Palliative Care Australia
Matters of life and death

Inquiry into the provisions of the *Aged Care Bill 2024*

Submission to the Senate Standing Committee on Community Affairs Legislation Committee

October 2024

(02) 6232 0700
pca@palliativecare.org.au
palliativecare.org.au

1. About Palliative Care Australia

Palliative Care Australia (PCA) is the national peak advocacy body for palliative care. PCA represents all those who work towards high-quality palliative care for all Australians who need it. Working closely with consumers, our Member Organisations and the palliative care workforce, PCA aims to improve access to and promote palliative care.

2. This submission

PCA welcomes the opportunity to make this submission to the Senate Standing Committee on Community Affairs Legislation Committee's *Inquiry into the provisions of the Aged Care Bill 2024.*

PCA acknowledges the contribution of our Member Organisations who provided advice informing this submission. PCA also consulted with members of the PCA National Expert Advisory Panel with expertise in the delivery of palliative care in aged care.

3. Context

PCA welcomes the introduction of the *Aged Care Bill 2024* to Parliament. The anticipated passage of the Bill into law in 2024 will enact the first recommendation of the Royal Commission into Aged Care Quality and Safety, and underpin the ongoing and positive reorientation for Australia's aged care system toward the wellbeing, safety, dignity and individual needs and preferences of older people. Passage of the Bill will allow important reforms to commence, including the introduction of the strengthened Aged Care Quality Standards. These will place unambiguous obligations on providers to provide timely access to palliative care and end-of-life care in all aged care settings where clinical care is provided.[1]

Vitally, the Bill recognises that all people using or seeking Commonwealth-funded aged care services have a right to equitable access to palliative care and end-of-life care when required. This is welcome. It is the culmination of many years of advocacy and effort to improve experiences of aged care for older people, and their families and carers, affected by life-limiting illnesses. If appropriately resourced, and accompanied by a framework for monitoring and reporting, the inclusion of this right in the new Act will be foundational to realising the Royal Commission's vision that palliative care become "core business" in aged care.[2]

---

[1] At Section 13 (14) (2), the Bill legislates the role of the Aged Care Quality Standards in setting standards for "how registered providers must deliver funded aged care services, including arrangements for planning and delivery of palliative care". The draft strengthen Aged Care Quality Standards include Standard 5, Clinical Care, which set out a range of requirements on providers relating to provision of clinical care, including palliative care end of life care (Standard 5.7), and Standard 3.1.6, related to Advance Care Planning.

[2] Royal Commission into Aged Care Quality and Safety, March 2021, *A summary of the final report*, p69 at: https://www.royalcommission.gov.au/system/files/2021-03/final-report-executive-summary.pdf

Importantly, the right to palliative care and end-of-life care is not yet a reality for all older people using aged care services, despite ongoing reforms to aged care. For example, while 92% of people who die in residential aged care each year would benefit from palliative care,[3] well below 1% of those living in residential aged care at June 2023 had entered in order to receive planned palliative care.[4] Surprisingly, this proportion is lower than prior to the Royal Commission, when on average 6% of aged care residents each year were assessed as requiring palliative care under the previous ACFI instrument.[5] This single data point illustrates a wider problem, namely that it is not possible - on the basis of currently available public data - to demonstrate that access to palliative care has improved since the Royal Commission. This remains the case despite evidence of many “green shoots” of change and improvement in this area, and the hard work of leading providers to change practice. It reflects the need for improved system-level monitoring, evaluation and reporting. PCA is hopeful the passage of the Act will support stronger efforts in this area.

