



**Submission to The Australian Human
Rights Commission**

***WILLING TO WORK: NATIONAL
INQUIRY INTO EMPLOYMENT
DISCRIMINATION AGAINST
OLDER AUSTRALIANS AND
AUSTRALIANS WITH DISABILITY***

December 2015

EXECUTIVE SUMMARY

Alzheimer's Australia welcomes the opportunity to provide a submission to the Australian Human Rights Commission's *Willing to Work: National Inquiry into Employment Discrimination against Older Australians and Australians with Disability*.

Alzheimer's Australia is the peak body providing support and advocacy for people with dementia, their families and carers in Australia. Dementia is the second leading cause of death in Australia and will have an increasing impact on the health system due to population ageing. Currently there are more than 342,800 Australians with dementia and this figure is expected to increase to almost 900,000 by 2050¹.

A common misconception is that people diagnosed with dementia are older and live in residential aged care². The reality in fact, is that 70% of people are living in the community at the time of diagnosis². Younger onset dementia can develop before the age of 65, even as young as 35 years of age¹. It is estimated that in 2015, approximately 25,100 people in Australia are living with younger onset dementia¹.

An Australian National Population survey found that 44% of people believed that people diagnosed with dementia are discriminated against or treated unfairly and 22% indicated they would feel uncomfortable spending time with someone who had dementia². Lack of awareness of dementia in the workforce and the community can lead to discrimination, stigma and social isolation. This often results in people with dementia becoming disengaged from workforce and community participation long before the condition requires them to^{2 3 4}.

A diagnosis of dementia should not lead to discrimination or deprive any Australian of being valued as an individual. The opportunities to contribute and pursue quality of life in the community through paid employment or volunteering opportunities are important to people with dementia, as they are to all Australians.

In the *Your experiences of living with dementia* survey undertaken in 2015 by Alzheimer's Australia, people with dementia identified sense of purpose, social interaction and keeping the brain active as key benefits of continued work and volunteering⁵. 45% of those surveyed were working at time of diagnosis, and 69% indicated that they were supported to continue in their role.

The survey and Alzheimer's Australia work in awareness raising, supporting volunteering opportunities through project work, and the Younger Onset Dementia Key Worker program provides learnings on the opportunities to reduce stigma and discrimination. They also show how people with dementia can be supported to participate actively in the workforce and in community activities.

1 Australian Institute of Health and Welfare (2015) <http://aihw.gov.au/dementia/>. Accessed 27 Nov 2015.

2 Phillipson L, Magee C, Jones S and Skladzien E. *Exploring dementia and stigma beliefs. A pilot study of Australian Adults aged 40 to 65 years*. Paper 28. Alzheimer's Australia. June 2012.

3 Dementia Friendly Societies: The way forward. Paper 31. Alzheimer's Australia. May 2013.

4 Mocerlin R, Scholes A and Velakoulis D. *Quality Dementia Care: Understanding younger onset dementia*. Alzheimer's Australia. June 2013.

5 Survey research conducted by Alzheimer's Australia. *"Your experiences of living with dementia."* 2015

Alzheimer's Australia believes that it is the responsibility of all Australians to actively enact and promote the objects of the Commonwealth Disability Discrimination Act (1992), namely to:

- (a) to eliminate, as far as possible, discrimination against persons on the ground of disability in the areas of:
 - (i) work, accommodation, education, access to premises, clubs and sport; and
 - (ii) the provision of goods, facilities, services and land; and
 - (iii) existing laws; and
 - (iv) the administration of Commonwealth laws and programs; and
- (b) to ensure, as far as practicable, that persons with disabilities have the same rights to equality before the law as the rest of the community; and
- (c) to promote recognition and acceptance within the community of the principle that persons with disabilities have the same fundamental rights as the rest of the community

Dementia is not a normal part of ageing ⁶ it is the single greatest cause of disability in older Australians (aged 65 years or older) ⁷ and the third leading cause of disability burden overall in Australia ⁸.

Alzheimer's Australia calls for individual, organisational, government and community action that:

- identifies, prevents and addresses discrimination against people with dementia
- provides people with early-stage dementia with information that assists them in their workforce participation planning and decision-making
- seeks to create dementia friendly environments, workplaces and communities
- invests in awareness raising about dementia and support for people with dementia to continue to contribute to the workforce and community.

The barriers that can be addressed through community, business and government investment and action include:

- awareness raising to reduce stigma
- awareness and support for dementia friendly communities, dementia friendly organisations and dementia friendly design
- capacity building within organisations and within the community to include and support people with dementia in workforce, volunteering and community activities
- providing people with dementia and their carers with accessible information and support to live as valued and contributing members of society.

