

March 2020

Palliative Care Australia

Response to the Royal Commission into Aged Care Quality and Safety Counsel Assisting's Submission on Program Redesign

Introduction

Palliative Care Australia (PCA) is the national peak body for palliative care.

PCA represents 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, we aim to improve access to, and promote palliative care.

We believe quality palliative care occurs when strong networks exist between specialist palliative care providers, primary generalist, primary specialist and support care providers and the community.

PCA has previously engaged with the Royal Commission into Aged Care Quality and Safety (the Commission) via the following:

- [PCA Issues Overview](#) (May 2019);
- [PCA Board Chair Witness Statement](#) (May 2019);
- [Appearance at the Perth hearings by the PCA Board Chair](#) (June 2019);
- [PCA Submission to the Royal Commission into Aged Care Quality and Safety](#) (October 2019);
- [PCA Response to the Royal Commission into Aged Care Quality and Safety Consultation Paper - Aged Care Program Redesign: Services for the Future](#) (January 2020); and
- [PCA Response to the Royal Commission into Aged Care Quality and Safety Counsel Assisting's Submission on Workforce](#).

Counsel Assisting's Submission on Program Redesign

PCA welcomes the release of the Royal Commission into Aged Care Quality and Safety Counsel Assisting's Submission on Program Redesign (Counsel's Submission) and the opportunity to submit a response to the Counsel's Submission. In particular, PCA would like to provide comment on *Part 3: Life Planning* and *Part 13: Standardised data collection and analysis*.

Life Planning

PCA supports the recommendations under *Part 3: Life Planning* in the Counsel's Submission that:

- The Australian Government in cooperation with other levels of government should fund and support education and information strategies to improve public awareness of resources to assist people to plan for ageing and potential aged care needs.
- These strategies should support a continuum of planning for ageing, including consideration of the limits of health care preferences for care, finances, housing and social engagement.
- These strategies should support greater use of the Medicare Benefits Schedule (MBS) -supported annual health assessment and bring people's general practitioners to the centre of their planning for ageing and aged care.

In particular, PCA supports funding education and information to the public around the benefits of advance care planning. Advance care planning provides a mechanism to improve the quality of care including end-of-life care for all people. It enables the coordination of access to resources and services, to match anticipated care needs, and offers individuals the opportunity to take control of decisions which affect their care. Advance care planning should be considered as an ongoing conversation between the individual, their care team and as appropriate, their family, significant others and carers.

In addition to education and information around advance care planning, PCA also supports working with the community to normalise discussions of death, dying, grief and bereavement. This will make care planning discussions more common and more accepted which, in turn, will support the aged care workforce to better be able to facilitate advance care planning within aged care services. PCA have launched the 'Dying to Talk' campaign which aims to reach into all Australian communities to normalise early conversations about the end of life, rather than waiting until more time critical or medical focused discussions need to occur. The resources (including discussion starter booklets, discussion cards and facilitator guides) have been developed to help Australians work out what's right for them if they were very sick or at the end of their lives and can be found at: <https://dyingtotalk.org.au/about-dying-to-talk/>

PCA supports the greater use of the MBS supported annual health assessment to bring general practitioners to the centre of planning for ageing and aged care. Whilst advance care planning is not the exclusive domain of any particular health sector or setting, general practitioners are frequently the first point of access for people to the health system. They provide a vital role in assisting people to access additional health and aged care services. Supporting general practitioners to engage in advance care planning discussions will further enhance the literacy of Australians around life planning.

The MBS should also allow for longer consultations which are necessary for palliative care nurse practitioners and palliative care specialists for inpatient case conferencing and family meetings. Advance care planning and Goals of Care discussions are not one-off as the medical opinion as well as the person's preferences may change as the person's condition change as they move towards the end of their life. It is important that these discussions occur so the person's preferences and values are known and the person has the option of documenting their preferences to guide health professionals supporting their care should they be unable to communicate or lose capacity. This also requires access to MBS rebates for long-term and primary care management provided by Nurse Practitioners.

Aged care staff also have a fundamental role to play in preparing for and facilitating advance care planning discussions and in ensuring residents and consumers are provided with opportunities to consider and

express their preferences, values and beliefs. Aged care staff need to be supported with the appropriate skills and training needed to undertake these conversations. PCA supports investment in workforce development and training (undergraduate and post graduate) to build the capacity of all professionals to engage in end-of-life and advance care planning discussions

Standardised Data Collection and Analysis

PCA supports the recommendation under *Part 13: Standardised data collection and analysis* in the Counsel's Submission that the Australian Government should 'implement a standardised data collection program designed on the 'collect once, use many times' principle'. PCA recommends that this data collection program should form part of the implementation of a National Minimum Data Set (NMDS) for palliative care.

Planning for the future, identifying unmet need and creating innovative services to address current and emerging palliative care needs, including those in aged care, requires reliable and comprehensive data. There is currently inadequate data about palliative care to understand current need, to plan for future demand and to understand workforce requirements particularly as it relates to those also accessing aged care services. Australia does not have a palliative care NMDS of data elements agreed for mandatory collection and reporting at a national level.

Eighty percent of people aged over 65 years who die in Australia have used at least one aged care program, however there is limited palliative care data available in aged care.¹ Furthermore, 35 per cent of all Australians who die do so in residential aged care, equating to approximately 60,000 people each year.² Staff working in aged care therefore need to be suitably trained and equipped to work with residents and consumers who have palliative care needs, and their families. The data available in residential aged care is restricted to funding claims for palliative care made under the Aged Care Funding Instrument (ACFI). The ACFI definition of palliative care focuses only on 'end of life' care therefore this data does not adequately reflect either the number of people who needed palliative care nor how many received palliative care. There is no Home Care Packages (HCP) or Commonwealth Home Support Program (CHSP) data available about the input of specialist palliative care, nor if these community aged care programs are providing funding for general palliative care such as provision of nursing services or allied health services relating to palliative care needs.

Without targeted data collection, and better data linkage across data sets there is an inability to accurately analyse how older Australians access services, how many Australians receive palliative care and in what setting, what their preferences are for place of care and place of death and where they die. This data is essential if we want to understand and plan for palliative care needs for older Australians into the future.³

¹ Australian Institute of Health and Welfare 2018. *Cause of death patterns and people's use of aged care: A Pathway in Aged Care analysis of 2012–14 death statistics*. Cat. no. AGE 83. Canberra: AIHW

² 7. Productivity Commission 2017, *Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services*, Report No. 85, Canberra. Pg. 109

³ Statement of Dr Jane Fischer, prepared for Royal Commission into Aged Care Quality and Safety, 29 May 2019.