Palliative care remains core business in aged care because:

- Thirty percent of deaths in Australia are in residential aged care,[6] rising to half for those 85 and over.[7]
- On average, people who enter residential aged care live for just over two years after admission.[8]
- The great majority of deaths in residential aged care are caused by life-limiting illness; and almost *all* residents have at least one life-limiting condition (an estimated 19% have palliative care neds arising from cancer, 20% from frailty or dementia; and 61% from organ failure).[9]

---

[3] Humphrey G, Inacio M, Lang C, Churches O, Sluggett J, Williams H, Morgan D, To T, Kellie A, Wesselingh S, Caughey G, May 2024, *Estimating potential palliative care needs for residential aged care: A population-based retrospective cohort study* in Australasian Journal on Ageing, 2024;00:1-10, DOI: 10.1111/ajag.13345

[4] At June 2023 the proportion of people living in residential aged care who had entered under AN-ACC Class 1, for the purpose of planned palliative care was just 0.1%, see: Australian Institute of Health and Welfare, GEN Aged Care Data, *People’s care needs in aged care at 30 June 2023,* 30 August 2024 at: https://www.gen-agedcaredata.gov.au/topics/people-s-care-needs-in-aged-care.

[5] Humphrey G, Inacio M, Lang C, Churches O, Sluggett J, Williams H, Morgan D, To T, Kellie A, Wesselingh S, Caughey G, May 2024, *Estimating potential palliative care needs for residential aged care: A population-based retrospective cohort study* in Australasian Journal on Ageing, 2024;00:1-10, DOI: 10.1111/ajag.13345

[6] *ABS, Classifying Place of Death in Australian Mortality Statistics, April 2021*

[7] AIWH June 2021, Interfaces between health and aged care systems, where do older people die? at: Interfaces between the aged care and health systems in Australia—where do older Australians die?

[8] AIWH GEN Aged Care Data, June 2023, People leaving aged care at: People leaving aged care - AIHW Gen (gen-agedcaredata.gov.au)

[9] Humphrey G, Inacio M, Lang C, Churches O, Sluggett J, Williams H, Morgan D, To T, Kellie A, Wesselingh S, Caughey G, May 2024, *Estimating potential palliative care needs for residential aged care: A population-based retrospective cohort study* in Australasian Journal on Ageing, 2024;00:1-10, DOI: 10.1111/ajag.13345

- Demand and preference for at-home aged care is growing rapidly,[10] with an attendant increase in the acuity and complexity of their support and care needs[11] and growing expectation for provision of palliative care at home.

The new Aged Care Act will play an essential role in supporting sustained focus on improving access to timely palliative care in aged care, to meet the needs of an ageing population.

PCA welcomes the introduction of the Bill,and anticipates swift passage of the Act to support ongoing reforms. However, there are opportunities to strengthen the Bill's provisions related to palliative care and end-of-life care. The Senate Standing Committee on Community Affairs Legislation Committee is an important opportunity for scrutiny and changes to improve the Bill.

4. Recommendations

PCA makes several recommendations to strengthen the Bill's provisions related to palliative and end-of-life care. These include suggestions for changes to the proposed text, and some key implementation considerations.

4.1. Recommended text changes

1. Change the wording in the **Statement of Principles** at (22)(3)(d) from:

   > "maintain or improve the individual's physical, mental, cognitive and communication capacities to the extent possible, **except where it is the individual's choice to access palliative and end-of-life care**" (emphasis added),

   which misrepresents palliative care as inconsistent with the maintenance and improvement of function, to:

   > maintain or improve the individual's physical, mental, cognitive and communication capacities to the extent possible, **with additional supports as required if the person requires palliative and end-of-life care**" (emphasis added).

2. In the **Objects,** include reference to the United Nations Declaration of the Rights of Indigenous Peoples, which sets out relevant commitments to the health and wellbeing of older Indigenous people.

---

[10] The numbers of people using aged care services at home grew by more than 350% in the decade to 2023, see: AIWH GEN Aged Care Data, 8 July 2024, *People using aged care* at: People using aged care - AIHW Gen (gen-agedcaredata.gov.au)

[11] Those entering aged care assessed at Home Care Package Level 1 dropped by 69% between 2021-22 and 2022-23; while those assessed as requiring Home Care Package Leve 2 increased by 91%, see: AIHW Gen Aged Care Data, 8 July 2024,*Admissions into aged care* at: Admissions into aged care - AIHW Gen (gen-agedcaredata.gov.au)

3. Foreground the right of older people to **health care and clinical care, including by** amending the Statement of Rights to include a right to assessment and re-assessment of both **clinical and non-clinical aged care needs,** or alternatively by addressing this in the definition of high-quality care.

