End of life care is everyone's affair - tackling the challenge of 'end of life'

Palliative Care Australia
submission to the
National Health and Hospitals Reform Commission

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1 Executive Summary

The current experience of end of life care[1] in Australia is disparate and inconsistent and we cannot, in good faith, promise patients at the end of their life access to care that is customised to preferences and reliably delivers good symptom control. Our health care system can do better.

Palliative Care Australia (PCA) welcomes the identification in the National Health and Hospitals Reform Commission's (NHHRC) first report of "*care for and respect of the needs of people at the end of life*" as a key challenge confronting the healthcare system and embraces this as a first step toward planning for a healthcare system that can promise access to reliable, evidence-based, end of life care that accords with patients' preferences.

PCA believes that there are **six key opportunities** that can be harnessed towards realising such a promise to patients:

- Acknowledging hospitalisation as inappropriate for many people at the end of life, and thus a potential indicator of sub optimal care, and reorienting resources and care delivery systems to support people to **die in-place**, promises to better enable the meeting of patients' care preferences and promote quality of life in a resource-efficient manner.

- Coordinating and promoting **advance care planning** will provide the opportunity to plan to better meet patients' needs and offer people living with an eventually fatal condition, and their families, the opportunity to be empowered to take control of the conditions of their care.

- Addressing **workforce education and shortages** by increasing education and training opportunities in end of life care and palliative medicine for health and allied health care workers, and ensuring workforce development plans for residential aged care facilities to include end of life care needs, will contribute greatly to preventing unnecessary and unwanted hospitalisations caused by the need for pain relief.

- Linking existing resources and systems to provide for coordinated case management systems and orienting funding and resource systems will achieve much better service integration and thus **continuity of care**.

- Recognising the significant health outcomes to be gained through a focus on the patient, family and carers as the "unit of care", before, during and after death, in accordance with a population **needs based service provision framework**, will help ensure timely access to both specialist palliative care, and other appropriate services as required.

PCA welcomes the NHHRC's commitment to extending the scope of the Australian Health Care Agreements (AHCAs) and establishing clear accountability structures as a much needed

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[1]The following definitions of end of life, end of life care and palliative care are used throughout this submission. Source: *Palliative Care Australia Strategic Plan 2008-2011*.
End of life: That part of life where a person is living with, and impaired by an eventually fatal condition, even if the prognosis is ambiguous or unknown.
End of life care: End of life care is care provided to people who are living with, and impaired by an eventually fatal condition. It is not limited by prognosis. End of life care can be provided by all health care professionals and is not limited to care provided by palliative care services or specialists. Quality end of life care is realised when strong networks exist between specialist palliative care providers, generalist health care professionals, other clinical specialists and support care providers and the community – working together to meet the needs of the population of people requiring care.
Palliative care is specialist care provided for all people living with, and dying from an eventually fatal condition and for whom the primary goals is quality of life.

opportunity to ensure reform targets are met across the health system. We acknowledge the NHHRC's proposed performance benchmarks as providing key measures of the impact of reforms to achieve needs-based end of life care.

We further urge the Commission to consider linking accountability, through a performance benchmark, to efforts to promote advance care planning, to ensure that advance care planning is centralised as a critical element in reform to achieve efficient consumer-centred care.

2 Introduction

PCA is the peak national organisation representing the interests and aspirations of all who share the ideal of quality care at the end of life for all. We believe our health care system can do better to make access to quality end of life care a reality for all Australians.

PCA welcomes the role of the NHHRC in developing a 'road map' toward a more effective and efficient, people-focused health care system and embraces this opportunity to detail possibilities for realising greater access to end of life care that is directed to promoting quality of life for people in accordance with their care preferences.

Good strategic planning around the management of the terminal phase of life promises better care for people at the end of life and to help alleviate the ongoing crisis around access and demand management, through a more effective and efficient use of services and the prevention of unwanted and unnecessary hospitalisations.

PCA convened a national stakeholder forum *A Matter of Life and Death: Confronting the new reality* on 13 March 2008. The forum was well attended with over 130 delegates representing a diverse array of stakeholders. The delegates discussed strategies to confront the changing demographics of end of life, and to develop practical opportunities for better care at the end of life.

On the basis of insightful discussion at *A Matter of Life and Death*, PCA advocates a vision for care at the end of life that is driven by a commitment to quality care for patients and takes this commitment as the basis for structuring ongoing quality improvement in care systems. Characteristic trajectories of end of life must provide the starting point for planning service delivery that situates the home – wherever that may be – as the primary place of end of life care.

