Submission No 10

INQUIRY INTO PROVISIONS OF THE PUBLIC HEALTH AMENDMENT (REGISTERED NURSES IN NURSING HOMES) BILL 2020

Organisation: Dementia Australia

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Dementia Australia™

Inquiry into the provisions of the Public Health Amendment (Registered Nurses in Nursing Homes) Bill 2020

A submission to the NSW Upper House Select Committee

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About Dementia Australia

No matter how you are impacted by dementia or who you are, Dementia Australia is here for you.

We exist to support and empower the estimated half a million Australians living with dementia and almost 1.6 million people involved in their care. Dementia is the second leading cause of death in Australia yet remains one of the most challenging and misunderstood conditions.

Founded by carers more than 35 years ago, today we are the national peak body for people impacted by dementia in Australia.

We involve people impacted by dementia and their experiences in our activities and decision-making, to make sure we are representative of the diverse range of dementia experiences across Australia. We amplify the voices of people impacted by dementia through advocating and sharing stories to help inform and inspire others.

Dementia Australia is the source of trusted information, education and support services. We advocate for positive change for people living with dementia, their families and carers, and support vital research.

We are here to support people impacted by dementia, and to enable them to live as well as possible.

Introduction

Dementia Australia welcomes the opportunity to provide a submission to the Inquiry into the provisions of the Public Health Amendment (Registered Nurses in Nursing Homes) Bill 2020. Our submission addresses several of the terms of reference of the Inquiry, particularly (d) the need for further regulation and minimum standards of care and appropriate staffing levels in nursing homes and other aged care facilities.

Dementia Australia supports registered nurses being required in residential aged care facilities, noting that this alone will not guarantee quality care for people living with dementia. Appropriate numbers and skill mix of staff (determined by resident need) as well as continuity of staff are also required. Crucially, we recommend that all aged care staff including registered nurses receive mandatory dementia education.

Dementia in Australia

Dementia is the term used to describe the symptoms of a large group of neurocognitive conditions which cause progressive decline in a person's functioning. Dementia is not just memory loss - symptoms can also include changes in speech, reasoning, visuospatial abilities, emotional responses, social skills and physical functioning. There are many types of dementia, including Alzheimer's disease, vascular dementia, frontotemporal dementia and Lewy body disease.

Dementia is one of the largest health and social challenges facing Australia and the world. It is estimated that there are more than 472,000 Australians living with dementia in 2021[1] and around 1.6 million people[2] involved in their care. Without a significant medical breakthrough, there will be almost 1.1 million people living with dementia by 2058.[3] In NSW, there are close to 157,000 people living with dementia in 2021, with that number expected to rise to more than 345,000 by 2058.

Dementia is a terminal condition and there is currently no cure. 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.[4]

[1] Dementia Australia (2018) *Dementia Prevalence Data 2018-2058*, commissioned research undertaken by NATSEM, University of Canberra
[2] Based on Dementia Australia's analysis of the following publications – M.Kostas et al. (2017) *National Aged Care Workforce Census and Survey – The Aged Care Workforce, 2016*, Department of Health; Dementia Australia (2018) *Dementia Prevalence Data 2018–2058*, commissioned research undertaken by NATSEM, University of Canberra; Alzheimer's Disease International and Karolinska Institute (2018), *Global estimates of informal care*, Alzheimer's Disease International; Access Economics (2010) *Caring Places: planning for aged care and dementia 2010–2050*
[3] Dementia Australia (2018) *Dementia Prevalence Data 2018-2058*, commissioned research undertaken by NATSEM, University of Canberra
[4] Australian Bureau of Statistics (2018) *Causes of Death, Australia, 2017* (cat. no. 3303.0)

It is generally not well understood that dementia is a progressive cognitive disability. Dementia is the single greatest cause of disability in older Australians (those aged 65 and over) and the third leading cause of disability overall.[5]

Although dementia is commonly perceived to be an age-related illness, it is not a normal part of ageing. Dementia is more common in older people but it can affect people in their 40s, 50s and even their 30s.[6] Dementia diagnosed under the age of 65 is described as younger onset dementia. There are an estimated 28,300 Australians living with younger onset dementia in 2021.

