MULTIPLE SCLEROSIS AUSTRALIA

Submission to the Australian Human Rights Commission Willing to Work: National Inquiry into Employment Discrimination against Australians with Disability

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Multiple Sclerosis Australia
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About Multiple Sclerosis Australia

MS Australia (MSA) is the national peak body for people living with multiple sclerosis (MS) in Australia. Our role is to work on behalf of all state and territory based member organisations to provide a voice for people living with multiple sclerosis across the country to support the development of:

- Research
- Advocacy and awareness
- Communication and information
- Services provided by our member organisations
- International collaboration

MSA advocates across all stakeholders, governments and communities, on behalf of our members, to represent people who are diagnosed with MS, their carers and the broader MS community.

Our Vision

Is consistent with the vision of the Multiple Sclerosis International Federation – **'A world without MS'**

Our Mission

MSA will support our members and work towards meeting the needs of people with MS, their families and carers. We will facilitate a national comprehensive representation of the Member organisations through advocacy and communication.

Our Purpose

On behalf of our members and people with MS, our purpose is to develop:

- **Research:**
  Supporting ongoing research to pursue further knowledge in targeting prevention, improving treatment, enhancing quality of life and ultimately, to find a cure.
- **Advocacy and Awareness:**
  Although MS impacts people differently, there are common, fundamental issues for people affected by the disease. We are steadfastly committed to giving these people a voice and remain willing and able to work with government and the Australian society to champion issues in a dynamic policy environment to bring about change to the lives of people living with MS.
- **Communication and Information:**
  Utilising traditional, contemporary and innovative channels to source information and share it with people with MS, our member organisations and our key stakeholders.
- **Support for our member organisations:**
  As MS specialists providing and facilitating high quality services that span the life-time needs of people affected by MS and other degenerative neurological conditions, their families and carers – from the point of early symptoms and pre-diagnosis, that addresses their changing needs.
- **International Collaboration:**
  Representing the MS cause and promoting collaboration with our domestic and international partners.

Introduction

MS Australia is pleased to provide a submission to the Australian Human Rights Commission Willing to Work: National Inquiry into Employment Discrimination against Australians with Disability.

The focus of the comments, suggestions and recommendations provided in this submission is on key areas that will impact on people affected by MS.

Our submission is framed around aspects of the discussion questions provided in the discussion paper.

1. What policies, workplace practices, programs or incentives assist with increasing participation of people with disability? How adequate are these policies, practices and incentives? What is the role of Government, peak business and employee groups, and individual employers?

MSA Position Statement on Employment

MS Australia's position statement regarding employment is as follows:

> Employment is one of the greatest quality of life impact issues for people living with multiple sclerosis (MS). Finding and retaining work is a significant contributor to life chances, poverty alleviation, family wellbeing, social participation and independence.
>
> All people with MS should be supported in maintaining the financial security and independence that arises from employment. Furthermore, we encourage employers to look at opportunities to offer enhanced workplace flexibility to people with MS to support their ongoing employment whilst effectively managing their symptoms.
>
> In addition, we encourage people with MS to disclose their MS diagnosis to their employer. Research indicates disclosure of an MS diagnosis to an employer increases job retention. Whilst individuals should consider their own personal circumstances when considering whether to disclose their diagnosis to an employer, the state MS Societies can provide resources to assist with this decision.

MS and employment – key facts

Employment is a key aspect of quality of life, due to its impact on physical, psychological, social and independent wellbeing. In contrast, lack of work comes at great cost to the individual, their family and wider society.

MS is the most common neurological disease in young and middle-aged adults, striking during the formative years of career development and planning for a family.[1] Affecting predominantly women (75% of diagnoses), it produces a complex array of physical, cognitive and emotional changes[2].

Loss of work is a common experience for people living with MS. Most people are working or in full-time education when they are diagnosed and 90% have a history of employment.[3] Data from 18 European countries suggested that almost half the people leaving the workforce do so

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[1] Johnson, K.L., Amtmann, D. et al (2004). *Medical, psychological, social and programmatic barriers to employment for people with multiple sclerosis.* Journal of Rehabilitation, 70, 38-49.

[2] Roessler, R.T., Rumrill, P. D., & Fitzgerald, S.M. (2004). *Factors affecting job satisfaction of employed adults with multiple sclerosis.* Journal of Rehabilitation, 70, 42-50.