4. Amend the Bill's proposed right to assessment and reassessment of aged care needs, to include a right to **timely** assessment and re-assessment, **and to access required aged care services**.

5. **Include definitions of palliative care, and end-of-life care, in the Act's Key Concepts** to provide a clear basis for community expectations and provider responsibilities in these areas.

6. Acknowledge the central role of **advance care planning** in a rights-based approach to aged care, for example by including it in the list of matters about which the Aged Care Quality Standards may prescribe requirements (Key Concepts, Division 2, Section 15 (b).

4.2. Implementation considerations

1. The Bill introduces **age-based eligibility criteria** that will further restrict access to aged care for people under 65 (and under 50 for First Nations people) in all but exceptional circumstances. Clarity is required urgently from Government about how younger people with significant care needs, including those with terminal diagnoses, will be supported outside of the aged care system. While PCA acknowledges the challenges inherent in agreeing portfolio and jurisdictional responsibilities for an improved service response, without a plan in place this highly vulnerable cohort people will continue to fall in the gaps between systems.

2. The Bill's supported decision-making framework is welcome, however clarity is still required about the practical interactions between the new framework and relevant state and territory legislation. If the issues in this area cannot be resolved ahead of the Act's passage, PCA suggests the implementation timeframe for supported decision-making provisions be phased to ensure all stakeholders are clear about their roles and the requirements of the new approach. PCA also recommends that an information campaign precede and accompany the Act's introduction, to assist people and providers to understand how the new approach differs from previously, and specifically the interactions with existing state and territory legislation.

3. Data and information collected to evaluate the success of the new Act should shed light on whether the right to equitable access to palliative care and end-of-life care in aged care is being realised over time.

4. As the Act’s aspirational definition of high-quality care is intended to change over time in response to evolving community expectations,[12] either the Act or its Rules should set out a process for regular review of and change to the definition.

These implementation recommendations are intended to reduce the risk of potential unanticipated consequences of welcome provisions in the Bill.

---

[12] Australian Government Department of Health and Aged Care 2003. *The new Aged Care Act: The foundations – Consultation paper*, p.35.

5. Detailed assessment of the Bill

This section describes key aspects of the Bill,and identifies areas for change.

5.1. Objects of the Act

The *Aged Care Bill 2024 gives* effect to Australia's obligations under the International Covenant on Economic, Social and Cultural Rights (ECOSOC) and the Convention on the Rights of Persons with Disabilities. These set out the human right to health[13], of which the right to palliative care is an aspect.[14] Appropriately, the Objects of Act include to "uphold…the rights of individuals under the statement of rights", which sets out the **right to equitable palliative care and end-of-life care as required**, for all people seeking or using funded aged care.

PCA recommends the Objects also give effect to Australia's commitments under the United Nations Declaration of the Rights of Indigenous Peoples, which sets out relevant commitments to the health and wellbeing of older Indigenous people including at Article 22 (1) and 24 (2).[15] This would provide a stronger legislative foundation for the commitments made elsewhere in the Act to the provision of "culturally safe, culturally appropriate, trauma aware and healing informed aged care".[16] The Act should be unambiguous that the requirement to offer care and services with these qualities also applies to all provision of palliative care in aged care settings. Currently this expectation is not necessarily explicit, as palliative and end-of-life care are dealt with in different clauses of the Act to the provision of care for First Nations people and people of diverse culturally and linguistic backgrounds.

5.2. Statement of Rights

PCA welcomes the inclusion of a "right to equitable access to palliative care and end-of-life care when required" for individuals seeking or using funded aged care services. This is an essential foundation for continued work to embed palliative care in aged care.

---

[13] United Nations International Covenant on Economic, Social and Cultural Rights, Article 12; United Nations Convention on the Rights of Persons with Disabilities, Article 25

[14] See United Nations General Assembly, 2019, *Universal Health Coverage, moving together to build a healthier world*, which recognises that all people must "have access without discrimination to…. Promotive, preventive, curative, rehabilitative and palliative essential health services" and World Health Assembly, 2014, *Strengthening of palliative care as a component of comprehensive care throughout the life course (WHA67.19),* WHA, Geneva which recognises that "access to palliative care… contributes to the realization of the right to the enjoyment of the highest attainable standard of health and well-being".

