

What are the key implications for people living with dementia and their care partners of the Royal Commission into Aged Care Quality and Safety Final Report?

'AJDC asks' is a new column in which we invite a range of contributors to consider topical issues relevant to dementia care



From left: Joseph E Ibrahim, Lucy O'Flaherty, Juanita Breen, Lynda Henderson and Danijela Hlis

Professor Joseph E Ibrahim
Head of the Health Law and Ageing Research Unit, Department of Forensic Medicine, Monash University, Victoria

The sense of anticipation surrounding the release of the Final Report of the Royal Commission was a mixture of hope and trepidation for the aged care sector and persons living with dementia. The Commissioners' 148 recommendations were a smorgasbord with something for everyone. In all, the term 'dementia' appears 17 times across the recommendations, with three headline ones in relation to dementia (establishment of a dementia support pathway, review of specialist dementia care services, and dementia and palliative care training for workers).

The remaining recommendations are designed to shift the aged care sector towards delivering better care for all older people, through improved workforce numbers, qualifications and

access to mental and allied health, as well as a new Act with a rights focus. The underlying assumption – that these general improvements in the system will eradicate the underlying discrimination issues facing people with dementia – is too optimistic.

While changes addressing the use of restrictive practice are most welcome, it would have been preferable to eliminate the practice. Similarly, while improving reporting and management of serious incidents is worthy, it's always better to prevent harm.

Gaps remain in addressing the institutionalised discrimination towards people with dementia. While the Royal Commission offers hope for the future, the proposed changes, should government choose to implement the recommendations, are a step in the right direction. It's just not quite the leap forward needed.

Lucy O'Flaherty
CEO of Glenview, a not-for-profit aged care organisation based in Tasmania

Dementia is recognised across several key proposals of the Royal Commission's Final Report, which is a demonstrable sign of the importance placed on dementia and the changes required within the aged care system.

Among a host of recommendations outlined in the report, an important one to note proposes changes in workforce capability by mandating minimum levels of training on dementia. This will ensure our aged care workforce has the required skills to deliver quality person-centred care to people living with dementia.

The recommendation that the Australian Government should establish a post-diagnosis support pathway for people living with dementia and their carers will be a tremendous help for people when they are navigating the complex system, in order to obtain information on care, education and social support services.

Another key recommendation centres on

environment. People living with dementia can become sensitive to their environment because it can change the way in which individuals perceive the surroundings. The report recognises that good design in aged care involves smaller, lower-density living arrangements rather than larger, more institutional settings. Dementia design elements are evident at Glenview's Korongee Village in Tasmania, which opened up in 2020. It is affirming to see the recommendation that dementia-friendly design should also be the norm for new residential aged care buildings.

Establishing high-quality care for people living with dementia across Australia will have a profound impact on their quality of life, and it is our responsibility as a society to provide this level of care to our elders.

Juanita Breen
Affiliate A/Prof with the Wicking Dementia Research and Education Centre, University of Tasmania ▶

I testified at the Sydney hearing in May 2019. As both a pharmacist and aged care researcher I spoke about the high and often inappropriate use of psychotropics in this setting, but also about what we can do to address this issue.

The Royal Commission's focus on restraint has certainly raised awareness. Since the Sydney hearing there have been some important developments such as Australia's first aged care restraint legislation. The Final Report goes further with tighter legislation on restraint which aligns with the NDIS and restricting initial prescribing of antipsychotics to psychiatrists and geriatricians.

Aligning the legislation makes sense, but I do have concerns about the Royal Commission's focus on antipsychotic use. Experience in the US and Canada has shown that targeting one psychotropic class exclusively usually results in prescribing shifts to easier to obtain medications such as benzodiazepines (eg, oxazepam) and opioids.

However, I feel that other recommendations made in the Final Report will reduce psychotropic use, especially mandated staffing ratios and better training in dementia care. The recommendation to rewrite the Aged Care Act to embed a stronger focus on human rights for older people, especially those with reduced capacity, is an essential first step to ensure restraint is viewed as an infringement of human rights, instead of a convenient way to manage the behaviour of people living with dementia.



