

**DEVELOPING A NEW REALITY FOR QUALITY CARE AT THE END OF LIFE:
A MEANS TO A BETTER END**

SUBMISSION TO NATIONAL PRIMARY HEALTH CARE STRATEGY



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DEVELOPING A NEW REALITY FOR QUALITY CARE AT THE END OF LIFE: A MEANS TO A BETTER END

Introduction

Palliative Care Australia (PCA) is the national peak body representing the collective membership of eight state and territory palliative care organisations and the Australian and New Zealand Society of Palliative Medicine. The mission of the organisation is to foster, influence and promote local and national endeavours to realise the vision of quality care at the end of life for all.¹

PCA agrees that all Australians should have access to primary health care services which keep people well and manage ill-health. We note the 10 key elements identified in the discussion paper *Towards a National Primary Health Care Strategy*.

A National Primary Health Care Strategy should recognise that it is important that every Australian has the opportunity to be born well, to develop well, to live well and to die well. It should recognise the breadth of primary health care from pre-conception to post-death including bereavement, and therefore should provide for appropriate palliative care when death is inevitable.

Historical background

With the increasing ability to identify, treat and cure disease, there has been an increasing focus on cure, with an increasing expectation of cure. Prior to the middle part of last century, death and dying were integral parts of primary health care.

Palliative care services emerged over the last 30 years to fill the space left by the emphasis on 'curative' treatment. As a result there has been an increasing trend for primary health care to refer, rather than manage end of life care, and as a consequence a reduction in both competencies and recognition of the role of primary care.

Current situation and the road ahead

PCA welcomes the development of a National Primary Health Care Strategy, and the opportunity to stress that quality end of life care is, and should be, part of the normal scope of practice of all primary health care professionals and services. This is not always the case.

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

Primary health care is the basis of our health system and needs more resources. The primary health care system, as the first and continual point of contact, and in many cases the coordinator of and key link in multidisciplinary health services, is integral to enhancing quality care at the end of life both for patients, and importantly their families.

The Australian Government's National Palliative Care Strategy has worked since 2000 to raise

¹ The following definitions of end of life, end of life care and palliative care are used throughout this submission. Source: Palliative Care Australia (PCA), *Palliative and End of Life Care – Glossary of Terms*, PCA, Canberra, 2008.

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 combines the broad set of health and community services that care for the population at the end of their life. Quality end of life care is realised when strong networks exist between specialist palliative care providers, primary generalist providers, primary specialists, and support care providers and the community – working together to meet the needs of the 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 goal is quality of life.

awareness of palliative care, improve the understanding and availability of services across Australia, and encourage discussion to support improved capability and capacity network.

The National Palliative Care Strategy has been vitally important in improving 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 and end of life care integration across the health system;
- defining the end of life population and their characteristic care needs; and
- meeting consumer needs, preferences and expectations.

Ensuring a more integrated, less ad hoc, communications strategy for the different programs and projects that come under the National Palliative Care Strategy will help ensure that the Australian community gets a clearer picture of the issues that confront us in death and dying, and of the services available.

As the current National Palliative Care Program is coming to a close in July 2010, it is vital that the funding of quality end of life care be made sustainable.

There are barriers which currently prevent people from being able to receive quality end of life care. Many people with terminal conditions must currently go to hospital just to receive pain relief and symptom management. Many – perhaps most – of these terminally ill people die in hospital, when in most cases they neither need nor desire acute care beds. They spend their last days or months in hospital, unnecessarily occupying these highly expensive acute care beds, when the option of quality primary health care, with the appropriate skills and resources, is what is needed.

Now is the time for us as a society to rethink the paradigm of health and care options for people with complex, chronic, and terminal conditions. A health service delivery model which integrates primary health care with specialist palliative care and other specialist services could work to provide much needed services, and be more cost-effective than the current arrangements.

