



**dementia
australia™**

**Royal Commission into violence,
abuse, neglect and exploitation of
people with disability**

**Health care for people with
cognitive disability**

Dementia Australia

March 2020

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 459,000 Australians living with dementia and the estimated 1.6 million Australians involved in their care.

Dementia Australia works with people of all ages 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 can 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 of all ages 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.



Recommendations

1. Provide a minimum level of mandatory dementia education to all medical students.
2. Provide a minimum level of mandatory dementia education for doctors and GPs, and ongoing professional development in dementia a requirement of registration.
3. Provide training to GPs and other health professionals (such as geriatricians and neurologists) on:
 - how to communicate a diagnosis of dementia;
 - where to refer people with dementia to for support (including to Dementia Australia); and
 - services in the disability and aged care systems to support people with younger onset dementia.
4. Develop a structured diagnostic pathway that supports post-diagnosis referral to early intervention supports, including those offered by Dementia Australia.
5. Develop care pathways that ensure healthcare professionals initiate timely discussions (ideally at the point of diagnosis) about advance care planning with a person with dementia and their family.
6. Provide increased training to the aged care workforce, GPs, and acute care staff about the unique palliation needs of people with dementia.
7. Provide dedicated dementia-specific palliative care services in primary and acute care settings, where staff are appropriately trained in dementia care needs.
8. Develop clinical nurse consultant roles, which specialise in dementia-specific palliative care.
9. Provide mandatory training in dementia to all hospital staff (including those in clinical, administrative, catering, cleaning and maintenance roles) to ensure that people with dementia and their families and carers are well supported at admission and throughout their stay in hospital.
10. Conduct reviews of hospital awareness and adherence to The National Safety and Quality Health Service Standards (especially actions 5.29 and 5.30) to ensure that they are appropriately utilised for patients presenting with cognitive impairment and/or delirium.
11. Ensure the physical environments of hospitals adhere to dementia-friendly design principles, including the provision of orientation cues and quiet spaces, in the design and layout of buildings.
12. Ensure physical and chemical restraints are used on hospital patients with dementia only as a last resort.
13. Develop a comprehensive national process (including a mandatory review of medications) to ensure that the transfer of people from hospital to residential aged care facilities is improved.
14. Utilise case conferencing and a multi-disciplinary approach to care and discharge planning to proactively address health concerns and provide a coordinated response to post-hospital care for people with dementia.

Introduction

Dementia Australia welcomes the opportunity to provide a submission to the Royal Commission into violence, abuse, neglect and exploitation of people with disability, in response to the issues paper on health care for people with cognitive disability. Although all people with dementia live with disability, our submission focuses primarily on the health care experiences of people living with younger onset dementia – that is, people with dementia under the age of 65 – as they are supported within the disability system.

Our submission has been developed in consultation with people living with dementia, families and carers, as well as Dementia Australia staff members. It addresses the experiences of people with dementia in the health care system during the process of being diagnosed with dementia and in hospital settings. We also discuss the importance of including people with dementia in decisions about their own health care.

Dementia in Australia

Dementia is the term used to describe the symptoms of a large group of neurocognitive diseases which cause a progressive decline in a person's functioning. Symptoms can include memory loss as well as 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 459,000 Australians living with dementia in 2020¹ and around 1.6 million people² involved in their care. Without a significant medical breakthrough, there will be almost 1.1 million people living with dementia by 2058.³

Dementia is a terminal condition and there is currently no cure. It is the leading cause of death of women in Australia, and the second leading cause of death overall. It is predicted to become the leading cause of death within the next five years.⁴

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

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 The National Centre for Social and Economic Modelling [NATSEM], University of Canberra

⁴ Australian Bureau of Statistics (2018) *Causes of Death, Australia, 2017* (cat. no. 3303.0)

⁵ Australian Institute of Health and Welfare (2012) *Dementia in Australia*

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

The impact of younger onset dementia

Younger onset dementia describes any form of dementia diagnosed in people under the age of 65. In 2020, there are an estimated 27,800 people with younger onset dementia. This number is expected to rise to 29,353 people by 2028 and 41,249 people by 2058.⁷

Although dementia is most commonly diagnosed in people over 65, the prevalence and impact of dementia in younger people is significant. The misconception that dementia is a condition of old age contributes to, and exacerbates, multiple challenges experienced by younger people with a diagnosis of dementia.

