

MULTIPLE SCLEROSIS AUSTRALIA

Submission to the Senate Select Committee on Work and Care inquiry

8 September 2022

**Associate Professor Des Graham
President**

**Rohan Greenland
Chief Executive Officer**

MS Australia
Level 19 Northpoint Building,
100 Miller St
NORTH SYDNEY NSW 2060
T: 02 8413 7977
F: 02 8413 7988

Introduction

MS Australia (MSA) is pleased to provide a submission to the Senate Select Committee on Work and Care inquiry as it relates to carers of people living with Multiple Sclerosis (MS).

The focus of the comments provided in this submission are on key areas that will impact people affected by MS and other neurological conditions for which our state member 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, their families, friends and carers. 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 and their carers, 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.

Summary of recommendations

Recommendation 1:

MS Australia supports flexibility in employment and workplace options, including the ability to request extended unpaid carer's leave, but such flexibility 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.

Recommendation 2

MS Australia recommends that this inquiry review the impact of recommendations made in previous inquiries regarding work and caring responsibilities, building on achievements such as the introduction of the Carers Gateway as a source of information and referral and addressing areas where gaps remain such as improved financial support for carers.

Recommendation 3

MS Australia recommends that Integrated Carer Support Service Model and those funded services participating in the Carer Support Framework be reviewed, utilising the lived experiences of carers to inform the evaluation terms, design and recommendations.

Recommendation 4

MS Australia recommends the establishment of specific programs to support people to transition from a carer's role to employment once their caring responsibilities end including access to training and education and grief and adjustment counselling.

Recommendation 5

MS Australia recommends introducing flexibility for carers by amendment of the eligibility criteria for Carer Payment and Carer Allowance in line with the Productivity Commission's Mental Health Inquiry recommendations, especially by replacing the 25 hour per month restriction on work, study and volunteering with a 100 hour per 4-week restriction on work only.

Summary

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 the 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 unpaid carers in general, and the recognition they rightly deserve whilst also undertaking paid employment.

The first assumption that should be challenged is that informal caregiving is an individual choice. Informal caregiving, especially for those who live with a progressive neurological or chronic disease and the associated functional impairments and disability, is often an inevitable part of life.

For an episodic illness such as MS, informal caring can occur across the lifespan of the disease and that of a person's life. It is often complicated by other disease diagnosis or co-morbidities and compounded due to the chronic and progressive nature of MS. Lived experience could also be influenced by the caregiver's own support needs and social and environmental factors.

Informal caregiving, whilst trying to maintain a connection to paid employment, cannot be discussed without some acknowledgement and recognition of the gendered or cultural nature of these roles.¹ A tension often exists within workplaces trying to manage the workplace priorities and demands, the need for certainty and trying to incorporate contemporary workplace practices within an existing workplace relations framework – whilst trying to balance the need to provide a supportive family friendly workplace.

An unintended consequence and impact of the COVID-19 pandemic was the positive shift in attitudes regarding flexible working arrangements and the belief that productivity can be maintained within such an environment. But the last few years of COVID have also highlighted the real consequences of loneliness and social isolation, and how a working from home pattern might negatively impact on career progression.

¹ <https://www.wgea.gov.au/sites/default/files/documents/australian-unpaid-care-work-and-the-labour-market.pdf>

Overall, this submission will aim to highlight the benefits of family friendly workplaces to both businesses, community, the economy and of course those families affected. We are aware of the need to find a workable balance²; and that there is not a “one size fits all” solution.

Despite some progress, unpaid caregivers in paid employment continue to experience legal, social and policy barriers. Their lived experiences continue to shape the Australian paradigm. We cannot have this discussion or make this submission without referring to these lived experiences and provide informal carers an equal place at the table.

Terms of Reference

a) The extent and nature of the combination of work and care across Australia and the impact of changes in demographic and labour force patterns on work-care arrangements in recent decades;

Carers, caregivers or informal carers are not a homogenous group. The *Commonwealth Carer Recognition Act 2010*³ defines carers as ‘people who provide personal care, support and assistance to another individual in need of support due to disability, medical condition, including terminal or chronic illness, mental illness or is frail and aged.’ This term is further defined for agencies under the *Commonwealth Carer Recognition Act 2010 Guidelines (2016)*⁴; *excluding other forms of informal caring such as that for a parent of a young child, as a foster carer or other forms of caring that might require an employee to take carer or parental leave.* Although broader definitions exist, it is important to know that this definition sets out how and when Commonwealth agencies can become involved or provide support (financial) to carers but also how this access criteria impacts on current data availability and transparency for informal carers in Australia.

For those carers within paid employment, the *Fair Work Act 2009*⁵ and *National Employment Standards*⁶ further define when an employee is deemed a carer, what evidence is required to satisfy this definition, what flexibility may exist in the workplace and what leave entitlements might be available for carers. Unfortunately, limited public data resources exist on quantifying the extent and use of carer’s leave for those living as informal carers within a place of employment, who do not have recourse to public funds.

To understand this phenomenon, researchers, policy and funding decision makers could also investigate the various reasons that exist for these informal caregiving arrangements. These may include but are not necessarily limited to, age and frailty of the person being cared for, episodic physical or mental illness, disability, health and chronic conditions or due to a terminal illness.

² https://humanrights.gov.au/sites/default/files/content/sex_discrimination/publication/strikingbalance/docs/STB_Final.pdf

³ <https://www.legislation.gov.au/Details/C2010A00123>

⁴ https://www.dss.gov.au/sites/default/files/documents/05_2016/carer_recognition_act_2010_guidelines_april_2016.pdf

⁵ <https://www.legislation.gov.au/Details/C2019C00270>

⁶ <https://www.fairwork.gov.au/tools-and-resources/fact-sheets/minimum-workplace-entitlements/introduction-to-the-national-employment-standards>

Other variables or enquiries can investigate the type of care and support provided to the number of hours per week dedicated to this task. There is no age limit to informal caregiving, which can include children and young people to those over 65 years of age providing informal care. Evidential data only appears to exist for those claiming some form of social security payment such as the carer allowance and does not include data on young carers.