[14] World Health Assembly, 2014, *Strengthening of palliative care as a component of comprehensive care throughout the life course (WHA67.19),* WHA, Geneva.

[15] United Nations Declaration on the Rights of Indigenous People, at: UN Declaration on the Rights of Indigenous Peoples | Australian Human Rights Commission

[16] See for example Aged Care Bill 2024, Part 3, Division 1, 23 (20 (i)

The Statement of Rights includes a right to **equitable access to assessment and reassessment of aged care needs**. While welcome, this does not extend to a right to **timely** assessment or re-assessment of needs. This is an oversight.

Timely assessment (and reassessment) are essential in an aged care system that supports and promotes the "safety, health, wellbeing and quality of life of individuals" (articulated as the primary consideration of aged care in the Bill's Statement of Principles). Timely assessment and re-assessment are specifically important for those who need palliative care or end-of-life care, as their health can change rapidly and clinical deterioration may be missed if timely assessment is not assured.[17]

Neither the Statement or Rights or any other part of the Bill includes a reference to assessment or reassessment of **clinical or health care needs**. This is disappointing, given clinical needs assessment and reassessment are crucial to the clinical care of older people and to their safety, health and wellbeing when using aged care services. Inclusion of a right to clinical assessment and reassessment would be consistent with the reality that most people receiving aged care have complex health needs,[18] and that many people enter aged care as result of deterioration in their health. Indeed, the Act's emphasis on "sickness" as a criteria for eligibility for aged care services[19] would seem to establish that access to health care, including clinical assessment and reassessment, are key requirements in aged care.

The Statement of Rights establishes each older person's right to assessment and reassessment for aged care services, but no right to **access** the services they are assessed as requiring. This a missed opportunity to clearly articulate that older people have a right to access the aged care services they need – as a basis to address undersupply and inequitable distribution of aged care services relative to need. Excluding the right to access aged care services also creates an inconsistency between aged care and health care, as the Australian Charter of Health Care Rights sets out the right of all people to access necessary health care.[20] This inconsistency undermines the integrated approach to the care of older people required from the health and aged systems.

In the context of palliative care, clear protocols support the collaborative provision of care by aged care workers and providers in partnership with palliative care clinicians and services.[21] It would be difficult to explain to an older person with a life-limiting condition that they have a

---

[17] Palliative Care Australia, National Palliative Care Standards for All Health Professionals and Aged Care Services, Ed 1 2022 at: https://palliativecare.org.au/national-palliative-care-standards-for-all-health-professionals-and-aged-care-services/

[18] AIHW, November 2023, Palliative care services in Australia, *Palliative care in residential aged care* at: Palliative care services in Australia, Palliative care for people living in residential aged care - Australian Institute of Health and Welfare (aihw.gov.au)

[19] Aged Care Bill 2024, Division 3 - Approval of access to funded aged care services, 68, individuals with an impairment or sickness and 69, individuals with a sickness

[20] Australian Commission on Safety and Quality in Health Care, Charter of Health Care Rights at: https://www.safetyandquality.gov.au/publications-and-resources/resource-library/australian-charter-healthcare-rights-second-edition-a4-accessible

[21] See for example Home Care Packages Program Operational Manual v1.4, August 2023, Section *16.4.12. Palliative Care* at: https://www.health.gov.au/sites/default/files/2023-08/home-care-packages-program-operational-manual-a-guide-for-home-care-providers.pdf

right to access care they require for their condition from a General Practitioner or specialist palliative care clinician – but no assured right to access nursing care, personal care or assistive technology under the Aged Care Act. This is incongruent with the rights-based principles. PCA therefore recommends the inclusion of a right to **access** aged care services in the Statement of Rights.

