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The new voice of Alzheimer's Australia

Select Committee on the Future of Work and Workers

A response from Dementia Australia

January 2018

About Dementia Australia

Dementia Australia (formerly known as Alzheimer's Australia) is the peak, non-profit organisation for people with dementia and their families and carers. We represent the more than 425,000 Australians living with dementia and the estimated 1.2 million Australians involved in their care.

Dementia Australia works with consumers, all levels of government, and other key stakeholders to ensure that people with dementia, their families and carers are appropriately supported – at work, at home (including residential aged care) or in their local community.

Our close engagement with consumers means that we are an important advocate for those impacted by dementia and we are also well placed to provide input on policy matters, identify service gaps and draw on our expertise to collaborate with a wide range of stakeholders, including researchers, technology experts and providers.

In addition to advocating for the needs of people living with all types of dementia, and for their families and carers, Dementia Australia provides support services, education and information aimed at addressing the gaps in mainstream services.

Dementia Australia is a member of Alzheimer's Disease International, the umbrella organisation of dementia associations around the world.



EXECUTIVE SUMMARY

Dementia Australia welcomes the opportunity to provide input to the Senate Select Committee on the Future of Work. Dementia Australia is the peak body providing support and advocacy for people living with dementia, their families and carers in Australia.

The care and support of people with dementia is one of the largest healthcare challenges facing Australia. There are more than 425,000 Australians living with dementia. By 2025, the number of people with dementia is expected to increase to more than 530,000. Without a medical breakthrough, the number of people with dementia is expected to be 1.1 million by 2056.¹ Dementia is now the leading cause of death for women in Australia, and the second leading cause overall, with projections by the Australian Bureau of Statistics estimating it will be the leading cause of death in Australia within the next 5 years.²

Often people with dementia can become disengaged from workforce and community participation long before the condition makes it challenging to remain involved.^{3,4,5} Lack of awareness of dementia in the workforce and the community can lead to discrimination, stigma and social isolation. Dementia Australia believes that 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 as important to people with dementia as they are to all Australians. 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.

We also urge the Committee to consider the quality and future of the aged care workforce as part of their inquiry. The aged care sector workforce is a critical element in the provision of quality services, and this workforce must be available in the future in sufficient numbers and at a high quality. There are currently significant threats to the availability and quality of the future aged care sector workforce in Australia. Although much greater numbers will be needed in the future, the current workforce is ageing, and services already report that they are experiencing difficulty in filling vacancies. At a time when the number of people needing access to aged care services is increasing, and the acuity of care required is also increasing, levels of direct care staff to residents in aged care services are often decreasing and the number and proportion of qualified nursing staff positions in aged care, particularly residential care, has fallen dramatically. Dementia Australia is concerned that these trends are already impacting on the quality of care offered to some of the most frail and vulnerable people in our community, and that the situation has the potential to worsen in the future as demand pressures increase.

Through our submission, Dementia 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

1 The National Centre for Social and Economic Modelling NATSEM for Alzheimer's Australia (2017). *Economic Cost of Dementia in Australia 2016-2056*.

2 Australian Bureau of Statistics (2016). *Dementia: Australia's leading cause of death?* Accessed online.

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

4 Alzheimer's Australia (2013). *Dementia Friendly Societies: The way forward*. Paper 31.

5 Mocellin R Scholes A and Velakoulis D. for Alzheimer's Australia (2013). *Quality Dementia Care: Understanding younger onset dementia*.

- invests in awareness raising about dementia and support for people with dementia to continue to contribute to the workforce and community
- recognises the pressures on working carers of people living with dementia by supporting flexible work arrangements.