Overall, the experience for people with younger onset dementia – who often receive a diagnosis when they are in full-time employment and actively raising and financially supporting a family – is different from those diagnosed with dementia at a later stage of life. Loss of income, self-esteem and perceived future purpose can pose multiple physical and psychological challenges for people with younger onset dementia and their families.

Intersection between health, disability and aged care systems

People with younger onset dementia are required to navigate their way through multiple care systems as their dementia progresses. While people living with younger onset dementia are generally eligible to access the National Disability Insurance Scheme (NDIS), due to the progressive nature of their condition and need for increasing supports – which may not be available in the disability system – many people with younger onset dementia also require support from aged care services. As such, people with younger onset dementia are typically required to straddle both the aged care and disability systems – neither of which is fully equipped to respond to the needs of people with younger onset dementia. Not only is it confusing to juggle two support systems, but the lack of a clear diagnosis and care pathway often results in people with younger onset dementia, their families and carers falling through the cracks, where both sectors see the other as better placed to respond.

In addition to the NDIS and aged care systems, the interface with the health system can be challenging for people with younger onset dementia, their families and carers. Broadly, the health system has a limited understanding of dementia and of younger onset dementia in particular.

⁶ There are also some rare forms of childhood dementia, including Sanfilippo Syndrome, Niemann Pick Type C Disease and others.

⁷ Dementia Australia (2018) *Dementia Prevalence Data 2018-2058*, commissioned research undertaken by NATSEM, University of Canberra

“Many medical practitioners have little to no understanding that younger onset dementia exists and are unfamiliar with how to approach an unwell person with this diagnosis. Concerns over pain or other illnesses are ignored or overlooked, often resulting in hospitalisation.” Dementia Australia staff member

To improve the systemic response to people impacted by younger onset dementia, greater education about younger onset dementia for staff within the health, disability and aged care systems is imperative. Staff who are educated in dementia and understand how to best communicate with and provide support and care for people with younger onset dementia are critical to ensuring that their health care needs are identified and addressed, timely and appropriately.

“My experience with the health care system has been very positive. From the start of the process from my GP to the current level of care has been outstanding. You have to navigate the system and trust the system which can be a little frightening and sometimes frustrating but we have been lucky to have found true professionals all the way.” Person living with dementia

Navigating three separate complex and confusing systems (disability, aged care and health care) compounds the stress and overwhelm experienced by people living with younger onset dementia, their families and carers. Greater collaboration, communication and information sharing is vital to create streamlined processes and pathways for people with younger onset dementia to access the health care and services they need, in a system that understands their condition.

As dementia progresses, many individuals will experience a number of physical and psychological comorbidities which require a health care response. Some of the additional health care needs arise from decreased mobility and physical function, unexpected weight loss and nutritional concerns, poor oral health and, mental health concerns. The unpredictability of dementia and how it impacts individuals means that access to additional supports such as nutritionists, dentists, physical therapists and psychologists need to be readily available to ensure emerging needs are met. Timely access to these supports, regardless of whether a person is living at home or in residential aged care, is integral to maintaining an individual’s independence, wellbeing and prevention of further illnesses.

Ultimately, Dementia Australia is advocating for more comprehensive and coordinated support for people with younger onset dementia, their families and carers to ensure that they receive the most appropriate support and care, regardless of which system/s provides it.

The diagnosis experience

Diagnosing dementia is not a straight forward process. People with younger onset dementia, especially, report experiencing a lengthy and distressing diagnosis process.

“An earlier diagnosis would have helped us to better manage our life together, and would have helped me to understand what was going on. Well before his diagnosis my husband had become difficult to live with, and I felt he was a poor partner. Once he was diagnosed, I engaged with Dementia Australia and received useful support and education, but I wish I'd received this help earlier.” Carer

Misdiagnosis

As a complex condition, dementia can be difficult to diagnose. There are over 120 different types or causes of dementia. This variation can require a number of diagnostic tests to determine a correct diagnosis, and even then some causes of dementia can only be truly diagnosed post-mortem.