Meeting the needs of all patients demands a vision of quality care and the will to confront the barriers to its implementation. Poor integration of services and alignment of resources across the health care system present a major hurdle on the road to quality end of life services. PCA believes that a health care system that can promise access to reliable, evidence-based, end of life care that accords with patients' preferences should be a key component of a National Primary Health Care Strategy.

The National Health and Hospitals Reform Commission's (NHHRC) interim report released on 16 February 2009 identifies *Caring for people at the end of life* as a key health reform area within their *Connecting care* theme. A key message in the report is that "Of the 130,000 people who die each year, many will be able to be supported prior to their death by generalist health professionals – their general practitioner or other primary health care professionals such as community nurses."

The Government's health reform agenda offers the prospect of a means to a better end, if opportunities are seized. PCA looks forward to engaging with the two major reform strategies towards meeting the challenge of quality care that is fully integrated across all care settings.



Donna Daniell
Chief Executive Officer
Palliative Care Australia
27 February 2009

Key element 1: All Australians should have access to primary health care services which keep people well and manage ill-health by being accessible, clinically and culturally appropriate, timely and affordable

Palliative Care Australia supports this key element. It is consistent with both the principles outlined in the *Guide to Palliative Care Service Development: A population based approach*² developed and published by PCA in 2005 and the *Standards for Providing Quality Palliative Care for all Australians*³. These national Standards incorporate criteria for primary care services.

We believe there are significant gains to be made in terms of quality of care and outcomes for all Australians at the end of life through greater engagement and recognition of the role of primary care services and professionals. The great majority of people with a life limiting illness spend most of their time at home being cared for by families, friends and primary care services.⁴ Not all these people will have adequate access to skilled primary care providers resulting in often inappropriate and unnecessary acute care admission and treatment.

Quality care at the end of life is realised when strong networks exist between specialist palliative care providers, primary care providers, other specialists, families and the community working together. It is most efficiently and effectively achieved in accordance with a needs-based service delivery model that acknowledges that patients have different needs that may change over time and is responsive to those needs.

There are significant barriers to the provision of accessible, clinically and culturally appropriate, timely and affordable care at the end of life within the primary care sector. These include:

- workforce shortages that inhibit access to quality care in the home from members of an appropriate multi-disciplinary team;
- workforce skills in the provision of high quality end of life care
- limited access to general practitioners and other primary care providers required to ensure pain and symptom relief is administered in a timely manner;
- limitations in access to respite for carers who often experience fatigue and burnout;
- restrictions of the Medicare Benefits Schedule (MBS) items that act as a barrier to affordable, in-home access to a multidisciplinary team of care providers;
- Pharmaceutical Benefits Scheme (PBS) prescribing criteria that limit access to general practitioners and other primary care providers to medicines which have demonstrated efficacy in pain and symptom management at the end of life; and
- The reluctance of many private health insurance funds to offer non-hospital-based palliative care options which make it difficult for primary care providers to develop and offer integrated services at the end of life.

In addition many families experience a considerable financial burden when providing end of life care at home, particularly in relation to the cost and availability of medicines. The current safety net thresholds are often too high to be of benefit to patients at the end of life meaning that many will not be able to access concessional MBS and PBS co-payments. This represents a financial burden that may make home care unaffordable for some families.

Residential aged care facilities are increasingly the place of death for people with terminal

² PCA (2005) A Guide to Palliative Care service Development: A population based approach

³ PCA (2005) Standards for providing quality palliative care for all Australians

⁴ Rhodes P & Shaw S. (1999) Informal care and terminal illness. 'Health Soc.Care Community 7: pp39-50

conditions, unless residents are transferred to acute care facilities. Accordingly, end of life care should be recognised as part of the normal scope of practice of both residential and community aged care services. We refer under Key element 5 to the *Guidelines for a Palliative Approach in Residential Aged Care* (launched in 2004) and the *Guidelines for a Palliative Approach for Aged Care in the Community Setting* (currently being developed).