Census data based on self-reporting might assist. According to the Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers (SDAC), in 2018 there were 2.65 million people (10% or 1 in 10 Australians) who provided informal care in Australia (ABS 2019).⁷ Again, these figures might only relate to those providing informal care who are over 18 years and view themselves as carers. This is an important distinction. Many families, friends and loved ones do not identify with this term and feel that 'carers' more relate to those paid to provide care in the community. It is therefore likely that the prevalence of carers, as provided by the ABS, is an underestimate.

Females are more likely to be carers than males, with 12.3% of all females providing care and 9.3% of all males.⁸ Significantly, 7 out of 10 *primary carers* are females⁹ According to the ABS, the average age of carers are 54 years, and 1 in 11 carers are under the age of 25 years.

According to a report "*The value of informal care in Australia*", prepared by Deloitte for Carers Australia in May 2020, the total number of informal carers in Australia has risen to 'almost 2.8 million informal carers, comprised of around 906,000 *primary carers* in Australia and 1.9 million *non-primary carers*. This represents a 5.5% increase in the number of carers since 2018 due to population growth.'

MS Australia highly commends this report as an essential reference to this inquiry.

Understanding MS in this policy context

MS is the most common acquired chronic neurological disease affecting young adults, often diagnosed between the ages of 20 to 40 and, in Australia, affects three times more women than men. As yet, there is no cure. There is no known single cause of MS, but many genetic and environmental factors have been shown to contribute to its development.

In MS, the body's own immune system mistakenly attacks and damages the fatty material – called myelin – around the nerves. Myelin is important for protecting and insulating nerves so that the electrical messages that the brain sends to the rest of the body, travel quickly and efficiently. As the myelin breaks down during an MS attack – a process called demyelination – patches of nerves become exposed and then scarred, which renders the

⁷ <https://www.aihw.gov.au/reports/australias-welfare/informal-carers>

⁸ Australian Bureau of Statistics 2018, *Disability, Ageing and Carers, Australia: Summary of Findings*, viewed 15 February 2021, available: <https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release#carers>

⁹ <https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release>

nerves unable to communicate messages properly, and at risk of subsequent degeneration.

This results in a range of symptoms, corresponding with the damage within the central nervous system (CNS), that can include a loss of motor function (e.g., walking and hand and arm function), loss of sensation, pain, vision changes and changes to thinking and memory. These symptoms can also interact with each other to compound functional impairments.

Due to the potential randomness of this auto-immune response, no person experiences MS in the same way.

Demographics and disease course

There are over 25,600 people living with MS in Australia, although recent figures suggest the incidence of MS in Australia and worldwide is increasing. Worldwide, 2.8 million people live with MS.¹⁰

Often a diagnosis of MS occurs when people are fully employed, planning a family, and making significant career choices.

There are three courses MS can take. Around 15% of the MS population is diagnosed with a progressive form of MS with no periods of remission, termed Primary Progressive MS (PPMS). How fast the disease progresses may vary, but the declining neurological progression is constant. Relapsing remitting MS (RRMS), the most common form of MS, is characterised by partial or total recovery after attacks (also called exacerbations, relapses or flares). 70 to 75% of people affected by MS initially begin with a relapsing remitting course. Secondary progressive MS (SPMS) is a relapsing remitting course which later becomes steadily progressive. Attacks and partial recoveries may continue to occur. Of the 70-75% who start with relapsing-remitting disease, more than 50% will develop SPMS within 10 years; 90% within 25 years. A further differentiation is made by categorising disease activity as active (with or without worsening) or stable.

Informal care for people living with MS

'MS has a significant social, financial, psychological, and physical impact on the affected individual as well as his or her family.'¹¹ It also has a significant economic impact on Australia. MS Australia commissioned the *Health Economic Impact of MS* in 2018¹². This report suggests that the total costs for all people with MS in Australia have increased substantially over time from \$1.24 billion in 2010 to \$1.75 billion in 2017 (an increase of 41%) due to both an increase in number of people living with MS and increased per person costs. To put this in context, the report suggests that the annual per person costs of MS are comparable to those of a person with Parkinson's disease, or the first year following a stroke and are three times higher than for a person with Type 2 Diabetes.

¹⁰ <https://www.atlasofms.org/map/global/epidemiology/number-of-people-with-ms>

¹¹ https://journals.lww.com/jnnonline/Abstract/2008/02000/Assessment_of_Caregiver_Burden_in_Families_of.5.aspx

¹² 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

The above economic impacts were based on the following survey methodology:

The baseline survey established basic health, employment and financial profiles of people with MS, as well as provided an indication of the indirect costs of MS (such as costs from lost wages due to early retirement, occupation change, and employment status change) and direct nonmedical costs (such as informal care costs due to carers' reduced employment).

The cost diary captured detailed information on various cost categories relating to MS, such as prescription medications, non-prescription medications, disposable equipment, health professionals, nursing services, community and private services, medical tests, hospital stays, special equipment-hire, special equipment-purchase (mobility, visual aids, communications, bathroom, kitchen, bedroom, general), alterations to home, alterations to car, and transport. The cost diary included (where possible) a comprehensive list of the items related to each cost category to assist respondents in reporting information on costs incurred due to MS. Participants were asked to complete the cost diary everyday over the six-month period to minimise the possibility of any recall bias.

