Parliamentary Joint Committee Inquiry into Australia's Human Rights Framework

A Dementia Australia submission

30 June, 2023

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Dementia Australia

Dementia Australia is the peak dementia advocacy organisation in Australia. We support and empower the more than 400,000 Australians living with dementia and the more than 1.5 million people involved in their care. Founded by carers more than 40 years ago, our organisation engages with people with dementia, their families and carers in our activities, planning, policy and decision-making, ensuring we capture the diversity of the lived experience of dementia across Australia. Our advocacy amplifies the voices of people living with dementia by sharing their stories and helping inform and inspire others. As the trusted source of information, education and support services, we advocate for positive change for people living with dementia, their families and carers, and support vital research across a range of dementia-related fields.

Dementia in Australia

Dementia is the term used to describe the symptoms of a large group of neurocognitive disorders which cause a progressive decline in a person’s functioning. Dementia is the second leading cause of death in Australia, yet it remains one of the most challenging and misunderstood conditions. Without a significant medical breakthrough, it is estimated that there will be more than 800,000 people living with dementia in Australia by 2058.[i]

Why we need an Australian Charter of Human Rights

Australia has Human Rights Acts in three States and Territories: Victoria, Queensland and the Australian Capital Territory (ACT). The ACT Human Rights Act has been operating effectively since 2004 and protects amongst other rights, recognition and equality before the law; protection from torture and cruel, inhuman or degrading treatment; freedom of thought, conscience, religion and belief; and taking part in public life. Every Western democracy other than Australia has a national Charter of Human Rights or an analogous law that sets out the rights and freedoms of its citizens. The Canadian Charter of Rights and Freedoms enshrines amongst other rights, fundamental freedoms and democratic, mobility, equality, and legal rights, and protects minority languages and education rights.

Australia is a representative democracy and is defined by amongst other principles, the right to freedom of election, freedom of assembly and political participation, freedom of speech, expression and religious belief, the rule of law and other basic human rights. For many Australian citizens, our system of representative democracy works well but the absence of a Charter of Human Rights means that there are inadequacies in our current laws, and for some citizens, fundamental human rights are not always respected, protected or guaranteed.

A Human Rights Charter ensures that people in the community understand what their rights are and can act if they are violated. Creating an Australian Human Rights Charter is important in setting out the kind of society that we want to be, articulating our shared values, and upholding those values by enshrining and protecting them in law.

The kind of model adopted in Victoria, Queensland and the ACT, and in international jurisdictions, has shown that the most significant impact of a Charter of Human Rights is in law, policy development and service provision. At a time when belief and trust in government and public institutions has been significantly eroded in these areas, a Charter will contribute to rebuilding confidence in the integrity of government and government actions at the Federal level.

Australia is a party to the seven core international human rights treaties including international Covenants on Civil and Political Rights and Economic, Social and Cultural Rights and international conventions on the Elimination of All Forms of Racial Discrimination**,** the Elimination of All Forms of Discrimination against Women and the Convention on the Rights of Persons with Disabilities. Australia is also a party to a number of international protocols protecting the human rights of women, children, people with disability, and protecting against torture and other degrading treatment or punishment.

Given Australia has already accepted a range of obligations in relation to human rights under international law, Dementia Australia believes that we should join other countries around the world and bring our own laws into line by adopting a national Human Rights Charter.

An Australian Charter of Human Rights will achieve three important objectives:

- It will require governments and public servants to consider and respect the human rights of Australian citizens when developing policies, creating new laws and delivering services. This will result in improved laws that will in turn help prevent human rights violations from occurring.

- A Charter would ensure people are fully informed and empowered about their rights and if these are breached, to act and seek justice.

- A Charter would list all our rights and freedoms in one place, so everyone from school children to new migrants, can learn about their rights and freedoms and understand the type of community we aspire to be.

How an Australian Charter of Human Rights will improve the lives of people living with dementia, their family members and carers

Contemporary Australian society is ethnically, culturally and socially diverse. The human rights of people from diverse groups and minority populations can be more vulnerable in the absence of a Human Rights Charter. It is critical that Aboriginal and Torres Strait Islander people, people from culturally and linguistically diverse backgrounds, the LGBTI community, children, people living with disability, older people, and people in remote and regional areas amongst other groups, are afforded the protections that a Charter of Human Rights would provide. As part of the disability community, people living with dementia encounter stigma and discrimination and face unique challenges in relation to the protection of their human rights.

The 2008 United Nations Convention on the Rights of People with a Disability (UN-CRPD) recognised dementia as a cognitive disability but unlike physical disability, community understanding of dementia as a disability remains limited. This is at least in part because, unlike a physical disability, the cognitive and other changes that are associated with the condition are often under recognised or rendered ‘hidden’ or ‘invisible.’ People living with dementia relate the common experience of being told that they ‘can’t possibly have dementia’ because they don’t appear, speak or act in a way that corresponds with community expectations or understanding of the disabling nature of dementia.[ii]

> ‘If you just saw them and didn’t know them, how would you even know if they had dementia?” (Australian resident with no lived experience of dementia) [iii]

The ‘invisible’ nature of a cognitive disability and the attitudinal and other societally imposed barriers mean people living with dementia can experience additional stigma or challenges when undertaking daily activities, engaging with the health care sector or interacting with people in the broader community.

