Dementia Australia™

Health and hospital services for people living with dementia in rural, regional and remote NSW

A submission to the Upper House Inquiry into health outcomes and access to health and hospital services in rural, regional and remote New South Wales

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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 Upper House Inquiry into health outcomes and access to health and hospital services in rural, regional and remote New South Wales (NSW).

Our submission addresses the experiences of people with dementia in the health system including the process of being diagnosed with dementia and post-diagnostic follow up, in hospital settings, and palliative care.

Governments, health professionals and service providers need to respond to the growing number of people living with dementia in rural, regional and remote NSW. They also need to ensure that best practice in dementia care and support is being provided to the current population of people with dementia and carers. The challenge is to design and deliver services that are flexible, innovative, locally appropriate and culturally safe to ensure people with dementia, their families and carers are well supported in the NSW health system.

Dementia Australia advocates for improvements in policy, resources and service delivery to ensure access to quality health services that is responsive to the needs people with dementia, their families and carers living in regional, rural and remote communities.

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 459,000 Australians living with dementia in 2020[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]

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[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

Dementia is not a natural part of ageing. Although it is more common in older people, it can affect people in their 40s, 50s and even their 30s.[4] 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 almost 29,500 people by 2028 and more than 41,000 people by 2058.[5]

In NSW there are almost 153,000 people living with dementia in 2020, including more than 9,000 people with younger onset dementia. It is estimated that there will be more than 345,000 people living with dementia in NSW in 2058.[6]

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.[7]

It is not widely understood that dementia is a progressive cognitive disability. It is the single greatest cause of disability in older Australians (those aged 65 and over) and the third leading cause of disability overall.[8]

The impact of dementia in rural, regional and remote areas

People living in rural, regional and remote communities are more likely to have restricted access to health services and other supports, which are crucial to maintaining a good quality of life for people living with dementia, their families and carers. Restricted access to supports and services can have numerous impacts to people with dementia, their families and carers, including: delayed diagnosis, poorer access to information regarding dementia, and limited access to a range of quality dementia supports and services. People living with dementia, their families and carers often report challenges accessing medical care, allied health services and palliative care.

People living in rural, regional and remote areas deserve to have equitable access to services and be supported to remain living in their local community throughout their experience with dementia. Living with dementia brings challenges for all people with a diagnosis and those who care for them. These challenges are compounded if a person lives

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[4] There are also some rare forms of childhood dementia, including Sanfilippo Syndrome, Niemann Pick Type C Disease and others.
[5] Dementia Australia (2018) *Dementia Prevalence Data 2018-2058*, commissioned research undertaken by NATSEM, University of Canberra
[6] Dementia Australia (2018) *Dementia Prevalence Data 2018-2058*, commissioned research undertaken by NATSEM, University of Canberra
[7] Australian Bureau of Statistics (2018) *Causes of Death, Australia, 2017* (cat. no. 3303.0)
[8] Australian Institute of Health and Welfare (2012) *Dementia in Australia*

in rural, regional and remote areas due to geographic isolation, travel distances, and limited services and resources.

The key concerns and challenges for people with dementia, carers and service providers in rural, regional and remote Australia include:

- assessment, diagnosis and management of dementia
- education and awareness of dementia
- opportunities for social engagement and community participation for people with dementia and carers
- access to community, respite and residential aged care
- access to specialist support services
- limited choice of providers
- cost of transport for specialist services
- availability of culturally appropriate services and supports
- workforce capability and capacity.

When individuals with dementia also experience other barriers to care, such as their location, ethnicity, sexuality or socio-economic status, access to quality care becomes exponentially more difficult. The availability of dementia care is difficult for those living in rural and remote areas due to their geographical isolation, a shortage of health care providers and patchier access to health services, as well as socioeconomic disadvantage, which limits their ability to access specific specialist services. For Aboriginal and Torres Strait Islander peoples, there are very few care options in regional, rural and remote communities and services. While being more culturally appropriate, community workers may lack the knowledge to tailor supports to meet the needs of people living with dementia. For example, dementia is not necessarily identified or understood as a medical condition in Aboriginal and Torres Strait Islander communities and pre-existing care options are often away from country and in institutional settings that may not be culturally appropriate. Additionally, dementia is competing for space with multiple health issues and is not always seen as a priority.