People living with dementia in residential aged care

Dementia prevalence in residential aged care is significant, with estimates suggesting that more than two thirds of all people living in residential aged care have moderate to severe cognitive impairment.[7] In addition, people living with dementia often have comorbidities and complex needs. The Australian Institute of Health and Welfare reports that 80% of aged care residents with dementia require high level care, which is almost double the amount of residents without dementia who have high care needs.[8] It is therefore essential that all residential aged care facilities are well equipped to meet the needs of residents living with dementia.

Aged care reforms over recent years have been increasingly based on the belief that supporting people impacted by dementia should be part of core business for service providers. Yet, as the Royal Commission into Aged Care Quality and Safety has demonstrated, dementia is not yet core business. There are still significant steps required for quality dementia care and support to become an intrinsic part of aged care services.

There have been multiple failings in the aged care system for people living with dementia, their families and carers – both at the individual provider and systemic level. The lack of a specific and consistent focus on dementia within legislative, regulatory, policy, funding and service delivery contexts means that the needs and preferences of people living with dementia, their families and carers are not fully or adequately addressed.

The impact of inadequate staffing in residential aged care on people living with dementia, their families and carers cannot be underestimated. The Royal Commission into Aged Care Quality and Safety has drawn attention to the worst examples of poor care, neglect and breaches of human rights of people with dementia living in residential aged care, including:

- Medication mismanagement

[5] Australian Institute of Health and Welfare (2012) *Dementia in Australia*
[6] There are also some rare forms of childhood dementia, including Sanfilippo Syndrome, Niemann Pick Type C Disease and others.
[7] Royal Commission into Aged Care Quality and Safety (2020) *International and National Quality and Safety Indicators for Aged Care*, Research Paper 8
[8] Australian Institute of Health and Welfare (2020) *Dementia Snapshot*, https://www.aihw.gov.au/reports/australias-health/dementia

- Inappropriate and overuse of physical and chemical restraint
- Physical and emotional abuse
- Poor palliative and end of life care

The current ability of mainstream aged care services to appropriately manage the complex and unique needs of people with dementia, and in particular, behavioural and psychological symptoms of dementia (BPSD), is worryingly inconsistent. This is despite the fact that most people with dementia will experience BPSD at some stage during the course of their disease trajectory.[9] BPSD can include depression, anxiety, apathy, agitation, hallucinations, verbal and physical aggression, screaming, sexual disinhibition and other disinhibited behaviours.[10]

The causes of BPSD are not always clear, but changes in behaviour may be triggered by biological, psychological, social or environmental factors. BPSD is not necessarily due to the pathology of dementia, but is largely an expression of emotion or unmet need that the person with dementia cannot otherwise express (such as pain, frustration, loneliness, confusion or fear).[11] These triggers are exacerbated in many ways by the environments of residential aged care homes and staff responses.

> "Staff call the person living with dementia aggressive, but they are scared, have unmet needs and don't have a voice." – Carer

Currently, both physical and chemical restraint are inappropriately used and overused, especially in residential aged care, as 'behaviour management' strategies. In Australia, one in three aged care residents with dementia are on antipsychotic medications and more than half of aged care residents with dementia experience high sedative load.[12]

All aged care staff must be equipped to more appropriately support people with dementia and implement non-pharmacological approaches to de-escalate responsive behaviours to ensure the use of restraint as it is intended: a very last resort.

The COVID-19 pandemic has further exacerbated the need for well trained staff. The impact of a second wave of COVID-19 on Victorian residential aged care services in particular further highlighted weaknesses in the aged care system, not least regarding the capacity and availability of the workforce, clinical governance and the challenge of balancing individual care and wellbeing needs of residents with the safety of all living or working in the service. Despite the pressures created by the pandemic, a number of aged care facilities continued to provide the same level and quality of care as before. As always, there are examples of facilities doing exceptional and innovative work in providing quality dementia care.

