



Submission to the Parliamentary inquiry into the recognition of unpaid carers

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The Neurological Alliance Australia is an alliance of 18 not-for-profit peak or national patient organisations representing adults and children living with progressive neurological or neuromuscular conditions or neurological disorders in Australia. The Alliance was established to promote improved quality of life for people living with these conditions and increased funding to support research. Members of the Alliance are: Dementia Australia, Brain Injury Australia, Emerge Australia, Huntington's Australia, Motor Neurone Disease (MND) Australia, MJD Foundation, MS Australia, Muscular Dystrophy Australia, Muscular Dystrophy Foundation Australia, Parkinson's Australia, Spinal Muscular Atrophy Australia, Leukodystrophy Australia, the Childhood Dementia Initiative, the Mito Foundation, Polio Australia, Fragile X Australia, the Brain Foundation and Migraine Australia.

Some NAA members are providers under the NDIS, offering support coordination, allied health and/or other supports. Most members provide information and navigation services funded through separate sources such as fundraising and philanthropy.

The Neurological Alliance Australia represents the 1 in 6 Australians living with the conditions represented by the members of the Alliance with an annual impact on the Australian economy of over \$100 billion.

Introduction

The Neurological Alliance Australia (NAA) is pleased to provide a submission to the *Parliamentary inquiry into the recognition of unpaid carers*.

The focus of the comments provided in this submission are on key areas that will impact on people affected by neurological disorders or progressive neurological and neuromuscular conditions and their carers, for which our member organisations provide services, support and advocacy. Included are suggestions provided by our member organisations and, in some instances, directly from people caring for those living with the conditions represented by the NAA.

The [Neurological Alliance Australia](#) is an alliance of national not-for-profit peak or national patient organisations representing adults and children living with neurological disorders or progressive neurological and neuromuscular conditions in Australia. The Alliance was established in 2010 to promote improved quality of life, coordinated services and greater research investment into these conditions.

The Alliance represents 1 in 6 Australians¹ living with these conditions that have no cure, with an estimated annual cost to the Australian economy of over \$100 billion². This group includes adults and children, carers, families, friends and workmates whose lives have been affected by a progressive neurological or neuromuscular condition or a neurological disorder. The impact of these conditions on individuals and families can undermine their resilience, which is a vital element of their ability to remain purposeful and in control of their lives in addition to preventing or minimising financial and emotional burden. The impact on quality of life is substantial and well documented. For example, on average, the Quality of Life (QoL) as measured by the health state utility valuation (HSUV) of the Australian multiple sclerosis (MS) population is 31% less than the Australian population norm.³

Caring for someone with a chronic condition or disorder can be deeply satisfying but also physically and emotionally exhausting.

Given the diversity in disease presentation and progression, people with progressive neurological and neuromuscular conditions and neurological disorders require a broad and diverse range of support that often includes unpaid care delivered by family and friends. Recognition, acknowledgement and support for the vital role of carers⁴ is a crucial component of maintaining the carer in this role.

¹ Based on WHO global study: *Neurological Disorders: Public Health Challenges*, A World Health Organisation Report retrieved from: <https://www.who.int/publications/i/item/9789241563369>

² Based on an aggregation of data from those NAA members who have commissioned economic impact studies

³ Health Economic Impact of MS in Australia. Retrieved from: https://www.msaustralia.org.au/wp-content/uploads/2018/08/executive-summary_health-economic-impact-of-ms-in-australia-in-2017-report_ms-research-australia.pdf

⁴ The NAA follows the Carers Australia approach to using the term 'carer(s)' as defined by the Commonwealth Carer Recognition Act 2010. The term should not be used broadly and without context to describe a paid care worker, volunteer, foster carer, or a family member or friend who is not a carer.

It should be noted that for many genetic-based neurological conditions carers often live with the same condition as the person they care for. For example, adult children caring for their mother with mitochondrial disease where the carer is living with the same condition at an earlier stage of progression. Fragile X is another example where mothers of adult sons with Fragile X are often managing their own symptoms of Fragile X carrier status (e.g. mental health, autoimmune conditions).

There are unique challenges for ageing parents of adult children with neurological conditions where the retirement of the carer is often impossible and there is an expectation that they will continue their 'parental responsibility' into old age (including from the NDIS) making the carer role particularly difficult to navigate.