⁶ Australian Institute of Health and Welfare (2015) <http://.aihw.gov.au/dementia/>. Accessed 27 Nov 2015.

⁷ Access Economics (2009) *Keeping Dementia Front of Mind: Incidence and prevalence 2009-2050*. Report for Alzheimer's Australia.

⁸ Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

RIGHTS AND BENEFITS OF WORKFORCE PARTICIPATION

Persons with disabilities have the same fundamental rights as the rest of the community and a society can be judged on how it treats people with disabilities and protects their rights free of discrimination. This includes the right to have opportunities for personal development and to be treated with dignity⁹.

The opportunities for social interaction and the benefits to general well-being that work and volunteering provide for older adults has been widely documented^{10,11}. Employment can be viewed not only as a primary function but an important part of a person's self-identity. Subsequently, loss of employment can result in feelings of dependency, disempowerment and reduced choice⁸. Actively engaging in the workforce, either through a paid or voluntary capacity increases a person's self-esteem, self-worth and quality of life^{6,7}.

This can resonate even more so for people living with dementia, finding it difficult to adjust to unemployment whilst accepting the diagnosis, the limitations the condition may bring and social isolation. People with younger onset dementia often have a greater awareness of their dementia diagnosis, which has been associated with a greater risk of depression¹².

Carers of people with younger onset dementia may also face discrimination and lack of support from employers to continue working while caring for a loved one¹³. According to a report in 2012, most carers reflected that their employers were understanding of their circumstances but others explained they were not supported to continue employment. For example, they were not offered flexible working conditions to support their caring duties, eventually leading them to resign¹³.

WHAT PEOPLE WITH DEMENTIA TOLD US

This year, Australia Alzheimer's conducted a survey with 58 people living with dementia to capture their employment and volunteering experiences¹⁴. The survey highlighted that almost 45% of respondents were employed at the time of diagnosis. A small number of respondents (n 13) chose to answer if they were supported to continue their role, their responses showed that the majority (69% n 9) were indeed supported. As one consumer responded *"I left work a year after diagnosis. I had a very supportive employer who allowed me to change my working responsibilities. I had support from colleagues and flexible/reduced working hours"*⁹.

Consumers identified that social interaction, keeping the brain active and a sense of purpose were all key benefits of continued work or volunteering. They were enabled *"to continue to contribute to the community,"* they *"[felt] valued and [wanted to] teach others to accept dementia"*⁹.

9 Commonwealth of Australia. (1992). Disability Discrimination Act 1992 Act No. 135 of 1992 as amended). <https://www.comlaw.gov.au/Details/C2014C00013> Accessed 30 Nov

10 Morrow-Howell N, Hinterlong J, Rozario P and Tang F (2003). *Effects of Volunteering on the Well-being of Older adults*. J Gerontol B Psychol Sci Soc Sci. 58 (3): S137-S145

11 Schwingel A, Niti M, Tang C, Ng T (2009). *Continued work employment and volunteerism and mental well-being of older adults: Singapore longitudinal ageing studies*. Age Ageing. Sep;38(5):531-7.

12 Mocellin, R Scholes A and Velakoulis D. *Quality Dementia Care: Understanding younger onset dementia*. Alzheimer's Australia. June 2013

13 Brown JA, Sait K, Ariella Meltzer A, Fisher K, Thompson D, Faine R (2012) Service and Support Requirements of People with Younger Onset Dementia and their Families, for NSW Department of Family and Community Services, Ageing, Disability and Home Care, Sydney.

14 Survey research conducted by Alzheimer's Australia. *"Your experiences of living with dementia."* 2015

The survey not only highlighted the social benefit for people with dementia but also the added support for carers that comes with continued work or volunteering, as one consumer conveyed *“my carer would then get a respite break while I was volunteering”*⁹.

Forty-five percent of consumers completing the survey expressed their wish to continue working or undertake volunteering. Many cited lack of support as a barrier. One consumer said, *“I should have acted upon my basic rights as was discriminated against, but no-one supported me or even told me I had these rights...”*⁹.

Other concerns identified by consumers, that if not addressed, present barriers to continued employment included difficulties in performing and completing duties/tasks, and instructions not being communicated in a way that supported understanding.

A diagnosis of dementia presents consumers with changing circumstances which they need to understand and navigate. Consumers identified the lack of knowledge about employment and volunteering opportunities as barriers to participation⁹.