It is critical that all aged care services have an appropriately skilled workforce that is qualified to provide safe, high quality care for people living with dementia. Over the past decade and

[9] Best Practice Advocacy Centre, New Zealand (2008) *Antipsychotics in Dementia: Best Practice Guide*, Available at http://www.bpac.org.nz/a4d/resources/docs/bpac_A4D_best_practice_guide.pdf
[10] Brodaty, H, Draper, BM, Low, L. (2003) Behavioural and psychological symptoms of dementia: a seven-tiered model of service delivery, *Medical Journal of Australia*, 178: 231-234
[11] Algase, D., et al. (1996) Need-driven dementia-compromised behaviour: An alternative view of disruptive behaviour, *American Journal of Alzheimer's Disease & Other Dementias*, 11(6): 10-19
[12] Royal Commission into Aged Care Quality and Safety (2020) *International and National Quality and Safety Indicators for Aged Care*, Research Paper 8

more, there has been a trend towards employing less skilled (and lower cost) staff in the delivery of direct care services. This is impacting the quality of care for people with dementia, and has the potential to worsen in future if a comprehensive workforce strategy, as detailed in the Matter of Care report[13], is not implemented as a matter of urgency.

The residential aged care workforce

A skilled workforce is essential to the quality of support and care provided by the aged care system. Building workforce capacity is critically important to people living with dementia, their families and carers as documented in Dementia Australia's 2019 communique *Our Solution: Quality care for people with dementia*.[14]

Dementia Australia is concerned that the ability of the aged care workforce to meet the needs of people living with dementia is significantly limited. The workforce is the foundation upon which the quality of aged care rests; and when this workforce lacks the necessary knowledge, skills and expertise, this can have a profound impact on people living with dementia, their families and carers.

Aged care workers who participated in the 2019 Australian Nursing and Midwifery Federation National Aged Care Survey[15] rated 'the level of experience and qualifications' and 'standards of care for dementia care' as two key areas of concern across the aged care sector. Previous censuses of the aged care workforce have also consistently highlighted dementia education as a priority.

In the most recent Aged Care Workforce Survey, 70% of the residential aged care workforce were personal care assistants (PCAs), followed by registered nurses at only 15% and, of all of the nurses in the sample, most did not report holding any aged care specific qualifications that went beyond training received as part of their primary nursing qualification.[16] The low number of registered nurses for a residential aged care population with increasingly high levels of acuity and complex care needs is problematic.

Only a small number of the aged care workforce indicated they had done further post-qualifying training, including courses in dementia, mental health, gerontology, and aspects of aged care (continence and wound care). The majority of residential aged care managers and leaders do not have qualifications in ageing or aged care. A staggering 71% of RNs, 79% of Care Leaders and 63% of Care Managers in residential aged care do not have specialised

[13] Aged Care Workforce Strategy Taskforce (2018) *A Matter of Care. Australia's Aged Care Workforce Strategy*, June 2018 https://agedcare.health.gov.au/sites/default/files/documents/09_2018/aged_care_workforce_strategy_report.pdf

[14] Dementia Australia (2019) *Our Solution: Quality Care for people living with dementia* https://www.dementia.org.au/files/documents/DA-Consumer-Summit-Communique.pdf

[15] Australian Nursing and Midwifery Federation (2019) *National Aged Care Survey 2019 – Final Report* http://anmf.org.au/documents/reports/ANMF_Aged_Care_Survey_Report_2019.pdf

[16] National Institute of Labour Studies (2017) *The Aged Care Workforce,* 2016 https://gen-agedcaredata.gov.au/Resources/Reports-and-publications/2017/March/The-aged-care-workforce

qualifications in ageing or aged care.[17] Registered and enrolled nurses may be employed in aged care services with no specific aged care or dementia experience or education.

Dementia Australia supports proposals from the Royal Commission that registered nurses should make up a greater proportion of the aged care workforce than is presently the case, noting that the proportion of registered nurses will have the most significant impact when the nurses in question have a solid clinical knowledge of dementia. As such, Dementia Australia recommends that workforce structures should be informed by the specific care needs of residents and that, in all cases, minimum levels of dementia education need to be built into qualifications, position descriptions and continuing education pathways.

Mandatory dementia education

Mandatory dementia education for all staff working in the aged care sector as well as improved education and qualification pathways is critical to improving the quality of care provided to people living with dementia. Having requirements around registration of the workforce is also critical to ensuring minimum and ongoing levels of knowledge and skill are maintained.

Clearly defined criteria and expectations of staff, and a program of training that supports the delivery of that criteria, are required. To support the needs of people with dementia, training must include:

- knowledge of dementia including developing a real empathy for the person living with dementia;
- the delivery of person-centred care;
- strategies for communication and engagement;
- psychosocial approaches to addressing unmet needs (including alternative methods to physical and chemical restraint use);
- pain assessment and management (particularly as people with dementia may be unable to verbalise their needs);
- appropriate end-of-life and palliative care; and
- emotional intelligence and mindfulness.

