



**Palliative Care** Australia  
*Matters of life and death*

# New Aged Care Act Exposure Draft

PCA Submission, March 2024

## 1. About PCA

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.

PCA acknowledges the contribution of state and territory Member Organisations who provided advice on this submission. PCA also consulted with individual members of the PCA National Expert Advisory Panel with expertise in palliative care in aged care, and other expert stakeholders.

## 2. Overview

PCA welcomes the opportunity to provide advice on the new *Aged Care Act – Exposure Draft*. PCA's view is that the new rights-based Act will provide an appropriate legislative basis for the significant reforms underway in aged care, including vital work to ensure equitable access to palliative care in aged care. PCA specifically welcomes the Act's inclusion of a right to **equitable access to palliative and end-of-life care when required** for all people seeking or using Commonwealth-funded aged care.

In this submission, PCA comments on the Exposure Draft's Key Concepts, Objects, Statement of Rights, Statement of Principles, definition of high-quality care, eligibility criteria and approach to supported decision-making.

Our primary concerns relate to:

1. The **need for definitions, and the use of inappropriate language**, to describe palliative and end-of-life care.
2. The practical implications of the **proposed aged-based eligibility criteria**, for people under 65 with life-limiting illnesses who enter aged care because there are no appropriate non-clinical support services for them outside the aged care system.
3. The potentially unclear and complex interactions between the new approach to **supported decision-making**, and existing state and territory legislation for guardianship, medical treatment decisions and Advance Care Directives.

PCA recommendations include 1) some changes to the **text** of the Exposure Draft, 2) **inclusions** in the Act or its Rules and/or subsidiary guidelines, and 3) opportunities to reduce risks associated with **implementation of key provisions**.

PCA's recommended changes to the Act's **text**, and additional issues to address in the (yet to be published) Rules or other subsidiary regulatory guidelines are:

1. **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. Specific advice about definitions is provided at Section 2.
2. Change the wording in the Statement of Principles at (22)(3)(d) to **correct the Exposure Draft's current misrepresentation of palliative care** as inconsistent with the maintenance and improvement of function. Proposed changes are at Section 5.
3. 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.
4. In the Statement of Rights, at 20(2)(a):
  - a. Include a right to **timely access to required aged care services** in addition to the current right to **assessment** and **re-assessment** of aged care needs; and
  - b. Distinguish between the right to assessment and re-assessment of **clinical and non-clinical aged care needs** (or alternatively address this in the definition of high-quality care, see 5. below)
5. In the definition of high-quality care, include reference to **the timely provision of advance care planning, palliative care and clinical needs assessment and re-assessment** (as appropriate to provider registration category).
6. Include a requirement for **palliative care needs assessment on entry to residential aged care and for those with complex health needs, and re-assessment as required**, either in the Act at *Part 2 – Eligibility for Entry*, or in the Rules or subsidiary regulatory guidelines for eligibility assessment and prioritisation.
7. Provide guidance, ideally in the Rules, about the **necessary requirements for palliative care training and qualifications for the aged care workforce**, to enable implementation and monitoring of the Royal Commission into Aged Care Quality and Safety's Recommendation 80 (Dementia and Palliative Care Training).

PCA also makes recommendations about **the implementation of aspects of the Act**, including opportunities to reduce the risk of **potential unanticipated consequences of welcome provisions** in the draft Act. The most important of these are outlined below.

1. The Act's proposed introduction of **age-based eligibility criteria** will compound the significant challenges facing people under 65 who have care needs arising from a life-limiting illness but whose needs are not met by any other sector. This includes people under 65 with functional support requirements caused by a life-limiting illness, but who are deemed ineligible for NDIS assistance, along with a cohort of

people under 65 who for a range of reasons have entered residential aged care for lack of any other alternative. 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. We acknowledge the significant challenges in establishing an improved service response for this group, underpinned by agreed and clearly articulated portfolio and jurisdictional 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.