These barriers however can be broken down through partnerships with organisations and services to support the continued employment and volunteering opportunities for people with dementia and creating socially inclusive communities, embracing the dementia friendly concept.

ADDRESSING THE SYSTEMIC PROBLEM OF DISCRIMINATION AGAINST PEOPLE WITH DEMENTIA AND THE BARRIER TO THEIR ENJOYMENT OF HUMAN RIGHTS

Dementia friendly communities reduce stigma, raise awareness and promote inclusiveness

The number of cases of people diagnosed with younger onset dementia is set to increase by a third in less than 10 years.¹⁵ With this growing number of dementia cases, many Australian workplaces might not have procedures and policies established to support people with dementia to continue employment. It is important to raise understanding of dementia in the workplace. In particular, creating a dementia friendly environment where the duties of people with dementia can be adapted and modified thus supporting them to remain in the workforce. Dementia friendly communities have proven to deliver a wide range of social and economic benefits to the areas that have embraced the dementia friendly concept¹⁶. Pilot projects have been established across Australia where local people living with dementia engage with community members and organisations to raise awareness of dementia and undertake initiatives that promote dementia friendly, inclusive communities.

Guidelines on the development of dementia friendly communities and dementia friendly organisations provide local communities and organisations with simple steps to ensure their organisations recognise and support the needs of people with dementia. The guidelines encourage engagement with people living with dementia and their carers, and help organisations to identify and address barriers to access and participation opportunities for people living with dementia¹⁷. Awareness raising and staff training are important aspects of a

¹⁵ Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

¹⁶ Dementia friendly communities. White paper. Alzheimer's Australia. September 2015

¹⁷ First steps to a dementia-friendly Australia. Alzheimer's Australia. 2014

dementia friendly action plan, as are simple alterations that can be made to the physical environment to improve navigation for people with dementia. These can include changes to signage, lighting and thoughtful design around colour contrast to make organisations accessible to the needs of people with dementia¹⁸.

A commitment to dementia friendliness at an organisational and at a community level values people living with dementia and their carers and families. It works to address and prevent discrimination, and to include people with dementia in community life, including in workplaces and as volunteers.

System navigators and capacity building removing barriers, realising opportunities

The Alzheimer's Australia Younger Onset Dementia Key Worker (YODKW) Program provides person-centred holistic support and cross-system, cross-community navigation. It engages with people with younger onset dementia and their carer at any point and throughout the dementia journey: from pre-diagnosis to entry into residential care. Programs like this provide the information, support and capacity building required to support people with younger onset dementia to live valued, contributing lives within the community. This includes information that helps with work decisions and adaptation within the workplace¹⁹, liaison with employers and accessing care and support.

Capacity building is an essential aspect of the YODKW program. The following case study shows how programs such as YODKW can work with organisations and community partners to facilitate capacity building that reduces stigma and discrimination and values people with dementia as contributors in social enterprise and social activity.

¹⁸ Dementia friendly communities. White paper. Alzheimer's Australia. September 2015

¹⁹ Alzheimer's Australia Younger Onset Dementia Help sheet - Employment

Case Study 1: The YOD Woodworking Program

People living with dementia can utilise and maintain skills and continue to be economically and socially engaged in community life. The woodworking program developed over the past twelve months is a partnership between Alzheimer's Australia ACT, Northside Community Services and the Majura Men's Shed to provide an inclusive and supported environment for people diagnosed with younger onset dementia.

The program offers people living with dementia engaged in the YODKW program the opportunity to participate in the development of a business venture and assists them to maintain engagement in work related and social activities.

The program values the skills and employment backgrounds of its members and provides the support for these skills to be maintained and maximised. With staffing support from Alzheimer's Australia ACT and the other community organisation partnerships, participants are actively involved in:

- the building and finishing of wooden/mosaic products
- the marketing, advertising and selling of the products
- the promotion of and fundraising for the program in the community.

The program helps participants build:

- Self-esteem and confidence
- Social engagement
- Creative expression
- Cognitive stimulation
- Spatial and temporal orientation
- General and fine motor function.

The growth of the Men's Sheds movement in recent years has been dramatic and they are now mainstream. The YOD Woodworking Program demonstrates how community based services and activities, such as the popular Men's Shed, can be adapted to suit the needs of people with dementia and create a socially inclusive, dementia friendly environment.