Dementia education should include experiential learning (for example, Dementia Australia's Educational Dementia Immersive Experience - EDIE) to enable aged care staff to develop empathy for people living with dementia. Immersive and experiential educational experiences have proven to be impactful and greatly contribute towards developing deeper insights into the world of living with dementia. Dementia Australia aims to incorporate immersive experiences into all of its education and inspire participants to alter their current practice and influence the practice of others.

Improved and mandated minimum levels and quality of dementia education alone will not lift the quality of care provided. Not only does the workforce need to be educated on the key

[17] *Ibid.*

concepts of quality dementia care, they also need to confidently understand how to translate that knowledge into practice.

> "(Aged care staff) need an understanding of what dementia is, we need real education not just the book work. People need to understand dementia." – Person living with dementia

Recognising that 90% of learning occurs in the workplace means that knowledge translation activities are critical for dementia education to improve practice which results in enhanced quality of life and care outcomes for people with dementia. Programs which assist staff to apply the newly acquired knowledge and skills is critical if staff are going to be supported to work in a different way to what they may have done previously.

Having organisational cultures which actively promote the ongoing learning of their staff are critical to this application of knowledge into practice. Introducing buddy programs for new staff with more experienced staff, developing the coaching and mentoring skills of key staff can also assist with this learning. Establishing dementia communities of practice can also help share the learning around practice change and improvement more widely across the sector as well as providing important support for the leaders at the coal face driving these changes in practice.

Staffing levels and continuity

People with dementia and carers have told Dementia Australia that workforce shortages are impacting on the delivery of care, with some suggesting that the increasing pressure on the aged care workforce is manifesting in critical mistakes being made. A common example often raised is the overuse of physical and chemical restraints, where restraints are used inappropriately to keep residents 'in place' when a facility is short on staff. Inexperienced staff, staff turnover, frequent shift rotations and poor hand-over procedures are also cited as some of the main causes of avoidable failures, as well as a substantial barrier to achieving quality dementia care.

Appropriate staffing levels are a critical component to delivering high quality and safe care, where staff have sufficient time to perform clinical and care tasks that meet the needs of an individual. In addition, continuity of care is particularly important for people living with dementia. Multiple staff changes can be confusing and distressing, and exacerbate symptoms of dementia. It is important that people with dementia are able to develop rapport and relationships with those who care for them. The use of casual and agency staff is therefore problematic - people with dementia need consistency in staffing.

Workforce skills mix

In addition to staff numbers, optimising the aged care workforce skills mix is important to address the current workforce challenges. Broadly, evidence supports that incorporating a

mix of skills is a good strategy for improving the quality of care.[18] However, currently the aged care workforce lacks a sufficient skills mix, where high numbers of personal care workers and decreasing numbers of registered nurses is potentially creating a gap in clinical oversight. Equally with allied health professionals only accounting for six percent of the workforce, specialised supports are clearly limited – which creates a particular issue for people with dementia who have more complex care needs.[19] As dementia progresses, people often require care for almost every aspect of their life; this includes personal care, psychosocial supports, clinical supports and allied health – such as nutritional and oral health. Caring for people with dementia therefore requires a rich mix of skills, which cannot be achieved with the current imbalance of the aged care workforce. Dementia Australia recommends that residential aged care providers implement appropriate staffing levels and skills mix based on a holistic model of care including a minimum level of suitability qualified direct care staff.

Conclusion

Dementia Australia recommends that all residential aged care facilities have a registered nurse on site at all times, noting that this alone is not enough to improve the quality of care provided to people living with dementia. We also need the appropriate numbers and skill mix of staff (determined by resident need) and continuity of staff. Crucially, all aged care staff must receive mandatory dementia education.

Dementia Australia would welcome the opportunity for further consultation on the Public Health Amendment (Registered Nurses in Nursing Homes) Bill 2020.

[18] Koopmans, L., Damen, N., and Wagner C. (2018) Does diverse staff and skill mix of teams impact quality of care in long-term elderly health care? An exploratory case study, *BMC health services research*, 18(1):988
[19] Australian Institute of Health and Welfare (2017) *Australia's aged care workforce*