The human rights of people living with dementia, their family members and carers have not always been well supported in the past, particularly in relation to access to services and the provision of appropriate care and support. The history of dementia care has been described as ‘anything but humane’.[iv] As recently as the 1960s, people living with cognitive impairment were concealed at home, rendered homeless by their impairment or institutionalized in state run psychiatric hospitals. In these settings, the lack of knowledge and awareness about dementia resulted in care that was rudimentary at best and consisted of a blunt divide between medical and physical care interventions. In institutional settings, physical and pharmacological restraints were used as routine measures.

The legacy of this approach persists to varying degrees in contemporary Australian community, residential aged care and disability settings, as revealed by the recent Royal Commissions into those sectors. As the detailed individual and organisational submissions, and the findings and interim findings from the Aged Care and Disability Commissions respectively made clear, the lack of protection of the rights of older people and those living with disability has resulted in poor care, mistreatment, neglect and in some cases abuse. [v]

The respective findings of both Commissions also made apparent that there were limited avenues for reporting of concerns and complaints around the provision of appropriate care and associated breaches of human rights, and that these reports were not always responded to in a timely or appropriate manner.[vi]

Dementia Australia has received feedback from people living with dementia, their family members and carers in relation to a range of issues that have included experiences that represent clear breaches of their human rights and include:

- Numerous reports over many years of inadequate care provided for people living with dementia in community and residential aged care settings including not seeking to identify, comply with or respect choices and preferences in relation to everything from appropriate meal choices to care and medical treatment preferences
- Multiple reports over recent years from carers documenting the rejection of respite applications by day respite and residential aged care providers on the basis of assumptions and judgements made about the dementia-related symptoms and care needs of their family member or friend
- A visitor to an aged facility reported witnessing a registered nurse signing legal documents on behalf of a person with dementia living in a residential aged care home without presence of a third party/representative or substitute decision-maker supporting the person with dementia.
- A person living with dementia, who had given blood all their adult life and had demonstrated capacity to make decisions about their desire to continue to do so, was refused the opportunity to donate blood, without explanation as to whether the reason was medical or on the grounds of capacity

- A person living with dementia and with demonstrated capacity to make decisions about their political preferences was denied the opportunity to vote at a recent Federal election because the appropriate assistance was not in place to support them to exercise their right to vote
- A person living with dementia with demonstrated decision-making capacity had her licence cancelled by the direction of her GP. Her GP did not discuss this with her or facilitate an opportunity for her to undertake a driving assessment or any other health-related assessment that would have supported her desire to continue to drive.

Recent research has highlighted the importance of embedding a rights-based approach to understanding dementia to ensure that people living with dementia, their family members and carers have access to appropriate services and supports.[vii] Dementia support and care can involve complicated clinical and ethical issues in relation to decisions about treatment, care and quality of life, made even more complex if the person with dementia is unable to participate in the decision-making process. Researchers have drawn a clear link between the formal protection of human rights and access to services and the provision of good quality support and care for people living with dementia, their family members and carers. [viii]

An Australian Charter of Human Rights, with enforceable laws, would support the right of every person living with dementia to access appropriate supports and services and importantly, to act if access or the provision of services and care was unsatisfactory and breached human rights. The Final Report of the Royal Commission into Aged Care Quality and Safety also insisted on the importance of this in recommending the recognition of the legally enforceable right to health and dignified treatment. [ix]

Dementia Australia believes that recognising dementia as a disability opens up opportunities to improve understanding of the condition within a rights-based approach. A Charter of Human Rights would ensure that people living with dementia would receive greater legal protections, entitlement to services, and encourage a positive cultural shift in the way that dementia is perceived and understood.

Conclusion and recommendation

Dementia Australia strongly supports the need for a legislated Human Rights Charter, a Charter that will ensure that the values shared by Australian citizens including fairness, respect, equality, and dignity are protected and upheld. A Charter would underpin government decision-making, and inform laws, policies and service provision. A Charter will ensure that every Australian citizen understands their rights and is empowered with the knowledge and confidence to act when their rights are violated.

Dementia Australia believes that a Charter of Human Rights will make a significant contribution to protecting the rights and improving the quality of life not only of people living with dementia, their family members and carers, but all Australian individuals and communities.

Dementia Australia urges the Inquiry to recommend a legislated Human Rights Charter.

We are grateful for the opportunity to make a submission to this important consultation in relation to an Australian Human Rights Charter. We thank you for considering our submission and we would welcome further opportunities to discuss the issues and recommendations raised in this submission.

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[i] Australian Institute of Health and Welfare (2022) Dementia in Australia, AIHW, Australian Government, accessed 20 January 2023.

[ii] Former CEO of Alzheimer's Switzerland Birgitta Martensen's account of her recent diagnosis includes the most recent and compelling example of this. https://www.alzint.org/news-events/news/my-life-with-alzheimers-disease-living-better-with-a-diagnosis/

[iii] Dementia Friends & Dementia Friendly Communities Program. Exploratory report, Kantar Consultants, 2019

[iv] [iv] McKenzie, M. (2004) 'A History of Dementia Care in the Age of Alzheimer's Disease'', *American Educational History Journal*; 31, 2; p.19

[v] Volume 1 Summary and Recommendations, Final Report: Care, Dignity and Respect, Royal Commission into Aged Care Quality and Safety, pages 205-206. Interim Report, Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

[vi] Volume 1 Summary and Recommendations, Final Report: Care, Dignity and Respect, Royal Commission into Aged Care Quality and Safety, pages 205-206. Interim Report, Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

[vii] Butchard, S and Kinderman, P. (2019). 'Human Rights, Dementia, and Identity', *European Psychologist*, 24(2), p.165

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[ix] Volume 1 Summary and Recommendations, Final Report: Care, Dignity and Respect, Royal Commission into Aged Care Quality and Safety, pages 205-206.