

## Response to Palliative Care Australia on the ‘National Palliative Care Standards - Generalist Supplement Consultation Draft’

Carers Australia welcomes the opportunity to comment on the consultation draft of the ‘National Palliative Care Standards Generalist Supplement’, as the national peak body representing the diversity of the 2.65 million Australians who provide unpaid care and support to family members and friends with a disability, chronic condition, mental illness or disorder, drug or alcohol problem, terminal illness, or who are frail aged.

This includes carers:

- Who have their own care needs
- Who are in multiple care relationships
- Who have employment and/or education commitments
- Aged under 25 years (young carers)
- Aged over 65 years, including ‘grandparent carers’
- From culturally and linguistically diverse backgrounds
- Who identify as Aboriginal and Torres Strait Islander
- Who identify as lesbian, gay, bisexual, transgender, intersex (LGBTI+)
- Who are living in rural and remote Australia, and
- That are no longer in a caring role (former carers).

Carers Australia are pleased that the Draft Standards are complementary to the Consensus statement: Carer and Consumer Engagement in Palliative Care and End-of-Life Care.<sup>1</sup> More carer-inclusive practices will support a patient-centred approach, as well as linking the carer to services and supports that can assist them, such as the Carer Gateway, and through activities such as social prescribing. Carers Australia are strong advocates for carer inclusion in services delivered to those they care for – whether these be clinical services or other types of support services.

### Identifying carers

Providing care can be rewarding yet demanding and socially isolating, where carers have among the lowest levels of wellbeing of any group of Australians and are at a greater risk of negative physical and mental health effects<sup>2</sup>. Broadly, we are pleased to see carers differentiated from family members within the Draft Standards, ensuring that carers can also receive practical and emotional support. This aligns with the *Carer Recognition Act 2010*<sup>3</sup> (Commonwealth) which aims to increase recognition and awareness of carers and acknowledge the valuable contribution they make to society. Within the Act it specifies that a person is not a carer simply because they: are the spouse, de facto partner, parent, other relative or guardian of an individual who requires care; or live with an individual who requires care.

It is also important to note the cornerstone of the Act is the Statement for Australia’s Carers, which sets out ten principles that articulate how carers should be treated and considered, including that they should be supported to enjoy optimum health and social wellbeing and to participate in family, social and community life, should be acknowledged as individuals with their own needs within and beyond the

<sup>1</sup>Palliative Care Australia, Consumers Health Forum and Carers Australia ‘Consensus statement: Carer and Consumer Engagement in Palliative Care and End-of-Life Care’ (2018) [\[accessed online\]](#)

<sup>2</sup> Deloitte Access Economics (2020) ‘The value of informal care in 2020’ for Carers Australia [\[accessed online\]](#)

<sup>3</sup> Australian Government, *Carer Recognition Act 2010*, No.123,2010 [\[accessed online\]](#)

caring role; that the relationship between carers and the persons for whom they care should be recognised and respected, and carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.

Carers Australia applaud the Draft Standards for having a specific Standard Element related to nominating a carer (3.1). Carers aren't always instantly identifiable. Coming from all walks of life, cultural backgrounds and age groups, health professionals should be actively identifying if a patient has a carer, even if the carer does not identify themselves that way. Further, all patients within generalist palliative care need to be asked about their care responsibilities to also identify additional carer-specific supports the person with a life-limiting illness may need to receive or consider on their palliative care journey.

Considering the carer as a part of the care team and embedding specific supports to carer identification supports a number of the Standards. We acknowledge that Standard Elements 3.3 and 3.4 support carer inclusion as part of the care team. Health professionals need to see the value in information that carers hold across the end-of-life care journey, from supporting decision making and understanding information provided by health professionals, through treatment, system navigation, social supports, medication management and hospital avoidance. As a 'partner in care' carers must feel able to raise queries or concerns at any stage to assist the person they are caring for.

It is also essential to highlight that early referral and timely access to respite services, planned and emergency, are critical to many carers' own health and wellbeing and can, in many cases, mean the difference between a carer being able to provide care and support or having no alternative but to seek other accommodation options, cease employment or risk further strain on the carer and wider family.

We recommend:

- Including assessment of care responsibilities within the Intent of Standard 1 (Assessment of needs)
- Addition of the following to Standard 3 (Caring for carers)
  - 3.1. add 'At least one carer is identified or nominated...'
  - 3.5 add 'community support, respite care (planned and emergency), and broader carer-specific supports such referral to the Carer Gateway'

### Definitions and terminology

On the definition of '**Family and carers**' within the A.2 Definitions, we request separation of 'carers' from 'family' to align with the *Carer Recognition Act (2010)*, noting the Act provides that "carers are people who provide personal care, support and assistance to another individual in need of support due to disability, medical condition, including terminal or chronic illness, mental illness or is frail and aged".

On '**Generalist Palliative Care**' we provide that the current definition of "care by all individuals and organisations that deliver palliative care as a component of their service outside of a specialist palliative care team" is very broad and may cause confusion, noting the PCA Service Development Guidelines statement provided on p.6 of the Consultation draft referring to generalist palliative care "To treat people living with a life-limiting illness, healthcare professionals (who are not specialist palliative care providers) should have minimum core competencies to manage physical symptoms, to provide or refer to psychosocial support services, and to discuss the goals of treatment and the person's prognosis". The difference between 'care' by individuals, including staff within supported residential services for people with disability, or non-health staff of residential aged care, is very different from the 'treatment' of people by health professionals in these settings, yet this suggests both would be considered Generalist Palliative Care and the expectation to be able to meet these standards. In addition, using the term 'Generalist' can

suggest a reduced level of care or expertise, or is often taken to equate to care provided by GPs or within a general practice setting, noting the terms 'primary palliative care', 'palliative care' and 'non-specialist palliative care' have also added to confusion.

Regarding '**Community support**' where currently the Consultation Draft definition is "Community Support includes services that provide the support needed for a person with disability to live in a non-institutional setting." This definition is confusing when you consider how community support is referred to within the document, as community support encompasses and is associated with many vulnerable or specific populations broader than for people with disability, including social services. For example, Standard 7 (Service Culture) - 7.4 'Services understand the community they serve and use this information to both provide optimal palliative care services and influence wider health, aged care, and community support systems to seek to optimally meet the needs of that community'. This would benefit from inclusion of '... mental health, disability care and community support systems...' Further, we highlight that the Standards refers to 'community providers', 'providers in the community,' 'community-based services', 'community support services', 'community settings' and 'community services' in addition to general references to community.

While Carers Australia appreciates these are palliative care standards, we believe it would be beneficial to make a statement on **Voluntary Assisted Dying** (VAD) being outside of these Standards, given the changing landscape in Australia and noting VAD is considered within end-of-life care in some jurisdictions<sup>4</sup> through legislation and guidance, and can often be perceived as within palliative care by consumers. This is particularly important for generalist settings, where VAD may be first raised.

We also consider it would be beneficial to:

- Include reference to supported decision making and shared decision making in the context of substitute-decision making
- Add "Their self-designated family and chosen carer(s) should be treated with the same level of dignity and respect, as they can often be *treated as* less important than biological relatives through assumed rights." With regards to lesbian, gay, bisexual, transgender, queer or questioning and intersex people (p.10).
- Add 'Clinically Non-beneficial treatments' throughout
- Difference between an advance care plan and advance care directive (mentioned p.31)

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<sup>4</sup> State of Victoria, Department of Health and Human Services 'Voluntary assisted dying Information for people considering voluntary assisted dying' 2019 [[accessed online](#)]