The report found that:

- There should be a continued focus on managing symptoms and supporting people with MS and their carers in employment, particularly for men with MS and people living outside of major metropolitan areas
- The direct personal costs and informal care costs increased with increasing disability severity
- Informal care costs and indirect costs from lost wages increased markedly from mild disability to moderate disability
- Informal care costs, and indirect costs from lost productivity were similar for both sexes. Indirect costs from lost wages however were higher for males relative to females. The higher indirect costs from lost wages for the male sex appear to be driving the trend observed in the analysis of total costs by sex.
- The direct personal costs, and informal care costs increased with age
- Informal care costs were substantially lower for people with RRMS than progressive forms of MS
- The direct personal costs and informal care costs were higher for people not using disease modifying therapies (DMTs). Specifically, the informal care costs declined from \$8,357 (in 2010) to 7,144 (in 2017). Better health outcomes for people with MS due to the use of more effective DMTs, and better (patient-centred) management of MS may explain this pattern.

The recent AIHW's *People with disability in Australia 2022*¹³ report's findings were consistent with the above, highlighting that for those deemed as primary carers, over 65% reported that their personal income levels decrease and their rate of expenses increase if they reside with the person they provide care too.

¹³ <https://www.aihw.gov.au/getmedia/5f322ec4-ef63-4c43-a854-64f7a2f55a04/aihw-dis-72-people-with-disability-in-australia-2022.pdf.aspx?inline=true>

MS Australia has contributed to a number of inquiries to highlight the economic impact of MS. Our recent submission the Senate Community Affairs References Committee inquiry into the “Purpose, intent and adequacy of the Disability Support Pension (DSP)”¹⁴ highlighted the impacts of these personal costs through lived experience examples. Living in poverty affects everyone in the family – limiting choice and control.

Geographical location and cost of living may impact on a person’s ability to access supports.

Key findings from the AIHW’s *People with disability in Australia*¹⁵ report found that:

- 1 in 13 (7.6%) people aged under 65 with disability delay or do not see a GP when needed because of cost.
- 1 in 4 (24%) people aged 15–64 with disability wait longer than they feel acceptable to get an appointment with a GP.
- 1 in 2 (47%) people aged 5–64 with disability *who need health care assistance receive only informal assistance*.

The report suggests that people with disabilities in Australia may therefore rely more on family and friends’ informal care to supplement their health care needs.

The same report suggests that 346 000 (or 2 out of 3) people with disabilities need help with healthcare activities. The more severe the disability impacts, the more likelihood of their need for informal support. People aged 5–64 with severe or profound disability who need assistance with health care are more likely (56% or 207,000) to receive informal assistance only compared to those with other disability status (25% or 42,000), and less likely (15% or 57,000) to receive formal assistance only (42% or 71,000).

Interestingly, it found that females aged 5–64, who need assistance with health care, are more likely (29% or 75,000) than males (19% or 53,000) to receive formal assistance only. Males are more likely (53% or 150,000) than females (40% or 101,000) to receive informal assistance only (ABS 2019a). This is consistent with previous gendered findings.

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:¹⁶

- There are **approximately 22,272 MS carers** across Australia
- **87%** of people living with MS have someone (unpaid or informal) who is their main source of support*
- **69%** of carers provide daily emotional support, rather than physical assistance

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

¹⁵ <https://www.aihw.gov.au/getmedia/5f322ec4-ef63-4c43-a854-64f7a2f55a04/aihw-dis-72-people-with-disability-in-australia-2022.pdf.aspx?inline=true>

¹⁶ <https://www.msaustralia.org.au/for-family-friends-and-other-carers/>

- **69%** of carers report that caring has an impact on their emotional wellbeing
- **45%** of carers are paying for health professional supports
- **61%** of were employed full time before they started to provide care for someone with MS
- **30%** of carers are employed full time while caring for someone with MS

b) the impact of combining various types of work and care (including of children, the aged, those with disability) upon the well-being of workers, carers and those they care for;

'Improving the wellbeing of people with disability and carers across the nation requires a collaborative response from all levels of government, extending well beyond the NDIS to many other service systems, such as housing, transport, health, justice, and education.'¹⁷

Significant advancement in awareness of MS has resulted in the earlier detection of MS in Australia. Paired with the availability of disease modifying therapies, people now diagnosed with MS have a much better disease trajectory than those diagnosed in previous decades. Although those newly diagnosed can now maintain a much higher quality of life, others continue to require ongoing support and care from their loved ones.

Case study

It is ten years since my daughter was diagnosed with MS at the age of 28. Learning that it was MS was a shock but it was also a relief to finally know what we were dealing with. Like so many others, we weren't given any information or guidance so I did my own research, phoning people and learning as much as I could about the treatments available.

Ten years later, I try very hard to keep up with what's going on in the field of MS, particularly as we have since had a second daughter diagnosed with the disease. The pace at which all the research and development that is going on with MS can make it difficult to keep up but staying informed is vital.

Caring for our daughters, one of whom lives at home with us, has impacted on us in every way. We are constantly juggling everyday life: work, caring, household tasks, paperwork, and hospital appointments. It's a delicate balancing act – one of our biggest worries is one of us falling seriously ill because that will upset the apple cart as far as the family is concerned.

Financially, the strain has been immense. We've got to put things into place for our daughters to secure their futures and consider suitable renovations to our home to ensure it's fully accessible in case it's needed in the future. I had imagined I would be retired by now but instead we have a role reversal, where we as parents are looking after our children, and we are having to work more years than we envisaged.

¹⁷ <https://www.pc.gov.au/inquiries/completed/disability-agreement/report/disability-agreement-overview.pdf>

In terms of support for others who are caring, I think the most important thing is that carers are given information on what's available locally, as well as nationally, on the help and entitlements that they can benefit from, as soon as they take on the role of carer.