The diagnosis experience

Diagnosing dementia is not a straight forward process and people with dementia, their families and carers often 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

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.

GPs are most often the first port of call for people with memory concerns and their families. However there are barriers to the diagnosis of dementia in general practice, including time constraints, diagnostic uncertainty, denial of symptoms and stigma.

People living in rural, regional and remote areas are less likely to receive a timely diagnosis due to the limited availability of local specialists, with people required to travel significant distances to see specialists. With more than one appointment often needed to confirm a diagnosis of dementia, this places considerable time and financial pressures on people with dementia, their families and carers.

> “Geriatricians are a very rare breed in remote and rural Australia. Mum never saw one, and the only one we had in our town was a visitor from Sydney once every three weeks. The cost was $300 per visit, which is prohibitive and it just didn't seem worth it.” Carer

> “Distance for people in remote and regional communities can be a problem. There is no public transport and you must have a reliable car for the many visits to doctors and the geriatrician. Accommodation can be a financial burden if you need to stay several days.” Carer

Although there is an increasing policy and program appetite for internet-based technology solutions in rural, regional and remote areas, their uptake is hampered by poor connectivity in some areas as well as the inappropriateness of some aspects of technology for people living with dementia with more advanced cognitive impairment. Having access to support people and/or advocates who can provide assistance in getting the most out of technology is essential.

> “Videoconferencing with a specialist doesn’t always work for a person with dementia.” Carer

Limited understanding of dementia by health professionals

A lack of understanding of dementia among health care professionals 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.

> “The GP is still the most disconnected person in all of this…who is looking at this holistically?” Carer

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 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.

> “We received virtually zero post diagnosis support. With Mums doctor retiring we had to find a new doctor. This was a nightmare with a shortage of doctors in town and most staying for 6 months to a year, Mum would have seen upwards of 8 different doctors from when she was diagnosed until she died…The doctor had little if any understanding of dementia and I feel that in rural and regional Australia this is the norm.” Carer

Communicating the diagnosis

It is 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 and carers report. Many 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.

> “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

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

Another concern is the immediate revoking of an individual’s driver’s license upon diagnosis of dementia. This has considerable impacts for people living with dementia and cares in rural, regional and remote areas.

> “She was in hospital and whilst there, was given a Mini-Mental State Examination (MMSE) while she was suffering from delirium, a completely wrong time to do this test. As a result of the MMSE, the junior doctor, without telling anyone contacted the RTA and had her driving license taken off her. She had driven for 55 years with not one traffic infringement or accident. Prior to entering hospital her driving was fine, and the loss of her license was a devastating blow in terms of her independence. It really beggars belief that a student doctor with little or no experience of dementia can take this type of action.” Former carer

> “I receive consistent feedback from newly referred clients that their experience with a referred consultation with a geriatrician is extremely disappointing. This is a common experience in those cases where the person with dementia is told, without any warning or empathy, that they will not be driving anymore, from that moment. Sometimes the person with dementia has actually driven themselves to the specialist appointment, and then has to find another way home! I think there is a case for reflecting on specific procedures in rural, remote and regional areas, where being able to drive is so essential. Note that in many cases the person living with dementia who experiences an abrupt and unexpected loss of license implemented during the consultation will then refuse to liaise with that geriatrician again. In remote and rural/regional areas the options for alternate specialists is very limited. A breakdown in relationship between patient and specialist has long term implications.” Dementia support worker

It is essential that driving cessation support is provided and that adequate transport is available for people with dementia and their carers so they can access local health services and supports and remain socially connected and meaningfully engaged in their local community.

