



**Advancing care, advocacy and research in support of those living
with motor neurone disease (MND)**

**Submission to the Joint Standing Committee on
the Social Policy and Legal Affairs Inquiry into
the *Carer Recognition Act 2010***

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About MND Australia

MND Australia is the national peak body of state organisations that support those living with and impacted by motor neurone disease (MND). Since 1993, we have been the voice for the MND community. Our national and international networks help increase understanding of the disease and advocate for the needs of those affected.

The six state MND associations provide direct support and services to people living with MND, their carers and families and the health professionals and service providers involved in their care in all states and territories.

Together we are committed to ensuring people living with MND, their carers and family have timely access to:

- care and support to meet their individual needs to enable them to live better, for longer, no matter their age or postcode
- diagnosis, clinical trials, technologies and therapies.

About MND

Motor neurone disease (MND) is the name given to a group of neurological diseases in which motor neurons – the nerve cells that control the movement of voluntary muscles – progressively weaken and die. With no nerves to activate them, people with MND lose their ability to walk, to speak, to swallow and to breathe.

MND affects each person differently with respect to initial symptoms, rate and pattern of progression and survival time. Average life expectancy is just 27 months from diagnosis, with more than half dying within two years of diagnosis.

There are no known causes for MND, apart from the 10 per cent of cases which have a genetic basis. There are no effective treatments and there is no cure. There are no remissions and progression of MND is usually rapid and relentless creating high levels of disability and a consequent need for a wide range of changing supports based on the person's complex needs.

Terms of Reference

House of Representatives Standing Committee on Social Policy and Legal Affairs inquiry into and report on the provisions and operation of the *Carer Recognition Act 2010* (the Act) in relation to unpaid carers, with a view to reform through legislative amendment. Limited to the Objects of the current Act, the inquiry will have regard to:

- 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.**

Executive Summary

Not all work is equal and nor is all work recognised. This was the impetus behind the initial development of the *Carer Recognition Act 2010*. Many carer representative organisations¹ advocated for full recognition of the role of carers in supporting Australians who are chronically ill, disabled, aged or otherwise infirm. However, the resulting Act failed to deliver full rights and legal recognition of carers. In effect the Act offers only tokenistic recognition with no legally binding commitments to the rights of carers across Australia.²

In 2018, the Australian Bureau of Statistics (ABS) conducted the Survey of Disability, Ageing and Carers³ at that time it was estimated that there were at least 2.65 million carers supporting people with disabilities (or the elderly) in Australia, of which about 861,600 were primary carers (an individual providing the primary care for the person requiring support). The growing shift in emphasis away from institutional care towards 'ageing at home' and community care has seen the role of carers become even more important in the community.

In Australia according to an ABS Time Use Survey⁴ women still shoulder one hour extra per day than men on unpaid duties. Women are also expected to compromise their work hours to manage these unpaid duties, according to the data that equates to an hour per day.

Furthermore, whilst unpaid care work is not formally considered in accounting for social policy, such as in formal GDP figures; it is collated in data sets and it has been given a dollar figure according to the Unpaid Care and Labour market Report 2021 by the Gender and Workplace Agency – the value of unpaid care in Australia is \$650.1 Billion or 50 per cent of GDP. This means that unpaid carers carry almost exactly half the burden of running the overall economy – the care economy is the economy.

¹National Carers Coalition, Submission to the 2008 Standing Committee on Family, Community, Housing and Youth, Inquiry into better support for carers.

<http://www.aph.gov.au/house/committee/fchy/carers/subs/sub571.pdf>

²Carer's Alliance, Federal carers recognition legislation a pale version of what family carers want, media release, 18 March 2010.

³ Australian Bureau of Statistics (ABS), A profile of carers in Australia, 2018, <https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release>

⁴<https://www.abs.gov.au/statistics/people/people-and-communities/how-australians-use-their-time/latest-release>

MND and Carers

“Mum felt herself becoming more of a carer than a wife; I often felt the same as a daughter...despite the ongoing support {from external services}, my sister and I were still faced with responsibilities far beyond our years, making it difficult to relate and feel supported by our peers.” – a young woman MND carer’s experience from Tasmania.⁵

MND is a confronting, devastating and fatal diagnosis, and it is often a disease that can consume the energy of an entire family. Many people living with MND can feel guilty about having to rely on family members for care and some people with MND feel strongly that their adult children should not be left responsible with their care.⁶ And there are people with MND who have no family to care for them.

MND Australia provides information to people with MND⁷ and their carers and the State MND Associations provide supports and services⁸ for people with MND and their carers. However, external supports can be limited especially if the client is aged 65 or over and ineligible for an NDIS package. This means that the bulk of the caring responsibility will fall to informal supports or family as carers.

The Carers Recognition Act 2010 in its current format is inadequate for carers of people with MND as it does not hold any legally binding commitments to carers from public service agencies, this includes the NDIS and Aged Care packages.

Responses to the Terms of Reference

Recognition of Carers in Australia

According to a Deloitte report (2021), *The Value of Informal Care in 2020*, unpaid or informal care made a significant contribution to Australia but, that value in formal terms is not captured in the GDP figures. Deloitte estimated that the replacement cost of informal care (that is if a service was utilised instead of informal care), would be in the vicinity of \$77.9 billion. Additionally, the loss of earnings from carers who provide informal unpaid care is estimated at \$15.2 billion.