PCA seeks to be an active participant in the health care reform debate and will be pleased to assist the Commission in its work. PCA can contribute by developing policy options which will enhance the care of people at the end of life, in a way which better integrates end of life care with acute care, chronic care, primary care, aged care, and community care.

We will be pleased to provide the Commission with the documents referenced in this submission, to arrange for visits to services which provide a good model of 'integrated' end of life service delivery, and to engage with the Commission at forums, or one-on-one, to develop these ideas and models into a workable road map to enhance and reform the health system.

PCA recognises the significant contribution by the Australian Government to the National Palliative Care Strategy (2000) and the investment in palliative care development through the national palliative care programs.

PCA works in collaboration with the Australian Government's Department of Health and Ageing (DoHA) to implement the National Palliative Care Strategy and to raise awareness of palliative care, improve the understanding and availability of services across Australia, and encourage discussion to support improved knowledge networks.

This strategy has been a vitally important component of the improvements that have occurred in end of life care over the last decade. However, it is time for the strategy to be reviewed as it no longer fully matches the challenges of:

- palliative care integration across the health system;
- defining the end of life population and their characteristic care needs; and
- meeting consumer needs, preferences and expectations.

Today people at their end of life need to transact with the many systems within our health and social care systems, with in many cases few links and enablers. This gives us the opportunity for new thinking, in recognition that improvement in quality care at the end of life requires a "whole of health" approach. This highlights the imperative for robust and wide ranging collaboration of many stakeholders.

To this end, PCA has taken the initiative to champion the establishment of a collaboration of end of life stakeholders to explore opportunities for realising access to quality care at the end of life across care settings. PCA notes that the existence of this end of life collaboration may enhance the Commission's scope to consult widely with all stakeholders.

3 Defining the end of life population

A key challenge in addressing the end of life care needs of Australians lies in the precursor step of identifying the end of life population. For most people there is not a neat period of time that can be readily labelled as "dying" which precedes death, nor a predictable time of death. Professor Joanne Lynn, an internationally renowned American gerontologist, academic and author, who works on palliative care programs for the US Government's Medicare and Medicaid programs (which covers some 83% of dying Americans because they are over 65 years of age). Professor Lynn, a keynote speaker at PCA's watershed national stakeholder forum in March 2008, has argued:

> *On the day that turns out to be one week ahead of death, the median lung cancer patient still has about a 50-50 chance to live two months. On the day that precedes death, the median patient with serious heart failure still has better than a 50-50 chance to live 2 months…Physicians cannot predict whether and when a seriously ill person will have a heart attack or a small complication that will start a cascade of problems and lead to death.*[2]

The uncertainty of time of death can challenge efforts to define the end of life population, which confounds the ability to plan and deliver care systems.

Murray et al advocate a 'no surprises' policy: if it would be no surprise if the patient were to die in the next 12 months then the patient requires assessment of scenarios and planning to meet their needs for end of life care.[3] In other words, end of life care is required at any time where death in the next year would not come as a surprise. For this population group, death is expected and as a consequence an opportunity is presented to understand and anticipate the needs and better plan to meet the promise of delivery.

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[2] J. Lynn, '(Re)orienting towards quality care at the end of life'. Presentation to PCA national stakeholder forum *A Matter of Life and Death: Confronting the new reality*, Canberra 13 March 2008.

[3] S. Murray et al.2004. 'Developing primary palliative care: People with terminal conditions should be able to die at home with dignity.' *BMJ* 329; 1056-1057.

4 The current reality of end of life care

In Australia, approximately 130,000 people die each year.[4] While the Australian Bureau of Statistics doesn't code cause of death data according to 'expected' and 'unexpected' deaths, Palliative Care Australia conservatively estimate that at least 100,000 deaths could be categorised as 'expected' and thus requiring access to better planning and coordination to realise their quality care at the end of life.[5]

Yet we have cause to question whether we are meeting the needs of this population in an equitable, quality and sustainable way. One problem is the lack of comprehensive data on how the people within this population group transact and utilise the existing health and care systems and how well needs were met. A mechanism to collect and analyse this data is imperative for ongoing service planning.

The current reality of end of life care in Australia is one of inequity and inconsistency. While some patients experience quality needs-based care, the reality for others is one of fragmented care that fails to acknowledge their care preferences and, too often, delivers insufficient support to meet social, emotional and physical needs at the end of life.

While the current pool of evidence and experience does not enable a reliable prediction of the time of a person's death, it does enable anticipation of a range of likely scenarios. Knowing what may happen informs the planning for how best to respond.

The challenge to deliver quality care at the end of life for all can be expected to be further confounded by increasing service demand. At an epidemiological level, not only is the size of the population requiring end of life care increasing (both in absolute terms and as a proportion of the population), but the duration of life lived with high care needs and the number of patients requiring complex care is increasing.

