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Parliamentary Joint Committee on Human Rights
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Dear Committee members

RE: Quality of Care Amendment (Minimising the Use of Restraints) Principles 2019

Dementia Australia was pleased to be invited to present on 20 August 2019 to the Parliamentary Joint Committee on Human Rights' Inquiry into the Quality of Care Amendment (Minimising the Use of Restraints) Principles 2019.

In 2019 there is an estimated 447,000 Australians living with dementia and without a significant medical breakthrough, we can expect there to be over one million people living with dementia in Australia by 2056.[1] Although around 70% of people with dementia are thought to live in the community, individuals with dementia account for some 52% of all residents in residential aged care.[2]

Although Dementia Australia are not legal experts on human rights law (and possible breaches), we have heard from multiple sources about the devastating impact – and overuse – of physical and chemical restraint on people with dementia living in residential aged care.

In short, Dementia Australia is concerned that the legislation amendment does not sufficiently prevent the inappropriate use of physical and chemical restraint and further add that it may not draw sufficiently on other forms of legislation with more rigorous safeguards and clarification on authorised representatives.

In my testimony, I highlighted our concern that the new legislation does not combat:

- The complexity caused by layers/competing pieces of legislation that govern the roles and responsibilities of prescribers, providers, consumers, informal and formal advocates and pharmacists in managing, administering and monitoring the use of restraints;
- The difficulty in determining whether a form of restraint is a 'last resort' and the roles and responsibilities of providers, prescribers/health practitioners, consumers, families, carers and advocates in that process;
- The lack of a tangible link to quality and compliance mechanisms – including mandatory reporting schemes;
- The overuse of antipsychotics as a form of chemical restraint and the inconsistent application of existing consent processes in the current regulatory environment;

[1] Dementia Australia (2018) *Dementia Prevalence Data 2018-2058*, commissioned research undertaken by NATSEM, University of Canberra
[2] The National Centre for Social and Economic Modelling NATSEM (2016) *Economic Cost of Dementia in Australia 2016–2056*

- The significant risk factors attached to the use of antipsychotics, including increased risk of falls, stroke and other serious side effects;
- The lack of mandatory training and education in dementia – and in non-pharmacological approaches to care and support for individuals with dementia.

To further support the above statements, Dementia Australia has prepared further information on the use of physical and chemical restraint as well the capacity of the workforce to support people with dementia in residential aged care.

Physical restraint

The use of physical restraint in aged care facilities varies, with evidence suggesting prevalence rates ranging from 12% to 49%.[3] 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,[4] [5] 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.[6]

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.

The impact of the legislation amendment on State and Territory legislation is also unclear, particularly with regard to responsibility for consenting to physical restraint. As outlined in submissions by the various State and Territory Public Guardians and Advocates, clarification is required with regard to who has the power to provide consent for physical restraint.

As pointed out in other submissions, a 'person responsible' does not necessarily have the legal authority to consent; a guardian/attorney according to the relevant State and Territory laws concerning substitute decision-making is required to provide informed consent for restraint.

Chemical restraint

The overuse and inappropriate use of chemical restraint 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.[7] International data suggests that only 20% of people with dementia derive any benefit from antipsychotic medications.[8]

Australian clinical guidelines recommend that antipsychotics are only prescribed after non-pharmacologic 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

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[3] Peisah C. & Skladzien E. (2014) *The use of restraints and psychotropic medications in people with dementia*, Alzheimer's Australia Paper 38
[4] Evans, D., Wood, J. & Lambert, L. (2003) Patient injury and physical restraint: a systematic review, *Journal of Advanced Nursing*, 41(3): 274-282
[5] 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
[6] Castle, N. G. (2006) Mental health outcomes and physical restraint in nursing homes, *Administration and Policy in Mental Health*, 33: 696-704
[7] Peisah C. & Skladzien E. (2014) *The use of restraints and psychotropic medications in people with dementia*, Alzheimer's Australia Paper 38
[8] Ibid.

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.

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."[9]

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."[10]

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.

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.

Residential aged care staff, on the other hand, have reported that they are just following the prescribing instructions of the GP or specialist.

It strikes Dementia Australia that there are missed opportunities for more a collaborative and informed decision-making process that includes families and carers (and people with dementia, where possible). The role of pharmacists also needs to be clarified in terms of initiating medication reviews and refilling ongoing repeat prescriptions of aged care residents.

Quality and regulatory processes that support the minimisation of restraint, as well as support for the underpinning training and other mechanisms that are required to make this possible, are imperative going forward.

The need for a skilled and dementia trained aged care workforce

Regardless of the legislation, we need a well-trained and skilled aged care workforce that understands how to support people living with dementia and use psychosocial and non-pharmacological therapeutic approaches rather than physical or chemical restraint as a first measure to manage behavioural symptoms of dementia.

A wide range of evidence demonstrates that these symptoms are generally an expression of unmet need, pain or distress. A lack of social engagement, deficits in appropriate clinical care, inadequate

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

[10] 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

treatment of pain, and a range of other environmental, physical and social deficits can lead to behaviours of unmet need.

The number of Australians with dementia is growing exponentially. It is critical that all aged care services are well equipped and motivated to provide safe, high quality care for people with dementia, as part of their core business. It is equally imperative that the Australian aged care workforce can meet the needs of all people within aged care, including people with complex needs such as dementia.

A cohesive, structured and integrated national dementia training and education program for all aged care staff must be a priority to create better outcomes for people living with dementia and their families and carers.

Conclusion

The process of this Inquiry has drawn 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.

Dementia Australia looks forward to the outcome of Inquiry and to collaborating with people with dementia, families, carers, providers and other stakeholders to ensure that the use of restraint is minimised and that people with dementia receive quality aged care services on a consistent basis.

Yours sincerely,

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Dementia Australia