



Australian
Human Rights
Commission

Australia's protection of older persons for long-term care, autonomy and independence

Submission to the Open-ended Working Group on Ageing

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1 Introduction

1. The Australian Human Rights Commission makes this submission. The Commission is an 'A status' national human rights institution established and operating in full compliance with the Paris Principles. Information about the Commission can be found at: www.humanrights.gov.au
2. The submission provides an overview of Australia's protection of older persons with regard to long-term and palliative care; and autonomy and independence.

2 Long-term and Palliative Care

2.1 Aged Care

3. In Australia, long-term care is known as aged care. The *Aged Care Act 1997* (Cth) (the ACA) and the Aged Care Principles provide the national legislative framework for funding and regulating aged care. The ACA provides a legal definition of aged care and recognises special needs groups.¹ Aged care services are also provided via contract arrangements or purchased privately. These services fall outside of the ACA.²
4. A number of Principles are made under the ACA. Principles cover eligibility requirements for approval to receive services, Accreditation Standards, Home Care Standards and Flexible Care Standards, and care recipients' rights and responsibilities.³
5. The ACA aims to facilitate access to aged care services by those who need them, regardless of race, culture, language, gender, economic circumstance or geographic location.⁴ The Australian Department of Health has an Aged Care Diversity Framework and is developing strategies for providing aged care to older Australians from diverse backgrounds.⁵
6. The Australian aged care system is underpinned by a philosophy of supporting people to age in place and remain part of their communities for as long as possible.
7. Over 1.3 million people received government-subsidised aged care services in 2017–18.⁶ Options for a continuum of care are offered under three main services: Commonwealth home support, home care packages

and residential care.⁷ Supply of residential and home care is capped and demand for home care packages currently exceeds supply.⁸

8. Access to government-subsidised services is facilitated via centralised assessment to determine a person's eligibility and priority for services.⁹ Residential and home care package recipients are means-tested and contribute to the cost of care. Hardship provisions are available for people unable to meet the costs.¹⁰
9. Flexible aged care programs and funding supplements provide additional support to older people in rural and remote areas, recognising the challenges of service delivery in these locations.¹¹
10. Reform to the aged care system is continuing, aiming to ensure the system is sustainable, affordable, consumer-directed and supports people to remain living in their home.¹²
11. The Aged Care Quality and Safety Commissioner is a statutory appointment made under the *Aged Care Quality and Safety Commission Act 2018* (Cth).¹³ The Aged Care and Quality and Safety Commission is responsible for protecting and enhancing the safety, health, well-being and quality of life of aged care consumers; and for education, regulation and complaints functions.
12. Complaints can be made to the relevant organisation providing assessments and services.¹⁴ If the complainant is not satisfied with the outcome, complaints can be further raised with an oversighting body or independent tribunal. In 2017–18, 75% of complaints received by the Aged Care Complaints Commission related to residential aged care.¹⁵
13. Inquiries and media have raised numerous issues regarding the provision, quality and safety of aged care.¹⁶ A Royal Commission into Aged Care Quality and Safety was established in 2018. An interim report is due by 31 October 2019.¹⁷

2.2 Palliative care

14. Medicare, Australia's universal health care scheme, provides Australians (and some overseas visitors), with access to health and hospital services.¹⁸

15. Palliative care is provided by publicly or privately funded hospitals, general practitioners, specialist palliative care services and by families, carers and volunteers.¹⁹ Services are delivered in the community, in-patient settings and residential aged care.
16. State and territory governments provide most palliative care services and operate health care complaint commissions (or equivalent). National palliative care projects are funded by the Commonwealth Department of Health, focusing on education, training and quality improvement.²⁰
17. Key national documents relating to the provision of palliative care include:
 - National Palliative Care Strategy²¹
 - National Consensus Statement: Essential elements for safe and high-quality end-of-life care, providing guiding principles to improve the safety and quality of end-of-life care²²
 - National Palliative Care Standards (5th edition). The Standards provide a vision of best practice care, which considers an individual's cultural, spiritual, physical, psychological and social needs, and includes information for applying the standards to a range of population groups.²³
 - National Safety and Quality Health Service Standards (Version 2), providing a statement on the standard of care consumers can expect from health services²⁴
 - Guidelines for a Palliative Approach in Residential Aged Care²⁵
 - Guidelines for a Palliative Approach for Aged Care in the Community Setting.²⁶
18. State and territory governments are responsible for legislation relating to advance care directives (ACD) and the appointment of substitute decision-makers.²⁷ Different types of advance directives operate in Australia, with some operating under common law and others under statute law.²⁸
19. ACD and guardianship arrangements generally apply across the various Australian state and territory jurisdictions, however there may be

limitations or additional requirements that impact their validity and application.²⁹