It is significant that a recent international poll by the *British Medical Journal* has found that "palliative care for all would make the greatest difference to health care."[6]

4.1 Disparity in access and inconsistent quality of care

The current experience of end of life care in Australia is disparate and inconsistent. Access to services and models of care employed is inconsistent. Anecdotal reports suggest care standards achieved are similarly inconsistent.[7]

Lynn is well known for proposing three different primary end of life trajectories that the majority of people at the end of life in the 21st century follow, described as:

- short and rapid decline prior to death (common to many cancers);
- ongoing health exacerbations followed by sudden death (common, for example, in many chronic heart or lung failure cases); and
- ongoing period of decreasing or low level function (common, for example, in many dementia cases).

[4] There were 133,700 deaths registered in Australia in 2006. Australian Bureau of Statistics, *Deaths: Australia 2006*. www.abs.gov.au/AUSSTATS [Accessed 30 April 2008.]
[5] This estimate is based on a basic analysis of ABS cause of death data for 2006 and subtraction of all assumed deaths that were accidental, resulted from suicide or could potentially be from acute illness. This figure is expected to be an under-estimation.
[6] http://makingadifference.bmj.com/
[7] *A Matter of Life and Death: Confronting the new reality* Report of Outcomes, PCA April 2008.

In Australia, as elsewhere, palliative care service delivery models have been developed to meet the needs of a particular, limited population – specifically cancer patients who experience a short and rapid decline prior to death.[8] Commonly services perform well for those with this end of life trajectory, but inconsistently for those with other characteristic end of life trajectories.[9]

Despite the considerable investment in palliative care over the past two decades, hospital remains the most likely place of death for the majority of Australians. The question is whether this reality is by design or default. Is this a good match of needs and care delivery and the most effective and efficient way to promote equitable access to quality care?

The standard and quality of end of life care received across **acute care** settings is inconsistent and inequitable. Access to specialist palliative care units and hospital-based consultation teams is not available for all patients. Acute care staff are not always skilled in the provision of patient-centred end of life care in accordance with the national palliative care standards. Access can be further limited by excess service demand on specialist units (possibly associated with service provision that is not best matched to needs as discussed later this submission), and by workforce shortages.

The appropriateness of care received by many patients in acute settings is less than ideal. Anecdotal reports suggest that it is not uncommon for high cost interventions to be delivered, against best available evidence and without fully informed decision making from the individual and/or their family.[10]

Fundamentally, the goals of care for acute care and palliative care are different. The dominant medical paradigm of deploying all possible treatments to save or lengthen life differs from that informing palliative care, which acknowledges that a duty to cure the curable should not necessarily be extended to patients who are dying and do not want, and are unlikely to benefit from, active treatment.

In the acute hospital sector, a significant proportion of the work is with ageing people and with patients at the end of life. In many acute settings, patients with palliative care needs are not identified and are thus not appropriately referred or are referred for inappropriate treatment. There is limited discharge planning and coordination of subsequent care. As a result, patients may not be provided with adequate care, may be forced to negotiate unreliable transitions between services, and be forced to navigate the complexities of the healthcare system.

PCA believes this is unacceptable – most people come to accept that dying is physically, socially and emotionally difficult, yet to find it is also a logistical catastrophe can be devastating.

Opportunity to realise quality end of life care in acute care settings lies in recognising that end of life care is part of the core business of hospitals, and working to ensure this core business is realised in accordance with established standards.

Potential to realise this opportunity lies in mandating end of life care standards for acute care settings that are based on the National Palliative Care Standards. The renegotiation of the Australian Health Care Agreements provides opportunity for meaningful performance indicators to be linked to palliative care funding for acute care.

In the care of patients with **chronic and complex conditions**, the picture is similarly one of inconsistency and inequity. At a recent national forum Professor Patricia Davidson outlined a

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[8] J. Lynn, 2008. Palliative care beyond cancer: Reliable comfort and meaningfulness.' www.bmj.com [Accessed 16/04/2008.]
[9] ibid.
[10] *A Matter of Life and Death: Confronting the new reality* Report of Outcomes, PCA April 2008.

system where there are “pockets of excellence” yet commonly an ad hoc approach that is facility and clinician-dependent.[11]

PCA welcomes the Commission’s priority challenge no. 4 – to redesign care for those with chronic and complex conditions so as to provide continuity of care from diagnosis through to death.

