Review of the Ageing and Adult Safeguarding Act 1995 (SA)

South Australian Law Reform Institute

30 June 2022

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About Dementia Australia

No matter how you are impacted by dementia or who you are, Dementia Australia is here for you.

We exist to support and empower the estimated half a million Australians living with dementia and almost 1.6 million people involved in their care. Dementia is the second leading cause of death in Australia yet remains one of the most challenging and misunderstood conditions.

Founded by carers more than 35 years ago, today we are the national peak body for people impacted by dementia in Australia.

We involve people impacted by dementia and their experiences in our activities and decision-making, to make sure we are representative of the diverse range of dementia experiences across Australia. We amplify the voices of people impacted by dementia through advocating and sharing stories to help inform and inspire others.

Dementia Australia is the source of trusted information, education and support services. We advocate for positive change for people living with dementia, their families and carers, and support vital research.

We are here to support people impacted by dementia, and to enable them to live as well as possible.

Introduction

Dementia Australia would like to thank the South Australian Law Reform Institute for the opportunity to contribute to the independent review Adult Safeguarding Unit.

Our submission addresses the relevant consultation questions within the organisation's sphere of expertise. In particular, we discuss the importance of empowering language and definitions, capacity and consent, expanding the responsibility of the Adult Safeguarding Unit to all people impacted by dementia, barriers to reporting and pursuing action on abuse, and promoting and protecting the autonomy of adults with dementia.

> **"We should support the person to live an active life in the manner they prefer. We should provide aids and an environment that facilitates independence. We should always respect the person's choices and if their choices increase their risk of harm or injury, we should explain how, when, and why. We should also communicate in the ways that are most intelligible for the person" Former carer**

Empowering language and definitions

Dementia Australia commends the South Australian Law Reform Institute for recognising the role of language in how society ascribes value to certain individuals and cohorts. For many years, people living with dementia and their families have campaigned for an end to stigmatising language such as ‘demented’ or ‘senile’. Following their lead, Dementia Australia developed **dementia language guidelines** for public use. When speaking about dementia and the people impacted by the condition, language should be accurate, respectful, inclusive, empowering, and non-stigmatising.

Similarly, critical discourse has highlighted problems in using terms like ageing ‘well’ and ‘vulnerable’. When describing a cohort as vulnerable, we inadvertently perpetuate a stereotype of weakness or deficiency. At the same time, we obscure the root causes of inequity, discrimination, and abuse, and focus our efforts on downstream solutions rather than the systemic drivers[1]. To this end, it is preferable to name the priority group in question, such as older Australians or people living with dementia. When referring to a cohort defined by their risk profile, a term like “people at greater risk of” should be considered.

Recently there has been some discussion about the appropriateness of terms like ‘ageing well’ and ‘living well with dementia’. Although originating from a benevolent etymology, there is a compelling argument that these terms reinforce stigma and negative stereotypes. That is, if ageing well is the goal, are some of us failing to age well? As an alternative, Dementia Australia has shifted to using ‘living as well as possible with dementia’. Although this is an emerging sentiment it should be brought to the Office for Ageing Well’s attention.

Expansion of the Adult Safeguarding Unit to all people living with dementia

Although increased age is the biggest unmodifiable risk factor for dementia, dementia is not an old person’s disease. In 2022, there are an estimated 28,800 Australians with younger onset dementia, defined as a person diagnosed before they turn 65[2]. Dementia Australia recommends that the Office for Ageing Well extend their function from “consulting with ‘the ageing’” to consulting with people impacted by dementia of any age, to better understand the community’s needs and experiences.

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[1] Amy S. Katz, Billie-Jo Hardy, Michelle Firestone, Aisha Lofters & Melody E. Morton-Ninomiya (2020) Vagueness, power and public health: use of ‘vulnerable‘ in public health literature, Critical Public Health, 30:5, 601-611, DOI: 10.1080/09581596.2019.1656800

[2] Dementia Australia (2018) Dementia Prevalence Data 2018-2058, commissioned research undertaken by NATSEM, University of Canberra

Dementia is the single greatest cause of disability in older Australians and the third leading cause of disability overall[3]. And yet, the condition is rarely recognised as a disability. People living with dementia, their families, and carers tell us that disability services have insufficient dementia knowledge and expertise. There is a need for increased support for people with younger onset dementia who are experiencing abuse or neglect. Dementia Australia believes the provisions of the Ageing and Adult Safeguarding Act 1995 (SA) and the Adult Safeguarding Unit could be safely adapted to the needs of all people living with dementia, with recognition of, and accommodations for, both their shared and disparate needs.

