# Palliative Care Australia

Patron: ***Her Excellency Ms Quentin Bryce, AC***
***Governor-General of the Commonwealth of Australia***

Palliative Care Australia

29 January 2010

**Mr Jason Harris**
**Budget Policy Division**
**Department of the Treasury**
**Langton Crescent**
**Parkes ACT 2600**
by email: prebudgetsubs@treasury.gov.au

Dear Mr Harris

***DYING WELL***
**Palliative Care Australia submission**
**outlining ideas and priorities for the 2010-11 Federal Budget**

**Introduction**

Palliative Care Australia (PCA), as the peak national body representing the palliative care sector, and those stakeholders who share a commitment to quality care at the end of life, welcomes the National Health and Hospitals Reform Commission's (NHHRC) strong support for the need to enhance the integration of specialist palliative care services with primary, acute, subacute, and aged care services, and with chronic condition-specific services, including dementia.

The final NHHRC report stresses that good quality care at the end of life must become integral to an effective health care system. Currently, there are many barriers to this.

Investment in the health reform agenda can make this real.

To enhance access to needs-based quality care at the end of life, we need to support a health service delivery model that supports a dual investment strategy based on stronger and better linked specialist palliative care services and increased primary care capabilities. This strategy will enhance in-home support through better integration of primary and community care with specialist palliative care services. This is the pathway to deliver upon the promise to meet patients' care needs and preferences, and to save unnecessary demand for hospital beds.

The under-pinning requirement is to seek ways to ensure that these primary care services offer a team-based range of services including general practice, allied health and nursing supports, with referral pathways to and from specialist services, to ensure that they can provide well co-ordinated multi-disciplinary care to meet the needs of people at the end of life. The palliative care service delivery model is a demonstrable model for multi and interdisciplinary care that operates across funding and care setting silos.

This creates discontinuity in health service funding and provision, and encourages service blocks which make it difficult to achieve transition between the different levels of service delivery.

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**National Palliative Care Program – Background**
In 2000 Australian health ministers endorsed Australia's first National Palliative Care Strategy and this informed the investments under the National Palliative Care Program.

Australian Government funding for palliative care has been made up of a collection of overlapping programs since 1998:

- Australian Health Care Agreement (AHCA, 1998-2003) $151m (with $10m to Commonwealth for national programs)
- AHCA (2003-2008) $188m (with $13m to Commonwealth for national programs)
- $55m in 2003 over 4 years (including $5m for Caring Communities Program)
- Palliative Care in the Community (2006-2010) $62.8m
- Local Palliative Care Grants Program (2005-2009) $23.1m

Since 2003 the above funding sources have been collectively known as the National Palliative Care Program.

The National Palliative Care Program supports four broad areas:

- support for patients, families and carers in the community
- increased access to palliative care medicines in the community
- education, training and support for the workforce
- research and quality improvement for palliative care services.

The 2009 Budget provided ongoing funding of $113m over four years to June 2013 and this funding has included a review of the current strategy.

Upon finalisation of the strategy the Australian government must take the next step to review the current investments under the National Palliative Care Program to ensure the most effective and efficient use of the funding provided under the service provision and development pools.

**National Palliative Care Program – Future priorities**
Palliative Care Australia recognises the ongoing investment by the Australian Government in palliative care through the funding of development initiatives under the National Palliative Care Program and the funding of service provision through the Australian Health Care Agreements.

However, there is growing evidence that the demand for quality end-of-life care is outstripping the resources provided to meet that need.

Investment is required in trialling and implementation of initiatives in health system reform which by definition will necessarily involve federal and state partnerships with service providers that cross the acute/sub acute/primary care boundaries. Some of these can be developed within the context of the broader response to the National Health and Hospitals Reform Commission report and the National Primary Health Care Strategy.

Palliative Care Australia would advocate that National Palliative Care Program funds are more strategically targeted in the future to leverage a greater return on the investment made so far and to develop a sustainable national infrastructure and a targeted approach to system capacity and capability development.

Palliative Care Australia recommends that a Budget commitment to enhance the commitment to the reframed National Palliative Care Program would be an important and effective element of health reform, and would enable vital initiatives in the following areas of need.

**Employing a needs-based service provision framework in planning**
A promise of quality care at the end of life to all does not mean that service delivery should be homogeneous. The type and level of end-of-life care required by patients is not a fixed quantity, but differs for each individual and for each person over time.

In practical terms, for the purposes of population-based service planning, people at the end of life can be conceptualised as having complex care needs, intermediate care needs, or needs appropriately addressed through primary care services. Level of need should be the determinant of the type of service provision required.