Palliative care is often not recognised as part of the core business of chronic disease care management, despite the fact most Australians die from an exacerbation of a chronic condition which they have lived with for months or years. The ‘siloing’ of health care specialities, combined with low levels of awareness of effective end of life treatment options means that chronic disease specialists are often unaware of how to ensure that effective and appropriate patient-centred care is provided. This is aggravated by the complications engendered around funding and responsibility in shared-care approaches. The result is that patients experience fragmented care, suboptimal pain management and symptom relief, or inappropriately interventionist care focused on cure rather than comfort.

Similarly with **care in the community** there is a great disparity in access to services and reported differences in the capacity of services to effectively meet the needs of people at the end of life. Inequities and inconsistencies are aggravated by workforce shortages.

Limited access to community care, including respite support, can lead to unnecessary hospitalisations when carers are overwhelmed by care requirements, or patients are unable to access appropriate pain and symptom relief from community providers due to limitations imposed through the Medicare Benefits Schedule (MBS) and as a result of disparity between the access to medicines in hospital compared to the community under the Pharmaceutical Benefits Schedule (PBS), or as a result of limited access to appropriately trained and resourced health workers.

Quality care at the end of life requires a multi-disciplinary approach that draws together a range of service providers to meet the patients’ and families’ physical, social and emotional needs. In many situations community care is fragmented across providers and provider settings, leading to a lack of continuity of care and impeding the ability to provide high-quality, interdisciplinary care.

In **aged care** also, access to, and the quality of, end of life care is inconsistent. Consistent linkages with specialist palliative services are not demonstrated. Only some aged care facilities enjoy ready access to primary care physicians well skilled in end of life care and to specialist palliative care physicians. Only some facilities, particularly high care facilities, have systems in place to limit hospitalisations by providing care in-place.

However, common limitations inhibit the provision of quality care at the end of life across aged care facilities. Perhaps most notable is sub-optimal pain management which results in people experiencing preventable pain.

At PCA’s recent national stakeholder forum, delegate discussion associated poor pain management with prescribing protocols and limited access to staff qualified to prescribe and administer opioids, as a result of inadequate staffing levels and workforce shortages. Limited access to physicians can create delays in initial prescription and ongoing administration of opioids, or lead to the prescription of pain relief medication that requires frequent administration, or that may be less effective, or unsuited to the individual case.

[11] P. Davidson, ‘The reality for chronic disease and end of life’. Presentation to PCA national stakeholder forum *A Matter of Life and Death: Confronting the new reality*, Canberra 13 March 2008.

4.2 Failure to deliver care in accordance with preferences

The process of dying and coming to terms with death is confronting for all involved – including health professionals. For patients and their families it can often represent the ultimate loss of control. Too often the health care system is complicit in the disempowerment of the individual through the denial of the opportunity of meaningful and informed choice over the circumstances in which they receive care and the type of care they receive.

Meaningful choice for people at the end of life is inhibited by systemic barriers pertaining to location of care. Limitations in access to quality care for those at home or in residential aged care too frequently results in emergency department visits and hospital stays. (Though not all related to chronic and complex care, it is notable that there were an estimated 500,000 potentially avoidable admissions to acute care hospitals in Australia in 2002.[12]) These unnecessary hospitalisations can result in detrimental health consequences with hospitals posing greater risk of infection and falls for elderly people.[13]

Unnecessary hospitalisation and failure to respect people's care preferences are potentially avoidable through planning for future care that is done in a considered way involving the patient, their care team and, optimally, their family, carers and loved ones. Advance care planning provides the opportunity for the people's care preferences to be clearly articulated and to enhance their choices and control over their care at the end of life.

In reality the provision of care that accords with people's preferences is often hindered by failure to discuss and implement advance care plans. For many patients, whether or not they are even aware of this option is dependent on their care location and care provider. In practice, advance care plans are often disregarded in acute care and other hospital settings, particularly if the patient is transitioning from an alternate care setting and care plans are not relayed, but also if the care plan does not accord with the service provider's care protocols. For the patient this can mean unwanted 'heroic' care interventions to extend life with little consideration of its quality. It also results in unnecessary and unwanted hospitalisations.

There is currently planning underway to integrate advance care planning into Australian health systems. This will involve tackling the different legal nature of advance care plans and directives in different State/territory jurisdictions, and promoting the concept among consumers as well as health professionals.

Earlier this year, the Australian Health Ministers' Advisory Council (AHMAC) – the advisory body of senior officials to the Australian Health Ministers' Conference (AHMC) agreed "to progress the development of nationally consistent guidelines for advance care directives and related issues concerning end of life medical decisions by health professionals through the Clinical, Technical and Ethical Principal Committee."

PCA supports moves and initiatives which will move the national implementation of the advance care planning agenda forward.

