Calvary

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Submission to the Community Affairs Committee – Palliative Care in Australia Inquiry

Our submission

Little Company of Mary Health Care (LCMHC or Calvary) welcomes the opportunity to provide a submission to the Community Affairs Committee – Palliative Care in Australia Inquiry. This submission is based on input from our clinicians, managers, executive and other staff in thirty-one services across Australia.

Who are we?

The care of people who are dying has been a core mission for Calvary for more than 126 years in Australia. Calvary services, provided by LCMHC, operate on a not-for-profit basis in six states and territories in Australia – New South Wales, the Australian Capital Territory, Victoria, Tasmania, South Australia and the Northern Territory. The annual revenue of LCM Health Care is in excess of $1 billion. Calvary provides care to people approaching and reaching the end of life in public and private acute care hospitals, residential and community aged care services, rehabilitation services, specialist palliative care services, and community support services. Many of the services are provided in regional and rural areas. Palliative Care is not only driven by our mission and values but is also comprehensively guided and supported in the Code of Ethical Standards for Catholic Health and Aged Care in Australia.

The religious order of the Sisters of the Little Company of Mary provides health care services around the world. The order has an international specialisation in the provision of palliative care services. In Australia, LCM Health Care operates five major specialist palliative care services in the hospital and community sector and has significant educational and research linkages.

LCM Health Care is fundamentally concerned with ensuring that people who are marginalised and vulnerable have access to holistic, quality services. Its services include supporting indigenous communities, disadvantaged rural communities and people at risk of homelessness.

Providing care across jurisdictions provides us with a unique opportunity to see the variability that exists in state and territory policy, funding and strategy related to the provision of service to provide care to people approaching and reaching the end of life.

In the same way, as providers of care across service settings we have developed an insight into the barriers that exist to the implementation of person-centred, integrated models of care that cross service and system boundaries.

Introduction

The expansion of modern palliative care in Australia in the mid 1980's, in part due to Commonwealth Government Palliative Care Strategy funding, bought with it significant improvements in care at the end of life for an increasing number of palliative care patients. Access to specialist palliative care has been shown world wide to improve the experience of people at the end of life, and also to improve the experience for their families and carers. Despite this expansion of services currently across Australia only 1 in 5 people approaching the end of life are able to access care through a specialist palliative care team. There is much that still needs to be done to improve the care and support provided to all Australians at the end of life. Specialist palliative care services remain primarily focused on the care of

patients with cancer. In the latest National Palliative Care Outcomes Collaborative data (Jan - June 2011) 84% of patients seen by specialist palliative care services had a diagnosis of cancer.[1] Increasingly older people and people with conditions other than cancer are recognised as needing access to care and support as they approach and reach the end of their life. Some effort has been made to provide care to those approaching the end of life with a non-malignant diagnosis, primarily to residents of aged care facilities through the Commonwealth funded A Palliative Approach in Residential Aged Care (APRAC) project but many Australians are still unable to access high quality care at this time of great vulnerability and need.

In Australia about half of all people will die in an acute care hospital[2]. People in the last six months of life with consume 21% of health care costs and occupy 24% of acute bed days.[3] While the most recent AIHW admitted patient report[4] indicates that palliative care episodes are increasing the fact remains that separations identified as palliative care account for less than 1% of all hospital separations. A point prevalence survey undertaken at Flinders Medical Centre in South Australia [5] revealed that more than one third (35%) of all patients in the hospital on the day of the survey met the criteria for a palliative care patient – significantly more than the <1% that are reported to have received palliative care. A failure to recognise that a person is approaching the end of their life leads to inappropriate interventions in the last year of life, increased use of hospital and emergency department services, diminished opportunities to focus on quality of life, lack of open and honest communication regarding end of life issues and a lack of support for families and carers. The reasons why there is a widespread failure to recognise that a person is approaching the end of life are complex and pervasive.

Our submission explores some of these issues and puts forward recommendations that if implemented would lead to cultural, structural, workforce and funding reforms that would better enable our health, community aged and social care systems to respond appropriately to the needs of all Australians as they approach and reach the end of life.