2. There is significant uncertainty in our sector about the practical implications of the new approach to **supported decision-making**. Clarity is needed about the extent of representatives' responsibility (if any) for substitute decision-making about health and medical matters in aged care settings; and how the new framework will interact in practice with relevant state and territory legislation.
3. PCA recommends that if these issues cannot be resolved ahead of the Act's anticipated implementation from 1 July, the approach to supported decision-making should be developed and implemented separately, potentially through subordinate legislation. Alternatively, the implementation timeframe for the Act's supported decision-making provisions should be delayed to ensure all stakeholders are clear about their roles in the new approach.

PCA also recommends that a comprehensive information campaign precede and accompany the Act's introduction, to assist people and providers to understand their roles in the new approach to supported decision-making.

4. 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 realised over time.
5. As the Act's definition of high-quality care is intended to change over time in response to evolving community expectations, it will be necessary for the Act or its Rules to set out a process for regular review of and change to the definition.
6. A great deal of detail related to the implementation of the Act (including matters relating to palliative and end-of-life care) will be provided in the Act's Rules and subsidiary guidelines, which are yet to be made public. All interested stakeholders must have time to consider and provide advice on these before they are finalised.

The new Aged Care Act underpins generational reform in aged care. Yet many significant elements of the new Act are yet to be decided. Notably the Act's Rules, and its chapter on fees, payments and subsidies are not yet public. Establishment of the new Support at Home program, due to commence from July 2025, will require an amendment to the Act.

Significant detail about how the Act will be implemented, including matters relating to palliative and end-of-life care, will be contained in the Rules, and subsidiary regulatory

guidelines including those for eligibility, assessment and prioritisation. **It will be essential for all interested stakeholders to have sufficient time to consider and provide advice on these documents, well in advance of their finalisation.** PCA looks forward to providing advice to ensure these documents support the integration of palliative care in aged care.

## 2. Definitions

The new Aged Care Act must include clear definitions of palliative and end-of-life care. 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** for all people using or seeking Commonwealth-funded aged care.

Definitions of palliative care, and end-of-life care, should be included in the Act's *Key Concepts*. The wording should be consistent with authoritative Australian definitions, particularly the definition of palliative care 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”.<sup>1</sup>

PCA acknowledges that challenges exist for full adoption of this definition across the aged care sector - including variable knowledge of palliative care, and a tendency by some to conflate palliative care with end-of-life care. In fact, many people with life-limiting conditions can benefit from palliative care from the time of diagnosis and alongside curative treatments. This is reflected in all authoritative definitions.<sup>2</sup>

The terms “end of life” and “end-of-life care” are variously defined and can refer to different time frames. Clinical, provider and community understandings of what these terms mean may differ, making clear definitions essential. The ACSQHC *National Consensus Statement on End-of-Life Care* provides a useful frame of reference, identifying the clinical care that is appropriate during the anticipated 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).<sup>3</sup> The expected characteristics of end-of-life clinical care in aged care settings are set out in the (draft) strengthened Aged Care Quality Standards at Outcome 5.7. These cover advance care planning, comprehensive

<sup>1</sup> 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.

<sup>2</sup> See Note 1.

<sup>3</sup> *National Consensus Statement: Essential elements for safe and high-quality end-of-life care*. Australian Commission on Safety and Quality in Health Care, 2023.

care, anticipating end-of-life care requirements, and clinical care in the final days of life.<sup>4</sup> Providing a definition of “end-of-life care” may also assist in clarifying the role of various parties where a recipient of aged care makes a request for voluntary assisted dying under state and territory legislation.

Including well-supported definitions in the Act’s *Key Concepts* will provide appropriate clarity to drive continued practice and policy improvement consistent with the recommendations of the Royal Commission into Aged Care Quality and Safety. These definitions should at the same time provide sufficient flexibility for aged care providers to respond to the individual needs of older people (consistent with the exposure draft’s Statement of Rights), in line with the requirements of the strengthened Aged Care Quality Standards.