People with dementia, especially people with younger onset dementia, often experience several misdiagnoses before it is confirmed they have dementia. Early symptoms of dementia, including personality change and social withdrawal, may present diagnostically similar to individuals with mental health concerns. For example, many people are diagnosed with depression or other mental illness, which can subsequently lead to the incorrect prescription of anti-depressants and other medications.

“I now understand that the symptoms of depression that I was experiencing are also very similar to those of Alzheimer's disease, yet if it wasn't for the third psychiatrist listening and trying to understand why I was still experiencing memory loss and cognition impairment, then my Alzheimer's disease would have gone undiagnosed for many more years.” Person living with dementia

Limited understanding of younger onset dementia by health professionals

A lack of understanding of dementia, particularly younger onset dementia, among health care professionals also presents a barrier to a timely diagnosis. GPs, who are most often the first point of contact for people who are worried about their cognition, lack a consistent understanding of dementia.

It is not known how many GPs have a thorough understanding of dementia, given dementia is only a small component of GP training and there is no mandatory professional development in dementia. Given the increasing number of Australians with dementia, greater consistency in the training of GP and primary care professionals will improve the quality of care and support provided to people at risk of dementia and people living with dementia, as well as their families and carers.

In cases where GPs have an awareness and understanding of younger onset dementia, individuals receive a quicker diagnosis, and consequently are able to access supports earlier. GP knowledge of dementia and a referral process to appropriate supports is important for ensuring that people with dementia, their carers and families receive a more timely diagnosis and access to support.

Communicating the diagnosis

“My path to a diagnosis took about eighteen months, what I thought was a long time, but from what I hear of other’s experiences was a short time... I was given my diagnosis – that I had Frontotemporal Dementia, 3 to 6 years to live and that I should go home and essentially prepare to die.” Person living with dementia

Receiving a diagnosis of dementia is both distressing and often unexpected for people under the age of 65. It is therefore critical that a diagnosis is communicated timely, clearly and compassionately. People need to feel reassured, supported and provided with information about support services available.

Unfortunately this is not the experience many people with dementia report. People with younger onset dementia, especially, express concern about the poor way in which their diagnosis was communicated – often with a lack of compassion, empathy and respect displayed in the delivery of the diagnosis.

People with dementia, families and carers also identify the common experience of being given very little information about dementia, their possible prognosis and what to do next. Too often, people with dementia, families and carers, report to Dementia Australia that they did not experience a comprehensive referral pathway following their diagnosis of dementia.

“Overall, my experience with the health care system left me feeling unsupported, confused and frustrated. There was no clear path of discovery to secure a diagnosis, increased understanding of the illness or how to care for a family member with Alzheimer’s. I spent a lot of time trying to find out who could help and how. I knew nothing about the illness to start and had to self-educate and try many avenues to receive the answers and or services needed to diagnose my mother and then manage her illness.” Carer

Recommendations

1. Provide a minimum level of mandatory dementia education to all medical students.
2. Provide a minimum level of mandatory dementia education for doctors and GPs, and ongoing professional development in dementia a requirement of registration.
3. Provide training to GPs and other health professionals (such as geriatricians and neurologists) on:
 - how to communicate a diagnosis of dementia;
 - where to refer people with dementia to for support (including to Dementia Australia); and
 - services in the disability and aged care systems to support people with younger onset dementia.
4. Develop a structured diagnostic pathway that supports post-diagnosis referral to early intervention supports, including those offered by Dementia Australia.

Including people with dementia in decisions about their health care

The importance of a timely diagnosis

Receiving a timely and accurate diagnosis of dementia is important. It provides an individual with an explanation for symptoms, allows for medication to be prescribed (for some people, with some types of dementia) to slow down the progression of symptoms, and importantly, it enables people with dementia to plan ahead and be involved in decisions about their future including their health care needs and wishes.