[1] PCOC Report 11 (October 2011) January – June 2011. Palliative Care Outcomes Collaboration.
[2] Rosenwax L, McNamara B. Who receives palliative care in Western Australia - and who misses out. *Palliative Med* 2006;20:439-445
[3] Menec V et al (2004) Patterns of health care use and cost at the end of life. Winnipeg MB: Manitoba Centre for Health Policy.
[4] Australian Institute of Health and Welfare (2011) Trends in Palliative Care in Australian Hospitals
[5] To THM, Greene AG, Agar MR, Currow DC. (2011) A point prevalence survey of hospital inpatients to define the proportion with palliation as the primary goal of care and the need for specialist care. Internal Medicine Journal: Brief Communication.

Summary of recommendations

System level reform

1. Build a comprehensive system for the care of people approaching the end of life that is based on a public health, early recognition and primary care intervention model.
2. Establish a clear accountability framework for the delivery of care to all Australians approaching and reaching the end of life that articulates both the specific role of specialist palliative care services and providers and the broader responsibilities of all health, community aged and social care providers.
3. Apply a more inclusive framework and terminology (end of life care) to national strategy and service development, data collection and clinical care that does not privilege or emphasis the specialist area of practice to ensure that the focus is on public health initiatives, building capacity in primary care, early intervention, prevention of unnecessary care escalation, and comprehensive care planning in the last year of life.
4. Ensure that reform and re-design strategies designed to improve access to care for people approaching the end of their life are inclusive of all parts of the health, aged and community care sectors, including private, not-for profit and volunteer based services.

Quality of care

5. Introduce through the Australian Commission on Safety and Quality in Health Care (ACSQHC) an Australian Health Standard (End of Life Care) to ensure system wide accountability for access, quality and safety for all Australians at the end of life regardless of setting of care, age, diagnosis, geography, socio-economic status or culture.
6. Introduce an equivalent national standard that would apply to all residential and community aged care services where the Australian Health Standard would not currently apply.
7. Maintain the use of industry developed standards (National Palliative Care Standards) to support improvement work linked to the Australian Health Standard.
8. Ensure that the care and support provided to people approaching and reaching the end of life is based on need, is person-centred and holistic regardless of the setting of care.

Advance care planning

9. Maintain flexibility in the use of specific advance care planning tools to support a dynamic process of advance care planning based on the principles of ongoing, open and honest communication and informed decision-making.
10. Adopt a national approach to the development of education and training to support the development of competence across the health, aged and community workforces in communication skills related to end of life decision-making.

Summary of Recommendations (cont)

Service models and settings of care

11. Clearly define the roles and accountabilities of all components of the health, community, aged and social care systems in the provision of care for people approaching and reaching the end of life, their families, carers and communities.
12. Remove the barriers to full participation of the private health care sector in the provision of care and support for people approaching and reaching the end of life, including barriers that relate to the provision of specific payments for palliative and end of life care by private funds.
13. Address the challenges experienced within the residential aged care setting to ensure that all older people approaching or reaching the end of their life in residential care have access to high quality, professional, safe, compassionate and effective care in accordance with the national standards.
14. Explore the opportunities for the use of new technologies including tele-health and the NBN to support linkages between primary and aged care services providing care to people approaching the end of life and specialist palliative care service.

Data and Information

15. Develop and adopt concise definitions for the collection of data that differentiate the different types and levels of care provided to people at the end of life
16. Implement data and information systems that capture the delivery of care to people approaching and reaching the end of life across all settings of care – specialist palliative care, acute care, residential and community aged care and primary care sectors to ensure a national, comprehensive picture of population need , access and service utilisation.
17. Revise the current National Health Data Dictionary coding definitions (based on clinical intent) to provide a more specific coding definition that is based on differentiated care level.

Workforce

18. Build whole of workforce competence in end of life care using the HWA template
19. Adopt a specific focus on competence development within primary care and non-specialist settings
20. Develop and implement strategies to ensure the retention and development of an adequately qualified and skilled specialist workforce to enable access to all Australians based on need regardless of setting of care, location or geography.