4.3 Current national initiatives to enhance end of life care

The National Palliative Care Strategy was endorsed by AHMC in 2000. This informed the investment in palliative care development under the National Palliative Care Program, which includes a range of initiatives that have significant potential to contribute to the realisation of health

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[12] J. Glover et al.2007. *Atlas of Avoidable Hospitalisations in Australia: ambulatory care-sensitive conditions.* Australian Institute of Health and Welfare. Canberra.
[13] ibid.

reform.

The 13 *Standards for Providing Quality Palliative Care for all Australians*[14] define the standard of care that all Australians should be able to expect. A major project, the National Standards Assessment Program, is now underway to establish a self assessment and service level quality improvement program for specialist palliative care services. Importantly, this program will be applicable across all primary care settings in the future.

The NHMRC-endorsed Guidelines for a palliative approach in residential aged care facilities set out both the intent and processes behind assuring quality care at the end of life for this care setting. The Guidelines have been introduced to all residential aged care facilities (RACFs), including indigenous facilities. Work is currently underway in capability building the general practice and specialist palliative care linkages with RACFs. This work has highlighted the challenges of quality care where workforce, service integration and training issues present major barriers.

The Palliative Care Outcomes Collaboration (PCOC) is a collaborative data collection program which tracks and compares clinical activity related to individual patients and will enable benchmarking across services. Together with the work of the National Standards Assessment Program these initiatives form the foundation for performance measuring quality care.

5 A vision for quality care at the end of life

Achieving sustainable effective reform to better meet the needs of those at the end of life requires a vision of quality care at the end of life and a commitment to action to achieve it. PCA advocates a vision for quality care at the end of life that:

- is driven by a commitment of quality care to patients delivered upon the promise of evidence-based care, customised to preferences, with good symptom control, future planning to avoid surprises, and which employs holistic care to support patients, their families and carers, to live life fully despite the constraints of illness;
- is committed to structuring ongoing quality improvement in care systems;
- considers all characteristic trajectories of end of life (rather than simply the traditionally-considered 'cancer trajectory') as the starting point for planning resource allocation and alignment in acknowledging the necessity of a needs-based approach;
- reorients thinking to conceive of the 'supported' home as a primary place of end of life care, without limiting access to acute services for those who require them;
- recognises that the investment in better end of life care works to prevent adverse physical, social and psychological morbidity in patients as well as their families and carers; and
- recognises the imperative of workforce development for all end of life care providers, including volunteers, family care givers and professional care givers.

6 Needs-based service delivery

It is imperative to recognise that 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. The end of life

[14] PCA 2005. *Standards for providing quality palliative care for all Australians*.

population is not a homogenous population group and a commitment to needs-based service delivery must meet each person's level of need.

In practical terms, Palliative Care Australia proposes, for the purposes of population based service planning, that all people at the end of life (including their family, caregiver/s and community) be conceptualised as falling within three broad subgroups – those whose care needs can be categorised as:

- complex, or
- intermediate, or
- appropriately addressed through primary care services.

The largest sub-group in the end of life population can have their needs met either through their own resources or with the support of primary care providers (for example generalist medical and nursing services as well as other specialist staff – oncologists, cardiac services, geriatricians and so on). Currently, almost two-thirds of all people whose death is expected fall within this group.

PCA estimates that under a third of people in the end of life population are currently seen by specialist palliative care services. While these people's care needs can be categorised as either intermediate or complex, it is not known how they are proportionally distributed between these groups.

Those people with 'intermediate' care needs may have sporadic exacerbations of pain or other physical symptoms or may experience social or emotional distress. This temporary increase in their level of need may require access to specialist palliative care services for consultation and advice, but they will continue to receive care from their primary care provider. A smaller proportion of people have complex physical, social, psychological and/or spiritual needs that do not respond to simple or established protocols of care. They usually require highly individualised care plans developed, implemented and evaluated by knowledgeable and skilled specialist palliative care practitioners, in partnership with primary care providers.

It is vital to reform of the health system that incorporates end of life needs that this be build around a needs-based service delivery model.

7 Key opportunities for shaping reform to effectively meet end of life needs

The vision of quality care at the end of life outlined above will require systems based solutions. The NHHRC has committed itself to addressing 12 key challenges to the health and healthcare system. These challenges cannot be understood in isolation but impact and inform one another – their solutions must likewise do so.

Meeting the challenge to "care for and respect the needs of people at the end of life" will require action against all 12 challenges. Each such action can contribute to meeting all 12 challenges.

PCA outlines below five key opportunities to progress action to meet the challenge of "caring for and respecting the needs of people at the end of life." These are not the only opportunities to advance action against this key challenge, but realising them would provide a solid foundation toward achieving greater access to quality care at the end of life.