A diagnosis of dementia does not automatically mean that a person can no longer make decisions for themselves; however, as dementia progresses it impacts significantly on individuals' decision making abilities and may result in people with dementia requiring a substitute decision maker.

Planning ahead

Dementia Australia encourages people who receive a diagnosis of dementia to plan ahead for their future. This includes preparing an Advance Care Directive to record their end of life wishes, appointing an attorney under an Enduring Power of Attorney to manage their financial and legal affairs, as well as an Enduring Guardian and/or healthcare decision maker to make health, lifestyle, care and accommodation decisions on their behalf.

Generally, giving a trusted individual decision making responsibilities empowers people with dementia by extending their decision making autonomy and allowing individuals to plan for when they no longer have capacity to articulate their wishes. By using supported decision making techniques, substitute decision makers can assist people with dementia to weigh up decisions and make informed choices about their own care.

However, in some cases, people living with dementia do not have an Enduring Power of Attorney or Guardian in place before their decision making abilities become impaired. This may be due to a quick progression of dementia, but in other cases this is due to a delayed diagnosis or lack of awareness of advance care planning processes.

Over time, dementia will inevitably lead to progressive cognitive and functional decline. Most people in the later stages of dementia require significant care and support across almost every aspect of their life. When reaching the end of life stage, many people with dementia may choose to refuse particular medical interventions, through an advanced care directive – particularly if interventions are considered intrusive. Ultimately, an individual's medical preferences should be upheld and substitute decision makers are critical to protecting the wishes and preferences of people with a cognitive impairment who cannot represent themselves. It is important all health care practitioners attempt to discuss medical interventions with the person living with dementia or their substitute decision maker before carrying out a procedure to ensure that medical decisions are aligned to the individuals' wishes.

Planning for palliative and end of life care

As previously noted, dementia is currently the second leading cause of death in Australia. Despite this, many people, even within the health profession, do not understand the terminal

nature of dementia. Consequently, people living with dementia face barriers in accessing appropriate palliative care services and having their end of life needs met.⁸

Access to quality palliative care, whether that be in an individual's home or in a residential aged care setting, is critical to ensuring people with dementia die well. It is imperative that health care staff are appropriately skilled to deliver palliative care to people with dementia in the various care settings. In addition, service redesign that includes improved coordination, integration and individualised care, is required to ensure people with dementia are able to access quality palliative care services and health care during the end of life across the different care settings.

Importantly, planning for palliative care and end of life should begin at the point of diagnosis and early intervention, when people with dementia are more likely to have capacity to make decisions and express their wishes. If this happens, the process of good palliative care and a good death, regardless of the setting, can be done not only well, but respectfully to the individual's wishes.

Recommendations

5. Develop care pathways that ensure healthcare professionals initiate timely discussions (ideally at the point of diagnosis) about advance care planning with a person with dementia and their family.
6. Provide increased training to the aged care workforce, GPs, and acute care staff about the unique palliation needs of people with dementia.
7. Provide dedicated dementia-specific palliative care services in primary and acute care settings, where staff are appropriately trained in dementia care needs.
8. Develop clinical nurse consultant roles, which specialise in dementia-specific palliative care.

The hospital experience

Generally, hospitals are not good places for people living with dementia. The confusion and distress associated with hospitalisation, regardless of whether it is planned or unplanned, can exacerbate symptoms of dementia as well as cause considerable stress for their families and carers.

Hospitalisation of people with dementia

People living with dementia are twice as likely to be admitted to hospital, and 2-3 times more likely to have an adverse event in hospital (for example falls, delirium and sepsis) than people of the same age who do not have dementia.⁹ When in hospital, people with dementia are at greater risk of adverse events and preventable complications such as falls, pressure injuries, accelerated functional decline, longer lengths of stay, premature entry to

⁸ For further information see Dementia Australia (2019) *Dying Well: Improving end of life and palliative care for people with dementia* available at <https://www.dementia.org.au/files/documents/19013-DA-Dying-Well-Discussion-Paper.pdf>

