# Inquiry into the recognition of unpaid carers

*House of Representatives Standing Committee on Social Policy and Legal Affairs*

**August 2023**

# SUBMISSION

# Inquiry into the recognition of unpaid carers

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MS Australia is Australia's national multiple sclerosis (MS) not-for-profit organisation that empowers researchers to identify ways to treat, prevent and cure MS, seeks sustained and systemic policy change via advocacy, and acts as the national champion for Australia's community of people affected by MS.

MS Australia represents and collaborates with its state and territory MS Member Organisations, people with MS, their carers, families and friends and various national and international bodies to:

- Fund, coordinate, educate and advocate for MS research as part of the worldwide effort to solve MS
- Provide the latest evidence-based information and resources
- Help meet the needs of people affected by MS

Multiple Sclerosis (MS) is the most 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.

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. For some, MS is characterised by periods of relapse and remission, while for others it has a progressive pattern of disability. MS robs people of quality of life, primarily driven by the impact of MS on pain, independent living, mental health, and relationships.

# Inquiry into the recognition of unpaid carers

MS Australia welcomes the opportunity to make a submission to the House of Representatives Standing Committee on Social Policy and Legal Affairs inquiry into the recognition of unpaid carers (Inquiry). MS Australia is pleased to contribute to a better understanding of the role of unpaid carers in Australian society and the role of a reformed *Carer Recognition Act 2010 (the* Act). This submission focuses on the recognition of carers in Australia, barriers in accessing support systems, and recommendations to enhance the effectiveness of the Act.

MS Australia supports raising recognition and awareness of the unpaid caring role, in order to deliver unpaid carers, including those who care for a person living with MS, services and support when and where they need it. To ensure that services are appropriate and address carer's needs it is essential that carers with lived experience are engaged in decision-making processes that directly impact them.

Due to the diversity in disease presentation and progression, people with MS require a broad range of supports that often include unpaid care delivered by family and friends. Supports may include assistance with everyday tasks such as personal care, life administration, providing transport, and contributing emotional support. Whilst caring can be meaningful and rewarding, the time and effort required to provide care requires significant adjustments to a carer's life. These challenges can impact the carer's wellbeing and ability to achieve their own goals. Recognition and support for the vital role of carers is crucial to ensure carers are able to maintain their role.

MS Australia makes the following recommendations:

## MS Australia Recommendations

- Amend the Act and Statement of Australia's Carers to:
    - ❖ Further clarify the meaning of carer and outline eligibility for carer support services.
    - ❖ Include improved accessibility and affordability of self-care services and respite care in schedule 1/statement 5 of the Act.
    - ❖ Promote the inclusion of carer lived experience in policy decision making and service design related to unpaid carers.
    - ❖ Acknowledge the value of unpaid care provided by carers supporting people with chronic illness.
    - ❖ Replace 'recognising' unpaid carers to 'recognising and valuing' unpaid carers.
    - ❖ Recognise the intersectionality of carer identities and acknowledge that discrimination based on culture, age, gender, disability and/or sexual identity can contribute to poor health outcomes in schedule 1/statement 1.
    - ❖ Respond to the recommendations of the Senate Select Committee on Work and Care Inquiry with a view to incorporating aspects of the recommendations into the Act, such as *Recommendation 1: the right to care alongside the right to work*.
    - ❖ Include a reference to flexible working arrangements and fostering carer-friendly workplaces to accommodate carers' needs in schedule 1/statement 9.
- The Federal Government undertake a co-design process with carers and their advocacy organisations to develop the new National Carer Strategy.
- Introduce a Carers' Income Tax Offset (CARITO) to be credited against income tax, in recognition of the value of carer's unpaid caring work.
- The Government pay carers a Superannuation Guarantee Contribution on the Carer Payment, based on the amount of Carer Payment they receive.

- The vision and objects of the Act, new National Carers Strategy and the draft National Strategy for the Care and Support Economy are aligned.

## 1. The effectiveness of the Carers Recognition Act 2010 and the associated Statement of Australia's Carers

The object of the Act is to increase recognition and awareness of carers and to acknowledge the valuable contribution they make to society. Feedback received from MS Australia Members indicates that among carers and service providers the Act is not well known and has not been effective at increasing recognition of the role of unpaid carers. Effective implementation of the Act including the dissemination of information and accessibility of support services, is key to ensure its intended benefits reach carers effectively.

MS Australia understands the reasoning for the use of a broad meaning of carer as outlined in the Act, as it ensures that carers are not excluded from support services or recognition. There is a tendency for people to not identify as carers unless they provide direct physical care, so a broad definition opens interpretation of the meaning to more people to identify with. The term personal care seems often associated with a medical model, and likely reinforces the connection with physical functioning. Feedback from MS Australia Members identifies that many family members and friends who provide care for people with MS don't identify as carers. MS Australia believes that the definition would benefit from clarification and outlining eligibility for carer support services. A carer's self-identification as a carer is crucial to carers seeking support, information, and resources, as such it is vital that the meaning is broad enough to capture all carers while at the same time providing enough detail for carers to identify with the meaning.