### 3. Objects

PCA welcomes the proposed rights-based Objects of the Act, noting these give effect to Australia’s obligations under the International Covenant on Economic, Social and Cultural Rights and the Convention on the Rights of Persons with Disabilities. These set out the human **right to health**<sup>5</sup>, of which the **right to palliative care** is a recognised component.<sup>6</sup> PCA recommends the Act also include reference 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).<sup>7</sup>

PCA commends the proposed Objects making clear that the Act’s aims include to “uphold the rights of individuals under the Statement of Rights”, which include the right to **equitable access to palliative and end-of-life care when required** for all people using or seeking Commonwealth-funded aged care.

PCA is pleased that the draft Objects set out that the Act aims to support an “aged care system that is designed to... facilitate access to integrated services in other sectors where required”. While this can be interpreted as supporting closer integration between aged care, health care (including palliative care) and disability services, **it would be useful for the Act**

<sup>4</sup> Australian Government Department of Health and Aged Care, *Strengthened Aged Care Quality Standards*, Final Draft November 2023

<sup>5</sup> United Nations [International Covenant on Economic, Social and Cultural Rights](#), Article 12; United Nations Convention on the [Rights of Persons with Disabilities](#), Article 25

<sup>6</sup> 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”.

<sup>6</sup> World Health Assembly, 2014, *Strengthening of palliative care as a component of comprehensive care throughout the life course (WHA67.19)*, WHA, Geneva.

<sup>7</sup> United Nations Declaration on the Rights of Indigenous People, at: [UN Declaration on the Rights of Indigenous Peoples | Australian Human Rights Commission](#)

**to state – for clarity – which “other sectors” are meant here.** Specific issues related to the interface between disability and aged care systems, as these affect people with life-limiting conditions and functional support needs, are addressed in more detail at Section 8, *Eligibility*.

#### 4. Statement of Rights

PCA welcomes the inclusion of a Statement of Rights in the Exposure Draft, consistent with the first recommendation of the Royal Commission into Aged Care Quality and Safety. Specifically, PCA welcomes the inclusion of a right to **“equitable access to palliative and end-of-life care when required”** for people using or seeking Commonwealth-funded aged care. This provides a foundation for ongoing efforts to more closely embed palliative care within aged care. It articulates the Royal Commission’s expectation that palliative care becomes “core business” in aged care.<sup>8</sup>

PCA notes that the rights set out in the Act are intended to be upheld only through the mechanisms proposed in the Act (and not through other legal processes such as tribunals or courts). Older people seeking to uphold their rights might reasonably be surprised by this limitation. The Act allows individuals to make a complaint to the Aged Care Complaints Commissioner, and it sets out penalties and consequences, including under the new duty of care, for providers and responsible persons who fail to provide care consistent with other provisions of the Act. This includes the requirements set out in the draft strengthened Aged Care Quality Standards, which set out standards for palliative care provision (at 5.7.3), and advance care planning (at 3.1.6) (as appropriate to provider registration category).

Older people, their carers, supporters and representatives, and the aged care workforce will require clear, plain language and multi-lingual information about these new aged care rights, what they may look like in practice in aged care, 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 also need to be made clear.

While the Statement of Rights includes a right to equitable access to assessment and re-assessment of **aged care needs** at (20)(2)(a), it does not include a right to **timely access to required aged care services**. This is a shortcoming. General community expectations of a rights-based Aged Care Act might reasonably include that the Act sets out a right to access necessary services. The Act’s development is an opportunity to clearly articulate the right of older people to receive the aged care services they require, as a basis to address inequitable geographic distribution and undersupply of these services relative to need.

PCA notes that neither the Statement of Rights, Statement of Principles nor the definition of high-quality care now include any reference to assessment and re-assessment of **clinical care needs**. PCA would welcome more focus on this essential aspect of aged care provision,

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<sup>8</sup> Royal Commission into Aged Care Quality and Safety, March 2021, *A Summary of the Final Report*, page 69.

whether in the Statement of Rights at (20)(2)(a), or in the definition of high-quality care (see Section 6).