However, a decision to expand the responsibility of either the Act or the Adult Safeguarding Unit must have the support of the community they seek to support. Therefore, Dementia Australia encourages the South Australian Law Reform Institute to consult further with people living with dementia, their families, and carers on any planned expansion.

Capacity and consent

People living with dementia have the right to autonomy. This includes the right to make 'bad' decisions. It is incorrect to assume that every person with dementia has lost decision-making capacity.

Decision-making capacity in people living with dementia can fluctuate and is situation specific – that is, the person's ability to make decisions is not static. Fatigue, medication, delirium, illness or sundowning can all impact the person. Capacity is neither a person's level of cognition, nor their physical function. A person with dementia may be unable to perform a certain task, but they can make meaningful decisions about whether they want assistance performing that task[4].

In recognition of the dignity and autonomy of people living with dementia, it is appropriate that the Adult Safeguarding Unit's guiding principles continue to follow a human rights-based approach. Nevertheless, maintaining a non-interventionalist model that continues to be safe for people living with dementia requires rigorous governance, procedures, staff education and, where appropriate, clinical oversight.

Implications surrounding fluctuating capacity can be overcome by dementia-informed practice. These practices might include:

- Ensuring Adult Safeguarding Unit workers are equipped to assess capacity or understand when to engage a relevant specialist
- Integrating capacity assessment tools into the information gathering process in an unobtrusive way
- Having a sensitive and respectful response to individuals that present with impaired meta-cognition (reduced ability to recognise one's own impairment)

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[3] Australian Institute of Health and Welfare (2012) Dementia in Australia

[4] Hegde, S., & Ellajosyula, R. (2016). Capacity issues and decision-making in dementia. Annals of Indian Academy of Neurology, 19(Suppl 1), S34–S39. https://doi.org/10.4103/0972-2327.192890

- Scheduling interactions at a time preferred by the person living with dementia (many people report better cognition in the morning)
- Communicating clearly and asking the person to repeat the information in their own words
- Supplying the person with a written record of the discussion and decision (when safe to do so)
- Providing routine follow-up to all individuals who refuse assistance, to ensure no-one falls through the cracks
- When appropriate, engaging with the person's supported decision-maker or another person nominated by the person living with dementia
- Permitting Adult Safeguarding Unit employees to direct people to the National Dementia Helpline for information and support

Dementia Australia recommends all Adult Safeguarding Unit employees complete comprehensive dementia education, such as the nationally accredited Dementia Essentials program. Staff in client-facing roles must maintain their skills with annual continuing professional development on dementia-related issues.

> **"The issue of informed consent is ignored when a dementia diagnosis is made - which is very wrong." Former carer**

Barriers to reporting and pursuing action on abuse

> **"Fear of not being taken seriously or listened to – a 'paternalistic' attitude of trivialising the issue as we know best for you." Person living with dementia**

The drivers of abuse and the risk of abuse are complex. Although individual characteristics (age, health, independence) are major factors, how these characteristics might overlap or interact are also important. For example, a study of elder abuse in India found a significant link between multimorbidity, rather than just illness or disability, and elder abuse[5]. Environmental or external influences, such as family stressors, is also thought to be a significant contributor. In fact, there is some evidence to suggest that different types of abuse – physical abuse, emotional abuse, and neglect – each have unique risk profiles[6].

Although the connection between dementia and elder abuse is largely accepted, we have a limited understanding of the prevalence of the problem. The National Elder Abuse Prevalence Study's final report estimates 14.8 per cent of older Australians experienced abuse in the last 12 months, however people with cognitive impairment were excluded from

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[5] Kshatri JS, Bhoi T, Barik SR, Palo SK, Pati S. Is multimorbidity associated with risk of elder abuse? Findings from the AHSETS study. BMC Geriatr. 2021 Jul 3;21(1):413. doi: 10.1186/s12877-021-02347-y. PMID: 34217225; PMCID: PMC8255025.