20. Euthanasia is currently illegal in all states and territories, although the Victorian government has passed legislation to legalise voluntary assisted dying, effective from 19 June 2019.³⁰

3 Autonomy and Independence

3.1 Promoting Autonomy and Independence

21. For this submission, 'independence' is understood as the ability of a person to perform functions related to daily living, and 'autonomy' is understood as the ability to have control over one's own decisions.
22. Australia promotes the independence of older people by, for example,
- supporting people who need care to remain living at home through in-home and community-based health and aged care services³¹
 - providing income support through social security frameworks³²
 - promoting social inclusion and community participation through
 - not having an upper age limit on the right to vote
 - concession schemes providing older people discounts for public transport and entertainment
 - government funding for community service groups that advocate for, and represent the views, of older people³³
 - encouraging the development of age-friendly cities through local grants and the development of accessible infrastructure and transport.
23. Australia promotes autonomy of older people, for example,
- adults are presumed to have the right to make their own decisions, which includes having control their own personal and financial affairs

- a common law principle allows competent adults to consent to or refuse medical treatment
- with some exceptions (such as federal judges and Australian Defence Force personnel), there is no mandatory age of retirement
- federal legislation makes it unlawful to discriminate against a person on the basis of age in certain areas of public life (for example, in the workplace).³⁴

24. This submission discusses two key aspects of autonomy and independence:

- Firstly, frameworks that allow a person to be appointed legally to control and manage another individual's personal and financial affairs, and medical care if they were to lose decision-making capacity (and put limits and conditions on that power).
- Secondly, ensuring people are able to live free from elder abuse.

3.2 Managing one's medical and financial affairs

25. Under common law in Australia, adults are presumed to have capacity until the contrary is proven.³⁵ To different degrees, the presumption of capacity has been set out in legislation.³⁶

26. This means every adult is free to make their own decisions if they have capacity, regardless of their age. Only where a person is deemed to not have capacity can a third party make decisions for that person, and control their personal, financial and medical affairs.

27. State and territory legislation allows a person to nominate a substitute decision-maker to make decisions on their behalf about personal, financial and health matters, in the event they lose capacity.³⁷ This promotes choice and autonomy in instances where a person loses decision-making capacity. Decision-making powers can be given in full, or with limitations or conditions (for instance, restricting their powers to certain functions like deciding where they live and what services are provided to them at home).³⁸ Substitute decision-makers are typically required to act in the best interests of the person, or act consistently with principles that uphold the fundamental rights of the person.³⁹

28. If the individual has not chosen a substitute decision-maker, an independent tribunal will appoint the most appropriate person/s.
29. A person can make directions about the types of medical treatment they wish to receive (or not receive) in the event they are unable to consent (whether this is provided for under the common law or legislation differs between each state and territory).⁴⁰
30. Each state and territory has a body that provides oversight of the conduct of substitute decision-makers, and can provide remedies.⁴¹

3.3 Freedom from elder abuse

31. Enabling older people to live free from elder abuse—whether this be physical, financial, psychological abuse, or neglect—is an important aspect of maintaining a person’s independence and autonomy. Elder abuse can compromise a person’s ability to make their own decisions and have control over their own personal, financial and medical affairs.
32. In 2017, the Australian Law Reform Commission (ALRC) conducted an inquiry into elder abuse in Australia.⁴² The Commission considered the national laws and legal frameworks and how they might better protect older people from abuse, and safeguard their autonomy. The report made 43 recommendations for law reform to safeguard older people and support their choices and wishes. The recommendations are in various stages of implementation.
33. Each state and territory has a helpline for those experiencing, or those who are concerned someone they know may be experiencing, elder abuse. In the most recent 2018/19 national budget, the Australian government committed \$22 million funding over 4 years to protect the rights of older Australians. This includes funding for increased specialist front line services to support older people and their families, like specialist elder abuse units, family counselling and mediation services.⁴³
34. One of the priorities of the Age Discrimination Commissioner the Hon Dr Kay Patterson AO is implementing the ALRC report.