Access to, and the quality of, end of life care is diverse and inconsistent in both residential and community aged care. Some aged care services enjoy ready access to primary care physicians well skilled in palliative care, and to specialist palliative care physicians. Some residential aged care facilities, particularly high care facilities, do have effective systems in place to limit hospitalisations by providing care in-place. Overall, though, more needs to be done to make residential aged care facilities culturally sensitive to the care needs of people with terminal conditions.

Supporting all aged care services to work towards providing quality end-of-life care will require additional resources to enable aged care facilities to provide appropriate palliation, pain and symptom relief.

This will include: appropriate access to general practitioners, to palliative care specialists under agreed and consistent referral and access criteria, and to nurses who can administer opioids. It will also include access to PBS-subsidised palliative medicines for residents of aged care facilities, and the structuring and resourcing of specialist palliative care services so that they are able to provide care and consistent support for primary health care providers in the residential aged care setting.

There are barriers, including inadequate pain relief and symptom management, in residential aged care facilities preventing people being able to receive quality end of life care. PCA calls for the introduction of systems for coordinating the management of pain and symptom relief for residents in residential aged care facilities that address limitations in who can prescribe and administer medication to ensure residents' care needs are met in a timely and ongoing manner.

Recommendations

1. That the National Primary Health Care Strategy recognise, and has demonstrable links with other supporting strategies, including the national palliative care strategy.
2. That the National Primary Health Care Strategy support waiving the Medicare Benefits Scheme (MBS) and Pharmaceutical Benefits Schedule (PBS) safety net thresholds for people at the end of life. This will enable immediate access to the concessional MBS and PBS copayments, and thus relieve the cost burden for people with terminal conditions.
3. That the National Primary Health Care Strategy support moves to enable consumers real choice of the provision of home based palliative care services and the coverage of these services under private health insurance products.
4. That the National Primary Health Care Strategy recognise the need for residential aged care facilities to have better links with primary care services to address the need for seamless care, including support for aged care services to develop and implement workforce and service development plans that acknowledge their end of life care responsibilities as part of needs-based service provision. This is likely to require increased levels of staffing with practitioners who can prescribe and administer pain and symptom management drugs.

Key element 2: All Australians should have access to primary health care services which keep people well and manage ill-health by being patient-centred and supportive of health literacy, self-management and individual preference

PCA supports key element 2 and believes that quality care at the end of life is necessarily patient-centred and incorporates the principles of self management and individual preference. The involvement of patients and their families in all aspects of care from decision-making through to the provision of direct care has long been a cornerstone of palliative and end of life care and is reflected in the national Standards.

Patient and family needs are as important as individual preference in determining access to primary and specialist services at the end of life. Needs based care ensures that patients and their families receive the right care, in the right place, at the right time and from the right person. Community capacity building strategies that work to improve health literacy, especially in relation to chronic and complex conditions and end of life can do much to contribute to self management and participation in decision-making and care. Palliative Care Australia has undertaken work to outline a range of strategies to support national capacity building in regard to end of life. The Community Capacity Building Working Group provides advice with regard to primary care providers and their role in enabling communities to increase their control of the health of their member, including the maintenance of independence and choice.⁵

Advance care planning provides the mechanism by which services can clearly communicate with patients about their needs and preferences for care at the end of life. Advance care planning should be considered as an ongoing conversation between the individual, their care team and as appropriate their family, significant others and carers. Facilitating end of life discussions and supporting and engaging in advance care planning is the responsibility of both health care providers and individuals. While primary health care professionals need to accept their responsibilities in this area, we need to recognise that it is not the exclusive domain of any particular health care sector or setting. The systemic challenge is to ensure that advance care plans are communicated across the health care sector and follow the patient as they move from one care provider to another.

A 1800 national helpline number could also help ensure improvements in access to quality care at the end of life.