⁹ Panayiotou, A (2018) *Preventing Avoidable Hospital Admissions for People with Dementia*, Final Report, Melbourne Ageing Research Collaboration Available at https://www.nari.net.au/files/files/documents/MARC/Project%20Updates/MARC%20Final%20Project%20Summary_PAHA_Sept%202018.pdf

residential care and death than others. People with dementia are two times more likely to experience falls, pressure injuries or infections in hospital.¹⁰

Analysis of hospital data by the Australian Institute of Health and Welfare (AIHW) indicates that people with dementia have longer hospital stays than people without dementia. This additional length of stay can exacerbate or worsen symptoms of dementia, potentially leading to a decline in cognition and physical functioning. It also creates additional complexities with regard to ongoing care planning, medication management and psychosocial support, and places pressure on residential aged care facilities to support residents who may be admitted with additional complexities as a result of extended hospitalisation.

Understanding of dementia

Despite being a common condition among hospital patients, cognitive impairment is often misdiagnosed or undetected in hospital.¹¹ People impacted by dementia report that hospital staff have a limited understanding of dementia, particularly of younger onset dementia.

“The ED environment has to change. You have bright lights, noise, lots of people shoving things onto and into your arms...My dad went in with a psychosis so he had security guards sitting on top of him.” Carer

Dementia training for hospital staff is inconsistent and there is still low awareness of how to support someone with dementia or how to create enabling environments, despite the introduction of cognition and delirium standards through the Australian Commission on Safety and Quality in Health Care. Admission processes, emergency protocols (including security arrangements and management of code ‘red’ situations involving people with dementia) and day-to-day care are typically not supportive of people with dementia (or cognitive impairment as a result of delirium).¹² To ensure hospital staff are equipped to support patients with dementia, Dementia Australia advocates for mandatory dementia education of all hospital staff. Education must include identification of dementia, communication methods and an understanding of dementia friendly or dementia inclusive principles.

Dementia enabling hospitals

The physical environment of hospital settings is a key contributor to the confusion and distress experienced by people with dementia. They are busy, hectic, noisy and bright. Signage is often unclear and long, unmarked corridors may look the same.

“Very few medical facilities have given any consideration to the ‘dementia friendly’ design principles. Indeed, much of the classical ‘hospital design’ is the reverse. Simple things like visible and readable signage would be a big step forward.” Person living with dementia

¹⁰ Australian Commission on Safety and Quality in Health Care (2016) *Caring for Cognitive Impairment – A National Campaign*

¹¹ Australian Commission on Safety and Quality in Health Care (2016) *Caring for Cognitive Impairment – A National Campaign*

¹² Delirium may be caused by severe illness, constipation, dehydration, infection, pain, drug effect or withdrawal. The causes of delirium are complex and in some people the cause cannot be easily identified. Dementia increases the risk of developing delirium approximately five-fold - Dementia Australia (2019) *Dementia and Delirium Q&A sheet* https://www.dementia.org.au/files/helpsheets/Helpsheet-DementiaQandA21_Delirium_english.pdf

To mitigate this, the physical environment of hospitals needs to be adapted to be dementia enabling. Information about good environmental and building design is available on the Dementia Training Australia website at www.dta.com.au/designing-for-people-with-dementia/

“Fundamentally the hospital setting can be very unsettling for a person with dementia. They are busy, noisy places with lots of personal which can be just so confusing and I have often found that even the mildest of clients will start displaying behaviours when in a hospital. At times I have seen people with dementia put in a room with what is known as a barn door as in the top half opens out and the bottom is locked. This is to ensure that the person does not wander off. But the person often becomes so distressed.” Dementia Australia staff member

Inappropriate use of restraints

A lack of understanding of dementia, as well as the physical environment and design of hospitals, contributes to the inappropriate use of both physical and chemical restraints as ‘behaviour management’ strategies in hospital settings.

Most people with dementia will experience behavioural and psychological symptoms of dementia (BPSD) at some stage during the course of their disease trajectory.¹³ BPSD can include depression, anxiety, apathy, agitation, hallucinations, verbal and physical aggression, screaming, sexual disinhibition and other disinhibited behaviours. 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).¹⁴ These triggers are exacerbated in many ways by the environments and staff responses across a wide range of settings, including in hospitals.

