



**dementia
australia™**

The new voice of Alzheimer's Australia

Queensland Health Transparency Bill 2019

A response from Dementia Australia

September 2019

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 447,000 Australians living with dementia and the estimated 1.5 million Australians involved in their care.

Dementia Australia works with people impacted by dementia, all governments, and other key stakeholders to ensure that people with all forms of 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 individuals and communities 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 comment on the Health Transparency Bill, introduced to Queensland Parliament on 11 September 2019. Overall, Dementia Australia is supportive of the Bill, which signifies an important step forwards in improving transparency across health and aged care services in Queensland. The intention of this legislation, which seeks to improve access to information around health and aged care providers, will enable people to make more informed choices around their own care – a concept that Dementia Australia, along with people living with dementia, families and carers, supports.

To improve the experience and outcomes for people with dementia in public and private health facilities, Dementia Australia has long advocated for mandatory dementia education and training for health care staff, especially in hospitals. The inclusion of whether or not a hospital is equipped to support people with dementia would be a valuable addition to the information reported, and would assure people with dementia, their families and carers about the safety and appropriateness of care whilst they are in hospital.

The proposal to introduce a requirement for public residential aged care facilities to maintain a minimum nurse and support worker skills mix ratio, in addition to a minimum number of hours per resident each day, is especially welcomed. Recognising that there is variance in what constitutes an appropriate mix of staff skills – which varies depending on the needs of individuals – more detailed information regarding the staff skills mix will enable more people with dementia to ensure they have access to information can assist them in making decisions about providers. Similarly, whilst an appropriate minimum time per resident will vary depending on the residents' levels of need, adopting a minimum time will provide more assurance around the delivery of safe care.

By extension, Dementia Australia advocates for the publication of nationally consistent information on providers, in order to enable greater transparency and to support individuals to make informed choices when attempting to navigate the aged care system and access services.

Across a number of sectors, reporting on staff ratios and skills mix has enabled consumers to make more informed decisions, and it has helped to foster a culture of transparency around performance and quality. For example, hospitals report nurse-patient ratios, child-care services report educator-child ratios and schools report student-pupil ratios. Using the same logic, reporting aged care staff-resident ratios would increase transparency around aged care services and potentially drive improvements in quality. Furthermore, evidence from our advocates indicates that the lack of transparency on providers is a key barrier to accessing supports. Consequently, people with dementia often struggle to find an aged care facility that is equipped to support their needs and matches their preferences.

Ultimately, people living with dementia, their families and carers need access to information which supports them in choosing a provider that can accommodate their unique set of needs. In part, this can be achieved through the basic disclosure of staff numbers and skills mix.

However, people with a lived experience of dementia have also reported that they would value additional, contextual information regarding a provider's capability to support the

needs of people with dementia, including access to specialist services, level of dementia training amongst staff, and the model of care underpinning the service.

Finally, and most critical to implementing this potential legislation, is the need to ensure published information is accessible and easy to navigate so that people can compare providers and services. Streamlining information, potentially through the My Aged Care website, to avoid duplication or confusion about where to find information on providers, should also be considered in the implementation of this legislation.

Background

Dementia is a progressive neurological disability and is the leading cause of disability burden for people over the age of 65 years in Australia.¹ Dementia affects people's abilities and memories and has a profound impact on the individual and those around them. People with dementia commonly experience social isolation, which can lead to a decline in mental and physical health. People with dementia are more than three times as likely not to have a friend to confide in, compared to the general public.² Some of this social isolation can be as a result of discrimination from those around them - not out of deliberate neglect, but because people may not know how to engage, include or maintain relationships with people with dementia.

Dementia is one of the largest health and social challenges facing Australia and the world. Dementia is not a natural part of ageing. It 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 is predicted to become the leading cause of death within the next five years.³

There are an estimated 447,000 Australians living with dementia and, without a significant medical breakthrough, there will be over one million people living with dementia in Australia by 2056.

Quality and safety information on public and private health facilities

People living with dementia are frequent users of acute care services, with around one in four people with dementia being admitted to hospital every year – which is twice the rate of admissions for people without dementia.⁴ Hospital admissions for people with dementia often occur due to comorbidities, such as hypertension and diabetes, which means they are often dealing with multiple diagnoses and complex care needs. Despite the frequency of people with dementia entering hospital, the clinical outcomes of people with dementia are considerably worse, where people with dementia often have longer stays, higher mortality rates and a higher likelihood for readmission.⁵ Whilst some of these differences will be

¹ Australian Institute of Health and Welfare (2012) *Dementia in Australia*

² Dementia Australia (2016) *Dementia and Loneliness report*

³ Australian Bureau of Statistics (2016) *Dementia: Australia's leading cause of death?* Accessed online

⁴ Gibson D. (2014) *Understanding what is different for patients with dementia in acute care hospitals*, presentation at Dementia Care in Hospitals Symposium, Sydney

⁵ Australian Commission on Safety and Quality in Health Care (2013) *Evidence for the safety and quality issues associated with the care of patients with cognitive impairment in acute care settings: a rapid review*

caused by the nature of the disease, evidence strongly suggests that hospitals need to be better equipped to support the outcomes of people living with dementia.