As a carer, you inevitably get tired and frustrated. It can sometimes lead to anger on both sides. But, just like all families, you think it through, you make it up and you keep going. Caring probably has made us closer but the truth is we love them just the same. It's unconditional love. It needs to be done and we just get on with it.¹⁸

Informal carers of people living with MS have been the subject of a number 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.¹⁹ Informal caregivers especially provide psychosocial, social and assistance with activities of daily living.

In a recent international qualitative study utilising photovoice²⁰ methodology where participants were able to document their experiences of informal caregiving to someone with MS via photo, video and written reflections, a number of interrelated themes were identified:

- challenges and troubles i.e., daily tasks and responsibilities such as housekeeping and navigating physical barriers in the environment. (39%)
- a sense of loss i.e., personal and shared experiences or activities, lack of time, and social constraints due to caring causing social isolation (38%)

'I like real ale and old pubs. Unfortunately I can't go to many with my partner as they usually have toilets that are difficult to get into with a wheelchair as they don't have disabled toilets which means I miss out on something I like to do.'

(Patrick, aged 52, caring for his partner)

'No time to enjoy life and do the things that I actually like, no time to relax... It's all about having the time! If you don't have enough time, then there is no quality of life...'

(Emma, aged 37, caring for her spouse)

'The time is simply not enough. Working full-time, caregiving and other responsibilities at home don't leave me much time to do the things that I like, which can be a little frustrating at times'

(Matt, aged 35, caring for his spouse)

- emotional impact of caregiving, including feelings of hopelessness, feeling useless, powerless, despair, anger (34%)

'I'm always concerned about my mother. What if she gets worse or never gets well?'

(Susan, aged 33, caring for her parent)

¹⁸ <https://www.merckgroup.com/es-es/informes/Living-with-MS-Carers-Perspective.pdf>

¹⁹ <https://onlinelibrary.wiley.com/doi/10.1111/hsc.13687>

²⁰ <https://bpspsychub.onlinelibrary.wiley.com/doi/full/10.1111/bjhp.12482>

*"I get worried about the possibility of her getting worse
(George, aged 54, caring for his spouse)"*

I worry sick every time one of my kids complain of pins and needles or tingling and numbness in their bodies. I can't handle if they have MS too.

(Jennifer, aged 46, caring for her parent)

- urge to escape the caregiving role and difficult situations, including feeling 'trapped in the home' (17%)
- a sense of anxiety about the unpredictable nature of MS (14%)

'To express their feelings about unpredictability, participants either used images of sky or sea which symbolized the uncertainty and the unknown beyond the clouds or the horizon. One carer took a photograph of a grey sky with heavy dark clouds and compared the unpredictability of MS with that of the weather, concluding that the unpredictability of MS is more difficult to deal.'

More positive benefits included:

- sharing precious moments i.e., hobbies, and positive shared activities such as exercise and gardening (34%); and
- helpful support including that of peer support groups, sharing experiences via the internet and socialising with friends (21%).

Whilst carer needs usually become greater over time for those caring for a loved one with MS, a consistent finding of higher caregiver stress related directly to the level of disability of the person living with MS, i.e., burden of mobility and physical barriers. Similarly, high caregiver burden is experienced when the person cared for experiences cognitive problems or neuropsychiatric problems, but also included lower working memory, lower information processing capacity, executive functioning and verbal fluency. There was a correlation between caregiver Quality of Life (QoL) and caregiver depression and cognitive decline of the person being cared for.

Research also acknowledged the contextual care factors, including the availability of respite and other community supports; someone to talk to and use of connective technologies through online peer and information support, especially during the recent COVID-19 pandemic.²¹

'Caring for a MS patient may negatively impact several objective and subjective aspects of caregiver's life, such as physical and emotional health, morale, work life, finances, social mobility, interpersonal relationships and sexual life.'²²

A recent 2020 study entitled *Caregiver Burden in Multiple Sclerosis: Recent Trends and Future Directions*²³ added the importance of understanding the

²¹ <https://doi.org./10.1007/s11910-020-01043-5>

²² https://www.researchgate.net/publication/319398449_Quality_of_Life_and_Burden_in_caregivers_of_Multiple_Sclerosis_patients

²³ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7242779/>

risk factors that might result in caregiver burden. These risks are broadly divided into three main categories:

- the characteristics of the recipient of care (i.e. the type of MS; level of disability; types (e.g. cognitive decline) and resulting impact of MS symptoms),
- characteristics of the informal caregiver (i.e. level of education/ income; physical health and relationship to the person being cared for) and
- social factors such as the duration of care; the extend of the wider support network; and availability and access to information.)

Another systemic scoping review in 2021²⁴ focussed on the multidimensional role of caregiving in the context of MS. Of 108 full studies included, the main caring tasks were listed as: “transferring, dressing, washing/bathing, mobility (including transportation), cooking, feeding, toileting, housekeeping, oral care, wound/medical care, communication (e.g. sending emails or handling phone calls), financial management (e.g. banking, helping with budgets) and shopping. The most common tasks reported were transferring (14/16 studies), dressing (14/16 studies) and washing/bathing (13/16 studies).

As with the above, 86 of the included studies focussed on the effects of caregiving (utilising various standardised questionnaires to extrapolate the data). Only 13 studies (12.0%) provided any reference to the benefits or positive consequences of caregiving, with only three of these studies having a specific objective or focus on identifying benefits (Buchanan & Huang, 2011b, 2012; Pakenham, 2005a).

Comments about benefits or positive consequences included strengthened relationship, personal growth of the caregiver, a sense of accomplishment or feelings of being needed.

The AIHW's *People with Disability in Australia 2022*²⁵ report found that 1 in 6 (17%) people with disability aged 15–64 experience social isolation (8.7% without disability).