[3] Doogan, C & Playford, E.D. (2014). *Supporting work for people with multiple sclerosis.* Multiple Sclerosis Journal, 20, 646-650.

within three years of being diagnosed[3]. Ten years after diagnosis, employment rates are as low as 25%[3]. Not only do people living with MS lose their jobs, they often move from high-demand to low-demand jobs, find it difficult to be promoted, to move between jobs and once unemployed, to return to the workplace[3].

Current employment support programs in Australia for people with disabilities emphasis finding “new” jobs for the unemployed, rather than the retention and protection of existing jobs, as is offered to approximately 85% of the registered participants of the MS Employment Services (in Victoria, NSW and the ACT)[3,7].

MS Australia has been taking an active interest in the development of the Australian Government’s new Disability Employment Framework, through the Department of Social Services (DSS). Its objective is to improve employment outcomes for people with disability and our hope is that it will realise this objective. A taskforce has been established within the DSS to develop the new Disability Employment Framework and a final draft of options is expected in early 2016 for the consideration of Government.

2. Are there distinct challenges face by different sized businesses and organisations, sectors and industries in employing Australians with disability?

Employment support service programs for people with MS must be driven by highly specialised, multidisciplinary teams of health professionals[4]. It requires an understanding of the complexities of symptom management and the need for holistic and proactive management of barriers to maintaining employment. This includes accommodating individual needs in the workplace in a timely and effective manner and the education of employers and the wider community[5].

Rehabilitation professionals need to constantly update their knowledge of MS, rehabilitation and employment. This is supported by the World Health Organisation[6]. Indeed, inadequately informed rehabilitation professionals may contribute to excessive disability with respect to MS and employment[1].

Financial modelling indicates the net benefit of maintaining employment to be greater than six times the cost of providing these services, equating to approximately $64k per person for each year they are employed[7].

3. What other data or information is available on employment discrimination against Australians with disability?

A person with MS lives on average 90% of expected lifespan. Premature retirement places a person with MS at risk of inadequate retirement savings, social isolation and disadvantages in re-entering the workforce[8].

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[4] O’Connor, R.J., Cano, S.J. et al (2005). *Factors influencing work retention for people with multiple sclerosis: cross-sectional studies using qualitative and quantitative methods.* Journal of Neurology, DOI 10.1007/s00415-005-0765-4.

[5] Sirvastava, S. & Chamberlain, M.A. (2005). *Factors determining job retention and return to work for disabled employees: a questionnaire study of options of disabled people’s organisations in the UK.* Journal of Rehabilitation Medicine, 37, 17-22.

[6] World Health Organisation & Multiple Sclerosis International Federation (2008). *Atlas: Multiple sclerosis resources in the world 2008.* ISBN 978 92 4 156375 8

[7] MS data 2010-2014

[8] Access Economics (2005). *Acting positively: strategic implications of the economic cost of multiple sclerosis in Australia.* Report for MS Australia, Winter.

Due to its association with loss of income and impaired quality of life, the impact of unemployment on people with MS and their families is therefore long-term and profound[9].

People with MS face two types of employment barriers. The first is made up of individual or disease-related factors such as education level, gender and disease characteristics such as type and severity of symptoms. The second is societal or work-related factors including business, eligibility for government program support, and the knowledge and attitudes of the public, employers, and health professionals [1, 4, 10], [11].

A study of Australians living with MS reported that disease-related factors and difficulty managing symptoms in the workplace contributed to loss of employment more so than work-related factors such as discrimination and being asked to leave. These findings are consistent with several international studies.[9]

4. What lessons and leading practices can we learn from other countries to address employment discrimination and increase workforce participation of Australians with disability?

Several helpful international studies have been referenced throughout this submission. See in particular references 3, 6, 10 and 11.

5. How adequately do existing laws protect Australians with disability from employment discrimination? How effective are the legal remedies for Australians with disability who have experienced employment discrimination? How could existing laws be amended or supplemented?

MS Australia, believes that the following examples are illustrative, not necessarily of direct workplace discrimination, but of where the systemic needs of people with a disability, who are in many cases doing their best to live with a chronic condition and maintain gainful employment, are placed at "the bottom of the pile" or deferred, forgotten about or placed in the "too hard basket".

