PALLIATIVE CARE AUSTRALIA'S PRE-BUDGET SUBMISSION 2018-19

Palliative care is everyone's business

PalliativeCare
AUSTRALIA

Executive summary

INITIATIVE	ESTIMATED COST
National Leadership	**$4.4 million over three years**
Palliative care as a COAG priority	
Appoint a National Palliative Care Commissioner	
Workforce Support and Planning	**$35 million over three years**
Investment in the Specialist Palliative Care Workforce	
Develop a National Palliative Care Workforce Strategy	
MBS Review to facilitate palliative care across settings	
Grief and Bereavement Support	**$825,000 over three years**
Grief and bereavement training for aged care and primary health care	
Establish a National Grief Awareness Day	
Evidence	**$650,000**
Equipment mapping project to enable palliative care within the home	

Introduction

Palliative care is everyone's business.

Palliative Care Australia's aim is to maximise quality of life, right until the end of life. More needs to be done to ensure that every Australian has the awareness, support and access to services required to achieve this.

Palliative Care Australia expects that people living with a life-limiting illness will have access to an effective continuum of palliative care services. This is based on key elements including:

- Timely assessment and referral to the services that best meet the needs of people living with a life-limiting illness;
- The provision of palliative care should be based on needs assessment, irrespective of the person's diagnosis, age, gender, Indigenous status, ethnicity, or sexual orientation.
- Informed communication on values and priorities for care through mechanisms such as advance care plans;
- Effective provision of care by multidisciplinary teams with the required workforce competencies;
- Continuity and coordination of care as people's needs change and they transition between different types of care; and
- All providers of palliative care services (whether generalist or specialist) need to have the capacity to assess where family members and carers sit along a continuum of need for bereavement support services and refer accordingly.

People living with a life-limiting illness will need to have palliative care provided in many different settings – in their homes, acute hospitals, general practice clinics, specialist clinics, and aged care homes. Australians who live in other institutions such as prisons and organisations caring for people with severe mental illness or severe disabilities also need to have palliative care provided when required.

At present, the number of people wishing to die at home with the support of a community-based palliative care service far exceeds the availability of that care, particularly for those with illnesses other than cancer. For many, access to community-based palliative care is determined by where they live, rather than where they would prefer to die.

PCA draws attention to the Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services, Productivity Commission Draft Report released in June 2017, which states that "without significant policy reform, tens of thousands of Australians will die in a way and in a place that does not reflect their values or their choices".

2018–19 pre-budget submission summary

INITIATIVE	ESTIMATED COST	BENEFITS
National Leadership		
Palliative care as a COAG priority	No additional funding	Palliative care is a state/territory and Commonwealth responsibility which crosses the health, aged care, community care, disability care and mental health sectors. **Palliative Care Australia seeks a commitment from COAG** to identify palliative care as a national health priority. All people with life-limiting illnesses that may benefit should be able to access palliative care services, regardless of age, diagnosis and location.
Appoint a National Palliative Care Commissioner	$4.4 million over three years	The current fragmentation of palliative care services in Australia needs addressing by appointing a **National Palliative Care Commissioner.** The focus of the Commissioner should be on assessing the efficiency and effectiveness of programs and services in supporting individuals faced with life-limiting illness and their families to live as well as possible to the end of life, and enable support in grief and bereavement. This would involve consolidating and simplifying existing program structures, addressing any duplication, and scoping issues related to equity of access. Specifically the Commissioner needs to: • improve communication across jurisdictions, • facilitate consistent approaches to supporting the palliative care sector across all settings, including primary health, community health, tertiary health, aged care and disability, • in partnership with state and territory governments, assess the needs of different regions and populations, in particular Aboriginal and Torres Strait Islanders, rural and remote populations and Australia's culturally and linguistically diverse populations, • facilitate harmonisation of end-of-life care planning laws, • examine existing palliative care services and programs across federal, state and territory governments, private and non-government sectors, • develop a national palliative care workforce strategy which includes aged care, tertiary care, primary health care and community-based care, • engage with states and territories to develop a palliative care data collection framework, and • oversee development of an implementation plan and monitoring and evaluation plan which will underpin the National Palliative Care Strategy to be released in 2018.

