A NEW PROGRAM FOR IN-HOME AGED CARE

Submission Palliative Care Australia

NOVEMBER 2022

PalliativeCare AUSTRALIA

1. About Palliative Care Australia

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.

PCA Purpose

PCA leads a united voice to strengthen our collective impact towards excellence in palliative care.

Vision

We see a world where quality palliative care is available for all, when and where it is needed.

2. Background

PCA welcomes the opportunity to make a submission on the *A New Program for In-Home Aged Care Discussion Paper.*

Those with palliative care needs have specific additional care needs. It is critical that these needs are considered and supported in the new In-Home Aged Care Program.

Most importantly, PCA supports a human rights approach that enables people's preferences for palliative care when and where it is needed.

PCA would be pleased to provide additional input to the ongoing development of the In-Home Aged Care Program and, in particular, on how palliative care needs can be appropriately integrated into the new In-Home Aged Care Program.

Definition of Palliative Care

PCA uses the definition of palliative care outlined in the *National Palliative Care Strategy 2018* (signed by the Australian Government and all State and Territory governments). It is based on a definition first outlined by the World Health Organization.

Palliative care is an 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.

The *National Palliative Care Strategy* provides that palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient's illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness

- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.[1]

3. Summary of key points

PCA makes the following key points with respect to the new In-Home Aged Care Program:

- PCA supports the development of a new In-Home Aged Care Program that assists with reducing palliative care-related hospitalisations.
- PCA recommends that the In-Home Aged Care Program specifically identifies and incorporates palliative care and includes clear mechanisms to support palliative care needs.
- KPMG estimates that for every $1.00 investment in home and community based palliative care there will be a return of investment between $0.53 and $1.56. Investing in palliative care makes good economic sense.
- PCA recommends that all elements of the new In-Home Aged Care Program are consistent with the PCA National Palliative Care Standards. PCA suggests that it may also be useful to consider these Standards in the context of developing Key Performance or Quality Indicators for providers (including Care Partners or similar) of in-home aged care.
- Consistent with a multi-disciplinary approach to palliative care, PCA recommends the design of the In-Home Aged Care program allows for:
    - Rapid and responsive referral to specialist palliative care services, where appropriate
    - A central role for primary care in meeting the bulk of less complex (and less expensive) clinical palliative care needs
    - A broad range of appropriate allied health services to complement clinical care.
- It is not clear how these different service systems will be funded and integrated into the Program, or precisely where the boundaries between this Program and other systems will lie. PCA would welcome an opportunity to work with the Department on these elements of the Program's design.
- PCA advocates for the inclusion of allied health in the In-Home Aged Care program as part of the multi-disciplinary palliative care approach.
- PCA endorses an In-Home Aged Care Program that ensures continuity of care across all settings, so that all people, but in particular vulnerable and diverse groups and those with rapidly changing needs, can receive seamless continuity of care between different health settings, including skilled discharge planning and in accordance with the PCA National Palliative Care Standards.
- PCA advocates that the In-Home Aged Care Program should explicitly provide for the provision of respite care, including both in-home respite and centre-based/overnight care, for those with palliative care needs.

[1] Definition of Palliative Care in The National Palliative Care Strategy 2018 | Australian Government Department of Health Based on World Health Organization, 2017.

- PCA advocates for all aged care staff, including Care Partners (or equivalent coordination roles) to undertake palliative care and dementia training and have a practical understanding of the PCA National Palliative Care Standards to support the delivery of the In-Home Aged Care Program.
- PCA encourages incorporation of a review period for the In-Home Aged Care Program, including consideration of whether the needs of all those requiring palliative care are being met and supported.

4. Inclusion of Palliative Care in the In-Home Aged Care Program

As Australia's population ages, the number of people requiring and using aged care services will further increase, as will the demand for palliative care in all aged care settings. The Royal Commission into Aged Care Quality and Safety's (the Royal Commission) final report acknowledges that too few people in aged care receive evidence-based end-of-life and palliative care. Many people instead experience unnecessary pain, untreated symptoms or indignity in their final days, weeks and months. The Royal Commission recognised the significant role palliative care must have in aged care:

> *'Palliative and end-of-life care, like dementia care, should be considered core business for aged care providers. People at the end of their lives should be treated with care and respect. Their pain must be minimised, their dignity maintained, and their wishes respected. Their families should be supported and informed.'*[2]

The Royal Commission made a number of recommendations to ensure high quality palliative care becomes core business for aged care services. However, we note that the A New Program for In-Homes Aged Care Discussion Paper does not reference palliative care.