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- ¹ See *Aged Care Act 1997* (Cth) sch 1 and pt 2.2 div 11.
- ² *Aged Care Act 1997*; Department of Health, Australian Government, *Legislation* (12 April 2017) Ageing and Aged Care. At <https://agedcare.health.gov.au/publications-and-articles/legislation> (viewed 10 January 2019); Parliament of Australia, *Aged Care: A Quick Guide* 2016. At https://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/pubs/rp/rp1617/Quick_Guides/Aged_Care_a_quick_guide (viewed 11 January 2019).
- ³ See *Approval of Care Recipients Principles 2014* (Cth). Also see *Quality of Care Principles 2014* (Cth). Also see *User Rights Principles 2014* (Cth)
- ⁴ See *Aged Care Act 1997* (Cth) div 2
- ⁵ Department of Health, Australian Government, *People from diverse backgrounds* (17 January 2018). At <https://agedcare.health.gov.au/older-people-their-families-and-carers/people-from-diverse-backgrounds> (viewed 11 January 2019).
- ⁶ Department of Health, Australian Government, '2017-18 Report on the Operation of the Aged Care Act 1997' (Report, 2018) 9.
- ⁷ Australian Government, *Need aged care services? This is the place to start: Find and set up services*, My Aged Care. At <https://www.myagedcare.gov.au/home-find> (viewed 11 January 2019).
- ⁸ Australian Institute of Health and Welfare, Australian Government, *Home Care packages program data report 1 July–30 September 2018*, GEN Aged Care Data (November 2018) refer Appendix D. At <https://www.gen-agedcaredata.gov.au/Resources/Reports-and-publications/2018/November/Home-care-packages-program-data-report-1-July---30> (viewed 14 January 2019).
- ⁹ Australian Government, *Need aged care services? This is the place to start: Assessment*. My Aged Care. At <https://www.myagedcare.gov.au/home-find> (viewed 11 January 2019).
- ¹⁰ Department of Health, Australian Government, *Residential Care and Home Care Frequently Asked Questions* (10 April 2018). At <https://agedcare.health.gov.au/aged-care-reform/residential-care-and-home-care-frequently-asked-questions> (viewed 11 January 2019).
- ¹¹ Department of Health, Australian Government, '2017–18 Report on the Operation of the Aged Care Act 1997' (Report, 2018) 65.
- ¹² Department of Health, Australian Government, *Recent Aged Care Reforms* (26 July 2018). At <https://agedcare.health.gov.au/reform/recent-aged-care-reforms> (viewed 11 January 2019).
- ¹³ *Aged Care Quality and Safety Commission Act 2018* (Cth)
- ¹⁴ Australian Government, *How to Make a Complaint* (1 January 2019) My Aged Care. At <https://www.myagedcare.gov.au/quality-and-complaints/how-make-complaint> (viewed 11 January 2019).
- ¹⁵ Aged Care Complaints Commissioner, Australian Government, 'Annual Report 2017–18'. At <https://www.agedcarequality.gov.au/about-us/corporate-publications/aged-care-complaints-commissioner> (viewed 14 January 2019). The new Aged Care Quality and Safety Commission assumed responsibility for aged care complaint functions from 1 January 2019.
- ¹⁶ Jane Phillips, Deborah Parker, Michael Woods, *We've had 20 aged care reviews in 20 years – will the royal commission be any different?* (20 September 2018) The Conversation. At <http://theconversation.com/weve-had-20-aged-care-reviews-in-20-years-will-the-royal-commission-be-any-different-103347> (viewed 11 January 2019).
- ¹⁷ Prime Minister, Minister for Health, Minister for Senior Australians and Aged Care, *Royal Commission into Aged Care Quality and Safety Media Release* (16 September 2018). At <https://www.pm.gov.au/media/royal-commission-aged-care-quality-and-safety> (viewed 11 January 2019).