Recommendations

5. That the National Primary Health Care Strategy formalises strategies to influence the development of healthy public policy that:
 - affirms death as part of life and seeks to support the enhancement of life skills through personal and social development;
 - actively supports those who are dying, their families and their carers;
 - informs the Australian community about all aspects of quality care at the end of life;
 - accepts quality care at the end of life as a basic human right;
 - allocates sufficient resources to enable access to quality end of life care (including primary care and specialist palliative care) for all, in accordance with PCA's population needs-based policy.
6. That the National Primary Health Care Strategy integrates strategies and initiatives to promote and support best practice in advance care planning.

⁵ PCA (2007). Community Capacity Building Working Party Final Report (unpublished).

Key element 3: All Australians should have access to primary health care services which keep people well and manage ill-health by being more focussed on preventive care, including support of healthy lifestyles

Key Element 3 is supported and reflects work already undertaken within the palliative care sector to incorporate health promoting principles and supportive policy at the end of life⁶.

Both palliative care and health promotion emerged from concerns that the overemphasis in mainstream health care on disease and its diagnosis, treatment and cure fails to adequately embrace the complexity of the experience of illness, including in the case of palliative care, the experience of dying.

Health promoting palliative care is a therapeutic concept first described by Kellehear in 1999 and later expanded by him into a model for practice.⁷ Much of the distress experienced at the end of life is socially constructed through discourses that privilege curative, mainstream medical narratives and that deny death and indeed ageing.⁸

Kellehear suggesting that the application of the principles of health promotion to end of life care could be of benefit to dying people, their families, and society more broadly. He argues that a health promoting focus on issues of death and dying and in the provision of care at the end of life may prevent avoidable morbidity in individuals, families, communities and societies as a whole.

Engaging health promotion and primary health care services in the implementation of strategies to support preventative and health promoting care at the end of life will reap benefits in terms of patient and family outcomes and potentially reduce costs associated with the treatment of avoidable morbidity associated with bereavement and loss.

Recommendation

7. That the National Primary Health Care Strategy engage with Palliative Care Australia and other key stakeholders to further explore the alignment of health promotion and palliative care philosophies towards building the community's capacity to support those whose lives are ending.

⁶ ibid

⁷ Kellehear, A. (1999a) *Health Promoting Palliative Care*. Melbourne, Oxford University Press.

Kellehear, A. (1999b) 'Health promoting palliative care: developing a model for practice' *Mortality* 4 (1), 75-82.

Kellehear, A. (2005) *Compassionate Cities: public health and end of life care*, London, Routledge

⁸ Scott, JF (1992) Palliative care education in Canada: attacking fear and promoting health. *Journal of Palliative Care*, 8 (1) 47-53

Key element 4: All Australians should have access to primary health care services which keep people well and manage ill-health by being well-integrated, coordinated, and providing continuity of care, particularly for those with multiple, ongoing, and complex conditions

PCA supports key element 4. Our policy document *A Guide to palliative care service development: A population based approach*⁹ outlines a framework for well-integrated, coordinated care at the end of life for all Australians. This framework outlines the important role of primary care providers in the provision of end of life care and seeks to ensure continuity of care for patients with chronic and complex conditions.

As the Australian population continues to age, an increasing number of Australians live the final stages of their life with chronic, complex conditions. The projected growth in the absolute and relative numbers of people who will require care at the end of life underlines the necessity of developing an approach to end of life care that prioritises quality care and promotes broad access through the efficient use of resources.

Achieving improved outcomes will require a “whole of health” system approach to redesign that builds a base of well-coordinated and adequately resourced primary care providers with well integrated access to specialist palliative care providers.

Primary care providers need to manage the end of life care needs of their patients, and to work in consultation with specialist palliative care and other specialist providers to meet the needs of patients whose needs may be complex. This necessarily requires primary care providers to have adequate skills, training and education, and established relationships with specialist palliative care providers.