Physical restraint can result in a range of adverse psychological and physical outcomes. Adverse physical effects include an increased risk of falls from struggling to get free; the subsequent risk of serious injury caused by falls, such as head injury and trauma, decreased mobility and weakening of muscles; and the development of pressure ulcers. Psychological impacts of being restrained include feelings of humiliation; loss of freedom or feeling ‘trapped’; depression; withdrawal; and increased stress and agitation.¹⁵

Chemical restraint is the use of medication, such as antipsychotics, to restrain an individual. Australian clinical guidelines recommend that antipsychotics are only prescribed after non-pharmacologic approaches to support a person with dementia have been attempted; yet we continue to see the over-prescription of these drugs. Antipsychotic medications have a range of serious side effects and are associated with an increased risk of stroke and mortality for people living with dementia. International data suggests that only 20% of people with

¹³ 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

¹⁴ 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

¹⁵ Evans, D., Wood, J. & Lambert, L. (2003) Patient injury and physical restraint: a systematic review, *Journal of Advanced Nursing*, 41(3): 274-282; Barnett, R., Stirling, C. & Pandyan (2012) A review of the scientific literature related to the adverse impact of physical restraint: gaining a clearer understanding of the physiological factors involved in cases of restraint related death, *Medicine Science and the Law*, 52: 137-142; Castle, N. G. (2006) Mental health outcomes and physical restraint in nursing homes, *Administration and Policy in Mental Health*, 33: 696-704

dementia derive any benefit from antipsychotic medications.¹⁶ Despite overwhelming evidence that antipsychotics are not effective or safe, they are still being routinely prescribed and administered – against the best practice advice outlined in clinical guidelines – to people living with dementia, and often as the primary (not ‘last resort’) ‘treatment’ for ‘managing’ people with dementia.

“My husband was taken to emergency after a small fall in his care facility. (By the time I was notified he had already been taken to emergency.) By himself in emergency, he became very anxious, agitated and aggressive. Before I arrived, security had been called, and the hospital organised a carer to come in to sit with him. During the day, security were called in a number of times to restrain him so that he could be sedated and examined. The security staff were professional, gentle and competent. All the staff were kind and did the best they could do, but the environment was alarming. Busy people filled the space and patients were wailing and calling. The environment was noisy, hectic and clinical. He was scared and was lashing out, so he was experienced as dangerous. He was sedated a number of times before he calmed. He never left the hospital - overnight he developed a chest infection from which he never recovered. He died three weeks later.” Carer

Discharge planning and support

“Hospitals often try to discharge people living with younger onset dementia once they are considered ‘treated’. Carers are bullied to try and take the person with dementia back into the home even if it is not possible. Colleagues have dealt with hospitals trying to take guardianship in order to discharge.” Dementia Australia staff member

People who have advanced stage dementia are often unable to return home after they have recovered from an illness that required hospital admission as a result of cognitive decline. As a result, they are often kept in hospital for prolonged periods, despite being physically well enough to return home, while they await placement in a residential aged care facility.

“Despite being well, people with dementia are held for weeks/months in a busy, clinical hospital ward environment until a respite or permanent care bed is found. The person being held there usually becomes increasingly anxious and their confusion is escalated. The medical staff often don’t have the training and definitely don’t have the time to appropriately support people who find themselves in this predicament.” Dementia Australia staff member

The process of transferring people with dementia from hospital to residential aged care needs to be improved. We need a streamlined process to ensure that care planning, medication reviews, and information handover is effective and supportive. The process also needs to be expedited so that people with dementia are not unnecessarily in hospital for an extended period of time while waiting for residential aged care. This is particularly a concern for people with younger onset dementia who require 24 hour care and accommodation, and

¹⁶ Peisah C. & Skladzien E. (2014) *The use of restraints and psychotropic medications in people with dementia*, Alzheimer’s Australia Paper 38

who may experience significant delays as an appropriate residential aged care facility which can support their care needs is identified.¹⁷

The effectiveness of post-hospital care and support for people with dementia is impacted significantly by barriers to accessing other health services such as rehabilitation and allied health services. Unlike other chronic health conditions, the progressive neurological impacts of dementia can often make engaging with traditional health services difficult and confusing. For example, some people with dementia are unable to follow instructions or remember to practice health activities, such as physiotherapy or nutritional advice. This should not mean that people with dementia are denied access to these services, yet people with dementia are routinely excluded. It is therefore critical that people with dementia receive additional discharge and post-hospitalisation support.