When seeking support, carers face further barriers. Feedback provided by MS Australia Members highlights that carers for people living with MS want practical support and information specific to MS. The information that is available on the Carer Gateway or resources on the Carers Australia website may not suit the diversity of experiences faced by carers. Accessing resources and services is also impacted by factors such as time constraints. A survey undertaken by our Member Organisation MS Plus in 2022 found that more than 1 in 2 MS carers identified lack of time as a barrier to living well. As such, carers need readily accessible information and education that is relevant to their lived experience and the type of unpaid care that they provide.

Schedule 1/statement 5 of the Act states "Carers should be acknowledged as individuals with their own needs within and beyond the caring role". This should be amended to include improved accessibility and affordability of self-care services and respite care. The importance of carers maintaining their own health and wellbeing beyond the caring role should be recognised.

**MS Australia recommends** that the meaning of carer in the Act is further clarified and outlines eligibility for carer support services.

**MS Australia recommends** that schedule 1/statement 5 of the Act is amended to include improved accessibility and affordability of self-care services and respite care.

## 2. Developments in the policy landscape at a Commonwealth level since the Act's passage in 2010

The National Carers Strategy 2011-2014 has now expired and MS Australia welcomes the opportunity to engage in consultation with the Federal Government when the Strategy is reviewed in late 2023. It is important that unpaid carers with lived experience are involved in the review process and that carers from a diverse range of backgrounds and experiences have their voices heard.

MS Plus, who provides services in NSW, ACT, Victoria, and Tasmania, recently completed a co-design project to better understand carers needs. A Carers Reference Group informed the research process to develop a Carers Strategy. Efforts were made to ensure the reference group members were representative of the diversity among MS carers. In addition to the reference group, further consultation was undertaken including surveys of all registered MS carers, focus groups and one on one interviews were held to gather additional detail and context regarding identified needs and suggested supports. MS Australia believes this process can provide a good model for the development of the National Carers Strategy.

**MS Australia recommends** that the Federal Government undertake a co-design process with carers and their advocacy organisations to develop the new National Carer Strategy.

**MS Australia recommends** that the Act be amended to specifically promote the inclusion of carer lived experience in policy decision making and service design related to unpaid carers.

## 3. The effectiveness of existing state, territory, and international recognition of unpaid care (statutory or other practice)

MS Australia has no feedback on this question.

## 4. Understanding the value of unpaid care

Carers are an integral part of Australia's healthcare system and are the foundation of our disability, aged, palliative and community care systems[1]. 87% of people living with MS have someone (unpaid or informal) who is their main source of support. MS Australia estimates that there are approximately 29,000 MS carers across Australia[2] for the 33,335 people living with MS. Unpaid carers in Australia deliver support that saves our health and care and support economy more than $77 billion a year[3]. It is important to acknowledge that caring for people with chronic illness comprises a significant group of carers which their value and contribution are not recognised enough. Carers of a person living with a chronic illness are more likely to have a prolonged caring role.

**MS Australia recommends** that the Act and The Statement for Australia's Carers acknowledge the value of unpaid care provided by carers supporting people with chronic illness.

**MS Australia recommends** that the Act be amended from 'recognising' unpaid carers to 'recognising and valuing' unpaid carers.

## 5. The needs of specific cohorts such as young carers, First Nations carers, LGBTIQA+ carers, or culturally and linguistically diverse carers

For specific cohorts, especially those from vulnerable communities, the diversity of carers and their needs should be acknowledged to ensure the appropriateness and accessibility of support services. Carers from a culturally and linguistically diverse (CALD) background are less likely to identify as having a caring role and less likely to seek support services or recognition. While young carers in particular are vulnerable to their health, mental health and wellbeing being seriously affected without adequate support in their caring role. The education and employment prospects for Australia's 235,000 young carers are poor. More than 60% of young carers have not studied beyond high school and on average are expected to receive income support for 43 years over their lifetime[4].

**MS Australia recommends** including in the Act an amendment of schedule 1/statement 1 reflecting the intersectionality of carer identities and acknowledging that discrimination based on culture, age, gender, disability and/or sexual identity can contribute to poor health outcomes.

## 6. The meaningful role that flexible workplaces play in unpaid care

MS Australia acknowledges that the Terms of Reference for this Inquiry advise the Committee to consider "where possible, the submissions and evidence presented to the Senate Select Committee on Work and Care, in addition to the interim and final reports, including all relevant recommendations to the terms of reference of this inquiry, to reduce duplication." The interim and final reports from the Work and Care Inquiry outline in detail the barriers that unpaid carers face in the workforce, including higher rates of insecure work and lower rates of formal education. These reports clearly identify the meaningful role that flexible workplaces play in unpaid care. The Work and Care Inquiry's final report outlines the key challenge for unpaid carers:

> *"It is time for a new right to care, alongside the right to work. In a world that increasingly relies upon the paid work of its citizens who are also carers, it is time for a new social contract around work and care—one appropriate to the 21st century."*[5]

**MS Australia recommends** that the Federal Government respond to the recommendations of the Senate Select Committee on Work and Care Inquiry with a view to incorporating aspects of the recommendations into the Act, such as *Recommendation 1: the right to care alongside the right to work*[6].