PCA welcomes the National Health and Hospitals Reform Commission’s identification of *care for and respect of the needs of people at the end of life* as a key health reform area.¹⁰ We believe that the recognition of the importance of quality care at the end of life at a whole of health system level provides significant opportunities for better integration and care coordination between primary care and specialist services.

There is growing international evidence and support for the view that getting end of life care right is a significant requirement for the overall reform of health care systems. Health system reforms in the UK, Scotland, Ireland and the US all emphasise the important role that primary care services play in the provision of quality care at the end of life.

The results of a recent BMJ (British Medical Journal) Group “Making a Difference” international poll has found that “palliative care for all would make the greatest difference to health care.”¹¹

The capacity of the current health system to provide access to quality care at the end of life for all Australians who may require it is questionable.¹² This is particularly true for patients with chronic and complex care needs, for example for people with dementia.¹³ Issues like communication difficulties, nutrition/hydration approaches and under-recognition of pain may be particularly

⁹ Palliative Care Australia (2005). *A Guide to Palliative Service Development: A population based approach*, Canberra

¹⁰ National Health and Hospitals Reform Commission (NHHRC, 2009). *A Healthier Future For All Australians – Interim Report December 2008*, Canberra. (<http://www.nhhrc.org.au/internet/nhhrc/publishing.nsf/Content/interim-report-december-2008>)

¹¹ <http://makingadifference.bmj.com/>

¹² Palliative Care Australia, *End of life care is everyone’s affair - tackling the challenge of end of life: PCA submission to the National Health and Hospitals Reform Commission*, PCA, Canberra, 2008.

¹³ Alzheimer’s Australia (2006), ‘Palliative care and dementia’ downloaded from <http://www.alzheimers.org.au/upload/PalliativeCare.pdf> on 17 June 2008.

problematic¹⁴. It has been estimated that the number of patients with dementia is expected to triple from 220,000 in 2007 to 730,000 in 2050.¹⁵

Primary health care services, particularly general practitioners and residential aged care facilities provide most of the care (along with families) for people with chronic and complex conditions including dementia. They need to be provided with adequate education, resources and support to enable them to provide well-coordinated, high quality care at the end of life.

Recommendations

8. That the National Primary Health Care Strategy integrate the following broad principles into the development of service planning, redesign and development:
 - recognising palliative care and end of life care as being vital for chronic disease specialities, care management and education;
 - recognising the need for effective linkages with and pathways to specialist palliative care and other specialist services;
 - resourcing chronic disease care to enable an effective end of life approach to care to be taken where appropriate;
 - introducing reform measures to ensure continuity of care, with appropriate linkages and referrals among different specialties, including population needs-based specialist palliative care services;
 - multidisciplinary work to develop an effective tool to help health practitioners to identify those requiring end of life care; and
 - providing resources and funds for the development and setting of performance measures for referral pathways for accessing specialist palliative care services as part of the National Healthcare Agreements.
9. That the National Primary Health Care Strategy seek engagement in the review of the National Palliative Care Strategy to ensure mutual alignment of the key elements to ensure that patients have access to seamless, well coordinated quality care at the end of life.
10. That the National Primary Health Care Strategy support funding to enable the establishment of a national alliance of organisations with an interest in chronic, ageing, disability, and quality care at the end of life issues.

¹⁴ Alzheimer's Australia (2006) *Palliative Care and Dementia*, <http://www.alzheimers.org.au/upload/PalliativeCare.pdf>

¹⁵ Access Economics (2005) Dementia estimates and projections: Australian states and territories, Report prepared for Alzheimer's Australia, at <http://www.alzheimers.org.au/content.cfm?infopaged=1926> cited in NHHRC Report – A Healthier Future for All Australians. (Chapter 7 page 186)

Key element 5: Service delivery arrangements should support safe, high quality care which is continually improving through relevant research and innovation

In Australia, approximately 130,000 people die each year.¹⁶ While the Australian Bureau of Statistics doesn't code cause of death data according to 'expected' and 'unexpected' deaths, PCA estimates 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.¹⁷

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. Better mechanisms to collect and analyse this data is imperative across acute, primary and specialist care sectors for ongoing service planning.