Dementia Australia
Information, education,
resource and advocacy
organisation for Australians

living with dementia and the people involved in their care

Dementia Australia welcomes the release of the Royal Commission's Final Report and is now calling on the Federal Government to demonstrate it is serious about making quality dementia care core business for aged care in Australia.

Getting quality care right for people living with dementia will have a profound and lasting impact for all – systemically, economically and as a human right. It is our responsibility as a society to provide appropriate care for those who are most vulnerable. Funding is important; however, dementia care should not just be a line item in the next health budget – it is about people, their care and wellbeing.

The Royal Commission has brought focus to key themes for the aged care sector to better meet the needs of people living with dementia, their families and carers, including dementia support pathways, specialist dementia care services, building workforce capacity, and dementia-friendly design of aged care accommodation.

Dementia Australia will be focusing on the detail of the Final Report and will continue to advocate to the Federal Government to ensure it acts on this once-in-a-generation opportunity to transform dementia care and the aged care system overall.

Further information on Dementia Australia's Quality Dementia Care initiative can be found at <https://bit.ly/3cyKCWB>

Lynda Henderson

Care partner, founding member of the Kiama Dementia Advisory Group, Dementia Australia dementia advocate, and member of the OPAN (Older Persons Advocacy Network) National Reference Group

Two years ago I testified at the Royal Commission's hearings into home care, along with V, the person I support, who has a rare form of younger onset dementia and is losing language. We criticised her previous Home Care Package (HCP) provider for inadequate staff education and care planning, price gouging, high fees and charges and inflexibility.

I've been assisting V to self-manage her HCP for the past six months. We feel like we're back in control of our lives after seven long years of being told what we're 'not allowed' to do. She has a nominal provider that holds her care plan and takes care of paperwork for a small fee. We chose her support team, who have the skills and experience that she needs.

We are Boomers, just a tad too old to be eligible for the NDIS, which means that V's funding is capped, regardless of her increasing needs.

We want a non-ageist system. We demand a new Aged Care Act that enshrines human rights, including the UNCRPD and the rights of older persons, and is based on the principle of 'no profit on care'.

Adequate support at home is what most people want. Informal, unpaid care from notional 'family' tries to fill the gaps left by government: it's unsustainable and unrealistic. We 'carers' (care partners/advocates) need space and time to take breaks, but our only options at present are to 'place' the person we love in an institution.

That's not living one's best life. People living with dementia want, need and are entitled to community inclusion, not segregation. It's time for innovation at the local level.

Danjijela Hlis

Dementia Australia advocate, member of OPAN/NOPRG (Older Persons Advocacy Network-National Older Persons Reference Group),

and passionate about better care for older people, especially from diverse backgrounds

The Final Report is the culmination of 28 months of work, with the Royal Commission taking receipt of over 10,500 public submissions, and hearing from 641 witnesses. I was one of them.

Recommendation 147 calls on the Department of Health to establish a taskforce to implement the Royal Commission's recommendations. To this I say, we – older people with lived experience – must be involved.

For me, it is very important that the rights specified for the new Act include rights for people providing informal care, and that the 'Key principles' of the new Act address the needs of informal carers, Aboriginal and Torres Strait islander people, and people of diverse backgrounds. Unfortunately, in my opinion, this is not enough to help achieve equality in quality care, but it is a start.

Commissioner Briggs' recommendation to establish a Council of Elders is an excellent initiative, and so is the recommendation to establish a dementia support pathway. The recommendations setting out instructions for designing for diversity, difference, complexity and individuality (Rec 30) and for respite support (32) are very important. But I am very concerned about the recommendation to implement a new aged care program that would combine all current programs – I fear too much confusion.

Today, as I read through all the 148 Recommendations, I have hope, I feel some disappointment, but overall, I believe that things will improve, provided that we, all diverse older people of Australia, are involved in and drive the changes that we want and need. ■