We will be pleased to assist the Commission in this, both through formal and informal consultations, and possibly research. We look forward to discussing these opportunities with the Commission.

7.1 Resourcing dying in-place

Hospitalisation, other than in a dedicated specialist palliative care service that may be co-located with an acute care setting, 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.[15]

Supporting dying-in place promises to better meet patients' care needs and preferences, and to save unnecessary demand for, and expenditure on, hospitalisation and associated transitions.

As part of the Department of Health and Ageing's National Palliative Care Program, evidence-based guidelines for a palliative approach in residential aged care[16] have been developed. Guidelines for a palliative approach for aged care in the community are currently under community consultation. Access to care in these settings that meets these guidelines will require systemic change.

Supporting the home – however described – as an appropriate place of choice for end of life care will require a re-prioritising in resource distribution to support enhanced coordination of service provision through community care. This must be accompanied by:

- reform to the Medicare Benefits Schedule (MBS) items to help ensure affordable in-home access to a multidisciplinary team of care providers including allied health professionals;
- adjustment to Pharmaceutical Benefits Scheme (PBS) prescribing criteria to remove barriers to general practitioners and other primary care providers prescribing appropriate, affordable pain and symptom management drugs;
- introducing a framework for better coordination of the delivery of end of life care to patients to minimise the impact of service barriers;
- increasing access to in-home support, including access to 24/7 on call support and support for carers;
- increasing access to respite care as required; and
- increasing recognition of and service development for post-death bereavement care for families and carers.

Supporting aged care facilities to work towards policies of adequately resourced dying in-place will require aged care facilities to be additionally resourced to provide appropriate palliation, pain and symptom relief. This demands:

- workforce development plans for the aged care sector that include end of life care needs and competencies, including appropriate access to general practitioners, nurses who can administer opioids, and to palliative care specialists;
- securing access to PBS-subsidised medicines for residents of aged care facilities;
- development of agreed and consistent referral and access criteria to specialist palliative care services for residents of aged care facilities and services;
- structuring and resourcing palliative care services so that they are able to provide care and

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[15] J. Glover. 2006. 'Avoidable hospitalisations: A national map of who is affected.' *The Australian Health Consumer*, No. 2 2006-2007; 14-15.
[16] *Guidelines for a Palliative Approach for Residential Aged Care Facilities*. NHMRC Endorsed 2006.

support primary health care providers consistently in this setting; and,

- options for coordinating management of pain and symptom relief pharmaceuticals through e-prescribing and tailored quality use of medicine software packages.

7.2 Realise continuity of care through greater service integration

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 and from an array of providers for people with end of life care needs, to ensure that mechanisms are in place to support seamless transitions at all key transition in the health and care systems;
- orienting funding and resource systems to provide greater integration, including through associating performance indicators for service collaboration with healthcare funding;
- training and education of the healthcare workforce must be predicated on an acknowledgement of the broad integration of end of life care across health services;
- implementing targeted clinical partnerships between palliative care specialist units and aged and chronic disease care specialities; and
- developing protocols for shared and integrated, rather than unilateral models.

There are examples of good interdisciplinary end of life care, well integrated with primary, chronic, and acute care, being provided within the microcosms of particular service providers.

For example, Calvary Health Care Bethlehem (CHCB) in Caulfield South in suburban Melbourne delivers care through its inpatient unit, community palliative care service, outpatient and day centres. This model enables seamless care delivery to patients and their families/carers as they move thought the various care settings. In all areas the team works in collaboration with the patient’s general practitioner, medical specialists and other health professionals or services to ensure optimal care delivery.

Palliative care at CHCB is provided by an interdisciplinary team with expertise in complex pain and symptom management, functional restoration, loss, grief and bereavement.

In addition to people diagnosed with cancer, palliative care is also provided to those suffering from neurodegenerative diseases (including Multiple Sclerosis, Motor Neurone Disease or Huntington’s disease, Parkinsonian syndromes, and other degenerative or inherited diseases of the nervous system), and advanced organ failure such as heart, lung or kidney failure.

PCA urges the Commission to consider these good examples of seamless care delivery as part of its road map for overall reform of the health system. We would be pleased to work with the Commission in looking at other examples, and examining the whys and hows of the success of these services, and developing the road map for transporting this model to the whole health service in Australia.

7.3 Ensuring a sustainable and resourced workforce

Shortages of adequately skilled health workers across all care settings are central to current limitations to broad access to needs-based palliative 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. Inadequate links to and resourcing of specialist palliative care services compound the difficulties in ensuring that care needs are met.

