



**dementia
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Medication Use by People Living with Dementia

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Introduction

Dementia Australia (formerly known as Alzheimer's Australia) is the peak, non-profit organisation for people living with dementia, 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 other 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, *Dispensing patterns for anti-dementia medications 2016-17*, which was funded by Dementia Australia.



The Issue

A wide range of evidence sources, including available data, research studies and feedback from people living with dementia, their families and carers, suggest that there continues to be widespread inappropriate use and overuse of medications, especially anti-psychotics.

Polypharmacy places people living with dementia at greater risk of medicine-related harm, medication errors, inappropriate use, side effects and adverse interactions.

Australian clinical guidelines recommend that anti-psychotics are only prescribed after non-pharmacologic approaches have been attempted; yet research continues to show over-prescription of these drugs. Inappropriate use of anti-psychotic medication constitutes a form of chemical restraint.

The Australian Institute of Health and Welfare (AIHW) report *Dispensing patterns for anti-dementia medications 2016-17*¹ contributes to a growing body of evidence which demonstrates the under-review of anti-dementia medications, the overuse of anti-psychotics and a lack of awareness of the impact of polypharmacy.

¹ AIHW (2019) *Dispensing patterns for anti-dementia medications 2016-17*, Australian Institute of Health and Welfare: Canberra

The Evidence

Use of anti-dementia medications²

A number of medications³ are currently available in Australia for treating the symptoms of dementia. The AIHW report focused on people with Alzheimer's disease who were dispensed anti-dementia medications subsidised through the Pharmaceutical Benefit Scheme (PBS).

They found approximately 58,500 people aged 30 and over were dispensed with anti-dementia medications in Australia in 2016-17. 551,000 anti-dementia medications were dispensed at a cost of \$20 million, with Government expenditure (through subsidies) comprising 80% of the total cost, while the average cost to people with dementia was \$7.35 per prescription. 65% of prescriptions were for donepezil, followed by galantamine (15%), rivastigmine (12%) and memantine (8%).

A specialist, such as a neurologist, psychogeriatrician, geriatrician or psychiatrist, will usually be involved in the prescription of anti-dementia medications. The AIHW found that the majority (80%) of prescriptions were by GPs; however, as people could be prescribed anti-dementia medications by more than one prescriber, 22% were prescribed by both GPs and other medical specialists including geriatricians (55%), neurologists (14%), and psychiatrists (14%).

To continue on the subsidised medication beyond six months, there must be a clinically meaningful response to the treatment (i.e. a person with dementia must show improvement on a commonly used test of cognitive function in the first six months of treatment). The AIHW found that:

- 27% of people were dispensed anti-dementia medications for the first time
- 75% of people initiating anti-dementia medications in 2016-17 continued with the medication beyond 6 months
- 24% discontinued taking anti-dementia medications in 2017-18.

These statistics raise questions about the adequacy of prescribing guidelines – are 75% of people staying on anti-dementia medications beyond 6 months because they are effective treatments or are follow up consultations or medical reviews not occurring as regularly as they should?

² Dementia Australia use the term anti-dementia medication as per the AIHW terminology, and the Anatomical Therapeutic Chemical Classification System which is controlled by the World Health Organization Collaborating Centre for Drug Statistics Methodology.

³ These fall into two categories, 'cholinesterase inhibitors' and 'N-methyl-D-aspartate (NMDA) receptor antagonists'. Cholinesterase inhibitors can lessen the cognitive symptoms of Alzheimer's disease for some people for a period of time. Three cholinesterase inhibitors (donepezil [common name Aricept], galantamine [Razadyne] and rivastigmine [Exelon]) are available for use by people with a diagnosis of Alzheimer's disease. They can also provide benefits for some people with Lewy body disease or vascular dementia. Memantine (common name Namenda, the only NMDA receptor antagonist covered by the PBS) can help improve thinking and daily functions for a time in people with moderate to severe Alzheimer's disease.

Over-prescription of anti-psychotics

The AIHW found that almost one quarter of the 58,451 people dispensed anti-dementia medications in 2016-17 were also prescribed anti-psychotic medications. This figure only applies to people who were also on anti-dementia medications; there are a great many more people with dementia who are not on anti-dementia medications who are prescribed anti-psychotics. As an example, it is estimated that approximately fifty percent of people living in residential aged care are receiving anti-psychotic medications and about 80% of those people have dementia.⁴ Research and anecdotal evidence suggests that in many cases these medications are prescribed inappropriately and/or without informed consent, which constitutes a form of chemical restraint.