It further stated:

‘Social support enables the inclusion of people with disability to participate in many facets of life. Informal support, often by family, friends and the larger community can assist people with disability to be included in society. This is essential for better health as social isolation and loneliness can be harmful to both mental and physical health (AIHW 2021).’

In fact, the report found that some people under 65 years living in residential care due to lack of suitable specialist disability accommodation in the community choose to remain in residential aged care placements if it meant that they could stay close to family and friends, providing them with an ongoing social connection and informal support.

²⁴ <https://onlinelibrary.wiley.com/doi/epdf/10.1111/hsc.13687>

²⁵ <https://www.aihw.gov.au/getmedia/5f322ec4-ef63-4c43-a854-64f7a2f55a04/aihw-dis-72-people-with-disability-in-australia-2022.pdf.aspx?inline=true>

c) the adequacy of workplace laws in relation to work and care and proposals for reform;

In a recent submission to the Productivity Commission's Carer Leave enquiry (26 August 2022), MS Australia supported legislative changes to increase flexibility in employment and workplace options, including the ability to request extended unpaid carer's leave.

Such provisions should however not be used to negate the need for, or seen as supplementation to, clearly defined roles and responsibilities for state and territory and federal governments to adequately commission supports to families affected by informal caregiving.

Similarly, workplace laws should prevent informal caregivers from being subjected to workplace discrimination, harassment or bullying due to their caring responsibilities.

As Chief Justice Allsop AO said in his Justice Speech at the Hochelaga Lecture entitled, Values in Law: How they Influence and Shape Rules and the Application of Law on 20 October 2016 ²⁶. "Law is derived in its very nature, by human values and should be flexible to accommodate changes in the values of a society. And that no system of law can engender loyalty and we must therefore also recognise the danger of absence of adequate rules". Workplace legislation and reforms will only be positively adopted if funding is allocated to awareness campaigns that highlight the benefits of such reforms and provide some form of incentives for employers to encourage adoption. These rules, across state and territory and federal boundaries, should not allow for the discrimination of carers due to exclusions in eligibility or normative assumptions i.e., someone's sexual orientation (i.e. same sex couples or same sex partners) or limiting the number of people that can identify as the principal caregiver (a role that can be shared).

Data published by the Federal Department's Workplace, Gender Equity Agency ²⁷ suggest that:

- only 4/5 employers have a formal flexible work policy and strategy
- only 63% allowed managers to make informal arrangements with employees and only 25% allowed some managers to make informal flex arrangements
- only 64% of employers are provided access to job sharing
- 56% of employers allowed access to compressed working weeks
- 43% provided access to purchase leave arrangements
- and only 65% of respondents (men and women) were likely to have flexible working arrangements approved during COVID.

Recommendation 1:

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.

²⁶ <https://www.fedcourt.gov.au/digital-law-library/judges-speeches/chief-justice-allsop/allsop-cj-20161020>

²⁷ <https://www.wgea.gov.au/sites/default/files/documents/flexcovidinfographic.pdf>

d) the adequacy of current work and care supports, systems, legislation and other relevant policies across Australian workplaces and society;

MS Australia will limit our response to these terms of inquiry, to outline that data transparency is key to making informed policy decisions and determine shared obligations between state and territory and federal responsibilities. This in particular, includes those Tier 2 services and supports outside the NDIS.

Similarly, the adequacy, through measuring performance outcomes, rests on clearly defined, well-funded and agreed outcomes measures to improve quality of life outcomes for family and friends who provide informal caring in Australia.

The review of the National Disability Agreement commenced in 2018. After several submissions and consultations, a final report was provided to the government in January 2019. The final report was released on 1 February 2019.

We believe that two of the recommendations are relevant to this inquiry:

- Recommendation 2.3 There should be a single set of outcomes across the National Disability Agreement (NDA) and the National Disability Strategy (NDS). As the overarching agreement, the outcomes should be outlined in the NDA. The new NDA should adopt the six outcome areas of the current NDS, with the addition of a seventh outcome for families and carers.²⁸
- Recommendation 5.2 The new National Disability Agreement (NDA) should establish a clear strategy for the collection, funding, and reporting of data required for the agreement's performance reporting framework.

There has not been a government response to this study as yet.²⁹

Previous inquiries

On 1 May 2009, the Australian Government's House of Representatives Family, Community, Housing and Youth Committee launched its Report on the inquiry into better support for carers entitled, *Who Cares ...?*³⁰ The Report made 50 recommendations designed to better support carers. The Government's response to these recommendations contained the usual mix of "agree", "disagree", "agree to further consider" and "note". Many of the issues identified remain today.

In March 2007, the Human Rights Commission released its landmark report "*It's About Time: Women, men, work and family*" that examined the relationship between family responsibilities and paid work. This Report made 45 recommendations designed to address the challenge to develop a paid work and family/carer responsibilities framework. Once again, many issues remain unresolved.

²⁸ <https://www.pc.gov.au/inquiries/completed/disability-agreement/report/disability-agreement-overview.pdf>

²⁹ <https://www.pc.gov.au/inquiries/completed/disability-agreement#report>

³⁰

https://www.aph.gov.au/Parliamentary_Business/Committees/House_of_Representatives_Committees?url=fchy/carers/report/fullreport.pdf

Recommendation 2

MS Australia recommends that this inquiry review the impact of recommendations made in previous inquiries regarding work and caring responsibilities, building on achievements such as the introduction of the Carers Gateway as a source of information and referral and addressing areas where gaps remain such as improved financial support for carers.

e) consideration of the impact on work and care of different hours and conditions of work, job security, work flexibility and related workplace arrangements;

Research indicates on average, caregivers of someone with MS, spent on average 6.5 hours a day dedicated to caring tasks.³¹ This often has consequences for their own employment by either having to miss workdays, reduce work hours or having to stop work completely. Within the health³², aged care³³, disability³⁴ and social security³⁵ service systems, people with MS and their carers often fall through the gaps. MS also has unique impacts on employment³⁶.