[6] Burnes D, Pillemer K, Caccamise PL, Mason A, Henderson CR Jr, Berman J, Cook AM, Shukoff D, Brownell P, Powell M, Salamone A, Lachs MS. Prevalence of and Risk Factors for Elder Abuse and Neglect in the Community: A Population-Based Study. J Am Geriatr Soc. 2015 Sep;63(9):1906-12. doi: 10.1111/jgs.13601. Epub 2015 Aug 27. PMID: 26312573.

participating[7]. Further research and investment are urgently needed to inform Australia's elder abuse response, including prevention, detection, and reduction. Dementia Australia suggests that, rather than shifting towards a prescriptive definition of risk, the definition should be broadened to encompass physical, emotional, environmental, and societal factors.

Coercion and fear of reprisal is a concern for people living with dementia, their families and carers and a significant barrier to registering complaints or abuse. Dementia Australia understands this is a common issue for people dependant on service providers (and their families), who fear care might be withheld or deteriorate after reporting abuse; however, people with dementia who rely on family members are also at risk. Other reported barriers to reporting complaints and abuse are:

- Delayed or slowed response times
- Follow up or further complaint pathways are unclear
- Lack of transparency
- Family not able to report or does not understand full extent of the risk
- Not knowing where to direct their concerns
- Stigma and discrimination associated with declaring vulnerability
- Concerns about confidentiality

Ensuring the continued safety of people with dementia is fundamental to empowering victims of abuse to come forward. People with dementia, their families and carers must also have full confidence in the system. This requires a cross-sectorial commitment from community, service providers, law enforcement, and the Adult Safeguarding Unit.

A flexible and dynamic approach to the development of safeguarding plans may also encourage people living with dementia and their families to pursue action within the scheme. The goals of the person with dementia must be central to every safeguarding plan, even when the plan is developed within a supported decision-making model. When undertaking multidisciplinary action, it is appropriate to refer the person and their family to Dementia Australia for information and support.

Promoting and protecting the autonomy of adults with dementia

Interviews with people living with dementia and carers regarding the meaning of autonomy suggests that it is not appropriate to apply a 'one size fits all' definition[8]. Whilst some people living with dementia have a powerful desire to continue at the forefront of decision-making, others have adopted an intersubjective relational model of autonomy, where decision-making

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[7] Qu, L., Kaspiew, R., Carson, R., Roopani, D., De Maio, J., Harvey, J., Horsfall, B. (2021). National Elder Abuse Prevalence Study: Final Report. (Research Report). Melbourne: Australian Institute of Family Studies.

[8] Wolfe SE, Greenhill B, Butchard S, Day J. The meaning of autonomy when living with dementia: A Q-method investigation. Dementia (London). 2021 Aug;20(6):1875-1890. doi: 10.1177/1471301220973067. Epub 2020 Dec 29. PMID: 33372553; PMCID: PMC8369913.

is shared with a trusted partner. This has implications for managing and responding to reports of abuse for both personality types.

It is essential to understand the person with dementia, the nature of their relationships, their goals, and needs. For the Adult Safeguarding Unit, this may involve exploring the person's support network beyond the carer dyad, understanding the person's history, knowing what the barriers to accepting assistance could be, providing them with the necessary information in an accessible way, and maintaining a dialogue with the person, either directly through the Adult Safeguarding Unit, a trusted health professional, or another specialist agency, like Dementia Australia.

The inconsistencies described in *Fact Sheet 9 Capacity and Consent* in relation to referrals and subsequent action (if that action is maintaining communication with the person living with dementia) suggests that the Ageing and Adult Safeguarding Act 1995 (SA) may not provide optimum protection for the rights and participation of people living with dementia.

Finally, Dementia Australia recommends that beyond this consultation, there are several opportunities to engage in co-design with people living with dementia, their family, and carers in the development of dementia-informed practice, policies, and promoting the autonomy of people living with dementia.

Dementia Australia welcomes the opportunity to provide further assistance to the South Australian Law Reform Institute as part of their review.