There is opportunity to begin addressing deficiencies by:

- promoting and valuing quality care at the end of life skills in health care staff working across all health care settings, including through the incorporation of end of life care into the core curricula of health and social workers and as a fundamental component of continuing education for health and social service providers;
- increasing educational opportunities for clinical staff to develop or further skills to support the provision of quality care at the end of life;
- developing and creating additional funded education and training opportunities in palliative care across Australia in nursing, medicine and allied health;
- working to ensure a sustainable workforce by attracting staff and health professionals to work in palliative care through competitive remuneration and conditions;
- facilitating health care services to support working practices that allow staff to most effectively use their skills to provide quality care at the end of life, including dedicating sufficient time to patients and their carers; and
- ensuring workforce development plans for residential aged care facilities are established that are inclusive of end of life care needs, and recognising the necessity of ensuring access to health professionals who are qualified to prescribe and administer pain and symptom relief; and
- recognising the role of the volunteer workforce in community and service based end of life care.

7.4 Coordinating advance care planning

PCA advocates that Australia as a nation embrace end of life planning as a way to improve the circumstances of dying.

Advance care plans provide a mechanism to better meet people’s needs. They offer terminally ill patients the opportunity to be empowered to take control of the conditions of their care. Further, advance care plans, in stipulating the preferred condition for care of the patient, provide a mechanism for limiting unnecessary and unwanted hospitalisations to provide unwanted care or interventions.

Yet, as noted above, advance care plans are currently poorly understood by the general public, implementation can be ad hoc and piecemeal, and adherence is not guaranteed. Broader application and implementation of advance care planning will require greater awareness and knowledge among treating practitioners to support the development of advance care plans, greater coordination across and among service providers to support the effective implementation of advance care plans, and enhanced community understanding of advance care plans.

Keys to achieving greater implementation of advance care planning include:

- a nationally coordinated communication plan to enhance community understanding and generate the community will to commit to integrating advance care plans into end of life care in a considered and sensitive way;
- education for healthcare practitioners across settings to increase awareness of advance care plans and to aid their development, identification and implementation; and
- a nationally coordinated system for identifying patients with advance care plans wherever they may receive care.

7.5 Better facilitate continual quality improvement in end of life care standards across the healthcare system

An opportunity exists to ensure the integration of the two existing quality improvement and performance measurement programs into health reform for end of life. These are the National Standards Assessment Program (NSAP) and the Palliative Care Outcomes Collaboration (PCOC). Implementation of the national palliative care standards across all primary and specialist care areas will support many of the reform objectives of the Commission.

Developed in 2005 through a national consultation process with consumers and health professionals in primary and specialist care areas, the PCA palliative care standards[17] and their policy framework[18] recognise and provide direction for delivery of care that supports respect for patient choice and rights, continuity of care, universal and equitable access to care based on needs and recognition of the needs of the whole person. NSAP has the potential when fully implemented across the health system to support implementation of quality improvement initiatives supporting reform objectives and to collect comprehensive and reliable performance data to support effectiveness and outcome evaluation.

8 End of life and measuring performance of the Australian Health Care Agreements

Palliative Care Australia welcomes the NHHRC's commitment to extending the scope of the Australian Health Care Agreements (AHCAs) beyond their traditional focus on ensuring free public treatment in hospitals to a wider ambit, involving additional primary health care services, including allied health and community health services.

Linking acute and primary care services with clear accountability structures is welcomed as a much needed opportunity to ensure reform targets are met across the health system.

8.1 Performance indicators against the AHCAs

Palliative Care Australia has been in consultation with the Australian Institute of Health and Welfare (AIHW) regarding their role in developing performance indicators against the next Australian Health Care Agreements. We welcome the AIHW's draft indicators with particular relevance to end of life care services:

- differential rates for community-based palliative care services per 1,000 population: by indigenous status, remoteness of residence and socio-economic status; and
- number of emergency department visits and hospital days in the last 30 days of life per person.

PCA has advised the AIHW that the following additional indicators would provide for a potential suite of indicators for real measurement of performance of reforms directed toward achieving access to quality care at the end of life that is centred on meeting needs and care preferences in a resource-efficient manner:

- waiting time from referral to palliative care assessment at 90th percentile;
- number of palliative care beds per 1000 population over the age of 65 years;
- proportion of patients in all care settings with evidence of an advance care plan; and

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[17] PCA (2005) *Standards for Providing Quality Palliative Care for all Australians.*
[18] PCA (2005) *A Guide to Palliative Care Service Development: A population based approach.*

- measure of average waiting time for admission to home care services for palliative care.

Enhancing data collection systems to properly identify palliative care services is likely to be a necessity to ensure an accurate understanding of palliative care service provision. PCA believes that a unique patient identifier for end of life will better enable data collection on health service utilisation across care settings.

