

The Treasury's Employment White Paper Consultation

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

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

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

Multiple Sclerosis (MS) is the most commonly acquired neurological disease in younger adults around the world with over 2.8 million people affected. More than 25,600 Australians live with MS and over 7.6 million Australians know someone or have a loved one with this potentially debilitating disease.

Symptoms vary between people and can come and go; they can include severe pain, walking difficulties, debilitating fatigue, partial blindness and thinking and memory problems. For some, MS is characterised by periods of relapse and remission, while for others it has a progressive pattern of disability. MS robs people of quality of life, primarily driven by the impact of MS on pain, independent living, mental health and relationships.

Employment White Paper

MS Australia welcomes the opportunity to respond to Treasury's *Employment White Paper* Consultation. MS Australia welcomes the development of a roadmap for Australia's workforce and hopes this will improve outcomes for Australians living with MS. This submission responds to the following section of the consultation Terms of Reference:

• **5.2** Improving labour market outcomes for those who face challenges in employment, including First Nations people, those who live in rural and remote areas, younger and older Australians, people with disability, and those who may experience discrimination.

MS Australia makes the following recommendations for the Employment White Paper:

MS Australia Recommendations

- A national campaign to improve awareness of the value of employing and retaining people with a disability, including:
 - broader communication on the programs and incentives that can be accessed by employers to support the employment of people with disability
 - resources and training to improve understanding around working with people with disability and creating a positive workplace culture
 - celebrating and building awareness of disability friendly employers across Australia
- Any future disability employment service or program should:
 - Have a focus on the needs of people with disability over program compliance and on sustained long-term employment for people with disability
 - Allow for expanded opportunities including volunteering, part-time work, education and training, work experience and career changes
 - Have expanded eligibility to include people currently in the workforce and those undertaking full-time study.
- The Australian government should work with the Business Council of Australia and associated peak bodies/organisations to develop pilot programs for people with a disability to access employment with Australia businesses, including financial incentives, resources and training

MS and Employment

Most people are diagnosed with MS between the ages of 20-40, with 75% being women. Often a diagnosis of MS occurs when people are fully employed, consolidating income, planning a family and/or making significant career choices. MS is a progressive, degenerative, neurological condition, where acquisition of disability often occurs gradually and may vary from person to person. People living with MS may experience the following symptoms that can affect their ability to function in the workplace:

- Reduced mobility, balance and strength
- Cognitive issues including memory, concentration, planning and problem solving
- Sensory issues including heat sensitivity and numbness
- Extreme fatigue
- Double vision

• Bladder and bowel issues

Symptoms can be triggered or made worse by stressful working conditions and requirements to work long hours. Additionally, many people living with MS have comorbidities that can substantially impact their employment outcomes including osteoarthritis, migraines, anxiety, depression and allergies¹.

Economic impact of MS

Analysis of MS Australia's *Australian MS Longitudinal Study* (AMSLS)² shows that the annual cost of a person living with MS is \$68,382, with \$21,858 of this attributed to indirect costs from lost wages. This represents a 17% increase in costs from 2010 (\$58,652 per person), however there was a significant reduction in the indirect costs of MS through lost wages and informal care. Lost wages now account for only 32% of the economic burden of MS compared to almost 50% in 2010. There are higher lost wage costs for men and those in rural and regional Australia.

This study shows that improving employment outcomes for people with MS in Australia and keeping more people in the labour market or returning to the workplace has a substantial economic impact. Increased work opportunities for people with MS and their carers significantly reduce the economic burden on both people with MS, their carers and the broader community. Employment can bring financial independence for people living with MS and help to meet MS related costs including home and car modifications, mobility aids and equipment, medications and health and community services.

Broader impacts of employment

Being employed has many benefits beyond the financial aspect. It can improve quality of life, contributing to a person's self-worth, independence and belonging, and provides a means of social interaction. The MS International Federation ranks employment as one of their seven principles to improve quality of life for people living with MS³. The principles state that equal participation in employment and education:

'Empowers and enables people with MS to contribute as valued members of the family and wider society. Participation also enhances visibility and public understanding of MS, which in turn contributes to removing stigma and discrimination.'

People with MS can contribute a range of skills, talents and qualifications to the workplace. Employing people with a disability can bring diverse and unique perspectives and skills to the workplace including creativity, problem solving, persistence and resilience. People with a disability generally take fewer days off work, stay in jobs longer, build strong connections with customers/clients and boost staff morale⁴.

MS Australia Employment & Workforce Survey

In February 2022, MS Australia undertook a national survey⁵ involving 1,748 Australian adults (including 525 people living with MS) to examine workplace attitudes towards those with a physical or mental health condition – including flexible work practices, job prospects, stigma, and disclosure.