Research

21. Adopt a national approach to the identification of national research priorities and align funding to these priorities.
22. Provide dedicated resources for the regular dissemination of research outcomes
23. Invest in the development of knowledge transfer methodologies to expedite translation of evidence into practice

Response to the Inquiry terms of reference.

The need for system level reform

Despite, or perhaps as a consequence of, decades of community and professional education within the professional and broader community there exists a widespread confusion about exactly what palliative care is. The term is variously used to describe a philosophy of care able to be incorporated into the practice of any individual or any health service (as in the WHO definition), a specialist area of clinical practice, a secondary or tertiary level specialist clinical service, or simply a clinical intention regardless of what is actually delivered (as in the NHDD coding definition).

The lack of clarity in the use of the term 'palliative care' hides significant differences in the quality and quantity of care that is actually provided to people at the end of life.

At present, there is very little understanding in the broader (or indeed in the professional) community that there is a difference and there is an expectation that all dying people need palliative care of the type and level provided by a specialist palliative care service. This belief is no doubt supported by the approach in Australia and some other developed countries where the focus has historically been on the development of the specialist area of practice – creating a gold standard that is unable to be sustained to the level required to meet population demand projections or replicated in non-specialist areas of practice. The qualitative and quantitative differences that relate to resourcing, staffing, competence and outcomes of the different service configurations that are currently grouped as palliative care create a significant degree of inequity in the care of people approaching and reaching the end of life.

In a recent editorial in the British Medical Journal [6] the editorial authors note that "Too many people are dying undignified graceless deaths in hospital wards or intensive care units, with doctors battling against death way past the point that is humane". In order to improve care at the end of life for all Australians, a new paradigm is needed that acknowledges openly that people will die and that accepts that all health professionals carry a degree of accountability to provide appropriate, high quality care. A useful mechanism to support the early recognition of people approaching the end of life (as distinct from those that are actively dying) has been proposed by Lynn[7] and adopted widely, including by the NHS End-of-Life Care Strategy[8] and the Gold Standards Framework[9] program in the UK. The mechanism proposed by Lynn is the "no surprise" question "Would I be surprised if this person dies in the next six-twelve months?" Applied routinely in the care of older people and those living with life limiting chronic illness it can ensure early response and primary care intervention to manage symptoms associated with life-limiting illness, including pain; timely and appropriate communication with the patient and their carers and family; offer an opportunity to meaningfully renegotiate goals of care as the patients disease progresses and support the delivery of medical care that is accordance with those goals.

There is a need to adopt a population based approach to the development and delivery of services to care for people approaching and reaching the end of life. The particular configuration of services that are available in any area currently will depend on a number of

[6] BMJ (2011) *Death can be our friend*. 2011:343:d8008

[7] Lynn J (2005) Living long in fragile health: The new demographics shape end of life care. In *Improving End of Life Care: Why has it been so difficult?* Hastings Centre Report; Special Report 35: No 6: S14-S18.

[8] Department of Health NHS (2008) End of Life Care Strategy: Promoting high quality care for all adults at the end of life. London

[9] National Gold Standards Framework Centre (2008) Prognostic Indicator Guidance: http://www.goldstandardsframework.nhs.uk (accessed 6 March 2012)

factors, not necessarily related to the needs of people or their families. These might include geographical location, the historical development of specialist palliative care services, state and local funding arrangements and the local health district commitment to palliative care. There is a need to establish and enforce nationally minimum requirements for service delivery based on population and socio – demographic need. This would include ensuring access to accessible, competent primary care and access to specialist palliative care services based on need for every Australian.

The current situation with regard to the care of people approaching the end of life, their carers, families and communities is characterised by failure at a number of levels:

1. **Failure to recognise when a person is approaching the end of life**
   A failure to recognise when a person is approaching the end of life leads to a continuation of futile or inappropriate care. It also leads to an increased inconsistency with the actual wishes of the person and their family – wishes that are more likely to focus on maintenance of dignity, comfort and care at home than the continuation of active, curative interventions in a hospital or other institutional care settings.