## 5. Statement of Principles

The draft Statement of Principles sets out how the Australian Government will seek to administer the Act. It articulates at 22(3)(d) 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).

This wording misrepresents palliative care and end-of-life care as inconsistent with the maintenance or improvement of individual capacity. In fact, palliative care focuses on sustaining quality of life through impeccable management of pain and other symptoms and the provision of person-centered care. Palliative care *does* contribute 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.<sup>9</sup> In recognition of palliative care’s inherent connection with enablement, quality of life and maintenance and improvement of capacity:

- The World Health Assembly 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”.<sup>10</sup>
- Recent WHO advice acknowledges the benefits of rehabilitative approaches within palliative care, with outcomes for patients including improved physical function, reduced pain and distress, improved psychological wellbeing and a sense of “confidence, security, hope and meaningful social support”.<sup>11</sup>

To state the problem clearly, the proposed text is factually incorrect in its presentation of palliative care and it is inconsistent with the definition of palliative care endorsed by all jurisdictions through the National Palliative Care Strategy. It also appears incompatible with the requirements of the draft *Clinical Standard for Palliative and End of Life care* (Outcome 5.7.3 in the strengthened Aged Care Quality Standards), which require 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.<sup>12</sup> It

<sup>9</sup> 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

<sup>10</sup> World Health Assembly 2014, *Strengthening of palliative care as a component of comprehensive care throughout the life course* (WHA 67.19) WHA, Geneva.

<sup>11</sup> World Health Organisation, 2023. *Policy brief on integrating rehabilitation into palliative care services*, Copenhagen: WHO Regional Office for Europe, p2-3.

<sup>12</sup> Strengthened Aged Care Quality Standards, draft, December 2023 at Aged Care Quality Standards and Glossary - Final Draft - Nov 2023 (health.gov.au)

is difficult to imagine a situation in which this would not include provision of care that aims to optimise a person's communicative, physical and cognitive capacity.

Given this, in PCA's view the proposed wording is not an appropriate basis for administration of the Act as it applies to palliative and end-of-life care. It seems likely the proposed text, if not amended, would also contribute to community and provider misperceptions of the role of palliative care and end-of-life care in aged care.

This problem can be resolved through minor changes to the draft text. **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".

This change would ensure consistency with recognised definitions of palliative care (see Section 1), and the requirements of the strengthened Aged Care Quality Standards.

An alternative, acceptable, wording change would be:

"[The purposes of aged care include to...] maintain or improve the individual's physical, mental, cognitive and communication capacities to the extent possible, **including when** it is the person's choice to receive palliative and end-of-life care."

PCA notes that the text of the Statement of Principles previously proposed in the Department of Health and Aged Care's August 2023 *A New Aged Care Act, The Foundations: Consultation Paper 1* included reference to maintain or improving "capabilities for as long as possible, **with a focus on enablement**". PCA considers that it would be appropriate to retain the term "enablement" as it describes a specific approach to care that aims to optimise individual function.<sup>13</sup> This approach should be actively promoted in the Act, and its subsidiary regulations.

In relation to the Act's proposed reference to individuals' "**choice** to receive palliative and end-of-life-care", PCA notes that palliative and end-of-life care should be provided, consistent both with the expressed preferences of older people and their **need for care**, as determined through **clinical assessment and re-assessment**. This reality should be reflected in the Act, for example through alternative 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** if the person requires palliative and end-of-life care".

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<sup>13</sup> NSW Agency for Clinical Innovation, *Enablement at: [Why is Enablement Important? | Consumer Enablement Guide](https://www.nsw.gov.au/why-is-enablement-important?)* ([nsw.gov.au](https://www.nsw.gov.au))

This would be consistent with the language in the Statement of Rights, which refers to “palliative and end-of-life care **when required**”.