There is strong economic evidence to support investing in expanding palliative care in aged care,[3] which can deliver a return on investment[4] in the form of reduced unnecessary and costly end-of-life emergency department visits and transport, hospital stays and intensive care unit admissions.[5]KPMG estimates that a $1.00 investment in home and community based palliative care can return between $0.53 and $1.56.[6] Investing in palliative care makes good economic sense.

The Australian Institute of Health & Welfare (AIHW) recently reported that in the five years to 2020, palliative care-related hospitalisations increased by 18%, a steeper rate than that for hospitalisations for all reasons (6%) over the same period. [7] PCA supports the development of a new In-Home Aged Care Program that assists with reducing palliative care-related hospitalisations.

All aspects of the provision of aged care programs, including respite care and in-home care, must have the flexibility to support quality, timely and person-centred palliative care, irrespective of the location or level of need. Further, access to palliative care is a human right as recognised by the

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[2] Royal Commission into Aged Care Quality and Safety (2021), Final Report: Care, *Dignity and Respect, Volume1 Summary and Recommendations*, pg. 94. Retrieved from: https://agedcare.royalcommission.gov.au/sites/default/files/2021-03/final-report-volume-1_0.pdf

[3] KPMG (2020), *Investing to Save – The economics of increased investment in palliative care in Australia*, page6, commissioned by PCA, www.palliativecare.org.

[4] KPMG (2020), *Investing to Save,* page 4.

[5] KPMG (2020), *Investing to Save,* page 4.

[6] KPMG (2020), Investing to save, page 36.

[7] AIHW: Palliative care services in Australia, About - Australian Institute of Health and Welfare (aihw.gov.au)

United Nations.[8] This includes the availability of palliative care after hours where people commonly need support for symptom control.

Too many Australians with life-limiting conditions miss out on appropriate palliative care. KPMG reports that 70 per cent of Australians would prefer to die at home, but few do so.[9] PCA supports programs that allow more Australians to remain in their homes as they age and receive palliative care in their preferred environment.

PCA recommends that the In-Home Aged Care Program specifically references palliative care and includes clear mechanisms to support palliative care needs.

5. The *National Palliative Care Standards*

The PCA *National Palliative Care Standards*[10] and *National Palliative Care Standards for All Health Professionals and Aged Care Services*[11] (collectively, the *PCA Standards*) have been developed with the aim of supporting better experiences and outcomes for people receiving palliative care.

The PCA Standards are generally normative standards but also incorporate aspirational components to support providers and services seeking to enhance capability and achieve best practice. PCA encourages consideration of the PCA Standards in all aspects of healthcare.

The PCA Standards provide expectations with respect to the following:

Comprehensive Assessment of Need

Initial and ongoing assessment comprehensively incorporates the person's physical, psychological, cultural, social and spiritual experiences and needs.

Developing a comprehensive care plan

The person, their family and carers and substitute decision-maker(s) work in partnership with multidisciplinary teams to communicate, plan, set goals of care and support informed decisions about the comprehensive care plan.

Caring for carers

The needs and preferences of the person's family, carers and substitute decision-maker(s) are assessed, and directly inform provision of appropriate support and guidance.

Provision of care

The provision of care is based on the assessed needs of the person, informed by evidence, and is consistent with the values, goals and preferences of the person as documented in their care plan.

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[8] United Nations Committee on Economic, Social and Cultural Rights. *General Comment No. 14: The right to the highest attainable standard of health*. Office of the High Commissioner of Human Rights. Contained in Document E/C.12/200/4/11. 2000. Retrieved from: http://www.refworld.org/pdfid/4538838d0.pdf.

[9] KPMG (2020), Investing to Save, page 23.

[10] https://palliativecare.org.au/publication/standards.

[11] https://palliativecare.org.au/publication/national-palliative-care-standards-for-all-health-professionals-and-aged-care-services.

Transition within and between services

Care is integrated across the person's experience to ensure seamless transitions within and between services.

Grief support

Families and carers have access to grief support services and are provided with information about loss and grief.

Service culture

The service has a philosophy, strategy, value, cultures, structure and environment that supports the delivery of person and family-centred palliative care.

Quality improvement

Services are engaged in quality improvement and research, based on best practice and evidence, to improve service provision and development.

Staff qualifications and training

Staff and volunteers are appropriately qualified, are engaged in continuing professional development and are supported in their roles.

