregiver experiences are not homogeneous.

As needs for care tend to increase with age, older people with MS may experience greater levels of disability.⁸

Caregivers, especially spouse caregivers, may similarly experience age related needs (reflective of their stage in life), health deterioration and complications

⁶ http://www.aphref.aph.gov.au_house_committee_fchy_carers_report_fullreport.pdf

⁷ <https://www.msaustralia.org.au/what-is-multiple-sclerosis-ms/#:~:text=MS%20Australia%20is%20the%20national,worldwide%20effort%20to%20solve%20MS.>

⁸ <https://www.msif.org/wp-content/uploads/2015/01/Ageing-with-MS-FINAL-web.pdf>

including health related burden as a result of their care responsibilities. This may include a reduction in their own quality of life.

Informal carers of people living with MS have been the subject of previous scientific enquiries and reviews, focussing on caregiver needs and experiences, caregiver burden, lived experiences of spousal care, factors that may influence a caregiver's quality of life and caregiver's tasks.⁹ Informal caregivers provide psychosocial, social and assistance with activities of daily living.

Research indicates caregivers of someone with MS spent on average 6.5 hours a day dedicated to caring tasks.¹⁰ This often has consequences for their own employment by either having to miss workdays, reduce work hours or stop work completely. Within the health¹¹, aged care¹², disability¹³ and social security¹⁴ service systems, people with MS and their carers often fall through the gaps. MS also has unique impacts on employment¹⁵.

Caregivers of people with MS often have to assist in navigating the complexity of these service systems with and on behalf of the people they care for. The social and economic benefits of informal caregiving in Australia was the subject of a report commissioned by Carers Australia in 2020, entitled, *The value of informal care in 2020*¹⁶. We encourage the Commission to include the findings of this report in their final report to the Federal Government.

Other caregiver services and support

Whilst outside the scope of this inquiry, which is limited to the consideration of unpaid carers leave entitlements, it is worth noting that the expansion and improvement of other carer supports and services such as the provision of assistive technology, carer payments, carer support, coaching and counselling, carer respite and carer-specific resources, can all make an enormous difference to alleviating the carer burden and enriching the caregiver experience.

⁹ <https://onlinelibrary.wiley.com/doi/10.1111/hsc.13687>

¹⁰ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7242779/>

¹¹ <https://www.msaustralia.org.au/wp-content/uploads/2022/06/anao-expansion-of-telehealth-submission-from-ms-australia.pdf> and <https://www.msaustralia.org.au/wp-content/uploads/2021/10/ms-australia-submission-to-gps-in-rural-remote-aust-inquiry.pdf>

¹² <https://agedcare.royalcommission.gov.au/system/files/2020-10/AWF.001.02000.01.pdf>

¹³ <https://www.msaustralia.org.au/wp-content/uploads/2021/10/submission-to-the-ndis-consult-an-ordinary-life-at-home.pdf>

¹⁴ <https://www.msaustralia.org.au/wp-content/uploads/2021/10/ms-australia-dsp-senate-inquiry-submission-final.pdf>

¹⁵ <https://www.msaustralia.org.au/wp-content/uploads/2022/02/msa-sub-to-dss-shaping-new-dis-employ-program-1-feb-2022.pdf>

¹⁶ <https://www2.deloitte.com/au/en/pages/economics/articles/value-of-informal-care-2020.html>

Conclusion

Informal caregiving should be viewed within the context of the broader Australian policy and strategy around health pathways and access, disability, social security and aged care.

The interrelatedness of these service systems can often best be appreciated when these systems fail, as is the case of the Australian aged care system failings and the resulting Royal Commission and its recommendations.

People do not fit neatly in one sector or another. Caregivers of people with chronic conditions such as MS often must assist in navigating all these systems – often at the same time.

Any support, such as an increase in the availability of paid or unpaid carer leave entitlements should therefore be viewed within this bigger picture. One policy setting change can improve the lives of those taking on the daily care needs of people living with chronic conditions, ill health, age related needs and disability.

There is still much to be done to improve the experiences and lives of those in caregiving roles in Australia.

KEY FACTS ABOUT MS:

- Multiple sclerosis (MS) is a neurological condition affecting the central nervous system (brain and spinal cord) that affects more than 25,600 people throughout Australia
- It is the most common chronic neurological condition diagnosed in young adults.
- MS is most commonly diagnosed between the ages of 20 and 40
- 75% of people diagnosed are women.
- MS varies significantly from person to person. For some people, it is a disease that comes and goes in severity with periods of unpredictable relapse and remission. For others it means a progressive decline over time. For all, it is life changing.
- Symptoms vary between people and can come and go; they can include severe pain, walking difficulties, debilitating fatigue, partial blindness and thinking and memory problems.