Terms of reference

- the effectiveness of the Act and the associated Statement of Australia's Carers in raising recognition and awareness of the unpaid caring role, including its obligations on public service agencies
- developments in the policy landscape at a Commonwealth level since the Act's passage in 2010
- the effectiveness of existing state, territory and international recognition of unpaid care (statutory or other practice)
- how to better identify the role of unpaid carers in Australian society and the role of a reformed Act, with regard to:
 - understanding the value of unpaid care,
 - the needs of specific cohorts such as young carers, First Nations carers, LGBTIQ+ carers, or culturally and linguistically diverse carers,
 - the meaningful role that flexible workplaces play in unpaid care, and
 - 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, and
- any other related matters, noting that the adequacy of payments for carers is out of scope for this inquiry.

Summary of recommendations

The NAA recommends:

1. That the Department of Social Services undertake an impact evaluation of the Carer Recognition Act 2010, the associated Guidelines and the Statement for Australia's Carers to determine their effectiveness for increasing the recognition and consideration of carers throughout APS agencies and the broader community.
2. That a future inquiry examine financial support for carers including the levels of the Carer Allowance, Carer Payment and the long term financial security of carers including improved superannuation arrangements.
3. 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 Carer Recognition Act, such as the right to care alongside the right to work and an estimate of the value of unpaid care being included in the annual budget papers.
4. That the Statement of Australian Carers be amended to include a reference to flexible working arrangements and fostering carer-friendly workplaces to accommodate carers' needs.
5. That the Statement for Australia's Carers be amended to include a reference to the needs of carers being underpinned by robust research into the needs of carers to ensure carer supports and services are "timely, responsive, appropriate and accessible".

The Carer Recognition Act 2010 including Statement for Australia's Carers⁵

Limited in scope

The Carers Recognition Act 2010 is a very brief document, that makes a series of very general, short statements in relation to the recognition of carers. It has limited scope and arguably fails to comprehensively address the diverse needs and challenges faced by carers, though presumably other related legislation may address these issues.

The Carer Recognition Act 2010 Guidelines⁶ state that:

“The Carer Recognition Act 2010 is intended to increase recognition and consideration of carers and drive much-needed cultural and attitudinal change throughout [Australian Public Service] APS agencies and associated providers, and as a result, the community as a whole.”

It is not clear in practical terms how this cultural and attitudinal change is monitored or evaluated nor how effective this approach has been in affecting change throughout the whole community.

Recommendation 1

That the Department of Social Services undertake an impact evaluation of the Carer Recognition Act 2010, the associated Guidelines and the Statement for Australia's Carers to determine their effectiveness for increasing the recognition and consideration of carers throughout APS agencies and the broader community.

Insufficient Financial Support

Carers often face financial hardships due to the demands of their caregiving responsibilities. Concerns have been raised regarding the adequacy of financial support provided to carers under the Act, including financial allowances and benefits that can enable carers to sustain their caregiving roles without significant financial strain. Concerns have also been raised regarding the barriers to obtaining the Carer Payment and Carer Allowance and the amount of time and energy needed to complete the application and assessment process. It is noted that the adequacy of payment for carers is out of scope for this inquiry.

According to the Executive Summary of the “Caring Costs Us: The economic impact on lifetime income and retirement savings of informal carers – a report for Carers Australia”, March 2022⁷:

⁵ Carers Recognition Act 2010. Retrieved from: <https://www.legislation.gov.au/Details/C2010A00123>

⁶ Carer Recognition Act 2010 Guidelines. Retrieved from: https://www.dss.gov.au/sites/default/files/documents/05_2016/carers_recognition_act_2010_guidelines_april_2016.pdf

⁷ Carers Australia *Caring Costs Us* Report. Retrieved from: <https://www.carersaustralia.com.au/programs-projects/caring-costs-us/>

- Every day, over 2.65 million carers provide care and support to people living with disability, chronic or life-limiting illness, are frail aged or have a mental illness, alcohol or other drug related condition
- It would have cost \$77.9 billion in 2020 to replace [informal] care with formal paid services, such as those accessed via My Aged Care or the National Disability Insurance Scheme (NDIS).
- The right to participate in economic, social and community life is recognised under the Act which states carers “should be supported to achieve greater economic wellbeing and sustainability and, where appropriate, should have opportunities to participate in employment and education.”
- Carers in Australia experience considerably poorer employment outcomes, with a 52.2% employment to population ratio compared with 75.9% for people without caring responsibilities.
- The education and employment prospects for Australia’s 235,000 young carers are also poor where 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.