The findings show that the general community overwhelmingly agree (83%) that people with health conditions in the workplace are 'just as capable' as anyone when it comes to working and eight out of ten (85%) believe workplaces are now more receptive to adapting roles to better fit employees. Importantly, the findings reiterated a widely held belief that meaningful work is a critical part of enjoying a good quality of life – with seven out of ten (70%) Australians feeling more connected to people and community because of their employment. However, the findings also show the reality of the workplace for people living with MS:

- 52% reported missed work opportunities due to their MS
- 28% were uncomfortable in the workplace because they felt people labelled them
- 17% felt the culture of the company they worked at did not make them feel comfortable enough to disclose their condition
- 41% chose not to disclose their condition at work saying it would 'change people's opinion' of them and 25% that it would 'jeopardise career prospects.
- 48% think they won't be seen as a 'long-term team member to invest in and promote'.

Overall, the findings show that there is a disconnect between community attitudes and workplace realities for those with a health condition. Many Australian workplaces are not keeping pace with community expectation towards supporting employees.

Accessing and retaining employment

Due to its varied nature, there is no 'one size fits all' approach to managing MS in the workplace. Some people have no need to alter their role or working conditions, while others may benefit greatly from small and reasonable adjustments.

People living with MS may need access to specialist disability employment support services to help them get navigate the workplace including recruitment, career advice, training, work experience, career changes and finding suitable employers and jobs.

People living with MS may also need to be supported by their workplaces through reasonable adjustments including:

- Flexible working arrangements including access to part-time work, flexible hours/working schedules, longer breaks and the ability to change hours/days as required
- Ability to work from home
- Disability accessible workplaces
- Access to home and workplace modifications and equipment

People living with MS can be further supported by having a supportive employer that has an open, responsible and productive approach to people with MS. They must be open to learning how the employee can be best supported and retained in the workplace. This in turn fosters a positive workplace culture for all employees and presents an inclusive and socially responsible organisation to customers.

Employment White Paper

Awareness and Engagement

The development of an Employment White Paper provides a unique opportunity to engage Australian employers on the benefits of employing people with a disability. Currently, there are 1 million Australians living with disability in the labour force with more wishing to enter and higher rates of unemployment and underemployment compared to the rest of the Australian population⁶. This labour force is currently underutilised and underappreciated.

MS Australia recommends a national campaign to improve awareness of the value of employing and retaining people with a disability, including:

- broader communication on the programs and incentives that can be accessed by employers to support the employment of people with disability
- resources and training to improve understanding around working with people with disability and creating a positive workplace culture
- celebrating and building awareness of disability friendly employers across Australia

The Employment White paper provides an opportunity to engage the Australian business sector on the potential opportunities of working with people with disability. **MS Australia** recommends that the Australian government work with the Business Council of Australia and associated peak bodies/organisations to develop pilot programs for people with a disability to access employment with Australia businesses. This should include financial incentive for business, resources and training.

Disability Employment Service

MS Australia recognises that the Australia Government has extended the current Disability Employment Service (DES) for two years while a new model is developed. The White paper presents an opportunity to establish clear policy for any future disability employment services to ensure they meet the needs of people with a disability and reflect current Australia workplaces. The current DES has a strong focus on compliance and reporting over meeting the needs of the person with a disability. For example, people with episodic conditions such as MS often have difficulties attending appointments, job searches, interviews and being able to meet all their DES obligations within the required timeframes. The inflexibility of the DES results in demerits or penalties for these participants rather than a program that adapts to their needs. The DES is focused on the sole outcome of gaining a job rather than a focus on career pathways and sustained long term employment. There is also limited opportunity to use the program to explore other opportunities and pathways including volunteering, part-time work, education and training, work experience and career changes.

Many people living with MS who are already employed need access to employment supports including to access new job opportunities, change to a career/position better suited to their disability and to engage with their employer. Additionally, people living with MS who are engaged in full time study need support to prepare for entry into the workplace. They should not have to wait until they have finished study to access these supports.

MS Australia recommends that any future disability employment service or program should:

- Have a focus on the needs of people with disability over program compliance and on sustained long-term employment for people with disability
- Allow for expanded opportunities including volunteering, part-time work, education and training, work experience and career changes
- Have expanded eligibility to include people currently in the workforce and those undertaking full-time study.

Refocusing the program in this way will also ensure a reduction in bureaucracy and administration and remove restrictive timelines, barriers to entry and long wait times.

Over four million Australians currently live with a disability⁷ and they represent a substantial part of the Australian community. They should be given the opportunity to engage in the workforce and access meaningful and sustaining employment. Reducing barriers to employment and supporting employer and employees will lead to more diverse and engaged workplaces across Australia.

Reference

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