To ensure that our aged care workforce is ready to meet the rising prevalence of dementia, we recommend that:

- a focus on ensuring access to high quality, appropriate aged care services by older people, including people with dementia, must be the primary consideration in all strategies relating to the future of Australia's aged care sector workforce across all forms of community and residential care.
- a comprehensive aged care workforce strategy that identifies and addresses current and future workforce supply and quality issues. The strategy should include consideration of new models of care and innovative uses of technology as well as the importance of leadership in promoting learning cultures within aged care providers.
- appropriate staffing levels and mandated minimum levels of qualified nursing staff, including a requirement for all stand-alone residential aged care facilities to have a Registered Nurse on site at all times. Funding arrangements for aged care should support appropriate staffing levels and skill mix.
- a cohesive, structured and integrated national approach to dementia education and education, including minimum standards for education for those working with people with dementia. This approach should include a focus on leadership and cultural change at an organisational level, to maximise opportunities to translate learning into improved practice. The approach should be supported by government and by the aged care industry, and focus on achieving sustainable changes to practice which lead to better outcomes for people living with dementia.
- given that the values, attitudes, and behaviours of direct care staff are critical in ensuring a culture of commitment to high quality, person-centred care, education for aged care personnel should go beyond the technical, to embrace social, emotional, and cultural values, and foster emotional intelligence.
- remuneration for staff in the aged care sector that is aligned with similar roles in other sectors, including acute health care, and clear career paths for nurses and other workers in the aged care sector. Funding arrangements for aged care providers should also support appropriate remuneration and career paths.

BACKGROUND: DEMENTIA IN AUSTRALIA

Dementia is one of the largest health and social challenges facing Australia and the world. It is the leading cause of death of women in Australia, the second leading cause of death in this country and it is predicted to become the leading cause of death within the next five years.⁶ Dementia is not a natural part of ageing. It is a disease of the brain and affects a person's ability to function and ultimately to care for themselves. It is a terminal condition that affects people's abilities and memories and has a profound impact on the individual and their loved ones. It is cloaked in stigma and misunderstanding,⁷ isolates people with dementia and their carers from social networks,⁸ and carries significant social and economic consequences.⁹ People living with dementia constitute one of the most vulnerable groups in our society. A wide range of evidence comprehensively demonstrates that the care provided to those living with dementia is worse than the care delivered to any other vulnerable group.

It is estimated that there are more than 425,000 Australians living with dementia and 1.2 million people involved in their care; by 2056 there will be over one million people living with dementia. To put it another way, by 2056 more than 650 people will be diagnosed with dementia every day. These numbers include more than 25,000 people with younger onset dementia, that is, dementia that develops before the age of 65, in people aged from their thirties-to-sixties and more rarely in a person's twenties. One in 13 people living with dementia today lives with younger onset dementia.¹⁰

The cost to our community

The cost of dementia to the Australian economy is already enormous and growing rapidly.

In 2017, dementia is estimated to have cost Australia \$14.67 billion. By 2025, the total cost of dementia is predicted to increase to \$18.7 billion in today's dollars, and by 2056, to over \$36.8 billion.¹¹ Of this, \$5.6 billion is attributable to the estimated loss of income of people with dementia and carers in 2017, a figure set to more than double to \$12.8 billion by 2056. Cumulatively, that equates to a staggering total cost of more than \$1 trillion over the next 40 years.

The cost of replacing the informal care of loved ones at home with formal (paid) care at a residential facility is also significant. Across all types of care requirements (not just dementia), Carers Australia estimated that the annual 'replacement value' of informal care exceeded \$60 billion per annum.¹²

6 Australian Bureau of Statistics (2016). *Dementia: Australia's leading cause of death?* Accessed online.

7 George, D (2010). Overcoming the 'Social Death' of dementia through language. *The Lancet*, 376, 586-87.

8 Blay, S and Peluso, E (2010). Public stigma: The community's tolerance of Alzheimer's disease. *American Journal of Geriatric Psychiatry*, 18(2), 163-71.

9 Access Economics for Alzheimer's Australia (2003). *The Dementia Epidemic: Economic Impact and Positive Solutions for Australia*. Available: www.fightdementia.org.au/research-publications/access-economics-reports.aspx.

10 The National Centre for Social and Economic Modelling NATSEM for Alzheimer's Australia (2017). *Economic Cost of Dementia in Australia 2016-2056*.

11 The National Centre for Social and Economic Modelling NATSEM (2016). *Economic Cost of Dementia in Australia 2016-2056*.

12 Access Economics (2010). 'The Economic Value of Informal Care in 2010', Carers Australia, p.3.

DEMENTIA AND 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 dignity.¹³

The opportunities for social interaction and the benefits to general well-being that work and volunteering provide for older adults has been widely documented.^{14,15} 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 choice. Actively engaging in the workforce, either through a paid or voluntary capacity increases a person's self-esteem, self-worth and quality of life.

