



Restrictive practices

A submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

25 August 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.

Introduction

Dementia Australia welcomes the opportunity to provide a submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Royal Commission) in response to the issues paper on restrictive practices. Our submission addresses the inappropriate overuse of restraint on people living with dementia, especially in residential aged care facilities, and how to minimise the use of restrictive practices.

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 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 29,353 people by 2028 and 41,249 people by 2058.⁵

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.⁶

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.⁷

¹ Dementia Australia (2018) *Dementia Prevalence Data 2018-2058*, commissioned research undertaken by NATSEM, University of Canberra

² Based on Dementia Australia's analysis of the following publications – M.Kostas et al. (2017) *National Aged Care Workforce Census and Survey – The Aged Care Workforce, 2016*, Department of Health; Dementia Australia (2018) *Dementia Prevalence Data 2018-2058*, commissioned research undertaken by NATSEM, University of Canberra; Alzheimer's Disease International and Karolinska Institute (2018), *Global estimates of informal care, Alzheimer's Disease International*; Access Economics (2010) *Caring Places: planning for aged care and dementia 2010-2050*

³ Dementia Australia (2018) *Dementia Prevalence Data 2018-2058*, commissioned research undertaken by NATSEM, University of Canberra

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

⁷ Australian Institute of Health and Welfare (2012) *Dementia in Australia*

The use of restrictive practices in residential aged care

A number of data sources confirm that restrictive practices are regularly used on people living with dementia in residential aged care facilities. The current Royal Commission into Aged Care Quality and Safety has highlighted the multiple systemic failings for people living with dementia and the impact of the inappropriate use of restraints.

Despite significant evidence of their ineffectiveness and wide array of adverse side effects, evidence suggests that restraints continue to be used as a first line of symptom management rather than the many effective non-pharmacological alternatives. It has also been well demonstrated that these symptoms can often be an expression of unmet need, pain or distress. A lack of social engagement, deficits in appropriate clinical care, inadequate treatment of pain, and a range of other environmental, physical and social deficits can lead to behaviours of unmet need.

The use of restraint on people living with younger onset dementia is likely to be considerable. People with younger onset dementia are generally stronger and physically fit than the average residential aged care resident and therefore regarded as 'difficult to manage' in residential aged care settings. There is a greater role for the National Disability Insurance Agency (NDIA) and disability services to play in supporting people living with younger onset in residential aged care settings in minimising the use of restraints and other restrictive practices.

Quality and regulatory processes that support the minimisation of restraint, as well as the provision of mandatory dementia education, are imperative to ensure the delivery of quality dementia care in which the use of restraint is a very last resort.

Physical restraint

The use of physical restraint in aged care facilities varies, with evidence suggesting prevalence rates ranging from 12% to 49%.⁸ Physical restraint may include methods such as bed boundary markers, deep chairs, lap belts, hand mitts, seat belts, or leg, wrist or ankle restraints; removal of mobility aids; or restriction of the person to a locked area/secure ward. 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,^{9 10} 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.¹¹

⁸ Peisah C. & Skladzien E. (2014) *The use of restraints and psychotropic medications in people with dementia*, Alzheimer's Australia Paper 38

⁹ Evans, D., Wood, J. & Lambert, L. (2003) Patient injury and physical restraint: a systematic review, *Journal of Advanced Nursing*, 41(3): 274-282

¹⁰ 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

¹¹ Castle, N. G. (2006) Mental health outcomes and physical restraint in nursing homes, *Administration and Policy in Mental Health*, 33: 696-704

Chemical restraint

The overuse and inappropriate use of chemical restraint (commonly antipsychotics, psychotropics and sedatives) on people with dementia is all too common in residential aged care. It is estimated that just over half of people living in residential aged care are receiving antipsychotic medications and about 80% of those people have dementia.¹²

International data suggests that only 20% of people with dementia derive any benefit from antipsychotic medications.¹³ Australian clinical guidelines recommend that antipsychotics are only prescribed after non-pharmacological approaches 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.

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.

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

The evidence for avoiding or minimising the use of chemical restraint is hardly new. The 2012 (then) Department of Health and Ageing’s Decision-Making Tool to support a restraint free environment in residential aged care also states “the application of restraint, for any reason, is an imposition on an individual’s rights and dignity and, in some cases, may subject the person to an increased risk of physical and/or psychological harm. The inappropriate use of restraint may constitute assault, battery, false imprisonment or negligence.”¹⁴

The Royal Australian and New Zealand College of Psychiatrists Professional Practice Guideline on the use of antipsychotic medications as a treatment of behavioural and psychological symptoms of dementia state: “When prescription of a medication is being considered, informed consent is essential. Therefore, it is necessary that information about the risks and benefits of prescribing a medication to a person with dementia is conveyed to the person or their substitute decision maker, and that this is understood.”¹⁵

¹² Peisah C. & Skladzien E. (2014) *The use of restraints and psychotropic medications in people with dementia*, Alzheimer’s Australia Paper 38

¹³ Ibid.