Situations do arise in which a person would benefit from palliative or end-of-life care, despite not having expressed a choice to receive this care. This can occur when a person does not have the ability to make this choice for themselves, for example in the event of advanced cognitive decline. PCA supports the Act’s rights-based presumption of decision-making ability, and notes the essential value of advance care planning in this context. Advance care planning enables people to document their preferences and wishes for care in advance of a potential future situation in which they cannot make, or communicate, their choices. The new Aged Care Act could better recognise the central role of advance care planning in a rights-based approach to aged care, at minimum by including advance care planning in the list of matters about which the Aged Care Quality Standards may prescribe requirements at Section 13 (14) (2). PCA makes additional comments about Advance Care Planning at Section 7 below, in relation to the Act’s proposed supported decision-making framework.

PCA welcomes recognition of carers in the Statement of Principles, consistent with the Commonwealth Carer Recognition Act. PCA notes that this is a limited acknowledgement as it entails no requirement to provide practical support to carers, for example to access information or assistance that they may require in order to sustain their care of an older person.

## 6. Definition of high-quality care

PCA supports the inclusion of a definition of high-quality aged care in the Act, consistent with the first recommendation of the Royal Commission into Aged Care Quality and Safety. Given that the delivery of high-quality aged care is dependent on a skilled workforce, PCA is pleased the Exposure Draft’s proposed definition now includes reference to “worker retention and training to facilitate delivery of the service by well-skilled and empowered aged care workers” (19, c, xi). This statement would be strengthened by inclusion of reference to qualifications, for example: “well-skilled, **appropriately qualified** and empowered workers”. Noting that Section 91 of the Exposure Draft indicates the Act’s Rules will set out workforce training requirements, PCA recommends the Rules provide **clear guidance on minimum requirement for role-appropriate palliative care training and education for aged care workers**. This will support implementation and monitoring of the Royal Commission into Aged Care Quality and Safety’s Recommendation 80, which requires regular training in both dementia and palliative care for aged care workers.

PCA notes that the proposed definition of high-quality care no longer includes reference to “regular clinical and non-clinical review to ensure that services and support continue to reflect... individual needs”, as previously proposed in *Consultation Paper 1*. As a result, the proposed definition of high-quality care is now silent on the provision of clinical care in aged care, including (specifically) clinical review. PCA would welcome more focus on this aspect of

high-quality aged care, potentially expressed as: **“clinical care and regular clinical review that meets the needs of the individual”**. PCA also recommends that the timely provision of advance care planning and palliative care (consistent with clinical need and the person’s expressed wishes) be included in the Act’s definition of high-quality care. While not all categories of registered aged care providers are required to provide advance care planning or clinical care, these are important aspects of high-quality aged care and it is reasonable to expect that high-quality providers in relevant registration categories prioritise these matters.

Though 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, PCA notes that several aspects of the proposed definition could be considered minimum or standard expectations of aged care providers. For example, the provision of care with kindness and respect for individuals’ life experiences, and the timely and responsive delivery of services, which are included in the definition at (19)(c)(i), might well be considered standard expectations of care. Given that such aspects of care are currently included in the definition of high-quality care, clinical matters seem equally appropriate to address.

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.

## 7. Supported decision-making arrangements

PCA supports the Exposure Draft’s framework for supported decision-making, but notes there is significant uncertainty in our sector about the potential practical implications of the new approach. At this point in the Act’s development, **it is unclear whether or not the proposed approach will simplify existing arrangements** for older people, their appointed substitute decision-makers, and providers - with the result that older people’s decisions are consistently enacted. This is a key test of the new approach.

The proposed approach will differentiate between *supporters* who will help an older person to navigate aged care and can receive and share information about the older person, and *representatives* who can make decisions on behalf of an older person in limited circumstances with the older person’s authorisation. PCA supports this approach as consistent with the intent of the Royal Commission into Aged Care Quality and Safety, and the relevant Australian Law Reform Commission good practice recommendations.<sup>14</sup>

PCA appreciates that the Act does not intend to over-ride appointments made under relevant state and territory legislation. However, it is not clear how the Act will interact in practice with existing state and territory legislation and administrative arrangements,

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<sup>14</sup> Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws*, ALRC Report 124, 2014

particularly in situations where an older persons' preferences are unclear or contested. Specific issues that require resolution ahead of the Act's passage into law are outlined below.