INITIATIVE	ESTIMATED COST	BENEFITS
Workforce Support and Planning		
Investment in the specialist palliative care workforce	$35 million over three years	At present there are **213 palliative medicine specialists across Australia, equating to less than 0.9 per 100,000 population or one for every 704 deaths.** Immediate funding is required to **support additional palliative medicine specialist trainee positions.** This must be underpinned by clear pathways for entry into graduate positions across tertiary, aged care and primary health care. To be recognised as a palliative medicine specialist and attain Fellowship of the Australasian Chapter of Palliative Medicine (FAChPM), physicians must complete a Palliative Medicine Advanced Training Program which requires three years of full time equivalent training under the supervision of a practising palliative care physician at an accredited training site. In addition, there is a need to **encourage and support nurses to achieve the qualification of palliative care nurse practitioner.** Nurse Practitioners provide a unique and highly advanced nursing skill set, and may be sole practitioners or part of a wider palliative care team. To work as a nurse practitioner the nurse must be recognised as an advanced practitioner in palliative care and have completed a Masters level qualification. At September 2017 there were 1,585 Nurse Practitioners registered with AHPRA in Australia, most of whom do not work in palliative care. A program specific to palliative care could be implemented similar to the previously funded *Supporting a Professional Aged Care Workforce* program which provided scholarships for registered nurses in the aged care sector to study courses leading to endorsement as a nurse practitioner.

INITIATIVE	ESTIMATED COST	BENEFITS
National Palliative Care Workforce Strategy	Included in the National Palliative Care Commissioner ask Standalone: $750,000	Complimentary to the National Palliative Care Strategy 2018, a **targeted palliative care workforce strategy needs to be developed** to addresses the palliative medicine specialist shortfall outlined above, the identified need to provide increased support for Australian to die at home if this is preferred, and given the projected doubling of annual deaths by 2050. This must include the role of GPs, nurses, aged care staff, community pharmacy, allied health and other health professionals and consider the disparities in availability across the states and territories and across inner regional, rural and remote locations. Additionally, it would provide guidance on appropriate staffing mix and numbers that are required to facilitate the delivery of palliative care to all Australians with a life-limiting illness regardless of age or diagnosis across all health settings, including tertiary, community-based and residential aged care settings, and ensure appropriate access to consultancy advice from specialised palliative care services.
Review of MBS items to facilitate palliative care across settings	No additional funding	**The provision of palliative care does not fit well within the current MBS items**. As an example, the inability of palliative care specialists to access the same MBS items for inpatient case conferencing and family meetings that rehabilitation specialists and gerontologists can needs addressing. Many tasks often focus around the conduct of family meetings and case conferencing with other health professionals while a person is receiving palliative care. This, in addition to discrepancies in access to community-based MBS items needs to be **examined by the MBS Review Taskforce as a priority**. Further, the role and remuneration under the MBS for general practice and nurse practitioners must be explored to facilitate family meetings, advance care planning discussions and best practice community-based palliative care, including the provision of home visits, after-hours support and the needs of residents within aged care services.