¹⁴ Australian Government (2012) *Decision-Making Tool: Supporting a restraint free environment in residential aged care*, Department of Health and Ageing

¹⁵ The Royal Australian and New Zealand College of Psychiatrists (2016) *Professional Practice Guideline 10 - Antipsychotic medications as a treatment of behavioural and psychological symptoms of dementia* https://www.ranzcp.org/files/resources/college_statements/practice_guidelines/pg10-pdf.aspx

Informed consent

Informed consent requires a decision based on a discussion and understanding of the purpose, risks, benefits, and alternatives to an intervention or treatment. The process of a 2019 parliamentary committee inquiry into the Quality of Care Amendment (Minimising the Use of Restraint) Principles¹⁶ drew attention to the abundant confusion surrounding informed consent for the use of chemical restraint, and the roles and responsibilities of approved providers, prescribers, families, carers and formal advocates in applying or reviewing any form of restraint.

It has been reported to Dementia Australia that, often in situations where consent is provided to use physical restraint, no alternatives to restraint are offered, and the family may feel obliged to provide consent for fear that the person with dementia may otherwise be asked to leave the facility.

Carers often report to Dementia Australia that when antipsychotics are prescribed for their loved one, they are either not informed at all or that they are notified in a context in which the staff of the approved provider or the GP presents the administration of medication as the only option. Carers also often report only learning about the use of medications when they receive the pharmacy bill.

GPs have anecdotally reported that they can be brought into an emergency situation without having a full background history or profile of the resident on which to make informed decisions about medication administration – and that they face pressure from providers to prescribe sedating medications. Meanwhile, residential aged care staff report that they are just following the prescribing instructions of the GP or specialist. A more collaborative and informed decision-making process that includes families and carers (and people with dementia, where possible) is needed.

The legislative requirements regarding the use of physical and chemical restraints are contained in the Quality of Care Principles 2014. The restraint requirements were first introduced to the Principles effective from 1 July 2019, with amendments strengthening the legislation applicable from 29 November 2019. These amendments place explicit obligations on providers to minimise the use of chemical and physical restraints in residential care settings.¹⁷ A review of the impact of the legislation is currently in progress and it remains to be seen whether these increased legislative requirements have led to changes in practice.

¹⁶ Dementia Australia's submission to this Inquiry is available at <https://www.dementia.org.au/sites/default/files/submissions/Minimising-the-Use-of-Restraints-DA-submission.pdf>

¹⁷ Aged Care Quality and Safety Commission (2020) *Minimising the use of restraints*, <https://www.agedcarequality.gov.au/providers/assessment-processes/minimising-restraints>

Case study

After experiencing symptoms for several years, Julia¹⁸ was finally diagnosed with younger onset dementia at the age of 54. Her condition progressed rapidly and within six months of the diagnosis she was living in residential aged care.

Following her move to residential care, Julia was prescribed Risperdone, an anti-psychotic medication, for a period of 18 months to manage 'aggressive outbursts'. This is despite clinical recommendations that these medications are only used for a short period. Julia's daughter, Harriet, was horrified when she realised this.

"You get swept up in what the doctors say...You put your trust in the doctors, you don't second guess them."

Harriet worked with Julia's doctor and the residential aged care staff to get Julia off the anti-psychotics. This was successful, and Julia's 'aggression', which was supposedly being treated by the antipsychotics, did not return. Reflecting on the experience, Harriet now suspects that the aggression was actually a response to trigger events and behaviour of the staff and residents at the aged care facility, not a symptom of dementia.

A few months later, Harriet noticed that Julia was always very sleepy during the day. Initially she assumed that this was a symptom of the disease progression. One evening though, she stayed late to observe what was happening to Julia at night. She discovered that a PRN¹⁹ medication had been given to Julia at least every second night for a period of 3 months to sedate her and stop her getting out of bed during the night. This was in addition to an anti-anxiety medication that Julia was taking.

"The nurse said to me "I have to give her medication to keep her in bed". I said "that's chemical restraint". He said "well you can call it that if you like, but we need to keep her in bed". And I told him again "that is chemical restraint!"

Use of restrictive practices in hospitals

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

"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." Support worker

¹⁸ Names have been changed.

¹⁹ Medicines that are taken "as needed" are known as "PRN" medicines. "PRN" is a Latin term that stands for "pro re nata," which means "as the thing is needed."

Despite being a common condition among hospital patients, cognitive impairment is often misdiagnosed or undetected in hospital.²⁰ People impacted by dementia report that hospital staff have a limited understanding of dementia. Carers report their loved one with dementia being physically restrained by being tied to bed frames or being chemically restrained.

“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).²¹ 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.

The importance of quality dementia care and skilled staff

To ensure the minimised use of restraint we need a commitment to quality dementia care. There are two fundamental issues that need to be present to achieve quality dementia care:

- A clear understanding of the clinical aspects of dementia and the disease trajectory;
- Taking a holistic and person-centred approach, including high-quality communication, with every individual.

To support the needs of people with dementia, training of aged care, disability and health care staff must include:

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

²⁰ Australian Commission on Safety and Quality in Health Care (2016) *Caring for Cognitive Impairment – A National Campaign*

²¹ 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

- emotional intelligence and mindfulness.