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 depression.¹⁶

Case Study: An individual's experience

Employed at an education institution, Alan (name changed) 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 Alan 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.

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

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 one.¹⁷ 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 resign.

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

14 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.

15 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*. 38(5): 531-37.

16 Moccillin, R, Scholtes A and Velakoulis D. for Alzheimer's Australia (2013). *Quality Dementia Care: Understanding younger onset dementia*.

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

What have people living with dementia told us?

In 2015, Dementia Australia conducted a survey with 58 people living with dementia to capture their employment and volunteering experiences.¹⁸ 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 person 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.”

Survey respondents 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”.¹⁹

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 person conveyed “my carer would then get a respite break while I was volunteering”. 45% of individuals completing the survey expressed their wish to continue working or undertake volunteering. Many cited lack of support as a barrier. One person 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...”*.

Other concerns identified by survey respondents that 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 people with changing circumstances which they need to understand and navigate. Individuals identified the lack of knowledge about employment and volunteering opportunities as barriers to participation.

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 BARRIERS OF DISCRIMINATION AGAINST DEMENTIA

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.¹⁹ 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 while they are still able to perform their duties appropriately. It is important to increase understanding of dementia in the workplace by creating a dementia friendly environment where the duties of people with dementia can be adapted and modified and their transition out of employment be managed through a planned and respectful process.

Dementia friendly communities have proven to deliver a wide range of social and economic benefits to the areas that have embraced the dementia friendly concept and engaged people with dementia as volunteers, advisors or paid employees.¹⁶ Pilot projects have been established across

¹⁸ Survey research conducted by Alzheimer's Australia. “Your experiences of living with dementia.”

¹⁹ The National Centre for Social and Economic Modelling NATSEM for Alzheimer's Australia (2017). *Economic Cost of Dementia in Australia 2016-2056*.

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 dementia.

Awareness raising and staff education are important aspects of a 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 dementia.

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 Dementia 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 workplace, 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.

Case Study: 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 Dementia 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 Dementia 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.

AGED CARE WORKFORCE AND DEMENTIA

Care for people with dementia is a core responsibility of all aged care providers, and there must be clear criteria and expectations to support this. For example, all providers should be required to demonstrate that their staff are appropriately educated in dementia care, and that this is maintained and continuously improved over time.

Dementia is an ever changing and progressive condition, often with complex physical comorbidities and potentially psychological and behavioural symptoms which require expert assessment by appropriately trained assessors, and care and management by appropriately trained staff. At present there are insufficient measures to ensure that these critical elements are in place.

The aged care workforce is a critical element in the provision of quality services, and this workforce must be available in the future in sufficient numbers, and at a high quality. To ensure quality, the workforce must have the appropriate education and training, skills, and attributes to provide the care and support that is needed. This includes the capacity to provide quality care and support to people with dementia, who are often frail and vulnerable, and may have complex care needs.

The prime consideration in developing strategies for the future aged care workforce must be the needs and wishes of the consumer. The overriding imperative is to ensure access by older people, including people with dementia, to high quality community and residential aged support and care services.

Ensuring adequate staffing levels and an appropriate skills mix

A recent Dementia Australia focus group of carers of people with dementia has identified significant carer concerns about workforce trends in residential aged care. Changes to the workforce have been distressing for residents with dementia, staff and families. Carers in this situation report feeling trapped, as they worry a move to another facility would jeopardise the health and further upset their family member. Carers who were/are satisfied with the care received still report one their biggest concerns was/is a change in management or a perceived shift to a "for profit" model happening around them. Carers have a high regard for residential aged care staff and would like to see them better compensated and acknowledged for the work they do.

Overwhelmingly, families consulted by Dementia Australia have expressed a strong desire to see aged care facilities invest in staff as a priority – to retain and support existing staff, increase staff remuneration and recognition, and roster adequate staff numbers to facilitate better, more person-centred care. Inexperienced staff, frequent shift rotations and poor hand-over procedures were cited by families as some of the main causes for avoidable failures, as well as a substantial barrier to achieving person-centred care.

Aged care services should have a skilled, experienced and adequate staff contingent to work effectively with people with dementia, and in many cases there is a great deal of room for improvement in this area. Facilities caring for people with dementia and particularly those with behavioural and psychological symptoms of dementia (BPSD), must have sufficient staff and an appropriate skills mix to provide the care required.