Currently both PCOC and NSAP provide, and are further developing as mechanisms, measure performance of specialist palliative care providers. They offer the opportunity to be developed as tools for the measurement of standards across all end of life care settings.

8.2 Performance benchmarks and the end of life care challenge

While many of the performance benchmarks proposed by the NHHRC pertain to the achievement of quality care at the end of life, a number are of particular specific relevance:

- potentially preventable hospital admissions per 1000 population;
- patient experience with being treated with dignity;
- proportion of patients aged 65 years and over who are discharged from an emergency department to home/nursing home who have evidence of communication back to relevant primary health care system;
- family experience with (end of life) care process; and
- number of emergency department visits and hospital says in last 30 days of life.

These speak to:

- the effectiveness of care systems supporting dying-in place and limiting unnecessary hospitalisations;
- the coordination of end of life care across service providers; and
- the patients' and families' experience of the end of life journey.

Palliative Care Australia acknowledges these as key measures of the impact of reforms to achieve needs-based end of life care that promotes service integration and seeks to uphold patients' preferences and conserve resources by supporting of dying-in place. We strongly urge the NHHRC to maintain these benchmarks.

Advance care planning

We further ask the Commission to consider promoting accountability through the introduction of a performance benchmark measuring advance care planning. Measuring the uptake and implementation of advance care plans, such as the "proportion of patients in residential care facilities with evidence of an advance care plan" would provides a critical measure of the degree to which patients and their care preferences are being centralised in the care process. This would need to be done in a way that protects people's rights not to have an advance care plan should they choose.

Advance care planning should be centralised as a critical element in reform to achieve efficient consumer-centred care as it offers an opportunity to uphold the patient's preferences in circumstances where their capacity for control over their own destiny is virtually lost, and does so in a way that promises to reduce resource wastage through unnecessary hospitalisations and unnecessary interventions.

Yet advance care planning is not widely understood across the healthcare system and its uptake will require initiatives such as benchmarks to generate the will to engage with what we believe must be a critical element of healthcare reform. Localising this benchmark to residential care facilities provides for resources to be rolled out to support the effective implementation of advance care plans in this setting.

Importantly, the Federal Government has demonstrated initial commitment to advance care planning as a critical process in people-centred care through funding the Respecting Patient Choices program through the National Palliative Care Program to undertake research. As noted above all States and Territories have recently demonstrated a commitment, through AHMAC, to move to reduce the divergence between the laws governing advance directives in Australia.

9 Key recommendations

PCA welcomes the NHHRC's acknowledgement of "*care for and respect of the needs of people at the end of life*" as a key challenge confronting the healthcare system. Meeting this challenge will require a needs-based approach to service planning and service delivery, which acknowledges that people at the end of life have heterogenous needs that may be varyingly met through complex, intermediate or primary care services.

PCA recommends the following key initial steps towards realising a healthcare system that can promise access to people-centred quality care at the end of life:

1. Acknowledge hospitalisation as inappropriate for many people at the end of life, and thus a potential indicator of sub optimal care, and reorient resources and care delivery systems to support people to die in-place.

2. Introduce systems for a coordinated approach to advance care planning that includes a social marketing component to engender greater community understanding of the centrality of advance care planning to achieving patient-centred end of life care.

3. Address workforce shortages, which have been associated with sub-optimal pain relief and unnecessary and unwanted hospitalisations, by increasing education opportunities in palliative medicine for clinicians and in palliative care for health and allied health care workers, particularly those working in community care.

4. Ensure workforce development plans for residential aged care facilities are established that are inclusive of end of life care needs, as a key measure toward supporting dying in-place for residential aged care facilities and reducing the impact of unnecessary transfers and hospitalisations.

5. Realise continuity of care through greater service integration by integrating existing resources and systems to provide for coordinated case management systems and orienting funding and resource systems toward integration.

6. Invest in the systems, including performance benchmarking and quality improvement, that ensure timely access to specialist palliative care services as required and in accordance with a population **needs-based service provision framework**. This includes the recognition of the significant health outcomes gained through a focus on the patient, family and carers as the "unit of care", before, during and after death.

7. To promote and measure reform that implements these actions, PCA recommends that the performance benchmarks proposed by the NHHRC with particular relevance to end of life care are retained.

8. The significance of advance care planning to respecting end of life care preferences is acknowledged through a performance benchmark associated with advance care planning within the renegotiated Australian Health Care Agreements.

9. PCA further recommends that the NHHRC continue to consult with PCA, and with the collaboration of end of life care stakeholders that PCA is championing, regarding policy and reform to achieve greater access to quality, needs-based care at the end of life.