In 2015, an economic analysis of motor neurone disease in Australia⁹ found the productivity loss due to informal care was \$68.5 million, or \$32,728 per person. Individuals bear most of

⁵ <https://www.acn.edu.au/publications/the-hive-2018/my-experience-caring-for-someone-with-motor-neurone-disease>

⁶ <https://healthtalk.org/motor-neurone-disease-mnd/impact-of-mnd-on-family-carers>

⁷ <https://www.mndaustralia.org.au/getmedia/7ddb1ee3-36d1-4f42-b2fa-60c44eb57097/More-Facts-about-MND.pdf>

⁸ <https://www.mndaustralia.org.au/mnd-connect/find-services>

⁹ [https://www.mndaustralia.org.au/getattachment/b276ef51-9e06-4ff3-98a6-4f89304913fb/deloitte-au-economic-analysis-motor-neurone-disease-australia-230216-\(1\).pdf?lang=en-AU](https://www.mndaustralia.org.au/getattachment/b276ef51-9e06-4ff3-98a6-4f89304913fb/deloitte-au-economic-analysis-motor-neurone-disease-australia-230216-(1).pdf?lang=en-AU)

these costs (\$44.0 million), with government bearing the rest (\$24.5 million). Each informal carer is estimated to provide 7.5 hours of care per day to people with MND.

These figures alone highlight that carers are neither adequately recognised nor valued. If carers were recognised then their contribution to the overall “care economy” would not only be formally recorded but their actions would be suitably remunerated.

National Disability Insurance Scheme (NDIS) and Carers

Technically the NDIS is required to comply with the Act, and in a recent transparency report¹⁰ the National Disability Insurance Agency claims compliance with the Act stating, “the role of carers is recognised by the agency as an important factor in developing participant plans”. However, our members tell us that carers are not considered “important” when developing participant plans for people with MND – and this is an experience that is nationwide. Noting again that while the Act states that agencies must comply, there is no binding legal obligation for agencies to do so, nor any means for an agency to be held account should they fail to comply with the Act.

A woman with MND who is not eligible for the NDIS so her family care for her and organise her care. She says, “My life has been consumed by endless emails and phone calls, coordinating care, constantly sourcing equipment, medical appointments, and 70 hours a week of hands-on care. Every week brings more and more pressure to cover the hours needed, as we all grow tired and frustrated by not having enough help instead of enjoying the time we have left. All three of the sisters own small businesses and if it were not for the fact that we have flexibility with our hours there is no possible way that we could manage the demands of keeping our Mum at home where we want her. We are stressed and anxious about how we can together manage the demands of our own families and business together with the urgent needs of our Mum. I’m personally torn between wanting to be at home to mother my own son and caring for my beautiful mum like she has done for me”. - Woman carer South Australia.

Aged Care and Carers

The Royal Commission into Aged Care Quality and Safety received numerous submissions from private citizens and carer organisations stating that getting recognition for the informal care role is not adequately recognised by providers or state agencies in Aged Care. Carers noted that they faced barriers in accessing support and training to help them manage their informal unpaid carer roles, despite the existence of the Act and the alleged requirement for compliance.

That the Commonwealth Carers Recognition Act (2010) is included as a key piece of legislation underpinning Home Care Package program policy and that aged care service

¹⁰<https://www.transparency.gov.au/annual-reports/national-disability-insurance-scheme-launch-transition-agency/reporting-year/2019-20-24>

providers are therefore required to comply with the Act. That the Framework for Carer Recognition be adopted in the Home Care Package Program to facilitate service providers providing services that both support the older person and maximises recognition and respite effect for carers.¹¹

The effectiveness of existing state, territory and international recognition of unpaid care.

Across the nation each State and Territory have a version of a Carers Act, the majority of which pre-date the Commonwealth Act and its policy setting. As noted in the Aged Care Royal Commission submissions, despite the presence of all these layers of legislation there is no actual formal legally binding recognition of carers. This is exacerbated by the absence of an overarching national carers framework¹²; the lack thereof fuels inconsistency and fragmentation of supports and services for carers.

The international perspective bears similar experience to here in Australia. This inquiry into the Carer Recognition Act should consider international experiences and advocacy efforts including for example Euro Carers¹³ which argues that care must be mainstreamed across all life sectors and not just limited to one or two issues (e.g disability, aged care). All people will require some form of informal care across their life course, thus appropriately and formally recognising this need for care and of the role of carers is right and just – it articulates the care economy.

How to better identify the role of unpaid carers in Australian society and the role of a reformed Act:

As noted previously, despite data being collated as to the value of unpaid carers in Australia, this data is not formally recognised. It is also probable that the data on unpaid carers is not comprehensive and that the figures may in fact be larger than these estimates. The current value of \$650.1 billion or 50 per cent of GDP is seriously significant and must lead to inclusion of unpaid care figures in future formal figures including GDP if Australia is to follow the trajectory of a Wellbeing Economy.

The impact of the COVID pandemic showed Australia that workplace arrangements can be flexible and that it is possible to work remotely¹⁴ – though not possible in all sectors, it is certainly possible across many work areas. Flexible work is an ongoing requirement for unpaid carers, not only does it provide opportunities to participate in the economy with

¹¹<https://agedcare.royalcommission.gov.au/system/files/2020-06/RCD.9999.0130.0023.pdf>

¹²National Carers Coalition, Submission to the 2008 Standing Committee on Family, Community, Housing and Youth, Inquiry into better support for carers.

¹³<https://eurocarers.org/>

¹⁴ <https://www.oecd.org/coronavirus/policy-responses/teleworking-in-the-covid-19-pandemic-trends-and-prospects-72a416b6/>

much needed income, it also provides social validation and interaction – vital aspects for wellbeing.

Recommendations

MND Australia recommends that the *Carer Recognition Act 2010* in its entirety be withdrawn and a new Act be developed in full consultation and co-design with carers across Australia to better reflect the full impact the role of carers have on the Australian community and economy; and to ensure the rights of carers are fully legally recognised and operationalised in accordance with Australia's obligations under the seven human rights treaties to which we are signatory.