Anti-psychotic medications are often used to manage what is commonly referred to as behavioural and psychological symptoms of dementia (BPSD). BPSD is often an expression of emotion or unmet need that the person with dementia cannot express otherwise (for example, pain, frustration, loneliness, confusion, fear). Environmental factors, such as overstimulation and lack of privacy, can also contribute to BPSD. Staff practices may inadvertently also provoke particular responses.

Anti-psychotic 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 anti-psychotics are not effective or safe, they are still being routinely prescribed and administered against clinical guidelines to people living with dementia often as the primary 'treatment' for managing BPSD.

The impact of polypharmacy

The AIHW dataset demonstrates that people living with dementia have numerous comorbidities and many are on multiple medications. For example, 77% of people who were dispensed anti-dementia medications were also dispensed medications for the cardiovascular system at least once. Other common additional medications included anti-bacterials for systemic use (e.g. for treatment of skin infections or urinary tract infections), agents acting on the renin-angiotensin system (e.g. for the treatment of hypertension) and analgesics.

Recent research⁵ which analysed a random 10% sample of PBS data for people aged 70 or more who were dispensed PBS-listed medicines between 1 January 2006 and 31 December 2017 found that, in 2017, 36.1% of older Australians were affected by continuous polypharmacy (5 or more medications). These estimates could also be low, as over-the-counter or complementary medicines or private prescriptions were not taken into account. Another study⁶ which examined the patterns of medication use from one-year prior to dementia diagnosis to one year after diagnosis, compared to patterns of medication use in people without dementia, found that following a diagnosis of dementia in older people, medication use increased by 11 percent in a year and the use of potentially

⁴ Peisah C. & Skladzien E. (2014) *Alzheimer's Australia Paper 38: The use of restraints and psychotropic medications in people with dementia*, p. 8.

⁵ Page, A.T. et al (2019) Polypharmacy among older Australians, 2006–2017: a population-based study, *Medical Journal of Australia*, 211 (2): 71-75

⁶ Gnjidic, D. et al (2018) The Impact of Dementia Diagnosis on Patterns of Potentially Inappropriate Medication Use Among Older Adults, *The Journals of Gerontology*, 73(10): 1410-1417

inappropriate medications increased by 17 percent. Potentially inappropriate or unnecessary medications included sleeping tablets, pain medications and antidepressants.

This evidence demonstrates the extent of polypharmacy in people with dementia, which places them at increased risk of adverse effects. Medication management of people with dementia can be underpinned by a lack of clarity around the roles and responsibilities of prescribers, aged care staff, carers and formal advocates and pharmacists while the relation of state or territory and federal legislation across the health and aged care settings creates further complexity and confusion.



Case study⁷

The following case study highlights impact of the issues discussed above, including the inappropriate use of anti-psychotics, polypharmacy, lack of medication reviews and the need for residential aged care staff who understand dementia.

After experiencing symptoms for several years, Julia⁸ 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. Julia wore an Exelon (Rivastigmine, a cholinesterase inhibitor) patch for 2.5 years to manage her symptoms, but was not trialled on memantine for more advanced dementia.

Following her move to residential care, Julia was also 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.

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 PRN⁹ 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!"

Again, Harriet advocated for her mother, and worked with the doctors and care staff to change this. They will now call Harriet for her consent to give Julia the PRN, although Harriet is uncertain about the procedure the facility will use to determine whether the PRN is required.

⁷ More examples of chemical restraint and inappropriate use of antipsychotic medications can be found at <https://www.dementia.org.au/news/alzheimers-australia-report-shows-misuse-of-psychotropic-medications-in-people-with-dementia/consumer-stories>

⁸ Names have been changed.

⁹ 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."

Dementia Australia Recommendations

Given the data reported within the latest AIHW report on dispensing patterns for anti-dementia medications as well as the feedback provided by people with a lived experience of dementia, Dementia Australia recommends that:

1. A review of anti-dementia medication usage patterns is undertaken to ensure that clinical guidelines for prescription and re-prescription are being followed.
2. Regular medication reviews are scheduled and occur in consultation with the person with dementia, their carer/family, GP, pharmacist and other health professionals.
3. Events such as falls or hospitalisations act as a trigger for a medication review.
4. Anti-psychotics are only used as a last resort to manage behavioural and psychological symptoms of dementia.
5. All staff working in residential aged care facilities receive high quality training in dementia care with a focus on alternatives to chemical restraint to minimise the inappropriate and unnecessary use of anti-psychotic medications.

A holistic approach to medication management is needed to ensure that regular reviews are conducted and that people living with dementia, their families and carers are empowered to make informed decisions about medications to improve their quality of life and limit unnecessary and potentially dangerous prescriptions.