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*³⁷.

The same report provides insights into the employment status of carers, suggesting a strong correlation between fewer work hours and the level and type of employment. For those listed as primary caregivers, the rate of full-time employment is half of the general population. There is thus some evidence that the demands of caring may impact on someone's work arrangements or available working hours.

Opportunity costs, foregone earnings and value to formal health care associated with unpaid caregiving, by the same report are conservatively estimating that:

“In 2020, the estimated earnings foregone for primary and non-primary carers was \$11.4 billion and \$3.8 billion respectively. Combined, the opportunity cost for all carers is \$15.2 billion. This is equivalent to 0.8% of GDP and 10.6% of the value of formal health care.”

³¹ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7242779/>

³² <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>

³³ <https://agedcare.royalcommission.gov.au/>

³⁴ <https://www.msaustralia.org.au/wp-content/uploads/2021/10/submission-to-the-ndis-consult-an-ordinary-life-at-home.pdf>

³⁵ <https://www.msaustralia.org.au/wp-content/uploads/2021/10/ms-australia-dsp-senate-inquiry-submission-final.pdf>

³⁶ <https://www.msaustralia.org.au/wp-content/uploads/2022/02/msa-sub-to-dss-shaping-new-dis-employ-program-1-feb-2022.pdf>

³⁷ <https://www2.deloitte.com/au/en/pages/economics/articles/value-of-informal-care-2020.html>

Caregiving may therefore negatively impact on someone's financial situation or income but potentially positively impacts on various areas within the care economy of Australia.

f) the impact and lessons arising from the COVID-19 crisis for Australia's system of work and care;

Research from Australian and international studies showed that flexible workplaces and practices promotes workforce participation (including attracting and retaining employees), gender equity, employee satisfaction, wellbeing and productivity. Flexible working also future proofed workplaces.³⁸ The COVID pandemic indeed challenged our traditional and cultural value on presenteeism and the associated productivity and accelerated trends of working online or virtual environments.³⁹

Several research papers have investigated the unintended consequences of this new work milieu.

Boundaries between work and personal responsibilities have become more challenging to manage and⁴⁰ social isolation and loneliness were noted as concerns⁴¹ and 'that social connectedness with work colleagues correlates with higher levels of wellbeing'⁴². Anecdotally carers of people with MS have confirmed that going to work has been their only 'break' or 'time for themselves'. For some, working from home was never a choice. Providing informal caregiving for someone who lives immune compromised placed additional psychological and physical restrictions and limitations on carers.⁴³

For employees with temporary or short-term contracts, who worked in areas such as hospitality, arts or the gig economy, the pandemic resulted in loss of employment and often periods of unemployment or under employment.⁴⁴ This was particularly pertinent for younger people in the workforce.

MS Australia commends the Harvard Business School's paper entitled *COVID-19 and the Workplace: Implications, Issues, and Insights for Future Research and Action*⁴⁵ and the G20 paper entitled *The impact of the COVID-19 pandemic on jobs and incomes in G20 economies*⁴⁶ to this enquiry.

³⁸ <https://www.dese.gov.au/employing-and-supporting-women-your-organisation/workplace-flexibility/what-flexible-working/case-flexible-work> and <https://www.wgea.gov.au/flexible-work>

³⁹ https://www.hbs.edu/ris/Publication%20Files/20-127_6164cbfd-37a2-489e-8bd2-c252cc7abb87.pdf

⁴⁰ https://www.researchgate.net/publication/348277852_Managing_boundaries_between_work_and_nonwork_domains_Personality_and_job_characteristics_and_adopted_style

⁴¹ <https://www.abc.net.au/news/2022-07-21/hybrid-work-can-leave-us-feeling-lonely-and-disconnected/101227102>

⁴² <https://www.australianunity.com.au/wellbeing/what-is-real-wellbeing/loneliness-in-the-age-of-remote-working>

⁴³ <https://www.msaustralia.org.au/for-people-with-ms/covid-19-and-ms/>

⁴⁴ https://www.ilo.org/wcmsp5/groups/public/---dgreports/---cabinet/documents/publication/wcms_756331.pdf

⁴⁵ https://www.hbs.edu/ris/Publication%20Files/20-127_6164cbfd-37a2-489e-8bd2-c252cc7abb87.pdf

⁴⁶ https://www.ilo.org/wcmsp5/groups/public/---dgreports/---cabinet/documents/publication/wcms_756331.pdf

The COVID pandemic tested and stretched each and every service system in our country, from health and front-line staff, to the ever-growing care economy (especially aged care and disability) to small and large businesses⁴⁷. This was subject to a Senate Select Committee inquiry earlier this year. The report commented on our state of readiness, lack of planning and preparedness and impacts.

Carers became more and more isolated during COVID, as other types of supports strained under the pandemic pressures.⁴⁸ Carers struggled to keep up with reliable trusted information, physical demands and emotional strain and changes in their supports, resulting in carer fatigue, burnout and breakdowns of care relationships.⁴⁹ They felt locked away, invisible, ignored and forgotten⁵⁰.

g) consideration of gendered, regional and socio-economic differences in experience and in potential responses including for First Nations working carers, and potential workers;

We have already referenced the demographic data related to the gendered nature of informal care in Australia earlier in this submission, especially the data by the Workplace, Gender and Equality Agency⁵¹. The research of Hussain, Wark and Ryan in 2018 entitled *Caregiving, Employment and Social Isolation: Challenges for Rural Carers in Australia*⁵² found that geographical distance and social isolation are key factors that should be considered for future service model development to address limited resource availability and choice within rural and remote locations in Australia. Their report also recommended that,

“The lack of flexible work opportunities was very evident for rural carers, and a recommendation is for further government supports to be made available in order both to alleviate severe economic marginalisation and as a proactive preventative measure for the rural carer cohort.”