- At present, it is unclear whether representatives' responsibility for decisions under the Aged Care Act will extend to health or medical treatment matters. For example, will representatives have responsibility for decisions about palliative and end-of-life care in aged care settings; or the commencement, non-commencement or cessation of routine or non-routine medical treatment?
- If representatives' responsibility for decision-making *does* extend to health and medical matters in aged care settings, what is the decision-making hierarchy and how will disagreements be resolved if a representative (or representatives) appointed under the Aged Care Act disagrees with a person (or people) appointed under state/territory legislation related to supported or substitute decision-making (ie guardianship, medical treatment decisions, and Advance Care Directives)?
- Could a representative over-ride provisions set out in a person's advance care planning documents, or their Advance Care Directive? This undesirable outcome seems unlikely given the Act's focus on enabling the preferences and choices of older people, and the emphasis on advance care planning in the strengthened Aged Care Quality Standards. However, it is an issue that requires clarification.

**Careful attention will be required to identify and resolve any unanticipated interactions between the new Act, and relevant state and territory legislation**, particularly where there may be inconsistency or difference of emphasis between different jurisdictions' approaches. Jurisdictions' frameworks for the appointment of substitute decision-makers vary. The terminology 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<sup>15</sup> are not nationally consistent. This complexity is a barrier to uptake of advance care planning and enactment of Advance Care Directives.<sup>16</sup> In this context, there is a risk that the approach set out in the exposure draft – if not well-explained and carefully implemented – will add to the existing complexity. Ideally, a process of national harmonisation in approaches to Advance Care Directives, substitute and

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<sup>15</sup> By way of detail, 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). If a substitute decision-maker is appointed under both the new Aged Care Act *and* state/territory legislation, and a tension arises between the different requirements on them when making decisions (e.g. between "best interests" and substituted decision-making) what advice will be offered to guide substitute decision-making, and which imperative would take primacy?

<sup>16</sup> Australian Government Department of Health, National Framework for Advance Care Planning Documents, May 2021,

supported decision-making, should take place ahead of the introduction of the new approach. This would provide necessary consistency across all sectors where supported and substitute decision-making occur, including health and disability as well as aged care.

If these issues cannot be resolved ahead of the Act's anticipated passage in July 2024, PCA recommends that either a) **the supported decision-making framework be developed and considered separately**, and potentially introduced as subsidiary legislation or b) **the implementation of supported decision-making approach be delayed following the Act's passage** to ensure all stakeholders are clear about their roles in relation to the new approach.

The new supported decision-making framework will be a significant change for older people, carers, family members, supporters or representatives, and for providers. **Supported decision-making is more than a framework to appoint nominees.** It is a set of practices including open communication about preferences and priorities, spending time to determine wishes and preferences, informal relationships of support, and statutory appointments and relationships.<sup>17</sup> The introduction of a supported decision-making framework in aged care will require a **comprehensive, plain language and multi-lingual information campaign** to assist people to understand what supported decision-making is, how the new framework will work, and the responsibilities of aged care providers, supporters, representatives, carers and family members. This information must include **clear advice about how the new framework will interact with existing state and territory arrangements** including for guardianship, enduring power of attorney and substitute decision-making.