Over the past decade and more, there has been a significant shift in the aged care workforce. There is a trend towards employing less skilled (and lower cost) staff in residential settings in the delivery of direct care services. At the same time as the acuity of care required has been increasing, there has been a substantial decrease in the proportion of qualified nursing staff in the aged care workforce, and an increase in the proportion of unlicensed and unregulated personal carers. The number of qualified nursing positions in residential aged care has decreased by 8.4% since 2003, despite the number of residential aged care places increasing by 25.2%, and the proportion of aged care residents assessed as having high care needs increasing from 64% to 83%.²⁰ Registered Nurse positions decreased from 21.4% of the direct care workforce in residential care in 2003, to just 14.7% in 2012; while the proportion of Enrolled Nurses decreased from 14.4% to 11.6% over the same period. Personal Care Attendants now comprise 68 per cent of the residential direct care workforce, while Community Care Workers comprise 81 per cent of the community direct care workforce.²¹

Research has shown that direct care workers are generally highly committed to care recipients, and are keen to have the time and the skills to improve the wellbeing of residents and provide quality care, which they see as core components of their work. However, aged care staff must also meet regulatory requirements, operate according to organisational schedules, and work within budgetary constraints. In the 2012 Aged Care Workforce Survey, 45 per cent of direct care workers said they did not spend enough time with care recipients. In particular, over 40% of nurses reported spending less than a third of their shift performing direct care. This reflects the increasing managerial role that nurses, particularly Registered Nurses, are performing while Personal Care Assistants in particular are taking more responsibility for direct care.²²

Although clinical care is only one component of quality, the reduction in direct nursing care to a residential care population with increasingly high needs may be problematic for achieving high quality care and avoiding unnecessary hospitalisations. How well nurses and direct care workers work together as a team is also a key factor as often there is not a good relationship based upon mutual respect which then adversely affects the communication between the two groups potentially compromising the quality of care and support provided. Ensuring overall adequate staffing levels is also important to ensure that staff have sufficient time to interact with residents and assist them in meeting their physical and social needs. To ensure quality and safety in residential aged care, funding arrangements should support appropriate staffing levels and skill mix.

Appropriate workforce education

To ensure quality dementia care, health care professionals and all care staff must be educated in key aspects of dementia care including: person-centred care, the fundamentals of caring for people with dementia, psychosocial approaches to addressing unmet needs, pain assessment and management (particularly as people with dementia may be unable to verbalise their needs), and appropriate end-of-life care.

The 2012 Aged Care Workforce Survey found that direct care workers in the aged care sector identified “Dementia” and “Palliative Care” as the top two areas where they require further

20 Australian Nursing and Midwifery Federation (2015). *Fact sheet 4: A snapshot of residential aged care*.

21 King D., Mavromaras K., Wei Z., He B., Healy J., Macaitis K., Moskos M., Smith L. for National Institute of Labour Studies, Flinders University (2013). *The aged care workforce 2012: Final report*.

22 King D., Mavromaras K., Wei Z., He B., Healy J., Macaitis K., Moskos M., Smith L. for National Institute of Labour Studies, Flinders University (2013). *The aged care workforce 2012: Final report*.

education and training.²³ This indicates an unmet need for education to improved knowledge, skills and confidence in caring for people with dementia.

The same survey found that working with “aggressive service users” (this is likely to include people with dementia who may be exhibiting behaviours of unmet need) was a normal expectation in 33% of facilities, with another 47% indicating that workers were required to do this in exceptional circumstances. The authors noted that this is likely to be a consequence of the growing number of older Australians with dementia and other mental health problems who are living in facilities.²⁴

A recent stocktake of Commonwealth-funded aged care workforce activities confirmed that the quality and quantity of aged and community care education varies significantly, with workplace placements for Certificate III students ranging from under 60 hours for some providers, up to two years for other providers. It was noted that industry involvement in the development of training packages is important to ensure that qualifications reflect contemporary industry requirements for existing roles, prepare workers for new and emerging roles, and support education pathways for career progression. The stocktake recommended, among other things, that greater targeting and evaluation of workforce training and education is needed to ensure responsiveness to identified workforce or skill gaps in the industry.²⁵

Similarly, a recent review of Commonwealth-funded dementia programs identified a need for better co-ordination and promotion of education and training programs, and improved consistency and quality across these services.²⁶

Dementia Australia offers a Certificate IV in Dementia Practice which is a consistent, high quality, practically based course and represents one means of addressing the current inconsistencies in education. By having at least one staff member in each facility or service outlet with this level of dementia education would provide a key local support for the ongoing provision of quality dementia support and care by other staff through mentoring and coaching.