The Palliative Care National Standards Assessment Program (NSAP) aims to support health care services to engage in continuous quality improvement and move towards best practice, as established in the *Standards for Providing Quality Palliative Care for All Australians*. The NSAP is a robust national quality improvement program that incorporates self assessment and peer review activities that align with existing accreditation mechanisms. Through this program, PCA is developing resources that will support and enhance the ability of services to improve the quality of care within their existing quality improvement processes and accreditation cycles. The NSAP was planned in phases to ensure broad-based consultation, coordinated resource development, maximum participation, and sector engagement. The national roll out of NSAP will be launched on 11 March 2009 as a quality improvement tool that will enable services to monitor and implement improvement strategies. Following national roll-out of the program to specialist palliative care services it is intended that a module for use in the primary care sector will be developed and implemented based on the national palliative care standards for primary care providers.

The NSAP is funded by the Australian Government Department of Health and Ageing. It supports the policy goals set out in the National Palliative Care Program and the National Palliative Care Strategy.

Other tools have been developed and implemented to support the delivery of quality care at the end of life within the primary care setting. The *Guidelines for a Palliative Approach in Residential Aged Care* were launched in 2004 and distributed to every aged care home in Australia to help aged care team members to apply a 'palliative approach' in residential aged care facilities. An Enhanced Version was issued in May 2006 after endorsement by the National Health and Medical Research Council.¹⁸ PCA has been involved in substantial projects implementing these Guidelines, including production of a Resource Kit, assisting the development of training resources for Certificate III and Certificate IV competency units in a palliative approach, ongoing production of the Residential Aged Care Palliative Approach Network (RACPAN) Newsletter, and working with the Australian General Practice Network and Divisions of General Practice on the Engaging GPs' Support for the Implementation of the Guidelines for a Palliative Approach in Residential Aged Care project.

Guidelines for a Palliative Approach for Aged Care in the Community Setting are currently being developed. These 'ComPAC' guidelines aim to promote good practice in end of life care for elderly

¹⁶ 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.]

¹⁷ 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 condition. This figure is expected to be an under-estimation.

¹⁸ The National Palliative Care Program, Australian Government Department of Health and Ageing. *Guidelines for a Palliative Approach in Residential Aged Care* (APRAC Guidelines). Enhanced Version approved by National Health and Medical Research Council May 2006 <http://www.nhmrc.gov.au/publications/synopses/files/pc29.pdf>

people living in the community, and will thus be a vital tool for primary health care providers.

We would however like to caution against an over reliance on the development, publication and dissemination of guidelines as the primary mechanism for achieving practice change. The UK National Health Service (NHS) has reported that guidelines have a “miserable record in changing practice”.¹⁹ The NHMRC is currently undertaking a review of the production, dissemination and use of clinical guidelines in Australia.

The Palliative Care Outcomes Collaboration²⁰ (PCOC), coordinated through the Centre for Health Service Development, University of Wollongong, is a voluntary quality initiative funded by the Department of Health and Aging to provide data to support palliative care services improve practice. PCOC is a collaboration between four universities whose aim is to develop and support a national benchmarking system that will contribute to improved palliative care outcomes.

CareSearch Knowledge Network is an online resource of palliative care information and evidence for patients, families and clinicians seeking evidence-based information related to palliative care. The site provides systematic reviews of the literature, tutorials on how to access and interpret evidence and support for research and data collection.²¹

Closer alignment of these national palliative care quality improvement initiatives with each other and with similar initiatives in the primary care sector will provide a stable platform by which improvement in care at the end of life within the primary care setting can be supported and monitored.