To improve the experience and outcomes of people with dementia in hospitals, Dementia Australia has long advocated for mandatory dementia education and training for hospital staff. This is primarily so staff can identify people with a cognitive impairment and know how to communicate effectively with them to deliver quality care. This is a particularly pertinent issue as a dementia is often unrecognised in hospitals, which can lead to hospital patients with dementia not receiving adequate or appropriate care.

The nature of a busy hospital environment can be overwhelming for people living with dementia which can exacerbate their symptoms. Therefore, Dementia Australia recommends that hospitals adopt a dementia-friendly environment, to reduce confusion and unnecessary distress for patients. Dementia-friendly hospitals are more supportive of people with dementia, and enable a less chaotic and overwhelming experience. The inclusion of whether or not a hospital is equipped to support people with dementia would be a valuable addition to the information reported, and would assure people with dementia, their families and carers about the safety and appropriateness of care whilst they are in hospital.

Recommendations

1. *Data should be collected on the level of dementia training amongst hospital staff.*
2. *Dementia-friendly hospitals should be noted within the quality and safety information published on all hospitals.*

Residential aged care information

a. Information about the care provided

Dementia is a complex health condition which progressively impacts people's cognitive and physical health in different ways – there is no single presentation of dementia symptoms. High quality dementia care therefore needs to be flexible and tailored to meet an individual's needs. Typically people with dementia will require a combination of health, allied health and psychosocial supports. Because of the complexity of dementia care, not all providers are equipped or have the capacity to deliver the level of care required, which is why people with dementia need access to information on providers so they can decide which provider can meet their needs. Contextual information on providers should therefore include the types of supports available to people with complex needs.

Effective care for people with dementia involves supports that aim to maintain an individual's level of independence and capacity. For example, research demonstrates that many people benefit from reablement approaches to care.⁶ Reablement refers to goal oriented care which focuses on maintaining or re-establishing daily living skills and community connections. Reablement approaches in aged care are proven to benefit people with dementia, including by maintaining physical function but also improving their general wellbeing – which is particularly important as people with dementia are often vulnerable to becoming isolated and

⁶ Tessier A, Beaulieu MD, Mcginn CA, Latulippe R. (2016) Effectiveness of reablement: a systematic review, *Healthcare Policy*, 11(4):49

lonely within institutionalised care settings.⁷ Increasingly, people living with dementia, their carers and families are in search of residential aged care facilities which will offer the best model of care, to support not only their medical health, but their wellbeing and quality of life. Therefore information regarding providers should also detail the model of care or approach to delivering care.

A key concern frequently reported by people with dementia, their carers and families, is the inappropriate use of chemical and physical restraints in aged care facilities. Currently, there is a considerable lack of transparency around the frequency of restraint use, including the use of chemical restraints. The sector has inconsistent reporting of restraints, especially when reporting how long a restraint was used, and if consent was obtained. Whilst there may be emergency occasions where a restraint is needed to ensure the safety of a resident, Dementia Australia maintain the view that restraints should always be the last resort, and used for a minimal period, when consent has been obtained and alternatives have been exhausted. Minimal use of restraints, and the use of alternatives to chemical and physical restraints, is an indication of high quality care and, therefore, is a key feature people living with dementia and their carers, will look for in choosing an aged care provider.

Recommendation:

3. *Details on the model of care underpinning aged care services should be included as contextual information.*
4. *To supplement the upcoming mandatory reporting of physical restraints, providers should also report the use of chemical restraints in facilities. Where applicable, providers should also highlight alternative approaches to physical and/or chemical restraint use which are being used in the facility.*

b. Information on staffing

There is a growing body of research that demonstrates the link between staffing levels and quality of care, where appropriate levels of staff positively impacts resident wellbeing and reduced the occurrence of pressure ulcers, infections including Urinary Tract Infections (UTIs), complaints of pain, and rates of hospitalisation.⁸ Undoubtedly, appropriately targeted workforce numbers are critical to the delivery of high quality dementia care, and publishing staffing numbers will provide much needed transparency around the capacity of the aged care workforce.

In addition to staff numbers, the expertise and skills mix of staff is important to the delivery of high quality care. Evidence supports that incorporating a mix of skills in the aged care workforce improves the quality of care.⁹ However, evidence reported to Dementia Australia suggests that staffing ratios and skills mix do not consistently support quality dementia care. Specifically, there is often an imbalance of clinical skills to social, lifestyle or personal

⁷ Poulos, C.J., Bayer, A., Beaupre, L., Clare, L., Poulos, R.G., Wang, R.H., Zuidema, S. and McGilton, K.S., (2017) A comprehensive approach to reablement in dementia, *Alzheimer's & Dementia: Translational Research & Clinical Interventions*, 3(3):450-458

⁸ Willis, E., Price, K., Bonner, R., Henderson, J., Gibson, T., Hurley, J., Blackman, I., Toffoli, L and Currie, T. (2016) *Meeting residents' care needs: A study of the requirement for nursing and personal care staff*, Australian Nursing and Midwifery Federation

⁹ Koopmans L, Damen N, 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.

supports – which is impacted by a lack of understanding and/or skills in dementia knowledge. Most recent estimates state that allied health professionals only account for six percent of the aged care workforce, indicating that specialised supports are clearly limited. This is concerning, particularly for people with dementia who have more complex care needs and require multidisciplinary care.¹⁰ As dementia progresses and changes an individual's cognitive abilities, people with dementia increasingly depend on others to support their wellbeing and quality of life. Support from others often includes personal care, psychosocial supports, clinical supports and allied health (e.g. dietetics, dentistry, podiatry, physiotherapy). Caring for people with dementia therefore requires a rich mix of skills, which cannot be achieved with the current state of the aged care workforce.