Palliative Care Australia recommends that all elements of the new In-Home Aged Care Program are consistent with the PCA Standards. PCA suggests that it may also be useful to consider these Standards in the context of developing Key Performance or Quality Indicators for providers (including Care Partners or similar) of in-home aged care.

6. Flexible and Multi-disciplinary Approach

PCA welcomes the references in the *A New Program for In-Home Aged Care Discussion Paper* to providing flexible and responsive care. The In-Home Aged Care program must have the funding and flexibility to respond to rapidly changing care needs, including 24/7 clinical care support. People with palliative care needs can have complex and urgent care needs, and these needs must be supported.

PCA advocates that the program be sufficiently flexible to deliver best practice palliative care in all reasonably foreseeable scenarios, including for people whose health deteriorates rapidly and those whose diagnoses are terminal but whose functioning declines over a long period and can therefore remain at home rather than enter residential aged care. This would align with the principles of the PCA Standards, the Aged Care Quality Standards and the UN's recognition of palliative care as a human right.

Multi-disciplinary and integrated

Consistent with a multi-disciplinary approach to palliative care, PCA recommends the design of the In-Home Aged Care program allows for:

- Rapid and responsive referral to specialist palliative care services, where appropriate
- A central role for primary care in meeting the bulk of less complex (and less expensive) clinical palliative care needs
- A broad range of appropriate allied health services to complement clinical care.

It is not clear how these different service systems will be funded and integrated into the Program, or precisely where the boundaries between this Program and other systems will lie. PCA would welcome an opportunity to work with the Department on these elements of the Program's design.

Palliative care is holistic and requires input from a broad range of healthcare professionals, including specialist and general practice doctors, specialist and other nurses, allied health professionals, volunteers, family, carers and others. Care must be integrated and funded in a way that promotes coordination and supports the most vulnerable.

PCA notes the importance of providing allied health services in aged care settings as many allied health professions can contribute to the non-pharmacological management/treatment of common palliative care symptoms such as pain, agitation, breathlessness, constipation, fatigue, insomnia, respiratory secretions, and altered mood (anxiety and depression). The involvement of allied health professionals not only increases quality of life but is also a cost-effective, public and preventative health service.

PCA notes that the indicative model for the In-Home Aged Care Program[12] includes reference to allied health. PCA advocates for the inclusion of allied health in the In-Home Aged Care program as part of the multi-disciplinary palliative care approach.

PCA endorses an In-Home Aged Care Program that ensures continuity of care across all settings, so that all people, including vulnerable and diverse groups and those with changing needs can receive rapid and seamless continuity of care between different health settings including skilled discharge planning and in accordance with the PCA Standards.

Respite Care

Palliative care sees a person with life-limiting illness within the broader context of their family and support network. Palliative care services can include support for carers through respite and home care options as well as providing grief and bereavement support.

As living and dying at home can increase the burden on informal carers, families and carers seeking respite for a person receiving palliative care need to know that their loved one's full palliative care needs will be met. Knowing that respite care will fully accommodate all the individual's needs, such as disability and diverse needs or other complex needs, will enable the carer and volunteer community to continue their support – without placing additional unnecessary pressure on the aged care and hospital systems.

PCA advocates that the In-Home Aged Care Program should explicitly provide for the provision of respite care, including both in-home respite and centre-based/overnight care, for those with palliative care needs.

[12] *A New Program for In-Home Aged Care- Discussion paper,* page 16.

Care Partners

People with palliative care needs have specific care requirements. PCA is generally supportive of the Care Partner approach outlined in the *A New Program for In-Home Aged Care Discussion Paper,* but emphasises the importance of all aged care staff completing core training in palliative care and possessing a working understanding of the palliative care needs of the person, in particular the need for responsiveness and flexibility of approach.

PCA advocates for all aged care staff, including Care Partners (or equivalent coordination roles) to undertake palliative care and dementia training and have a practical understanding of the PCA Standards to support the delivery of the In-Home Aged Care Program.

Review

Unfortunately, given many people in aged care do not receive quality palliative care, funding and modelling formulated on the basis of current aged care service models and delivery may fall well short of what is required to deliver best-practice palliative care.

PCA encourages incorporation of a review period for the In-Home Aged Care Program, including consideration of whether the needs of those requiring palliative care are being met and supported. Implicit in this process is the collection of sufficient service delivery data relating to the provision of palliative care. PCA is mindful of the known gaps in palliative care data sets, most notably in data related to care delivered in the community and at home. Further, a timely review should allow adjustment to be made to funding parameters (such as the 25% funding pool) and to ensure currency and alignment with best practice palliative care. This would support providing evidence-based palliative care into the future.