2. **Failure to adequately resource and build capacity in primary care services**
   The failure to adequately resource and ensure capability at a primary care level leads to diminished emphasis on the need for early recognition that a person is approaching the end of life – especially for people with chronic illness, dementia or general frailty of old age. A failure of care in the primary care setting leads to inappropriate care escalation and inappropriate institutionalisation – both costly to the health system. Building community capacity and resilience through public health focus initiatives receives scant attention at policy or service delivery, with the emphasis on the establishment and delivery of secondary and tertiary level specialist services. There is little support for families, carers or communities and in many cases institutionalisation at the end of life occurs as a consequence of the failure to adequately support informal carers at home and in the community.

3. **Failure to provide access to specialist palliative care based on needs**
   Ability to access specialist palliative care is dependent on a number of factors – few of which have any association with person or carer need. Services have been developed in accordance with available funding rather than any strategic or systematic assessment of population need. The availability of specialist palliative care services in regional and rural areas is variable and almost non-existent in some areas. Specialist Palliative Care Services continue to be predominately focused on the needs of cancer patients and there are considerable barriers to access for people approaching the end of their life as a consequence of other conditions or old age.

Difficulties with the accessibility of services – due to service availability, health service provider perception or knowledge or community resistance contribute to late referral and sub-optimal outcomes for some people. Persistent resistance to referral to specialist palliative care for those with complex care needs leads to unnecessary or avoidable pain or other symptom burden at the end of life and reinforces negative stereotypes around death and dying in the community.

The observation is that the Australians most likely to access specialist palliative care services are middle-class, English-speaking, non-indigenous Australians, a simple fact that

points to a structural discrimination in relation to access to care for people who do not fit this stereotype.

Special needs groups – the disabled, children, people of Aboriginal or Torres Strait Islander background or people from culturally and linguistically diverse backgrounds have significant additional barriers to accessing care on a needs basis.

Concerted effort is required on behalf of health services, including specialist palliative care to ensure that both the care and the environment where care is provided are culturally appropriate and safe for Aboriginal and Torres Strait Islander people.

There is limited and minimal access to specialist services to support children and adolescents who are living with life limiting illnesses. The needs of children, their parents and families differ in important areas to those of adults and access to specialist paediatric palliative care services is often crucial to ensure these needs can be properly assessed and met.

The final report of the National Health and Hospitals Reform Commission (NHHRC) *A Healthier Future for All Australians* released in 2009 put forward four specific recommendations in relation to palliative and end of life care. These were:

- *Recommendation 54*
  We recommend building the capacity and competence of primary health care services, including comprehensive Primary Health Care Centres and services to provide generalist palliative care support for their dying patients. This will require greater educational support and improved collaboration and networking with specialist palliative care service providers.
- *Recommendation 55*
  We recommend strengthening access to specialist palliative care services for all relevant patients across a range of settings, with a special emphasis on people living in residential aged care facilities.
- *Recommendation 56*
  We recommend that additional investment in specialist palliative care services be directed to support more availability of these services to people at home in the community
- *Recommendation 57*
  We recommend that advance care planning be funded and implemented nationally commencing with all residential aged care services and then being extended to other relevant groups. This will require a national approach to education and training of health professionals of the common law right of people to make decisions on their medical treatment, and their right to decline treatment.

The Calvary services provided by Little Company of Mary Health Care support the recommendations of the NHHRC and ask the Committee to review the extent to which these recommendations have been adopted into policy.

Little Company of Mary Health Care is in the process of implementing a 4 year strategic plan to improve the care we provide to all people who are approaching or reach the end of life in our care. The LCMHC Palliative and End of Life Strategic Plan 2011-2015 incorporates strategic objectives that serve to build competence and capacity across our services in health, residential and community aged care and in the community to deliver

high quality care at the end o f life. This work would be enhanced if there were a nationally consistent approach to system reform, service redesign and workforce development.