Recommendation

11. That the National Primary Health Care Strategy support the development and introduction of research and data collection methods to help improve the quality of care by primary health care professionals in serving the end of life population.

¹⁹ Chidgey et al (2007) *Journal of the Royal Society of Medicine*: 100:448-52.

²⁰ http://chsd.uow.edu.au/pcoc/about_pcoc.html

²¹ <http://www.caresearch.com.au/Caresearch/Default.aspx>

Key element 6: Service delivery arrangements should support better management of health information, underpinned by efficient and effective use of eHealth

This element is supported. It is our view that eHealth would provide a great advantage in achieving the objective of quality care at the end of life for all Australians. Patient held medical records that can support continuity of care for patients and families will support better sharing of information, including patient wishes and advance care plan across care settings.

Clinicians and families report frustration with the repeated history taking, and disconnect in the sharing of vital information to support quality care. This interferes with effective delivery of care, e.g. between palliative care team members; the GP; other specialists; community nurses; domiciliary care, the pharmacist, and allied health professionals.

Recommendation

12. That the National Primary Health Care Strategy support the development of a national communication strategy under the National Palliative Care Strategy, targeting consumers, health professionals and community organisations, and including an 1800 national helpline number, to ensure coordination and consistency of information about palliative and end of life care, and advance care planning.

Key element 7: Service delivery arrangements should support flexibility to best respond to local community needs and circumstances through sustainable and efficient operational models

This element is supported. While some patients experience quality needs-based care, the reality for others is often one of fragmented care that fails to acknowledge patient and families care preferences and, too often, delivers insufficient support to meet social, emotional and physical needs at the end of life. At the centre of the needs-based approach to care provision is an acknowledgement of heterogeneous care needs at the end of life and a recognition that the end of life needs of many patients are appropriately met by primary care providers (generalist, and other specialist and support care), with specialist palliative care providers contributing direct, indirect care or consultation advice as required.²²

Existing service delivery arrangements are inadequately integrated to support seamless coordination of care as patients move between levels of care. States and Territory Departments of Health are in the process of implementing Palliative Care Role Delineation Frameworks as part of their palliative care policy to ensure clear, unambiguous and adequately resourced accountability for care at the end of life. These role delineation frameworks explicitly describe the role of primary care providers.

To support better integration and coordination of service delivery to respond to community needs palliative care is developing in many states regional consortia or networks to facilitate operational cohesiveness and integrated service planning. These regional planning groups incorporate primary health services to ensure vertical and well as horizontal alignment of services to meet patient needs. The NHHRC advocates in its interim report for the establishment of Comprehensive Primary Health Care Centres.²³ The alignment of these to the regional palliative care consortia/networks may offer opportunity for integration of specialist palliative care and primary care services.

Recommendation

13. That the National Primary Health Care Strategy work to support structural and procedural integration of specialist palliative care and primary health care providers to meet population needs-based end of life care.

²² Palliative Care Australia, *Palliative and End of Life Care - Glossary of Terms*, PCA, Canberra, 2008.

²³ NHHRC op cit

Key element 8: Supporting the primary health care workforce are working environments and conditions which attract, support and retain workforce

Primary care providers need to manage the end of life care needs of their patients , and to work in consultation with specialist palliative care providers to meet more complex needs that exceed the resources capability of the primary care sector. This requires primary care providers to have adequate skills, training and education and established relationships with specialist palliative care providers.

In addition, supporting more academic appointments in Primary Care would benefit teaching and research, and enhance career satisfaction for primary health care professionals.

Teamwork has been the basis of good palliative care since its inception. In palliative care we are very fortunate to work in a supportive team based environment which encourages career satisfaction. For many staff this is a great attraction. A spirit of teamwork and cooperation involving all health professionals, as well as the patients and their carers is vital to the effective provision of quality end of life care. Models of interdisciplinary teamwork developed in palliative care may be useful as a template for development in the primary care sector.