Carers in Australia experience poor employment outcomes. Many carers struggle to balance their caregiving responsibilities with employment. When carers leave the paid workforce due to caring responsibilities, there should be supports in place to encourage re-entering the paid workforce when possible.

The employment to population ratio is 75.9% for people without caring responsibilities, compared to 52.2% for people with a caring role[7]. The employment statistics for carers of people living with MS tells a similar story. 61% of carers were employed full time before they started providing care for someone with MS, this dropped to 30% of carers working full time while caring for someone with MS[8]. MS Plus surveyed a group of MS carers in 2022 and asked them questions about their paid employment. Of the survey respondents, 69% have changed their work in some way due to their caring role: 39% have given up work, 19% have reduced work or worked part time, and 12% have taken on a less demanding job. One respondent increased their workload to provide financial support and appropriate care for the person with MS[9].

When asked for recommendations on how employment barriers can be addressed 31% of surveyed carers reported that they would benefit from employment support[10]. Carers suggested initiatives such as training on how to talk to their employer about their caring responsibilities and advocate for flexible working conditions so they can stay in the workforce. Carers also identified a need for support on re-entering the workforce after a period of absence due to caring responsibilities. Support may include practical advice on how to explain their employment gap and interview preparation.

In order to re-engage and retain carers in the workforce, workplaces must offer flexible workplace provisions which allow employees to combine paid work with an unpaid caring role. The Statement of Australian Carers, schedule 1/statement 9 of the Act, states that, "Carers should be supported to achieve greater economic wellbeing and sustainability and, where appropriate, should have opportunities to participate in employment and education". This statement does not directly address the need for flexible working conditions, including paid carer leave or flexible working hours or exploring opportunities to better support the individual needs of employees who are carers. Through organisational policies and practices such as training, consultation, and the recognition of carers in HR policies, workplaces can foster a supportive culture in which carers feel comfortable disclosing their caring responsibilities.

**MS Australia recommends** that schedule 1/statement 9 of the Act includes a reference to flexible working arrangements and fostering carer-friendly workplaces to accommodate carers' needs.

## 7. The Government's broad agenda in relation to the care and support economy, the importance of employment participation, and a strong focus on gender equity

MS Australia supports a closer examination of the gendered nature of caring and gender equity in caring roles given that 7 out of 10 primary carers in Australia are female[11]. The economic and social implications for female carers disproportionately taking on unpaid caring roles are enormous. Caring roles are one of the contributing factors to the gap between men and women's superannuation savings in retirement. In turn this superannuation gap is one of the reasons that older women are increasingly facing poverty and financial insecurity in retirement.

A 2022 KPMG report on valuing unpaid caring work[12] recommends introducing a Carers' Income Tax Offset (CARITO) to be credited against income tax, in recognition of the value of unpaid caring work. This would have a similar design to the current Low and Middle Income Tax Offset (LMITO). While not a gender specific initiative, given that the majority of caring roles are undertaken by women this would have a substantial benefit for female carers.

**MS Australia recommends** the Introduction of a Carers' Income Tax Offset (CARITO) to be credited against income tax, in recognition of the value of their unpaid caring work

It is estimated that, on average, a primary carer will face a reduction in their lifetime earnings during their working life of about $393,000 and a reduction in their superannuation balance at age 67 of about $175,000[13]. This creates significant financial distress for carers and their families and increased government expenditure on paid services when carers can no longer afford to stop working and due to increased eligibility for the Age Pension. Carers Australia proposes addressing this gap by having the Government pay a Superannuation Guarantee Contribution on the Carer Payment, based on the amount of Carer Payment each carer receives. It is estimated that this could close the superannuation deficit for carers by about 37%.

**MS Australia recommends** the Government pay carers a Superannuation Guarantee Contribution on the Carer Payment, based on the amount of Carer Payment they receive.

The care and support economy has a significant impact on women's economic equality as women make up the majority of workers in these sectors and the majority of unpaid carers. The development of a Draft National Strategy for the Care and Support Economy (National Strategy) provides an opportunity to ensure that the vision and objects of the Act, National Strategy and the new National Carers Strategy are aligned. They should all seek to support the workforce participation of carers and improved pay and working conditions across the sector.

**MS Australia recommends** the vision and objects of the Act; new National Carers Strategy and the draft National Strategy for the Care and Support Economy are aligned.

# References

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