Currently, figures estimate that 52% of people living in residential aged care have a diagnosis of dementia.¹¹ Therefore there is undoubtedly a need for staff to be trained in dementia care. However, currently dementia education is not a mandatory requirement of the aged care workforce - at best it is offered as an elective or offered by individual providers to up-skill staff. Recognising that there is not yet mandatory requirement for dementia education, reporting on the prevalence of staff with dementia education would support people living with dementia to choose an aged care home which is equipped to meet their needs.

One of the key features of high quality aged care – for people with or without dementia – is a model of care which can flexibly support the unique needs of each resident. Person-centred care is about treating each individual according to their goals, values and aspirations for care. This differs to traditional models of care which are focused on delivering standardised practices, which respond to an individual's diagnosis or disabilities, rather than an individual's goals or values. Whilst embedding a person-centred model of care requires sufficient staff capacity – which is why an appropriate amount of resident-staff time is important – delivering high quality care also relies on appropriate staff training and education on the delivery of person-centred approaches, strong leadership and management and a workplace culture which values a person-centred approach to care.

Therefore, whilst Dementia Australia supports the recommendation to implement a minimum staff-resident time, it is important that the minimum timeframe reflect the variability in care needs of individuals and allow staff to adapt their time to suit each resident's needs – therefore supporting a person-centred approach to care. In addition to time per resident, we also strongly suggest that Queensland Health consider implementing reporting measures that reflect other key features of delivering high quality care. This includes a facilities model of care, sufficient staff training and education, and the capabilities and effectiveness of leadership and management – all of which are critical to the delivery of high-quality care.

Recommendations:

- 5. The prevalence of dementia training amongst aged care staff should be provided.***
- 6. In addition to staff skills ratio, providers should provide contextual information on access to specialist supports – such as allied health supports.***

¹⁰ Australian Institute of Health and Welfare (2017) *Australia's aged care workforce*

¹¹ Australian Institute of Health and Welfare (2019) *GEN fact sheet 2017–18: People's care needs in aged care*, Canberra: AIHW

7. *The minimum time spent with residents should be flexible, and adjusted according to the resident's levels of care needs.*

Publishing information

One of the key asks of people impacted by dementia is for clear information on providers to enable them to compare services and reach an informed decision on the provider that will best meet their needs and preferences. Therefore, Dementia Australia is pleased that the Health Transparency Bill seeks to publish key information on providers to help Queenslanders make decisions around their care.

However, we also acknowledge the existing efforts by My Aged Care, which is similarly developing the My Aged Care website to include key information on providers to enable comparison. The key strength of the My Aged Care website is the potential for a streamlined system which pulls information on aged care providers into one place. Therefore, by creating a separate system, there is a risk that it adds to the confusion people already experience in navigating the aged care system. It could also create an additional reporting burden for providers. A partnership approach, whereby Queensland health feed information in to the My Aged Care website, would resolve any potential duplicative systems.

In the development of My Aged Care, a consistent message around accessibility and user-friendly information has been a concern, especially for people living with dementia and their carers. Ultimately, information on providers needs to be written in plain English, easy to compare between providers and there needs to be consideration to people from special needs groups, such as people from culturally and linguistically diverse communities who may need translations. Consideration of the needs of people in rural and remote locations, who may not have immediate or convenient access to online information, is also required.

Recommendation

8. *Information on providers should be published using existing mechanisms, such as the My Aged Care website, rather than creating duplicative systems.*

Conclusion

Dementia impacts at least 52% of people living in residential aged care facilities, across Australia.¹² People with dementia are also twice as likely to enter hospital each year, compared to people of the same age without dementia.¹³ Therefore, Dementia Australia is supportive of the proposals made in the Health Transparency Bill which seek to improve transparency around aged care and health services, and potentially enable more people to access the care they need.

The recommendations made within this submission are based on the experiences of our advocates – people living with dementia and their carers – and will ensure that any future

¹² Australian Institute of Health and Welfare (2019) *GEN fact sheet 2017–18: People's care needs in aged care*, Canberra: AIHW

¹³ Gibson D. (2014) *Understanding what is different for patients with dementia in acute care hospitals*, presentation at Dementia Care in Hospitals Symposium, Sydney

transparency legislation keeps in mind the needs of people with dementia, who are amongst some of the highest users of residential aged care and hospitals.

Dementia Australia thanks the Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee for the opportunity to consult on the proposal for the Health Transparency Bill, and welcome any further opportunities to consult on this legislation as it progresses.