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. Provide incentives to attract and retain dementia qualified health professionals in rural, regional and remote locations.
5. Develop a structured diagnostic pathway that supports post-diagnosis referral to early intervention supports, including those offered by Dementia Australia.
6. Provide local transport options to enable access to health and community services for people living with dementia.

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.

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 health care.

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.

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.[9]

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.

> "The palliative care nurses from the base hospital came and visited Mum and were a fantastic support. They called every week, and I could call them at any time for help."
> Former carer

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.

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[9] 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

Recommendations

7. 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.
8. Provide increased training to the aged care workforce, GPs, and acute care staff about the unique palliation needs of people with dementia.
9. Provide dedicated dementia-specific palliative care services in primary and acute care settings, where staff are appropriately trained in dementia care needs.
10. Develop clinical nurse consultant roles, which specialise in dementia-specific palliative care.
11. Enable and enhance palliative care support services in community-based settings through funding models that help people with dementia to die in their own home where they have identified a wish to do so, supported by family and carers.

Hospitalisation of people with dementia

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.

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.[10] When in hospital, people with dementia are at 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 than others. People with dementia are two times more likely to experience falls, pressure injuries or infections in hospital.[11]

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.

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[10] 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

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

Understanding of dementia

Despite being a common condition among hospital patients, cognitive impairment is often misdiagnosed or undetected in hospital.[12] People impacted by dementia report that hospital staff have a limited understanding of dementia, particularly of younger onset dementia.

> "The emergency department 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).[13] 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 gave 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

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

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

[13] 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

> known is 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.[14] 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).[15] 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.[16]

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 dementia derive any benefit from antipsychotic medications.[17] Despite overwhelming evidence that antipsychotics are not effective or safe, they are still being routinely prescribed

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[14] 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

[15] 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

[16] 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 12 Castle, N. G. (2006) Mental health outcomes and physical restraint in nursing homes, *Administration and Policy in Mental Health*, 33: 696-704

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

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.

> "She was placed in a T-BASIS[18] unit to work out which medication would be appropriate to deal with sometimes aggressive behaviour. The place was abysmal, depressing...She was placed on different drugs and there was no communication as to what they were. It was a hit and miss approach and did nothing good for her. They eventually placed her on Risperidone that made her behaviour worse I stopped its use when we got home." Former carer

Discharge planning and support

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 support worker

The process of transferring people with dementia from hospital to residential aged care needs to be improved. A streamlined process is needed 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. Yet there is often limited availability of residential aged care in rural, regional and remote areas, particularly facilities that provide quality care for people living with dementia.

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.

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[18] Transitional Behavioural Assessment and Intervention Service (T-BASIS) operated by NSW Health

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.

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 (for example delirium, dehydration etc.)

Multi-purpose services

Multi-purpose services (MPS) provide a range of health services, including acute care, subacute (including respite and palliative care), emergency, allied health, oral health, primary health and community services. Often the only service available in small towns is a MPS so they need to be dementia-friendly and supportive, and have the flexibility to respond to the needs of people with dementia in their community. Reports to Dementia Australia indicate that the built environments of many MPSs are not dementia-friendly or enabling for people with dementia. In addition, greater dementia education and training for staff is needed. The experience below, as told to us by a former carer, illustrates the devastating impact a lack of understanding of the needs of people living with dementia can have.