Financial Security including Superannuation

Long term financial security is essential to achieving the economic well-being and sustainability set out in the Statement for Australia’s Carers⁸.

Carers Australia’s “Caring Costs Us Report”, stated that, “The economic impact on lifetime income and retirement savings of informal carers recently released by Carers Australia found, on average, the superannuation balance at age 67 of a primary carer is reduced by about \$17,700 for every year they are in that caring role. Similarly, lifetime earnings are reduced by \$39,600 for every year they are a primary carer”⁹.

Further, there were two major, fully costed policy solutions recommended in this Report:

- Government paying into the superannuation accounts of primary carers based on the amount of Carer Payment they receive
- Increasing the Carer Allowance as it is likely that the number of people willing to be primary carers would increase as a result, with further savings to government due to decreased reliance on paid care services

Despite technically being out of scope for this inquiry, both of these policy options require close examination and consideration.

⁸ Statement for Australia’s Carers. Retrieved from: <https://www.legislation.gov.au/Details/C2010A00123> see Schedule 1

⁹ Carers Australia *Caring Costs Us Report*. Retrieved from: <https://www.carersaustralia.com.au/programs-projects/caring-costs-us/>

Recommendation 2

That a future inquiry examine financial support for carers including the levels of the Carer Allowance, Carer Payment and the long term financial security of carers including improved superannuation arrangements.

Lack of Flexibility in Employment

Many carers struggle to balance their caregiving responsibilities with employment.

Senate Select Committee on Work and Care inquiry

On 3 August 2022, the Senate established a Select Committee on Work and Care to inquire into and report on a range of issues regarding the combination of work and care across Australia.

This Committee's interim report was published in October 2022¹⁰ and included seven recommendations for "immediate action", stating that:

"As this report and the committee's final report will show, the evidence is clear that there are many adverse and sometimes long-term challenges and consequences for people trying to balance work and care - and sometimes for those they care for. The evidence is also clear that the case for more immediate change is pressing—some of it urgent—to improve the lived experience of working carers.

In this interim report the committee makes a start on seven more immediate challenges which received considerable attention in hearings and submissions and for which specific remedies were discussed. We look forward to their consideration in the next phase of the committee's work, along with discussion of longer-term challenges."

The Committee's 264-page final report was published in March 2023¹¹ and included 33 recommendations.

The Executive Summary of the final report states,

"Australians now have a right—indeed, an obligation—to work, but they do not have a right to both work and care. This mattered less when the paid workforce was mostly made up of men – with women doing unpaid work at home: it matters a great deal now when the labour force is almost half women and an ageing population is increasing the need for care.

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."

The Federal Government is yet to respond to these recommendations.

¹⁰ Senate Select Committee on Work and Care, Interim Report. Retrieved from: https://www.apf.gov.au/Parliamentary_Business/Committees/Senate/Work_and_Care/workandcare/

¹¹ Senate Select Committee on Work and Care, Final Report. Retrieved from: https://www.apf.gov.au/Parliamentary_Business/Committees/Senate/Work_and_Care/workandcare/

Many of these recommendations provide details that could be used to enhance the Carer Recognition Act, such as recommendation 1 which states, “This reform package should ensure that Australians have a right to care, alongside their right to work, and our systems and laws should provide unequivocal support for this important role through a new work and care social contract fit for the 21st century”, and recommendation 2 that suggests including a statement in the Federal Budget papers providing an estimate of the annual financial contribution of unpaid care to the national economy.

Recommendation 3

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 Carer Recognition Act, such as the right to care alongside the right to work and an estimate of the value of unpaid care being included in the annual budget papers.

Employment arrangements

The benefits of providing specific workplace arrangements for carers has significant benefits for employers, including staff retention, improved productivity and job satisfaction of employees, which in turn reduces recruitment and training costs.

Offering flexible workplace provisions which allow employees to combine paid work with an unpaid caring role is essential to enable businesses to foster a productive, efficient and effective workforce.

As stated earlier, whilst the Statement of Australian Carers, appended to 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”, it does not address the need for flexible working conditions, such as flexibility around paid carer leave or flexible working hours, to accommodate carers' needs and ensure their employment rights are protected.