47

https://parlinfo.aph.gov.au/parlInfo/download/committees/reportsen/024920/toc_pdf/Finalreport.pdf;fileType=application%2Fpdf

⁴⁸ https://parlinfo.aph.gov.au/parlInfo/download/committees/commsen/3b0504ac-bd44-4fc3-8030-90ac84c1b8ea/toc_pdf/Senate%20Select%20Committee%20on%20COVID-19%2020%2007%2001%207838%20Official.pdf;fileType=application%2Fpdf#search=%22committees/commsen/3b0504ac-bd44-4fc3-8030-90ac84c1b8ea/0000%22

⁴⁹ <https://www.sane.org/information-and-resources/the-sane-blog/wellbeing/covid-when-the-carer-needs-care> and <https://www.carersaustralia.com.au/coronavirus-information/covid-19-advice-for-carers/>

⁵⁰ <https://www.theguardian.com/society/2020/jun/10/family-carers-hidden-army-not-invisible-just-ignored>

⁵¹ <https://www.wgea.gov.au/gender-equality-and-caring>

⁵² <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6210659/>

This and other reports prepared by collaborations such as the National Rural Health Alliance⁵³ and Carer's Australia's 2018 report, *The tyranny of distance? Carers in regional and remote areas of Australia* should inform future directions, model design and the allocation of resources and ongoing research.

h) consideration of differences in experience of disabled people, workers who support them, and those who undertake informal caring roles;

MS Australia will limit our response in this term, to focus on the needs of people over 65 years not in receipt of specialist's disability supports, similar to those eligible for supports under the National Disability Insurance Scheme (NDIS). As MS is often a progressive disease, disability acquisition occurs as people age, complicating and compounding their barriers to social inclusion, participation and enjoying a comparable quality of life. These systemic barriers create a surplus and vicarious burden for carers, family members and loved ones.

Case study – Tig's caregiving story

Marilyn, aged 77 years, is the third generation of her family to be diagnosed with MS. She was diagnosed in 1962, sixty years ago. Marilyn is a retired home economics and textiles teacher.

I have been Marilyn's partner for over 52 years and share the daily challenges of living with MS.

I have an advanced degree in "wheelchair pushing" and post graduate qualifications in "breakfast-in-bed making". Recently I was awarded a doctorate in "washing up the evening dishes". I do have to improve my education all the time. We have two adult sons and loving grandchildren.

We both have been very involved in the local community, including regular volunteering for MS Plus, previously at their café (I made a great cup of coffee or tea) but now am a part of Facilities Management, assisting with infrastructure support, maintenance and other tasks.

Combining work and care responsibilities have not been a problem. Marilyn values her independence, and she has her own activities on the days on which I work. (2 days per week). Marilyn still drives but often experiences parking issues if a disabled parking is not available close to the door where she needs to be. She therefore sometimes gets a cab to allow her to get as close as possible to the door, for example, when she goes to the pool every week.

I have worked in the railways for 38 years before being employed with Australia's national accreditation body, NATA, for the past 22 years. I am a permanent employee, with all the benefits associated with this, although I have told them that at 79 years of age, I'm not 'a long-term proposition'. Nonetheless, I have job security. My employer is very supportive, caring, and benevolent. I am able to change my hours, when necessary, but I try to

⁵³ <https://www.ruralhealth.org.au/> and https://www.ruralhealth.org.au/sites/default/files/fact-sheets/fact-sheet-22-carers%20in%20the%20bush_0.pdf and <https://apo.org.au/node/168981>

minimise this as this can impact on my availability to other staff, particularly interstate staff.

I can (and do) take carer's leave when this is necessary. My employer is fully aware of our family situation and supports me when I need it.

Work definitely adds to my well-being – I enjoy it, and the staff provide socialisation. I have a supportive manager. I go at a defined time, and I am home at a defined time (provided the trains are on time, which they are mostly). I have an easy commute these days. If we had remained in our previous location, I would be well-retired by now, due to the travel impost. I aim to be home by 5.30, as Marilyn can get fatigued as the day goes on, and I can help with the evening's activities, i.e., meal preparation, washing up etc. Fixed going and returning times are a must – Marilyn needs certainty in knowing when help is available.

During COVID, I was set up in our lounge room, being able to work from home. It was a bit of a nuisance for Marilyn, who felt that she had to be careful not to disturb me. I considered that I was intruding on her free movement around the house. I also tended to work longer hours, often spread over extra days. She was glad to see me return to the office.

I do not wish to work more than 2 days per week. This gives me plenty of time on the other 5 days to provide caregiving duties. I am Marilyn's primary caregiver. We only get support from the local council for a few hours a week. Female carers come in on one of the days I am at work to assist Marilyn with having a shower and getting dressed.

Recently, I have had to take sick leave as I was diagnosed with pneumonia. I was hospitalised for a week and am still recovering but planning to return to work next week. During my time in hospital, we had to rely on neighbours and our boys, who luckily live close by, to ensure Marilyn received the support she needs.

My employer has allowed me to return to work with a part working from home arrangement, providing me with flexibility to travel to work after the morning rush to avoid further exposure to potential infections.

I'm not really up with legislation. We've always just done our own thing. I do get a Carer's Allowance and am thankful for this. We have benefited from involvement with MS Plus and its support is much valued.