Provision of staff education in relation to dementia care has been proven to have positive impacts to both the workforce and the individual living with dementia. For example, comprehensive training has been shown to reduce behavioural and psychological symptoms of dementia, in addition to having a positive impact on the way staff behave towards individuals.²² When staff are adequately educated and understand how to communicate and act empathetically, there are marked improvements to staff-resident relationships, residents' moods, and the use of psychotropics.

“One of the RNs said that over the last 6 months [since the completion of dementia education] he has not only seen a decline in prescription of medication, but also a decline in staff requesting it from him.” – Dementia educator

Dementia education should include experiential learning (for example, Dementia Australia's EDIE) to enable aged care staff to develop empathy for people living with dementia. Immersive and experiential educational experiences have proven to be impactful and greatly contribute towards developing deeper insights into the world of living with dementia.

“[Since the completion of dementia education] I now have greater confidence in my caring role. I can cope with aggressive behaviours and differentiate between the person and the behaviour caused by the dementia. I have much more empathy for my residents.” – Aged care worker

People living with dementia and carers report that workforce shortages are impact on the delivery of quality care, with some suggesting that the increasing pressure on the aged care workforce is manifesting in the overuse of restraints. Inexperienced staff, staff turnover, frequent shift rotations and poor hand-over procedures are also cited as some of the main causes of poor practices. Appropriate staffing levels are a critical component to delivering high quality and safe care, where staff have sufficient time to perform clinical and care tasks that meet the needs of an individual.

Continuity of care is particularly important for people living with dementia. Multiple staff changes can be confusing and distressing, and exacerbate symptoms of dementia. It is important that people with dementia are able to develop rapport and relationships with those who care for them. The use of casual and agency staff is therefore problematic – people with dementia need consistency in staffing both in home and residential aged care services.

In addition to staff numbers, optimising the workforce skills mix is important with evidence demonstrating that incorporating a mix of skills is a good strategy for improving the quality of care.²³ Currently, the aged care workforce lacks a sufficient skills mix, where high numbers of personal care workers and community care workers, and decreasing numbers of registered nurses is creating a gap in clinical oversight. Equally with allied health

²²Spector, A., Orrell, M. and Goyder, J. (2019) A systematic review of staff training interventions to reduce the behavioural and psychological symptoms of dementia, *Ageing Research Reviews*, 12: 354– 364

²³Koopmans, L., Damen, N., and Wagner C. (2018) Does diverse staff and skill mix of teams impact quality of care in long-term elderly health care? An exploratory case study, *BMC health services research*, 18(1):988

professionals only accounting for six percent of the workforce²⁴, specialised supports are limited – which creates a particular issue for people with dementia who have more complex care needs.

A well-trained and skilled workforce who understands how to support people living with dementia and use psychosocial and nonpharmacological therapeutic approaches rather than physical or chemical restraint as a first measure to manage behavioural symptoms of dementia is imperative.

The impact of the COVID-19 pandemic

Dementia Australia is concerned that the use of physical and chemical restraint on people living with dementia in residential aged care may have increased as a result of the aged care facility lock downs during the COVID-19 pandemic, and the need to ensure people with dementia adhere to social distancing measures.

The impact of a second wave of COVID-19 on Victorian residential aged care services especially has highlighted weaknesses in the aged care system, not least regarding the capacity and availability of the workforce, clinical governance and the challenge of balancing individual care and wellbeing needs of residents with the safety of all living or working in the service.

The restriction on physical contact between family members has been especially distressing. Absence of physical affection is magnifying feelings of isolation and loneliness in many people living with dementia as well as families and carers. Physical touch is a universal language that soothes, comforts and reassures. It is an essential element of compassionate care for people with advanced dementia, particularly for people who can no longer verbalise their needs. It is therefore reasonable to assume that long periods without any physical affection will have a detrimental effect on people with dementia.

The stress and anxiety of lock down can exacerbate the symptoms of dementia and lead to responsive behaviours in people living with dementia; so too can disruptions to daily routines and reduced freedom of movement. In at least one aged care facility, residents are being sedated rather than using person-centred activities to address the disruption in routine.

“Very little consideration given to ‘Isolation Effect’. Care facility was totally preoccupied with physical and compliance impacts of COVID-19 protocols. Then, when some residents became ‘aggressive’, they treated this in their normal context (progression of dementia) with sedative drugs and more isolation.” Carer

“My father is a very social person. He acted out during the first few weeks, as he wasn’t getting the interaction as before.” Carer

A consistent focus on human rights, dignity and wellbeing of people living with dementia, families and carers needs to be embedded in any pandemic response to ensure policy and

²⁴ Australian Institute of Health and Welfare (2017) *Australia’s aged care workforce*

public health decisions do not contribute to a greater use of restrictive practices on people living with dementia.

Conclusion

Dementia Australia hopes the issues identified in our submission assist the Commissioners in understanding the inappropriate overuse of physical and chemical restraint on people living with dementia and what needs to be done to ensure the restraint is only used as a very last resort.

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 are considered and responded to.