Recommendation

14. That the National Primary Health Care Strategy ensure adequate funding to provide equitable, needs-based access to allied health, nursing and supportive care to facilitate multidisciplinary care for patients receiving end of life care through primary care providers.

Key element 9: Supporting the primary health care workforce are high quality education and training arrangements for both new and existing workforce

A key element in providing quality needs-based end of life care is ensuring that those involved in the provision of end of life care, whether as primary or specialist palliative care providers, are equipped with the skills and resources to perform their roles effectively and safely.

The role of primary care providers includes assessment, triage, clinical management, referral to specialist palliative care providers where appropriate, and care coordination using a palliative approach for patients with end of life care needs.²⁴ Primary care providers thus require, as a core skill, the capacity to perform this role effectively.

In recent years the end of life care educational requirements of primary care providers have been increasingly acknowledged, most notably by the Palliative Care Curriculum for Undergraduates (PCC4U) Project, and projects designed to promote competency in end of life care among currently practising primary care workers in the aged care sector. The reach of these projects to date has been, understandably, limited. Notably, however, the PCC4U Project represents both a recognition of the necessity of undergraduate education in end of life care for all primary health care professionals, as well as steps towards achieving this goal. This project has been explicit in outlining the palliative care capabilities required by primary care health providers:

- effective communication in the context of an individual's responses to loss and grief, existential challenges, uncertainty and changing goals of care;
- appreciation of and respect for the diverse human and clinical responses of each individual throughout their illness trajectory;
- understanding of principles for assessment and management of clinical and supportive care needs;
- the capacity for reflection and self evaluation of one's professional and personal experiences and their cumulative impact on one's self and others.²⁵

Recommendation

15. That the National Primary Health Care Strategy implement strategic initiatives to ensure that primary health care providers have the required skills, competencies and knowledge to provide safe and effective end of life care to their patients,, and in particular to:
 - acknowledge end of life care as a basic core competency for primary health care workers that should be included in the core curricula of health worker education and as an element of ongoing training;
 - support the development of interdisciplinary education and training programs for primary care and specialist palliative care.

²⁴ Palliative Care Australia, *A Guide to Palliative Service Development*, 2005.

²⁵ Palliative Care Curriculum for Undergraduates Project Team, *Principles for including palliative care in undergraduate curricula*, Australian Government Department of Health and Ageing, Canberra, 2005.

Key element 10: Primary health care is fiscally sustainable, efficient and cost effective

Primary health care is the basis of our health system and needs more resources. The primary health care system, as the first point of contact, and in many cases the coordinator of and key link in multidisciplinary health services, is integral to enhancing quality care at the end of life.

Part of a primary health strategy should include an end of life strategy and must include the philosophy that underpins palliative care provision across the spectrum and the place of care. The proper resourcing and funding of specialist palliative care services to provide support for primary care providers is vital, and cost-effective, as part of the provision of care to individuals by all levels of care.

Now is the time for us as a society to rethink the paradigm of health and care options for people with complex, chronic, and terminal conditions. A health service delivery model which integrates primary health care with specialist palliative care services could work to provide much needed services, and could save money.

Good strategic planning around the management of care at the end of life promises better care for people and may 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 hospitalisation.

In accordance with the needs-based policy approach, consideration needs to be given to funding models based on anticipating needs against supply, and projecting service needs, at what level. We need to define end of life care needs, then undertake a whole of Australia assessment of where the population needs are, and what funding and resourcing is needed. Giving Palliative Care Services a regional responsibility for the provision of palliative care and giving the services the necessary funds to broker resources and to pay the GPs is a model that needs to be considered.

Recommendation

16. That the National Primary Health Care Strategy recognise that a health service delivery model which integrates primary health care with specialist palliative care and other specialist services could work to provide much needed services, and be more cost-effective than the current arrangements.