Recommendations for system level reform

1. Build a comprehensive system for the care of people approaching the end of life that is based on a public health, early recognition and primary care intervention model.
2. Establish a clear accountability framework for the delivery of care to all Australians approaching and reaching the end of life that articulates both the specific role of specialist palliative care services and providers and the broader responsibilities of all health, community aged and social care providers.
3. Apply a more inclusive framework and terminology (end of life care) to national strategy and service development, data collection and clinical care that does not privilege or emphasis the specialist area of practice to ensure that the focus is on public health initiatives, building capacity in primary care, early intervention, prevention of unnecessary care escalation, and comprehensive care planning in the last year of life.
4. Ensure that reform and re-design strategies designed to improve access to care for people approaching the end of their life are inclusive of all parts of the health, aged and community care sectors, including private, not-for profit and volunteer based services.

Ensuring quality of care for all Australians as they approach and reach the end of life

People have a right to receive high quality care as they approach and reach the end of life regardless of where that care is provided or who provides it. Indeed, caring for people at the end of life can be said to truly be ‘ everybody’s business’ including families, friends, communities, health, aged and social care services. The lack of robust and concise accountability and quality criteria for all health, aged and community service providers allows a ‘someone else will do it’ approach that almost guarantees that some people will not receive care of an appropriate standard.

Accountability for the provision of high quality care for people approaching and reaching the end of life, their carers and family should not be restricted to specialist palliative care services.

There have been national standards for the provision of care at the end of life in Australia for more than two decades. The current edition of the national standards[10] incorporates criteria that apply to both specialist and primary care providers. These standards were based on comprehensive community consultation with patients, carers and health, aged care and community professionals and providers and have been endorsed by every state and territory as part of their state palliative care plans. The Standards form the basis for the National Standards Assessment Program (NSAP) for specialist palliative care services – a program funded by the Commonwealth Department of Health and Ageing that is designed to support improvement effort towards meeting the expectations of quality set out in the standards. Currently more than 80% of specialist palliative care services nationally participate in this program. All Calvary palliative care services participate in the NSAP.

[10] Palliative Care Australia (2005) Standards for providing care for all Australians (4th Edition)

However the palliative care standards have not been explicitly adopted by non-specialist health service areas and therefore are not used to ensure the structural and procedural requirements to achieve quality are met in these settings of care.

In particular the standard of care for older people living in residential aged care facilities as they approach and reach the end of life is challenged by a number of structural and funding inadequacies that impact on the ability to provide high quality care – despite the best intentions of those services. The current ACFI based funding system does not provide sufficient resources to provide high quality care to residents as they approach the end of life. It does not adequately reflect the progressively increasing care needs, for the resident or their family that accompany an end of life journey and does not allow for sufficient, or sufficiently qualified, staff to meet those needs. As the proportion of people approaching and reaching the end of life within a residential aged care facility increases these facilities will have even less capacity to provide high quality care that is in accordance with residents needs and wishes.

Recommendations for ensuring quality

5. Introduce through the Australian Commission on Safety and Quality in Health Care (ACSQHC) an Australian Health Standard (End of Life Care) to ensure system wide accountability for access, quality and safety for all Australians at the end of life regardless of setting of care, age, diagnosis, geography, socio-economic status or culture.
6. Introduce an equivalent national standard that would apply to all residential and community aged care services where the Australian Health Standard would not currently apply.
7. Maintain the use of industry developed standards (National Palliative Care Standards) to support improvement work linked to the Australian Health Standard.
8. Ensure that the care and support provided to people approaching and reaching the end of life is based on need, is person-centred and holistic regardless of the setting of care.

Advance Care Planning

Advance care planning most importantly provides individuals with the chance to make their wishes known regarding their personal end of life experience. Conversations about advance care plans and goals of care need to begin early in the disease trajectory, but especially when it is recognised that the individual is approaching the end of their life. Clinicians, community service providers and carers need to be comfortable and competent in initiating or participating in these conversations and in the negotiation of goals of care.