PCA notes that representatives and supporters will require information about the limits of their role in relation to Voluntary Assisted Dying (VAD). Because VAD can only be accessed by eligible people who have decision-making capacity, a preference for VAD cannot be included in advance care planning documents and substitute decision-makers cannot request VAD on behalf of another person.<sup>18</sup> Noting that only a very small proportion of people are eligible for VAD due to legislative requirements, some older people may wish to discuss VAD in the context of advance care planning and their end-of-life care preferences and choices. Representatives and supporters, as well as clinicians providing care to older people and aged care providers, will require information and support to be ready for these conversations. Professionals need to understand their obligations in relation to the provision of information about VAD, and referral to VAD practitioners, consistent with the relevant legislative framework in their jurisdiction.<sup>19</sup>

<sup>17</sup> Carney in Australian Law Reform Commission, *Supported and substitute decision-making*, 2014, 2.69 at [2. Conceptual Landscape—the Context for Reform | ALRC](#)

<sup>18</sup> 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 \(advancecareplanning.org.au\)](#)

<sup>19</sup> 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 \(advancecareplanning.org.au\)](#)

The process of advance care planning is central to supported decision-making. PCA therefore reiterates the recommendation made at Section 5, namely that the Act make reference to advance care planning in the list of matters about which the Aged Care Quality Standards may prescribe requirements, at Section 13 (14) (2).

## **8. Eligibility and assessment for aged care services**

The Exposure Draft sets out proposed age-based eligibility criteria that will limit access to Commonwealth-funded aged care services 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 homeless or at risk. People aged 50-64 who meet these limited criteria for entry 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.

The most significant impacts of this proposed change will be felt by people under 65 who require residential aged care because there are no appropriate support options for them outside the aged care system. The proposed age-based criteria are consistent with the Royal Commission into Aged Care Quality and Safety's vision of "no younger people in residential aged care", however further restricting access to aged care for people under 65 with significant care needs is likely to compound, rather than resolve, the challenges for these people. Those affected include a growing number of vulnerable younger people who have functional support requirements resulting from a life-limiting condition but who are deemed ineligible for NDIS support. In such circumstances, people under 65 with significant care needs will continue to require residential care, whether in residential aged care (which has to date been a provider of last resort) or through another service system.

The Act's introduction of age-based eligibility underscores the urgency of an improved service response, outside of aged care, for people with significant care needs who are under 65. **Viable alternatives to aged care must be in place before the new Act is fully implemented**, otherwise an age cutoff will have negative unintended consequences. **An immediate improved service response should be underpinned by clear agreement between governments** about portfolio and jurisdictional responsibilities to provide care and support for people under 65 who have functional support needs arising from a life-limiting condition.

This proposition is consistent with the Act's proposed Statement of Principles, which makes clear at 22(11) 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 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.** We acknowledge the significant challenges in establishing an improved service response for this group, which would be underpinned by agreed and clearly articulated portfolio and jurisdictional 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.

National Cabinet’s December 2023 commitment to develop a system of foundational disability supports, consistent with the findings of the Independent NDIS Review, is relevant in this context.<sup>20</sup> This reform process holds the prospect of durable long-term improvement in the services and care available to people under 65 with functional support needs (noting that some people with advance life-limiting illness require significant day-to-day non-clinical care and support, which may be beyond the intended scope of “foundational supports”). This longer-term process does not remove the imperative to ensure an **urgent improved response ahead of the passage of the new Aged Care Act.**

In relation to the proposed exceptions to the age-based criteria (i.e. homeless or at risk of homelessness, Indigeneity), PCA notes that there are other exceptional 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. In the absence of realistic alternatives to aged care for people under 65 who have significant care needs, there may be benefit in clarifying (for example in the Rules) a carefully defined process that would allow consideration and transparent reporting of exemptions to the proposed age-based criteria in exceptional limited circumstances – as has been proposed by national organisations working with older people and carers.<sup>21</sup> The numbers and reasons for entry to aged care by people under 65 should be continue to be carefully monitored and publicly reported at regular intervals including through the AIWH GEN aged care data collection.<sup>22</sup> 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).