The rights in the Act (including the right to palliative care and end-of-life care) are upheld through the regulatory, complaints handling, investigatory and recourse functions of the Aged Care Quality and Safety Commission, and Aged Care Complaints Commissioner. The Act is explicit that rights cannot be tested or upheld by tribunal or court processes. For success, this "closed system" approach will require high community and provider trust in the capacity of the Aged Care Quality and Safety Commission, and Aged Care Complaints Commissioner, to undertake their work promptly, transparently and independently. Older people, their supporters, and the aged care workforce will require clear, plain language and multi-lingual information about the new aged care rights, what they look like in practice, and the mechanisms through which these rights can be claimed and upheld. Overlap with, and differences from, the ACSQHC Charter of Health Care Rights will need to be made clear.

5.3. Statement of Principles

The Statement of Principles includes regrettable wording that mispresents palliative care as inconsistent with the maintenance and improvement of individuals' capacity and function. At Division 2, Section 25(3)(d) the Bill sets out that the purposes of aged care include to:

> "maintain or improve the individual's physical, mental, cognitive and communication capacities to the extent possible, **except where it is the individual's choice to access palliative and end-of-life care**" (emphasis added).

Concerningly, this statement appears to suggest that when palliative care or end-of-life care commence, care and services that maintain or improve a person's holistic wellbeing should cease. This is not the case. Inclusion of this text in the Act will reinforce community and provider misperceptions of the role of palliative care and end-of-life care in aged care; and risks inscribing in law a dismissive attitude to the holistic care needs of those with advanced palliative diagnoses.

In reality, maintenance and improvement of function do not stop when palliative care commences. Fundamentally, palliative care clinical practice aims to improve quality of life through management of pain and other symptoms whether psychological, psychosocial or spiritual. This *actively contributes* to maintenance and improvement of function, including when people are approaching end of life, where evidence demonstrates that people place a high priority on continuing to participate in daily activities for as long as possible, albeit in modified ways.[22] Recent WHO advice acknowledges that rehabilitative approaches within palliative care have positive patient outcomes including improved physical function, reduced pain and distress, improved psychological wellbeing and a sense of “confidence, security, hope and meaningful social support”.[23]

Palliative care is relevant from early in the progression of illness, including from time of diagnosis with a life-limiting condition. *Most* people receiving aged care have high complex health needs which commonly include a life-limiting illness amenable to palliative care. The proposed text runs counter to the intent of the rights-based Bill in suggesting that people should not receive rehabilitative, habilitative or assistive interventions if they are also receiving palliative care for a life-limiting diagnosis such as cancer or dementia.

The WHO specifically recognises that “access to palliative care… contributes to the realisation of the right to the enjoyment of the highest attainable standard of health and well-being.”[24] This is consistent with the definition of palliative care endorsed by all Australian jurisdictions through eh National Palliative Care Strategy. The proposed text in the Bill may also be inconsistent with the requirements of the *Clinical Standard for Palliative and End of Life Care* (Outcome 5.7 in the strengthened Aged Care Quality Standards)for aged care providers (as appropriate to registration category), to plan and deliver care that prioritises comfort and dignity, and to support the older person’s spiritual, cultural and psychosocial needs.[25] It is difficult to envisage care with these qualities that does not also maintain or enhance individual capacity to the extent possible.

In short, the wording in the Bill is an inappropriate basis for administration of the Act as it applies to palliative and end-of-life care.

PCA recommends amending the text so that it reads:

> “[The purposes of aged care include to…] maintain or improve the individual’s physical, mental, cognitive and communication capacities to the extent possible, **with additional supports as required** if it is the individual’s choice to access palliative and end-of-life care”.

PCA notes that palliative and end-of-life care should be provided consistent not only with the “choice” of older people but also their **need for care** as determined through **clinical assessment and re-assessment.** Situations do arise in which a person does not have the ability to make a choice to access palliative and end-of-life care, for example in the event of

---

[22] Morgan D, Taylor R, Mack I, George S, Farrow C and Lee V (2022). *Contemporary occupational priorities at the end of life mapped against Model of Human Occupation constructs: A scoping review.* Australian Journal of Occupational Therapy 2022;69:341-373

[23] World Health Organisation, 2023. *Policy brief on integrating rehabilitation into palliative care services*, Copenhagen: WHO Regional Office for Europe, p2-3.