It is also important that workplaces foster a carer-friendly culture to ensure carers accessing flexible workplace arrangements are supported by managers and colleagues and not viewed negatively.

Recommendation 4

That the Statement of Australian Carers be amended to include a reference to flexible working arrangements and fostering carer-friendly workplaces to accommodate carers' needs.

Limited Awareness and Implementation

Awareness and understanding of the Carers Recognition Act 2010 among carers, service providers, and the broader community is insufficient. Effective implementation of the Act's provisions and its associated Guidelines, including the dissemination of information and accessibility of support services, is crucial to ensure its intended benefits reach carers effectively.

Whilst awareness of the Carers Recognition Act 2010 is arguably insufficient, there are a plethora of mostly on-line resources and services such as the Carer Gateway, Carer Help, and CareSearch.

The Carer Gateway was introduced in 2015 to provide the same level of support and connection to services to all carers across Australia no matter where they live.

According to the Senate Select Committee on Work and Care Final Report¹², the Federal Government, “has committed more than \$770 million to 2023–24 to support informal carers through the Carer Gateway, designed to connect carers with a nationwide network of service providers. Despite a national advertising campaign to explain the Carer Gateway, the committee was told that since 2020, only four per cent of carers have registered through the gateway with local service providers”.

Increased consultation with, and research into the needs of, carers will undoubtedly lead to a more tailored approach to addressing the services and support needs of carers.

Carer research

The Senate Select Committee on Work and Care final report recommended “that additional research be funded to independently analyse and publicly report on the circumstances and experiences of carers in Australia”.

To date, the personal and societal impacts of those who care for and support people with neurological conditions have not been quantified in Australia or overseas. In addition, there is a lack of a deep understanding of their support roles and needs, the factors associated with support burden, and how roles and burden change throughout the course of the condition. As a result, no strategies have been developed to mitigate support burden, nor have holistic interventions been developed to assist those who care for and support people with neurological conditions.

The NAA believes that research on the needs of carers must be evidence-based, involve robust, enduring cohorts, and be longitudinal, not just at a point in time. Ideally, the research will involve the carer, the person being cared for plus the wider network of people linked to both.

Carer services and support should focus on physical and economic needs and also the psycho-social and emotional needs of carers which could be considered as important, if not more important, than physical support.

One example is a study by Jennifer Ervin and Dr Tania King, University of Melbourne that gathered evidence looking at the link between unpaid caregiving and the mental health of working-age adults in high-income OECD countries. The study concluded that unpaid caregiving is detrimental to the mental health of working-age adults. Further, where evidence could be ordered by gender,

¹² Senate Select Committee on Work and Care, Final Report. Retrieved from: https://www.apf.gov.au/Parliamentary_Business/Committees/Senate/Work_and_Care/workandcare/

caregiving was consistently negatively associated with mental health for women¹³.

Another example is a study currently under development by the Menzies Institute for Medical Research in partnership with MS Australia and Carers Australia - Mitigating the burden of caring to improve the lives of people with MS and their support network: The Australian Multiple Sclerosis Carers Study.

This project aims to:

1. Measure the personal and economic costs of caring for and supporting people with MS, and determine the factors associated with an increased carer burden.
2. Assess how the burden, roles, quality of life and needs of carers/support people change over the disease course and assess whether potentially modifiable factors identified in Aim 1 are important drivers of change.
3. Translate the findings of Aims 1 and 2 through recommendations and the development of online resources, including a MOOC specifically for those who care for and support people with MS.

Research of this kind will lead to improved quality of life and have positive flow-on effects on the lives of the people with neurological conditions and Australian society more broadly.

Recommendation 5

That the Statement for Australia's Carers be amended to include a reference to the needs of carers being underpinned by robust research into the needs of carers to ensure carer supports and services are "timely, responsive, appropriate and accessible".

Conclusion

In conclusion, the NAA is pleased to provide a submission to the Parliamentary inquiry into the recognition of unpaid carers. We look forward to working with the Department to make constructive suggestions for implementing improvements to the quality of life of carers of people living with neurological and neuromuscular disorders and conditions.

¹³ The real cost to unpaid carers, University of Melbourne. Retrieved from <https://pursuit.unimelb.edu.au/articles/the-real-cost-to-unpaid-carers>