- ¹⁸ Department of Health, Australian Government, *Medicare*, (1 August 2018). At <https://beta.health.gov.au/medicare> (viewed 10 January 2019).
- ¹⁹ Supporting Australians to Live Well at the End of Life, National Palliative Care Strategy 2010
- ²⁰ Department of Health, Australian Government, *National Palliative Care Projects* (16 August 2018). At <http://www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-program.htm> (viewed 10 January 2019).
- ²¹ Department of Health, Australian Government, *Palliative Care*, (23 October 2017). At <http://www.health.gov.au/internet/main/publishing.nsf/Content/Palliative%20Care-1> (viewed 14 January 2019).
- ²² Australian Commission of Safety and Quality in Health Care, National Consensus Statement: Essential elements for safe high quality end of life care (27 May 2015). At <https://www.safetyandquality.gov.au/publications/national-consensus-statement-essential-elements-for-safe-high-quality-end-of-life-care/> (viewed 14 January 2019).
- ²³ Palliative Care Australia (PCA), 'National Palliative Care Standards 5th Edition' (Standards, PCA, 2018) 13-19.
- ²⁴ Australian Commission of Safety and Quality in Health Care, NSQHS Standards (second edition), 9 August 2018. At <https://www.safetyandquality.gov.au/our-work/assessment-to-the-nsqhs-standards/nsqhs-standards-second-edition/> (viewed 14 January 2019).
- ²⁵ Department of Health, Australian Government, *Palliative Care Guidelines for the Aged Care Sector* (23 October 2017). At <http://www.health.gov.au/internet/main/publishing.nsf/Content/pcg-acg> (viewed 10 January 2019).
- ²⁶ Department of Health, Australian Government, *Palliative Care Guidelines for the Aged Care Sector* (23 October 2017). At <http://www.health.gov.au/internet/main/publishing.nsf/Content/pcg-acg> (viewed 10 January 2019).
- ²⁷ Advance Care Planning Australia, *Advance Care Planning and the Law*, (2018). At <https://www.advancecareplanning.org.au/for-health-and-care-workers/legal-requirements> (viewed 11 January 2019).
- ²⁸ Queensland University of Technology, *Advance Directives*, End of Life Law in Australia (12 March 2018). At <https://end-of-life.qut.edu.au/advance-directives> (viewed 11 January 2019).
- ²⁹ Advance Care Planning Australia, *Advance Care Planning for your State/Territory: NSW* (2018). At <https://www.advancecareplanning.org.au/resources/advance-care-planning-for-your-state-territory/nsw> (viewed 11 January 2019).
- ³⁰ *Voluntary Assisted Dying Act 2017* (Vic) pt. 1 s 2
- Queensland University of Technology, *Euthanasia and Assisted Dying*, End of Life Law in Australia (18 December 2018). At <https://end-of-life.qut.edu.au/euthanasia> (viewed 14 January 2019).
- ³¹ For more information see: <https://www.myagedcare.gov.au/not-sure-start-here>
- ³² For more information see: <https://www.dss.gov.au/about-the-department/benefits-payments>
- ³³ For example, COTA Australia is the peak policy development, advocacy and representation organisation for older Australians.
- ³⁴ *Age Discrimination Act 2004*
- ³⁵ Australian Law Reform Commission, *Australian Privacy Law and Practice* (ALRC Report 108).
- ³⁶ See, for example, *Powers of Attorney Act 2014* (Vic) subsection 4(2); *Mental Health Act 2014* (Vic) section 70); *Guardianship and Administration Act 2000* (Qld) sch 1, pt 1.
- ³⁷ The terminology for these planning documents differs between jurisdictions. However, they can generally be understood as comprising enduring power of attorney or guardian, and advanced care directives.
- ³⁸ Australian Law Reform Commission (2017) *Elder Abuse—A National Legal Response* (ALRC Report 131). At <https://www.alrc.gov.au/inquiries/elder-abuse> (viewed 11 January 2019) 164.

³⁹ Australian Law Reform Commission (2017) *Elder Abuse—A National Legal Response* (ALRC Report 131). At <https://www.alrc.gov.au/inquiries/elder-abuse> (viewed 11 January 2019) 163.

⁴⁰ These are known as ‘advanced care directives’. These are written directions which are recognised under the common law and in most state and territory legislation (all except New South Wales and Tasmania).

⁴¹ Depending on the state and territory, these bodies will be Guardianship Tribunal, a Supreme Court or a Civil and Administrative Tribunal.

⁴² Australian Law Reform Commission (2017) *Elder Abuse—A National Legal Response* (ALRC Report 131). At <https://www.alrc.gov.au/inquiries/elder-abuse>

⁴³ Budget 2018-19 *Fact Sheet Safeguarding Quality and Rights*. At <https://www.budget.gov.au/2018-19/content/factsheets/5-safeguarding-quality-rights.html> (viewed 11 January 2019).