In relation to the proposed entry criteria of having “care needs”, PCA observes that many people over 65 enter aged care because they have disability support needs. This includes people with age-related disabilities, and people with life-long or pre-existing disabilities who enter aged care as their care needs increase as they age. In this context PCA notes with concern anecdotal reports of NDIS participants over 65 who are advised that their care

<sup>20</sup> Meeting of National Cabinet, December 2023 at: [Meeting of National Cabinet – the Federation working for Australia | Prime Minister of Australia \(pm.gov.au\)](https://www.pmc.gov.au/news/2023/12/14/meeting-of-national-cabinet-the-federation-working-for-australia); Disability Reform Ministerial Council, February 2024 at: [DISABILITY REFORM MINISTERIAL COUNCIL \(DRMC\) \(dss.gov.au\)](https://www.dss.gov.au/ministerial-council/drmc)

<sup>21</sup> Aged Care Act Exposure Draft - Key issues paper, national organisations working with older people, January 2024 at: [Aged Care Exposure Draft Key Issues Paper Jan 2024 \(open.org.au\)](https://www.open.org.au)

<sup>22</sup> Australian Institute of Health and Welfare, GEN Aged Care Data, Younger People in Residential Aged Care at: [Younger people in residential aged care - AIHW Gen \(gen-agedcaredata.gov.au\)](https://www.aihw.gov.au/gen-agedcaredata)

needs would be best met in and only in aged care settings. It is imperative that people with disabilities (and/or functional support needs) who are eligible for aged care are assisted by the sector / scheme most appropriate for their circumstances. This is consistent with the proposed Objects of the new Act, which set out that aged care should “facilitate access to integrated services in other sectors where required” and with its Statement of Principles which sets out that aged care should not be used to stop individuals “accessing the best available services” to meet their “needs goals, goals and preferences”. These are appropriate principles to guide resolution of the challenges that beset the aim of closer integration between health, aged care and disability sectors – consistent with Recommendations 4, 8, 69, 70 and 71 of the Royal Commission into Aged Care Quality and Safety, the National Health Reform Agreement Long-Term Reforms Roadmap,<sup>23</sup> and Recommendation 2.11 of the Independent NDIS Review which makes clear that “the Australian Government should implement legislative change to allow participants once they turn 65 to receive supports in both the NDIS and the aged care system concurrently and to clarify when aged care supports are reasonable and necessary”.

The Exposure Draft 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 from the Exposure Draft 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 documented elsewhere (for example in AN-ACC reporting), 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. PCA therefore recommends the Act, or its Rules and other subsidiary guidelines, require early assessment of palliative care needs on entry to residential aged care and for those with complex health needs receiving in-home care, as well as timely re-assessment.

## **9. Data and evaluation**

The Exposure Draft sets out a right to equitable access to palliative and end-of-life care for people seeking and using Commonwealth-funded aged care. But without a framework for data collection, data sharing and evaluation, it will not be possible to determine the extent to which this right is realised over time.

Review of the Act’s implementation, whether through the proposed 5-year implementation review or regular review undertaken by the Office of the Inspector General of Aged Care,

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<sup>23</sup> National Health Reform Agreement (NHRA) Long-term Health Reforms Roadmap, October 2021 at: [National Health Reform Agreement \(NHRA\) – Long-term health reforms roadmap | Australian Government Department of Health and 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 program. 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, 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). Future changes to the suite of National Quality Indicators currently collected may assist in this work; for example information about palliative care workforce training could be collected as an additional “workforce” indicator.

## **10. Concluding remarks**

The new Aged Care Act underpins positive generational reform in aged care. Yet many significant elements of the new Act are yet to be decided. Notably the Act’s Rules, and its chapter on fees, payments and subsidies are not yet public. Establishment of the new Support at Home program, due to commence from July 2025, will require an amendment to the Act.

A great deal of detail about how the Act will be implemented - including matters relating to palliative and end-of-life care - will be contained in the Rules, and subsidiary regulatory guidelines including those for eligibility, assessment and prioritisation. It will be essential for all interested stakeholders to have sufficient time to consider and provide advice on these documents, well in advance of their finalisation. PCA looks forward to providing advice to ensure these documents support the integration of palliative care in aged care.