[24] World Health Assembly 2014, *Strengthening of palliative care as a component of comprehensive care throughout the life course (WHA 67.19)* WHA, Geneva.

[25] Strengthened Aged Care Quality Standards, draft, December 2023 at Aged Care Quality Standards and Glossary - Final Draft - Nov 2023 (health.gov.au)

advanced cognitive decline. This should be reflected in the Act, for example through wording such as:

> "[The purposes of aged care include to…] maintain or improve the individual's physical, mental, cognitive and communication capacities to the extent possible, **with additional supports as required <u>if the person requires palliative and end-of-life care".</u>**

PCA supports the Act's presumption of decision-making ability, and notes the essential value of advance care planning in this context. The Bill could better reflect and recognise the role of Advance Care Planning in a rights-based approach to aged care. For example this could be included in the list of matters about which the Aged Care Quality Standards may prescribe requirements at Division 2, Section 15 (b), together with palliative care which is already recognised in the Section.

5.4. Definitions in the Bill

Definition of high-quality care

The Act's definition of high-quality care is intended to encourage providers to "aim higher" than the minimum requirements set out in the strengthened Aged Care Quality Standards, however many aspects of the proposed definition could reasonably be considered minimum or standard expectations of aged care providers. For example, the provision of care with kindness, and timely and responsive delivery of services, which are included in the definition, might well be considered minimum expectations of care. Given that such aspects of care are currently included in the definition of high-quality care, it would be equally appropriate to include a reference to access to high-quality health care, and clinical care.

As it is anticipated that the definition of high-quality care will change over time as practice and community expectations evolve, it would be appropriate for the Act, its Rules, or other subsidiary regulatory documents to set out a process for regular review and change to the definition.

It is positive that the Bill's definition of high-quality care includes reference to "training of the aged care workers to facilitate the delivery of the service by well-skilled and empowered aged care workers". This statement would be strengthened by inclusion of reference to qualifications, for example: "well-skilled, appropriately qualified and empowered workers". PCA notes that provision of training in palliative care and end-of-life care remain imperative across the aged are workforce, including for those in clinical nursing roles, allied health professions and for personal care workers. Access to palliative care training is a specific priority for in-home care workforce, particularly given the recent confirmation that the Support at Home program will include a short-term End-of-Life Care Pathway.

Missing definitions: Palliative and end of life care

Definitions of palliative care, and end-of-life care, should be included in the Act's *Key Concepts*. This will assist in clarifying community expectations and provider requirements related to the Act's establishment of a right to equitable palliative and end-of-life care when required.

The definition of palliative care should be consistent with that in the *National Palliative Care Strategy 2018*, which makes clear that palliative care is a **multidisciplinary team-based approach** that:

> "…improves the quality of life of patients and their families facing the problems associated with life-limiting illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual".[26]

The definition should reflect that palliative care is relevant from early in the progression of life-limiting illness, including from time of diagnosis.

The definition of end-of-life care should reflect the understanding in the *National Consensus Statement on End-of-Life Care,* namely that end-of-life care is relevant to the final year of life (when a person is considered "at risk of dying"), the "medium term" in which a person is likely to die soon; and the "short term" or final weeks, days or hours of life (noting that such timeframes are inherently uncertain).[27] Providing a definition of "end-of-life care" may also assist in clarifying the role of various parties when a recipient of aged care makes a request for voluntary assisted dying under state and territory legislation.

6. Implementation challenges

This section identifies implementation challenges that arise from positive inclusions in the Bill.

6.1. Supported decision-making framework

PCA welcomes the introduction in the Bill of a supported decision-making framework that proceeds from the presumption that older people have decision-making capacity. It is positive that the Bill acknowledges this framework must operate effectively with existing state and territory legislation for guardianship, enduring power of attorney, medical treatment decisions and advance care planning and directives. Appropriately, the Bill sets out that people appointed as guardians (and similar roles) under state/territory law:

---

[26] World Health Assembly 2014, *Strengthening of palliative care as a component of comprehensive care throughout the life course (WHA 67.19)* WHA, Geneva. This World Health Organisation definition is included in the *National Palliative Care Strategy 2018*, which is endorsed by all Australian jurisdictions.

