dementia australia™

Hospital Care for People Living with Dementia

August 2019

This page is left blank intentionally

Contents

Introduction

Dementia Australia (formerly known as Alzheimer's Australia) is the peak, non-profit organisation for people living with dementia, 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.

Dementia Australia translates the experiences of people impacted by dementia as well as research, policy and data sources into tangible policy recommendations. In this paper, we include statistics from the Australian Institute of Health and Welfare (AIHW) report, *Hospital care for people with dementia 2016-17*, which was funded by Dementia Australia.

The Issue

In general, a broad range of evidence suggests that 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. Individuals with dementia, as well as families and carers, often report a change or decline in physical or cognitive health during or following a hospital visit. Hospital stays are also stressful for carers and families of people with dementia because it can significantly increase their caring responsibilities. Not only might they have to navigate the hospital system but they are also likely to be a key point for providing assistance and reassurance to the person they support.

There are two categories of cognitive impairment experienced in the hospital setting: dementia and delirium (with or without dementia). 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. Yet delirium is potentially preventable in up to two thirds of hospitalised patients and is often treatable if it develops.[1]

Individuals in hospital with cognitive impairment, regardless of whether it is cause by dementia or delirium, 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 residential care and death. People with dementia are two times more likely to experience falls, pressure injuries or infections in hospital.[2]

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. 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 cognitive impairment.

[1] Dementia Australia (2019) *Dementia and Delirium Q&A sheet* https://www.dementia.org.au/files/helpsheets/Helpsheet-DementiaQandA21_Delirium_english.pdf

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

The Evidence

The Australian Institute of Health and Welfare (AIHW) report, *Hospital care for people with dementia 2016-17,*[3] focuses on hospital care provided for people with dementia in Australia and explores whether the number of hospitalisations have increased over the past decade, as well as the outcome of these hospitalisations.

The AIHW found that in 2016-17 there were approximately 94,800 hospitalisations with a least one diagnosis of dementia. Dementia was the principal diagnosis in 22% of these hospitalisations. The average length of stay for people with dementia was 13 days, compared to the average length of stay for all hospitalisations in 2017-18 of 2.8 days.[4] It is also worth noting that Indigenous Australians were 1.5 times as likely to be hospitalised with dementia compared to the rest of the population.[5]

These demographic characteristics provide the framework for a growing body of evidence surrounding the challenges of hospital stays for people living with dementia and complement the feedback people with dementia, families and carers regularly report to Dementia Australia. The most compelling themes emerging from the AIHW data centred on longer lengths of stays for people with dementia and the challenges of recognising dementia in hospital presentations. These challenges remain relevant despite the introduction of specific cognitive impairment standards as part of the National Safety and Quality Health Service Standards.[6]

[3] AIHW (2019) *Hospital care for people with dementia 2016-17,* Australian Institute of Health and Welfare: Canberra

[4] AIHW (2018) *Admitted patient care 2016–17: Australian hospital statistics*, Australian Institute of Health and Welfare: Canberra

[5] The AIHW dataset was not categorised by State/Territory which means that we are unable to compare how people with dementia fare in different hospital and health care systems. Recently, the Australian Academy of Science and the Australian Academy of Health and Medical Sciences called for the COAG Health Council to address health data availability and linkage as a priority. Dementia Australia supports this call for increased availability of health data.

[6] Three actions in the second edition of the *National Safety and Quality Health Service (NSQHS) Standards* relate specifically to cognitive impairment. Actions 5.29 and 5.30 in the Comprehensive Care Standard focus on developing and using a cognitive impairment system. Action 8.5 incorporates the recognition and response to delirium and deteriorating behaviour in the organisation's system for recognising and responding to acute deterioration. The NSQHS Standards require that health services incorporate best-practice strategies for early recognition, prevention, treatment and management of cognitive impairment in patient care plans (where relevant), and manage the use of anti-psychotics medications in accordance with best practice and legislation.
The Standards outline that a well-designed system for caring for patients with cognitive impairment will support clinicians to routinely screen for cognitive impairment in patients aged 65 years or over using a validated tool and screen patients of any age at risk of delirium and when the patient, carer, family or other key informants raise concerns about cognitive impairment. Further information is available here

The experience of hospitalisation for people living with dementia

Previous research has shown that 6.5% of all hospitalisations in Australia are potentially avoidable if conditions are managed earlier. 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 the same age who do not have dementia.[7]

The AIHW found that the rate of dementia hospitalisations decreased by almost a quarter between 2006-07 and 2016-17. However, the rate of hospitalisations for delirium superimposed on dementia increased by over 400% during the same period. This marked increase in the rate is the result of increased awareness and consequently recognition of delirium. Unfortunately though, this also indicates that delirium is significant factor in the hospitalisation of people with dementia and Dementia Australia is concerned that hospital staff are not able to appropriately respond to people with dementia who have a superimposed delirium.

The AIHW found that of people who present to hospital with at least 1 diagnosis of dementia, 97% of these hospitalisations were of the highest or second highest clinical complexity; and 83% of dementia hospitalisations involved at least one procedure, with an average of 3 procedures per hospitalisation.

Further, people living with dementia admitted to hospital have multiple comorbidities. There was an average of eight diagnoses recorded in dementia hospitalisations. Type 2 diabetes was the most common comorbid condition and was present in 24% of dementia hospitalisations.

Dementia was the principal diagnosis in approximately 1 in 5 dementia hospitalisations and recorded as an additional diagnosis in 4 in 5. The high rate of comorbidities and dementia as an additional diagnosis condition highlights the importance of assessing for cognitive impairment to enhance the treatment of people with dementia as a secondary diagnosis. Despite being a common condition among hospital patients, cognitive impairment is often misdiagnosed or undetected in hospital.[8]

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

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

The clinical complexity and multiple comorbidities of people living with dementia, overlayed 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 (e.g. delirium, dehydration etc.)

Unplanned transition to residential aged care

The AIHW found that of the almost 95,000 dementia hospitalisations:

- 48% of stays ended with the person going home (including existing residence in aged care)
- 6% ended in death of person with dementia
- 29% ended with the patient being transferred to another hospital or the type of hospital care changing
- 17% ended in a new admission to residential aged care

It is concerning that almost a third of people with dementia stay within the hospital system rather than moving to a more supportive or familiar environment. Further, almost 20% are moving to residential aged care, presumably in unplanned circumstances. The most common pathway resulting in an admission to residential aged care was to commence as a new admission with dementia as an additional diagnosis only, accounting for 44% of these hospitalisations.

The average length of stay was 21 days for these people – nearly double that for hospitalised people with dementia not awaiting a residential aged care placement. 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.

Dementia Australia Recommendations

Given the data reported within the latest AIHW data on hospitalisations of people with dementia as well as the feedback provided by people with a lived experience of dementia, Dementia Australia recommends that:

1. Hospitals provide mandatory staff training in dementia to ensure that people with dementia and their families and carers are well supported at admission and throughout their stay in hospital. Dementia training should be undertaken by all staff including people in clinical, administration, catering and cleaning roles.
2. The physical environment of hospitals adheres to dementia-friendly design principles, including the provision of orientation cues and quiet spaces, in the design and layout of buildings.
3. Hospitals conduct a review of 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.
4. Case conferencing and a multi-disciplinary approach to care planning are utilised to proactively address health concerns to reduce avoidable hospital admissions for people living with dementia.
5. A comprehensive national process (including a mandatory review of medications) is developed to ensure that the transfer of people from hospital to residential aged care facilities is improved.

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 those individuals with dementia who are hospitalised.