Learning pathways are needed for support and care staff to develop knowledge, skills and emotional intelligence, from basic level to advanced practice level. Government and aged care service providers have a shared responsibility to develop and fund education and career pathways for the aged care workforce. Government must maintain a commitment to supporting ongoing education to develop and sustain a workforce skilled in dementia care, and employers must also be committed and contribute to education.

Education programs must respond to the evolving characteristics of the workforce, including targeted education for the increasing proportion of the workforce which comes from culturally and linguistically diverse backgrounds.

Further, there is a need to move dementia education from providing knowledge to enabling the translation of knowledge into practice. Currently, education is essentially provided on the presumption that simply undertaking an activity or using a particular resource results in practice change; little import is given to whether this actually occurs. Practice change requires more than simply creating an awareness of knowledge; measures are needed to translate this to practice including a focus on ongoing mentoring and coaching within the workplace. Within workforce investment, priority needs to be placed on developing a cohesive, structured and integrated national dementia education program. Focus should be on practice changes, and on education activities that lead to better outcomes for people living with dementia and long-term sustainable

23 King D., Mavromaras K., Wei Z., He B., Healy J., Macaitis K., Moskos M., Smith L. for National Institute of Labour Studies, Flinders University (2013). *The aged care workforce 2012: Final report.*

24 King D., Mavromaras K., Wei Z., He B., Healy J., Macaitis K., Moskos M., Smith L. for National Institute of Labour Studies, Flinders University (2013). *The aged care workforce 2012: Final report.*

25 Health Outcomes International for Department of Social Services (2015). *Stocktake and analysis of Commonwealth funded aged care workforce activities: Final report.*

26 KPMG (2015). *Analysis of dementia programmes funded by the Department of Social Services.*

change. Education on evidence-based care models, and on culture change processes, should be included.

Dementia education should be linked to clear levels of competency and/or practice standards, so that the learning outcomes of all dementia education activities may be aligned with the competencies/practice standards. Ideally, the outcomes of each education activity would be assessed using a framework to ensure that they achieve the intended outcomes and lead to practice change.

Alongside the development of individuals in the workforce, strategies are needed to develop leadership and cultural change at an organisational level, and maximise opportunities to translate learning into improvements in practice. This will help promote an environment within which formal dementia education is more likely to lead to lasting practice change and improvement. A cohesive, structured and integrated national approach to dementia education is needed, including minimum standards for education for those working with people with dementia. This approach should include a focus on leadership and cultural change at organisational level, to maximise opportunities to translate learning into improved practice. The approach should be supported by government and by the aged care industry, and focus on achieving sustainable changes to practice which lead to better outcomes for people living with dementia.

CONCLUSION

The decision of a person with dementia to continue employment before and after a dementia diagnosis is complex. 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 employer, that it may affect a person's decision including 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 Dementia Australia's survey indicates that some employers can and do support staff to continue working. 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.

Dementia is also one of the major chronic diseases of this century, which required a trained workforce to tackle the complexities associated with it. With the continued ageing of the population and the growing numbers of people with dementia, quality care for people with dementia must be core business for the aged care system, including both home-based care and residential care.

To ensure quality care and support, aged care services must have adequate numbers of skilled, qualified staff, committed to providing person-centred care. The workforce must have the appropriate education, skills, and attributes to provide quality care and support for older people, including people with dementia, who frequently have complex care needs.

Dementia Australia welcomes this Inquiry and looks forward to its recommendations informing a plan that will address discrimination and support people with dementia to participate in the

workforce and in volunteering capacities, as well as helping ensure that our aged care workforce is well equipped to deliver quality care and support to people living with dementia. Our communities, our economy and our society will be stronger and more inclusive as a result.