We are very down on NDIS, because Marilyn has had MS for over 60 years, but she is not eligible (too old) for any support from NDIS. We consider this extremely unfair and to be a form of discrimination. Apart from the local council, we do not receive any disability support from My Aged Care (which is means tested) except for a reduction in the amount payable for Marilyn's art classes, or any other community service. All the home modifications, adaptations, purchasing of mobility aids and equipment (wheelchairs) has been acquired at our own cost over the years. We also are planning to modify the bathroom to make the shower more accessible for Marilyn and to allow her to get to the toilet easier from the bedroom. But this is all at our own cost. If Marilyn was able to access the NDIS, they could have helped with this. And the high cost of mobility aids and equipment.

I think that individual situations depend very much on the attitude of the employer.

I consider that I am in a very fortunate arrangement. I well recognise that the amount of caregiving depends on the condition of the person being cared for, and I feel that a carer supporting a profoundly disabled person needs more support than is currently available.

A bit more for caregiving arrangements keeps people out of hospitals and nursing homes.

Along with our partners in the Assistive Technology for All Alliance⁵⁴, MS Australia believes that access to assistive technology allows people to have⁵⁵:

- Increasing independence and participation in everyday activities
- Reducing reliance on families and Carers, thereby improving personal relationships and minimising carer stress
- Minimising the onset of secondary health conditions
- Reducing the risk of accidents and falls
- Helping people to remain living in their own homes for as long as possible.

Australia's aged care system is continuing to fail people living with disabilities, those living with chronic conditions and progressive disease such as MS.⁵⁶ This leaves carers, family and loved ones having to try to supplement these systemic gaps, at their own cost to their finances, health and wellbeing. As we previously stated, with increased disability, carer burden and risks increase.

The Department of Social Services is currently in the process of finalising a new National Disability Strategy for 2020-2030. MS Australia wants to ensure access to a fair and equal national assistive technology program is included in the new National Disability Strategy once and for all.

i) consideration of the policies, practices and support services that have been most effective in supporting the combination of work and care in Australia, and overseas;

Targeted information resources, improved access to care coordination support, training for primary care providers and research were some of the outcomes suggested by the New South Wales Ministry of Health's rapid evidence check review report entitled *Best Practice in caring for carers* released in 2015. The Government's subsequent 2018 carer blueprint highlighted the importance of improved system integration.⁵⁷

⁵⁴ <https://assistivetechforall.org.au/>

⁵⁵ <https://assistivetechforall.org.au/wp-content/uploads/2021/10/2021-ATFA-briefing-paper.pdf>

⁵⁶ <https://anmj.org.au/aged-care-failing-older-australians-and-in-need-of-major-overhaul-report-finds/>

⁵⁷ https://www.dss.gov.au/sites/default/files/documents/12_2018/icss-service-blueprint-version-13.pdf

In a two-phase approach in July 2019 and from April 2020, the Australian Government implemented the Integrated Carer Support Service Model's Carer Gateway during the peak of the COVID pandemic.⁵⁸

Recommendation 3

MS Australia recommends that Integrated Carer Support Service Model and those funded services participating in the Carer Support Framework be reviewed, utilising the lived experiences of carers to inform the evaluation terms, design and recommendations.

j) any related matters.

Transitioning from caring to employment

Currently, there are no specific programs to support people to transition from a carer's role to employment. There is a need for targeted and tailored programs to support carers as they move to Jobseeker or other social security payments once their caring responsibilities end and to be able to transition into mainstream employment. Elements of these transitional programs should include access to training and education, plus grief and adjustment counselling.

Recommendation 4

MS Australia recommends the establishment of specific programs to support people to transition from a carer's role to employment once their caring responsibilities end including access to training and education and grief and adjustment counselling.

25-hour rule needs review

Currently if a carer "ceases to care" for more than 25 hours per week, a review of their carer allowance may be initiated. A review of this 25-hour rule is required to remove ambiguity and perceived constraints on their capacity to participate in work, education and volunteering.

In its Mental Health Inquiry Report⁵⁹, handed down in November 2020, the Productivity Commission made the following recommendations regarding the eligibility criteria for the Carer Payment and Carer Allowance:

"The Australian Government should amend the eligibility criteria for Carer Payment and Carer Allowance for mental health carers, and consider adopting these changes for other carers. Amendments for mental health carers should include:

- for Carer Payment, replacing the requirement to provide 'constant care' with the requirement to provide 'care on a regular basis every week'

⁵⁸ <https://www.dss.gov.au/disability-and-carers-carers/integrated-carer-support-service-model#:~:text=Services%20and%20support%20for%20carers&text=It%20is%20an%20Australian%20Government,the%20second%20from%20April%202020.>

⁵⁹ <https://www.pc.gov.au/inquiries/completed/mental-health/report>

- for Carer Payment, replacing the 25 hour per week restriction on work, study and volunteering with a 100 hour per month restriction on work only
- for Carer Allowance, replacing the requirement to provide 'care and attention on a daily basis' with the requirement to provide 'care on a regular basis every week'
- for Carer Allowance, removing the requirements for the carer to either live with the care recipient or to provide care that relates to the care recipient's bodily functions or to sustaining their life and for more than 20 hours per week".

Reducing barriers and increasing flexibility to accessing income support will go some way to alleviating the financial stress and burden placed on carers.

Recommendation 5

MS Australia recommends introducing flexibility for carers by amendment of the eligibility criteria for Carer Payment and Carer Allowance in line with the Productivity Commission's Mental Health Inquiry recommendations, especially by replacing the 25 hour per month restriction on work, study and volunteering with a 100 hour per 4-week restriction on work only.

Conclusion

Given the diversity in disease presentation and progression, people with MS require a broad and diverse range of support that may include care delivered by family and friends. Recognition, acknowledgement and support for the vital role of these carers are crucial in maintaining them in this role.

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.