Fundamental to ensuring that all people at the end of life receive care that is appropriate to their needs is sufficient resourcing of both specialist palliative care and primary care services, and the development of clear, standardised referral criteria.

**A coordinated, whole-of-health, integrated response**
While there are examples of good interdisciplinary end of life care provided in a seamless manner, the reality for many patients is one of fragmented service delivery where they or their loved ones are required to navigate the unnecessary complexities of the healthcare system.

Opportunities to reduce fragmentation in service delivery and enhance continuity of care include implementing a nationally consistent approach to the coordination of care across settings for people with end-of-life care needs, and orienting funding and resource systems to provide greater integration.

Hospitalisation should be viewed as being inappropriate for many people at the end of life. In many cases, adequate care can be more effectively and efficiently provided in the place of residence, without the risks to patients implicit to hospitalisation, and in a manner that accords with patients' care preferences.

We must build primary health care capacity and competence, supported by specialist palliative care services, to provide support for their dying patients.

The inability to manage preventable pain in the home or in residential aged care facilities, combined with difficulties in accessing medication and community care services, contribute to the current overloading of hospital services.

The under-pinning requirement is to ensure that primary care services offer a team-based range of services including general practice, allied health and nursing supports, with referral pathways to and from specialist services, to ensure that they can provide well co-ordinated multi-disciplinary care to meet the needs of people at the end of life. This will require a focus on workforce development.

**Workforce development strategy**
Shortages of adequately skilled health workers across all care settings are central to current limitations to broad access to needs-based care at the end of life. Shortages of health workers and limited access to appropriately qualified staff have been associated with sub-optimal pain relief in both residential aged care facilities and home care situations, and thus to unnecessary and unwanted hospitalisations when care needs cannot be met.

**Advance care planning: A key component of health literacy**
Advance care planning - the most important investment we make as a society to ensure quality care at the end of life that accords with the individual's needs and preferences - is a key way to enhance health literacy.

Advance care planning should be consumer-driven and controlled, providing a reliable and flexible mechanism to anticipate and express care choices, in partnership with and supported by the health system.

Broader application and coordination of advance care planning provides a mechanism to plan and thus better meet patients' needs, while limiting unnecessary hospitalisations.

**Conclusion**
All Australians ought to be able to expect to die with their preventable pain and other symptoms well managed, with the people they wish to be present, and whenever possible, in the place of their choice.

Palliative Care Australia conservatively estimates that at least 100,000 deaths in Australia each year could be categorised as 'expected' thus requiring access to better planning and coordination to realise good quality care at the end of life – regardless of their care setting.

This Budget provides the government with the opportunity to provide cost-effective health system reform for those 100,000 Australians and their families and loved ones.

These opportunities include:
1. A commitment to invest in the **full evaluation** the National Palliative Care Program and ensure ongoing commitment to national development initiatives that prove to be efficient under a reframed National Palliative Care Program.

2. As part of the commitment to <u>a reframed national program</u> the following areas require higher prioritisations:

- **Community education**
    - *Promote, through a national community initiative, the value of information, end-of-life and advance care planning by Australians, as supported by a harmonisation of state and territory laws governing the use of advance directives and system development*
- **Quality performance agenda**
    - *Establish mechanism for detailed population planning for end of life to determine demand*
    - *Establish national service provision model that works to align all care settings to efficiently meet demand in accordance with quality performance measure*
- **Workforce development**
    - *Remove the systemic, financial and structural barriers to enable multidisciplinary end-of-life care in primary care settings*
    - *Recognise specialist palliative care as a discipline in undergraduate, continuing professional education and postgraduate*
- **Research**
    - *Invest in targeted research into pain and symptom management and system change to improve quality.*

3. A commitment to ensure that palliative and end of life care is **ranked as a priority** within the first phase of **health and aged care reforms,** particularly in relation to growing the capacity of primary care and aged care to reduce the inappropriate demand for acute care servicing.

- *Implement the findings of the review of the Aged Care Funding Instrument to enable quality care in residential aged care facilities at the level accessible in other care settings.*
- *Invest in additional Medicare item numbers to enable direct and consultative care from specialist palliative care providers in primary care setting.*

4. A commitment to reduce the end-of-life **cost and administrative burden on families and carers.**

- o *Waiving the requirement for patients to reach the Medicare Benefits Scheme and Pharmaceutical Benefits Schedule safety net thresholds will make a difference when incomes are reduced and care costs are increased.*
- o *Align the recent changes to the carers payments for children with the adult population to reduce red tape and burdens on families in need.*

Yours Sincerely

**Donna Daniell**
Chief Executive Officer