The evidence around the implementation of formal structures for advance care planning is thus far not encouraging. There may be specific populations for which advanced care planning programmes appear to have increased benefit, such as in dementia care or advanced frailty where benefits such as reduced emergency department transfers from residential aged care facilities have been demonstrated. Much of the emphasis to date has been placed on measuring advance care plan completion rates with little attention to the quality of the plan. Whether quality of or satisfaction with end of life care has improved as a consequence of the use of a specific advance care tool is not known.

It is vital that advance care planning be viewed as a dynamic process with patient preferences often changing over time. An advance care plan needs to be the avenue in which to open conversation between medical staff, patients and families and those responsible for care. It is not to be seen as the final word and should always be used as the basis for communication and discussion with the patients or their nominated substitute decision maker as care needs change.

It is perhaps of greater importance that a substitute decision maker is nominated by the patient to assist with decision-making if the situation occurs where a person is unable to communicate their own wishes. Formal systems should be implemented to ensure that, as far as possible, each person will have a nominated substitute decision maker, and that this information is communicated to all health professionals and carers as the person navigates the health, community and social care systems.

Recommendations for advance care planning

9. Maintain flexibility in the use of specific advance care planning tools to support a dynamic process of advance care planning based on the principles of ongoing, open and honest communication and informed decision-making.
10. Adopt a national approach to the development of education and training to support the development of competence across the health, aged and community workforces in communication skills related to end of life decision-making.

Care across settings and integrated models of care

The distinction between palliative and end of life care and curative care is now more blurred than ever. More effective cancer treatments, advancements in medical practice in the management of chronic disease and improved technology all mean that people will continue to receive active, curative care for longer than might have previously been possible. In the last year of life, on average, people will have between 1.7 and 2.5 emergency department presentations and 7.8 inpatient admissions with an average length of stay of 5.6 days[11]. The health expenditure of an individual in their last year of life is more than the total expended in the rest of their life[12].

The reality is that in the last year of life people will move between care setting and models of care in accordance with their needs. The current siloed system of care does not facilitate the patient journey at the end of life. End of life care must be become an integrated component of all health care, with appropriate accountability, funding and workforce frameworks developed and implemented to support the full integration. The exploration of the potential benefits of new technologies (for example e-health) to develop systems of care that bring services to people through the establishment of integrated networks of care is an urgent priority.

Specialist palliative care services are best used to provide input into the management of the more complex patients – consistent with the role of secondary and tertiary level services in

[11] Rosenwax LK, McNamara BA, Murray et al (2011) Hospital and Emergency Department use in the last year of life: a baseline for future modifications to end of life care. *Med J Aust*; 194: 570-573.
[12] Saul P. (2009) We need to talk of death in our perfect health storm. *Sydney Morning Herald* March 30.

other clinical specialities. The bulk of care at the end of life is, and will need to continue to be provided by non-specialist services, with the support of specialist palliative care services if needed.

Integration of care needs not only to occur across clinical boundaries but must also occur across public/private sector boundaries. There are currently significant barriers to full private sector involvement in the provision of end of life care. Even though mechanism exist for the provision of funding through the private sector (Private Health Insurance Act 2007 – Broader Health Cover) it is clear that private insurers have not supported this type of cover. Reasons for this include fear of cost shifting from the public to private sector, lack of clarity in the definition of types and levels of care required as people approach and reach the end of life and lack of clarity about the nature and components of service to be provided and funded within the private sector. These factors are compounded by the nature of the competitive health insurance funding model , making it unlikely that any fund will offer a product ahead of its competitors, the need to provide robust case-type definitions for eligibility and the lack of specific case type data.

Integration of care across setting would be enabled through the introduction of patient controlled electronic health records (PCEHR). Calvary Healthcare ACT is conducting one of 12 national projects testing elements of the Australian Governments $465 million investment in eHealth records systems. Calvary Healthcare ACT was chosen to develop the national system because of our strong focus on providing quality, up-to-date care, especially in the areas of aged and palliative care and in the management of chronic disease. These consumers often require complex care from a range of different healthcare providers and they stand to benefit greatly from a healthcare system that can provide better integrated, more holistic care.