Disability parking

It appears that Victoria is the only jurisdiction in Australia that does not participate in the Australian Disability Parking Scheme. Despite repeated attempts by people with a disability in Victoria to have the system changed, repeated calls on successive Transport and Roads Ministers in Victoria who have recognised in their correspondence that "these arrangements will address a number of longstanding issues with the current scheme; providing additional benefits to legitimate permit-holders and reducing the likelihood for abuse of the scheme" and an action item in Victoria's State Disability Plan Implementation Plan 2013-2014, to "finalise the detailed operational arrangements of the Australian Disability Parking Scheme, in consultation with a range of stakeholders", no change has occurred. In fact, this "action item" is repeated in the Victorian State Disability Plan 2013-2016 Statement of Achievements (page 49), even though it has not yet been achieved!

The most recent advice MS Australia has received on this issue from VicRoads is that "some work has been undertaken to progress the administrative arrangements to facilitate the introduction of the Scheme in Victoria. The details of how the scheme would operate in Victoria have not yet been able to be developed or implemented due to limited funding".

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[9] Simmons, R., Hendrie, D., McDonald, E., Tribe. K., & Vowels, L. (2004). *The economic impact of multiple sclerosis in Australia: summary statement of preliminary results from the Australian MS Longitudinal Study.* 26 November, Canberra Hospital.

[10] O'Day, B. (1998). *Barriers for people with multiple sclerosis who want to work: a qualitative study. Journal of Neurological Rehabilitation*, 12, 139-146.

Change in the system for a person with a disability to obtain a car GST free

Recently, MS Australia was alerted by a person with MS to changes in the system for people with a disability being able to obtain a car GST free.

People with MS with a disability are able to apply to the Australian Tax Office (ATO) for a medical assessment to purchase a car or car parts GST-free, providing the car is used for gainful employment. Until July this year, the medical assessment was undertaken for the ATO by Medibank Health Solutions. In July, Medibank Health Solutions was sold to Sonic Health Plus. Regrettably, arrangements were not made by the ATO for Sonic Health Plus to take over these medical assessments.

MS Australia was alerted to this fact by a person with MS who has been trying to buy a car since July! Since that time and through many conversations held by MS Australia with the ATO, the ATO has now put temporary arrangements in place so that people with a disability can go ahead with their car purchases. The ATO has assured MS Australia that they are working on a permanent solution to this matter and we will maintain a watching brief to ensure this happens, though at the time of writing this submission, no changes had been made to the ATO web-site in this regard.

6. What difficulties are there for employers in understanding and complying with legal obligations?

Employers may need to be informed of the nature of MS and its symptoms and the wide range of accommodations and adaptions that can often allow people to remain productive employees for many years. Well-intentioned support networks may advise people to leave work as a way of dealing with stress, fatigue or pain, without appropriate consideration of the consequences of unemployment. Having a better understanding of the disease may reduce the effects of such damaging misconceptions[11].

Anecdotal evidence indicates that small workplace modifications can make enormous differences to people with MS. This requires qualified Occupational and Physical Therapists with a special interest in MS, who are trained to undertake comprehensive workplace assessment and provide expert recommendations for change.

7. What are the distinct challenges face by certain groups of people with disability (e.g. women, Aboriginal and Torres Strait Islander peoples, people from culturally and linguistically diverse backgrounds or LGBTI people) in relation to employment discrimination?

A distinct challenge faced by people with MS are the invisible symptoms they experience – these include symptoms such as fatigue, numbness, body temperature control, “brain fog” and cognition and continence issues. The invisibility of these symptoms has some synergy with the way the invisibility of mental health symptoms are described, and are often not well understood or recognised in the workplace, nor in the broader community.

For example, during November 2015, a woman with MS, Justine Van Den Borne, received considerable media attention following a nasty note being left on her car windscreen when Justine left her car in a disabled spot in a Melbourne shopping centre. Justine is affected by MS and has successfully turned this unpleasant experience into a major advocacy opportunity for people with MS and people with a disability – her Facebook site received well over 200,000 likes

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[11] Jongbloed, L. (1996). *Factors influencing employment status of women with multiple sclerosis.* Canadian Journal of Rehabilitation, 9, 213-222.

and around 40,000 comments, mostly from people with disabilities sharing similar experiences. Justine has since had several media appearances, including on Channel 10's The Project.

As MS Australia said in the media at the time, Justine has dealt with this situation really well but we can only imagine this setback happening to someone who was housebound or building up the courage to have their first trip in their car or their first day driving to work. This setback, and the consequences for a person with a disability, could be devastating.

MSA commends the Human Rights Commission for conducting this inquiry and we are grateful for the opportunity to make a submission.

Please contact MS Australia by email to info@msaustralia.org.au for any further information.

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