Volunteering projects piloted across Australia by Alzheimer's Australia have identified good communication, trust, and flexibility as key enablers to capacity building that removes barriers to participation for people with dementia. Organisations supporting volunteer programs must build quality partnerships with host organisations in order to sustain the program over time. A case study follows:

Case study 2 – Side by Side Project

The Side By Side project is a partnership between Life Care and Bunning's Warehouse with support through Alzheimer's Australia South Australia. The project engages people living with Younger Onset Dementia within the workforce, creating opportunities for them to re-connect with the community on a weekly basis, developing new meaningful task skills while having a valued workplace.

Support is offered from A Life Care staff member or a buddy volunteer from Bunning's Warehouse. The positive outcomes exceeded expectations among the participants themselves, as one participant expressed *"I am learning new skills – although I am picking them up slowly."* Carers also reported their partners improved self-esteem and social interaction *"The Side By Side program is great for____. To have the opportunity of a full and active day in a workplace communicating with others is fantastic."*

HOPE: A newsletter for younger people with dementia, their care partners, friends, health professionals and care staff. July 2012 issue E 11. Alzheimer's Australia

EVERYONE'S RESPONSIBILITY

The Commonwealth Disability Discrimination Act (1992) states that:

(2) For the purposes of this Act, a person (the **discriminator**) also **discriminates** against another person (the **aggrieved person**) on the ground of a disability of the aggrieved person if:

(a) the discriminator does not make, or proposes not to make, reasonable adjustments for the person; and

(b) the failure to make the reasonable adjustments has, or would have, the effect that the aggrieved person is, because of the disability, treated less favourably than a person without the disability would be treated in circumstances that are not materially different.

It is incumbent on us as a society to build awareness within organisations and our communities that failure to support access and participation by people with disabilities, including people with dementia, is discrimination and must be addressed.

CONCLUSION

A person with dementia's decision to continue employment before and after a dementia diagnosis is complex²⁰. They may have limited choices and the decision may be taken out of their hands if there was no support to transition into other roles. People with younger onset dementia especially may take early retirement for fear of stigma if they disclose their diagnosis to their employer²¹. Accessible information and support is required, and factors

that may affect a person's decision include safety and duty of care, the extent to which symptoms affect the person's ability to do their job, the pace at which symptoms are progressing and the support that is required or offered by employers to continue working.

The experience of people with dementia reported via the Alzheimer's Australia's survey indicates that some employers can and do support staff to continue working.

However, this is not a universal experience. A case study follows from a gentleman 'A' participating in a YOD research project, highlights the discrimination and barriers experienced by people with dementia.

Case Study 3

Employed at an education institution, 'A' began struggling with ongoing work commitments. Upon visiting the GP he was informed not to worry and that his behaviour was due to stress.

Instances followed where of lack of judgement, inappropriate behaviours and problems with driving began to concern his family. Then a new computer system was introduced at his workplace, which he had difficulty operating. After the first week of lectures in February, his wife had a call from the head teacher who said, 'Don't let 'A' come back to work on Monday because his students complained about him.' They had noticed changes in 'A' at work for a while but put it down to stress.

'A' could not understand why he wasn't allowed to go back to work and became very frustrated. The family tried to find ways to keep him busy and active. They started a paper run that was not successful and started taking him to a community centre which runs activities for over 55s. However, there was lack of understanding and support offered at the community centre; his daughter was not welcome due to her young age and the other community members had little understanding or awareness of dementia, eventually leading 'A' to stop attending.

For A, there was no support offered to remain in his workplace or to remain socially engaged in his community.

Discrimination and barriers to participation must and can be addressed. Creating dementia friendly communities that provide information, awareness, access to navigators and capacity builders (such as YODKWs) and guidance on dementia friendly principles can assist.

The social impact of a diagnosis on employment is articulated by a consumer diagnosed with younger onset dementia at the age of 45 years *"giving up work...made me feel that I was not contributing or not worthwhile... have to be accepting of the diagnosis and understand the limitations that it may bring"*¹⁷. However, with support he has found that his past experience and qualifications are now embraced in his volunteer roles. *"My specialist told me that*

whatever it was I was doing, I should continue to do it...might not be on a salary, or be full-time staff, but {i} now feel employed and valued”²¹.

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- providing people with dementia and their carers with accessible information and support to live as valued and contributing members of society.

Alzheimer’s Australia welcomes this Inquiry and looks forward to its recommendations informing a plan that will address discrimination and support people with dementia and other disabilities to participate in the workforce and in volunteering capacities. Our communities, our economy and our society will be stronger and more inclusive as a result. Alzheimer’s Australia looks forward to being involved and working towards this end.

21. HOPE: A newsletter for younger people with dementia, their care partners, friends, health professionals and care staff. July 2012 issue E 11. Alzheimer’s Australia.