[27] *National Consensus Statement: Essential elements for safe and high-quality end-of-life care*. Australian Commission on Safety and Quality in Health Care, 2023.

- Must receive the same information as supporters nominated under the Aged Care Act.
- Do not need to be supporters nominated under the Aged Care Act to be involved in decisions where authorised under state and territory law.

Nonetheless significant uncertainty remains about how the supported decision-making provisions of the Act will interact in practice with existing state and territory legislation and administrative arrangements, particularly in situations where an older persons' preferences are unclear or contested. For example:

- Which legislation takes precedence, and how will disagreements be resolved, if a supporter appointed under the Aged Care Act disagrees with a person (or people) appointed under state/territory legislation? This might arise when decisions are related to commencement or cessation of medications, medical treatment decisions, implementation of Advance Care Plans or Directives, and commencement of palliative care or end-of-life care.
- How will supporters balance potentially conflicting imperatives, where they are nominated as supporters under the Aged Care Act (where a supported decision-making framework applies) but are also authorised under state/territory law to take a substitute decision-making approach that may, depending on jurisdiction, prioritise the "best interests" of the older person rather than the older person's expressed preferences?[28]

Currently, jurisdictions' frameworks for substitute and supported decision-making vary. Terms used for documents and appointees, administrative requirements (for example for witnessing forms), the legal basis for enactment of Advance Care Directives, and the guidance for substitute decision-makers are not nationally consistent. This complexity is already a barrier to uptake of advance care planning and enactment of Advance Care Directives.[29] It is possible that the new framework will add to this complexity, rather than reduce it. Ideally, a process of legislative harmonisation would take place to bring consistency to the various approaches currently in place nationally.

Supported decision-making is more than an administrative framework for decision-making and information sharing. It is a set of practices including open communication about preferences and priorities, spending time to determine wishes and preferences,

---

[28] Only three jurisdictions (Victoria, Queensland and the ACT) have formally enacted a supported decision-making approach in legislation related to guardianship and medical treatment making. In these jurisdictions, substituted decision-making applies, meaning appointed decision-makers have a clear responsibility to act in accordance with the person's wishes and preferences. However, guidance to assist substitute decision-makers to make decisions varies nationally, with some jurisdictions continuing to place greater priority on substitute decision-makers' responsibility to prioritise the "best interests" of the older person (while also considering the person's wishes and preferences).

[29] Australian Government Department of Health, National Framework for Advance Care Planning Documents, May 2021,

informal relationships of support, and statutory appointments and relationships.[30] The introduction of the framework is likely to be challenging for many older people, supporters and families, and providers, to navigate - at least initially. A **comprehensive, plain language and multi-lingual information campaign** will be required to assist people to understand how the new framework will work, and the responsibilities of aged care providers, supporters, representatives, carers and family members. This should include **clear advice about how the new framework will interact with existing state and territory legislation and arrangements** including for guardianship, enduring power of attorney and substitute decision-making. Interactions with state and territory legislation and practice related to VAD will also require consideration.[31]

If these issues cannot be addressed in a timely way, PCA recommends **the implementation of the supported decision-making approach be phased, following the Act's introduction,** to ensure all stakeholders are clear about their roles in the new approach.

6.2. Eligibility and assessment

New age thresholds – unintended consequences

The Bill introduces age-based eligibility criteria that will limit access to aged care to people aged 65 or over with care needs, and those aged 50 to 64 who have care needs and who are either Aboriginal or Torres Strait Islander, or are homeless or at risk. People under these age thresholds will need to have been advised of alternatives to aged care, and still express a wish to enter aged care, before they are eligible for funded aged care services.

Consistent with the Royal Commission into Aged Care Quality and Safety's vision of "no younger people in residential aged care", this legislative change makes clear that aged care is not an appropriate location for younger people.