> "I cared for my mother who was living with dementia…She was mobile, conversing and eating well…When I placed Mum in respite care at the MPS, I expected that they would look after her just as I had. How sadly mistaken I was…I had prepared for her stay in respite; with 7 changes of day and nightwear, snacks, including biscuits, lollies, soft drinks. I had packed medications and toiletries including…wipes to remove crusted matter daily from her eyes. On entering the facility for some bizarre reason the staff thought she was blind. Alarm bells should have started ringing then but I had been advised that this was an excellent facility…I drove down to visit Mum and found her lying in bed in a foetal position, dehydrated, eyes gummed up, teeth not cleaned. She was incoherent…I discussed the situation with the aged care support workers and their response was that they were learning

> her behaviour. Shame on me for not taking her out of that place then and there. But instead I got her out of bed, cleaned her eyes, brushed her teeth, got some fluids into her and we went for a walk. During the entire time I was at the facility the RN did not get up from her desk. After attending to mum’s personal care and taking her outside into the garden for some fresh air, we returned to her room for lunch. The food was almost inedible and Mum struggled to eat any of it…I then left but called daily to check on her health; being assured each time that she was well. Mum died while in their “care”. When I went to pick up Mum's things after her death none of the snacks that I had provided had been touched. Nobody had cared enough to give her any of it. What happened in the two weeks prior to the death of my poor mother, I hate to think.” Former carer

It is only through a collaborative approach to dementia care in hospitals and multi-purpose services – one that involves people living with dementia, their families and carers, hospital staff, government, providers and regulatory bodies – that we can ensure 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 and multi-purpose services. The following must be considered:

- 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

12. Provide mandatory training in dementia to all hospital and multi-purpose services 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.
13. 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.

14. Ensure the physical environments of hospitals and multi-purpose services adhere to dementia-friendly design principles, including the provision of orientation cues and quiet spaces, in the design and layout of buildings.
15. Ensure physical and chemical restraints are used on hospital patients with dementia only as a last resort.
16. Develop a comprehensive process (including a mandatory review of medications) to ensure that the transfer of people from hospital to residential aged care facilities is improved.
17. 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 system is challenging for people impacted by dementia to navigate and, in their experience, there is generally a lack of understanding of dementia. We need a health care system that is equipped to respond to the needs of people living with dementia, their families and carers.

Governments, regional health professionals and service providers need to be prepared to respond to the growing number of people with dementia living in regional, rural and remote areas. They need to work collaboratively with Primary Health Networks (PHNs), local health district services, the aged care sector, and people who are impacted by dementia to understand the key issues facing people with dementia in regional, rural and remote areas. Dementia plans need to be developed and implemented to improve services and supports across regional, rural and remote communities. Specifically these plans should include reference to:

- Funding workforce development and training for GPs and allied health professionals working in rural and remote locations, specialising in all forms of dementia and dementia care. This needs to include incentives for attraction and retention of qualified professionals and support.
- Developing entry-level workforce training to increase workforce capacity and support in regional, rural and remote communities who can help people with getting a diagnosis and early post-diagnosis connect with social supports/programs and identify services and useful information in the local community.
- Working with internet providers and tech companies to explore the most effective telehealth technology to support people living with dementia and their carers living in regional, rural and remote communities. This is particularly important at the point of diagnosis to improve access to culturally relevant information and support services (e.g. online communication help sheets such as ‘how to use technology effectively’

and ‘how to make your internet connection more stable’ to support people to use the technology effectively).
- Working with the transport sector to ensure adequate transport is available for people with dementia and their carers to remain living in the community. This is to support them in accessing local health services and supports to remain socially connected and meaningfully engaged.
- Working with Dementia Australia through initiatives like Dementia Friendly Communities to build community awareness and understanding of dementia (types of behaviours and symptoms) to enable support and understanding, and reduce stigma.
- Developing a support program with trained care workers to facilitate enablement at the point of diagnosis. This is to include promotion of referral pathways and relevant information to access local support services within the community.
- Exploring options to make funding and service delivery more flexible for people living with dementia, their carers and families in regional, rural and remote communities.

Dementia Australia hopes the issues and recommendations identified in our submission assist the Inquiry Committee members to understand the health care issues people with dementia face. We would welcome the opportunity for further consultation to ensure that the experiences and needs of people with dementia, their families and carers in the health care system are addressed.