INITIATIVE	ESTIMATED COST	BENEFITS
Grief and bereavement support		
Targeted grief and bereavement training for aged care and primary health care staff	$525,000	Palliative Care Australia is informed of many instances when a lack of support in grief and bereavement from aged care services and primary health care, including GPs, significantly impacts on surviving family members. About 10% of bereaved people experience complicated grief which is prolonged (beyond six months) or intense grief, resulting from a failure to transition from acute to integrated grief (RACGP 2016, The General Practice Mental Health Standards Collaboration). Complicated grief is associated with substantial impairment in work, health and social functioning. GPs in particular have a critical role in exploring grief and bereavement, however, there is a need to ensure GPs have up-to-date knowledge in identifying issues related to grief, approaches to care and referral pathways. 35% of all deaths in Australia occur in residential aged care (PCA, Economic Research Note 4, 2017) and there is a need to ensure awareness of grief and bereavement of all staff, including non-clinical, as often long-term and close relationships are formed with residents and their families. Upskilling the workforce in this area would not only assist in supporting the families and carers of the person who has died, but also foster an environment of support for other residents and the staff themselves, an important component of self-care and staff retention. **It is proposed that a website including an online training package, locally based referral pathways and resources is developed** in consultation with Primary Health Networks and the relevant peak bodies for aged care and primary health care providers to: • upskill health professionals in understanding grief and bereavement, including their own responses which is of particular important with the aged care sector, • assist in early identification of complex grief, • facilitate appropriate and timely referral to other support services if indicated, • assist in normalising death and conversations surrounding grief and bereavement in the wider community, and • reduce reliance on more costly mental health funding in the longer term by avoiding complex grief.

INITIATIVE	ESTIMATED COST	BENEFITS
Establish a National Grief Awareness Day	$300,000 over three years	It is proposed that a day each year is recognised and supported by the Australian Government to provide an **opportunity to raise awareness of the impact that death and loss can have on individuals, families and the broader community**. The day would celebrate the lives of people who have died and assist in normalising conversations regarding death and dying to assist people in preparing for their end-of-life. There were 158,504 deaths in Australia in 2016 (ABS, Deaths, Australia 2016) and some of the goals of National Grief Awareness Day would be to remove the stigma surrounding grief and death, assist people in reaching out and asking for assistance before and during bereavement. The appropriate date to hold the day would be decided in collaboration with other health organisations. This day would also be an avenue of disease or condition-specific organisations to highlight the importance of support for people during grief and bereavement due to the death of a person. For example, the top three leading cause of death in Australia in 2016 were Ischaemic heart disease, dementia and cerebrovascular disease including stroke. The budget ask is for seed funding to establish branding, promotion and distribution of resources to promote the day.

INITIATIVE	ESTIMATED COST	BENEFITS
Evidence		
Equipment mapping project to enable palliative care within the home	$650,000	The current evidence shows that home-based palliative care improves consumer quality of life and that person-centred palliative care within the home is cost-effective. Where palliative care provided in the community a person is 87.5% more likely to remain in the community until death (PCA, Economic Research Note 2, 2017). **The ability to access suitable equipment and medical supplies easily and in a timely manner can heavily influence whether people can remain at home or need to be cared for elsewhere**, often against their preferences and at an increased cost. Palliative Care Australia is proposing to **conduct a national mapping exercise to provide evidence for appropriate use of resources and streamline referral/ access pathways** where the purpose is to support people to remain at home whilst receiving palliative care and improve their safety and quality of life, as well as that of their carers. Currently families and carers may access equipment through a range of different programs that are funded in each of the health, aged care and disability sectors, at Commonwealth and state level. Some equipment is also funded by private health insurers and non-government organisations. In most states and territories, public hospitals also provide equipment and home modification services for some people after a hospital admission to support their return home and rehabilitation. This project would: • Identify current referral pathways, funding sources and eligibility criteria across all jurisdictions and relevant sectors for home modification and equipment. • Identify gaps or barriers in access, which may be structural, financial, personal or cultural. • Make recommendations to improve access.

Palliative Care Australia incorporated

t 02 6232 0700 e pcainc@palliativecare.org.au w www.palliativecare.org.au ABN 85 363 187 904

a **Street:** Unit 8, 113 Canberra Avenue, Griffith ACT 2603 **Mail:** PO Box 124, Fyshwick ACT 2609

PalliativeCare AUSTRALIA

Palliative Care Australia is funded by the Australian Government.

Australian Government
Department of Health