The Act's introduction of aged-based eligibility underscores the need for coordinated support for younger people with high care needs, outside of aged care. This includes for younger people with high functional support needs resulting from a life-limiting diagnosis who are ineligible for NDIS support. **Viable alternatives to aged care must be in place with urgency**, otherwise an age cutoff will have negative unintended consequences. This is consistent with the Bill's proposed Statement of Principles, which makes clear that:

> "The Commonwealth aged care system focusses on the needs of older people, **and should not be used inappropriately to address service gaps in other care and**

---

[30] Carney in Australian Law Reform Commission, *Supported and substitute decision-making, 2014,* 2.69 at 2. Conceptual Landscape—the Context for Reform | ALRC

[31] QUT Australian Centre for Health Law Research and Advance Care Planning Australia, *Navigating the topic of Voluntary Assisted Dying in Advance Care Planning Conversations, Guiding Principles for Health Professionals,* 2024 at: S1868_ACPA_GuidingPrinciples_QUT_FinalWEB.pdf (advancecareplanning.org.au)

> **support sectors** preventing individuals from accessing the best available services to meet the needs, goals and preferences of those individuals."

PCA calls on government to explain how it plans to meet the needs of this group outside of the aged care system in the immediate term. PCA recognises the significant challenges inherent in establishing an improved service response for this group, which requires cross-jurisdictional and cross-portfolio agreement about responsibilities. However, without a plan in place, there will continue to be negative outcomes for a group that has historically fallen through the gaps between service systems. Although National Cabinet has committed to improving mainstream responses to the care needs of people with disabilities, and creating a system of "foundational disability supports", consistent with the recommendations of the 2023 NDIS Review,[1] this process is potentially long-term. An urgent **improved response is required. A guarantee of appropriate support should be in place before the new Aged Care Act comes into effect.**

PCA notes that in addition to the limited exclusion criteria listed in the Bill, there are other circumstances in which exceptions to the proposed age-based eligibility criteria may also be appropriate. This includes for people who are prematurely aged for reasons other than homelessness, and those with health conditions such as younger onset dementia whose care needs may be very similar to those of older people but who are below the age cut-off. Therefore, it would be appropriate to clarify (for example in the Rules) a transparent and carefully defined process to consider and report on more flexible exemptions to the proposed age-based criteria in exceptional circumstances. The numbers and reasons for entry to aged care by people under 65 should continue to be carefully monitored and publicly reported at regular intervals including through the AIWH GEN aged care data collection.[1] This should include separate reporting on numbers of people under 65 entering both permanent residential aged care, and short-term residential aged care (transitional and respite care, in particular consecutive or frequent respite admissions).

Routine assessment of palliative care needs

The Bill sets out the broad characteristics of a single assessment process for aged care. PCA supports the intent of enabling easier entry to the aged care system, and smoother transitions between types of care and services (including between home-based and residential aged care). It is not clear how this process will incorporate the assessment of palliative care needs. This is important, because many people enter aged care with non-complex palliative care requirements that are not necessarily well documented , and the majority of people receiving aged care will have at least some need for palliative care during the time they use aged care services. If these needs are not routinely assessed, including on entry to residential aged care, it is less likely that they will be met, or transparently reported as an indicator of system performance.

6.3 Data and evaluation

Review of the Act’s implementation, whether through the Bill’s proposed 5-year implementation review or regular review undertaken by the Office of the Inspector General of Aged Care, should explicitly consider the extent to which the right to equitable access to palliative care has been achieved. Some data exists that could assist in making this determination, including information held by the Palliative Aged Care Outcomes Program (PACOP) and the End of Life Directions in Aged Care (ELDAC) Program, collected from aged care providers who voluntarily participate in those Commonwealth-funded programs. Other information will need to be routinely collected, including about the proportion of the aged care workforce that has completed palliative care training and education, the provision of palliative care needs assessments and re-assessments by aged care providers, and provision of palliative care across all AN-ACC Classes (not just within AN-ACC Class 1, which captures only those who enter residential aged care for the purpose of receiving palliative care).

7. Concluding remarks

The recommendations in this submission are intended to highlight opportunities to strengthen the provisions related to palliative care and end-of-life care in the Bill. PCA welcomes the opportunity to contribute to the Inquiry process and ensure consideration and scrutiny of the Aged Care Bill 2024. This will ensure the best possible legislative framework underpins continued positive reforms to aged care.