Impact of hospitalisation

People with dementia as well as families and carers often report a change or decline in physical or cognitive health during or following a hospitalisation. Hospital stays are also stressful for carers and families of people with dementia because it can significantly increase their caring responsibilities as they have to negotiate the hospital system as well as provide assistance and reassurance to the person they support.

“People with dementia experience neglect (in the health care system) for sure. Clients are often left unchanged in soiled continence aides, their teeth are not cleaned, assistance with feeding and dignity around showering are ignored. They are just left to yell out in discomfort as they cannot verbalise their needs. I have had reports of NDIS carers having to do this instead and when asked why it wasn’t done, the hospital staff respond with its not our job.” Dementia Australia staff member

The clinical complexity and multiple comorbidities of people living with dementia, overlaid with the symptoms of dementia and the unfamiliar hospital setting, can mean:

- Cognitive impairment is misdiagnosed or undetected
- Hospital staff are unaware of a person’s dementia symptoms and are not trained in how to support someone with dementia
- There is an increased risk of disorientation for the person with dementia which can exacerbate their symptoms
- There is heightened stress for carers trying to navigate the hospital system as well as support the person they can for in an unfamiliar environment
- There is a risk of longer length of stay and additional health complications (for example delirium, dehydration etc.)

It is only through a collaborative approach to dementia care in hospitals – one that involves people living with dementia, their families and carers, hospital staff, government, providers and regulatory bodies – that we can ensure hospitals are supportive environments for patients with dementia and their families and carers.

Dementia Australia advocates for models of care that are supportive of people with dementia to be implemented in hospitals. The following must be considered:

¹⁷ Access to appropriate residential care and accommodation for people with younger onset dementia is a significant issue that the Royal Commission into violence, abuse, neglect and exploitation of people with disability needs to address and, as such, Dementia Australia is preparing a submission to the Commission on this.

- Cognitive needs are recognised early;
- Staff are trained in dementia and know how to escalate concerns to dementia specialists if necessary;
- Additional support is provided to patients with dementia (for example through trained volunteers)
- Non-pharmacological approaches and diversional therapies are a first line of approach instead of physical and chemical restraints;
- Timely medication reviews are conducted;
- Care and discharge planning include the person living with dementia, their family and a multidisciplinary team.

Recommendations

9. Provide mandatory training in dementia to all hospital staff (including those in clinical, administrative, catering, cleaning and maintenance roles) to ensure that people with dementia and their families and carers are well supported at admission and throughout their stay in hospital.
10. Conduct reviews of hospital awareness and adherence to The National Safety and Quality Health Service Standards (especially actions 5.29 and 5.30) to ensure that they are appropriately utilised for patients presenting with cognitive impairment and/or delirium.
11. Ensure the physical environments of hospitals adhere to dementia-friendly design principles, including the provision of orientation cues and quiet spaces, in the design and layout of buildings.
12. Ensure physical and chemical restraints are used on hospital patients with dementia only as a last resort.
13. Develop a comprehensive national process (including a mandatory review of medications) to ensure that the transfer of people from hospital to residential aged care facilities is improved.
14. Utilise case conferencing and a multi-disciplinary approach to care and discharge planning to proactively address health concerns and provide a coordinated response to post-hospital care for people with dementia.

Conclusion

Although some people do have positive experiences, broadly the health care system is challenging for people with dementia and their carers to navigate and in their experience lacks understanding and compassion. We need a health care system that is equipped to respond to the needs of people living with dementia.

Dementia Australia hopes the issues and recommendations identified in our submission assist the Commissioners to understand the health care issues people with dementia face. We would welcome the opportunity for further engagement with the Royal Commission to ensure that the experiences and needs of people with dementia, their families and carers in the health care system are considered and responded to.