Recommendations for the integration of care

11. Clearly define the roles and accountabilities of all components of the health, community, aged and social care systems in the provision of care for people approaching and reaching the end of life, their families, carers and communities.
12. Remove the barriers to full participation of the private health care sector in the provision of care and support for people approaching and reaching the end of life, including barriers that relate to the provision of specific payments for palliative and end of life care by private funds.
13. Address the challenges experienced within the residential aged care setting to ensure that all older people approaching or reaching the end of their life in residential care have access to high quality, professional, safe, compassionate and effective care in accordance with the national standards.
14. Explore the opportunities for the use of new technologies including tele-health and the NBN to support linkages between primary and aged care services providing care to people approaching the end of life and specialist palliative care service.

Robust, comprehensive and complete data and information systems

People approaching the end of life – like people at every stage of their life have differing levels of need, different levels of resources available to them and different goals and expectations of care. The current high level, non-differentiating data definitions (for example the definition used in the National Hospitals Data Dictionary to capture 'palliative' episodes of care) do not provide sufficiently sophisticated data to plan and develop services that are based around people's needs and individual journeys.

System level data collection should include but not be limited to episodes of care provided in specialist palliative care service and should also capture various care types and levels provided to people approaching then end of life across care settings.

Failure to collect appropriately differentiated data provides a skewed picture that in the main is focused on the 'haves' and that ignores the much larger group of people who are discriminated against in relation to access to high quality care as they approach the end of life – older Australians, those with chronic non-malignant conditions, those with disabilities, children and those from Aboriginal or Torres Strait Islander backgrounds or from other culturally or linguistically diverse backgrounds.

The inadequacy of the existing data collections makes it difficult to determine the extent to which the current use of resources is efficient or effective. In order to understand gaps in care, resources to collect routine care must be in place. Such data allows not only individual patients' needs to be identified and tracked, but also allows population level data to be considered.

Recommendations for data and information

15. Develop and adopt concise definitions for the collection of data that differentiate the different types and levels of care provided to people at the end of life
16. Implement data and information systems that capture the delivery of care to people approaching and reaching the end of life across all settings of care – specialist palliative care, acute care, residential and community aged care and primary care sectors to ensure a national, comprehensive picture of population need , access and service utilisation.
17. Revise the current National Health Data Dictionary coding definitions (based on clinical intent) to provide a more specific coding definition that is based on differentiated care level.

Ensuring a skilled and adequate workforce

Fundamental to any reform of health, community, aged and social care systems for the care of people approaching the end of life is the need to reform the workforce to provide re-designed services. A skilled and adequate workforce requires a focus on the development of capability and competence across the entire health, aged and community and social care sectors. The re-designed workforce will need to be flexible, multidisciplinary and based on an agreed competence framework.

Workforce issues related to the care of people approaching the end of life incorporate issues that relate to its size, characteristics and competence.

The current specialist palliative care workforce is ageing and specific strategies that address succession planning and recruitment will need to be in place to ensure that the specialist workforce is able to meet future demand projections for the care of people approaching and reaching the end of life. There is a critical shortage of palliative medicine specialists, especially outside of metropolitan areas in all states and territories. Initiatives to retain and attract new and younger worker need to be put in place – for example education, job-sharing, employment flexibility and measures to prevent work related stress and burnout. Workforce redesign to accommodate new and enhanced roles (for example nurse practitioner roles) would support broader more equitable access to specialist care and advice.

Expansion of programs like the current Program of Experience in Palliative Care (PEPA) will be required on an incremental and ongoing basis to ensure that it keeps pace with workforce demand. Current funding levels for PEPA are inadequate to meet existing demand and as more people require care in non-specialist setting this demand will only increase.

In particular the current workforce is not adequately resourced or configured to meet the needs of people who desire to be cared for at home as they approach the end of their life. Anecdotally, one of the most common reasons that people are admitted from home to specialist palliative care is because their family and carers are not able to cope with the informal care demands associated with providing care at home. As an informal caregiver for a person approaching the end of life the demands are significant. They are required to meet personal care needs (for example bathing, toileting, mouth care, management of

continence), maintain the home, provide medications and other medical interventions, monitor the person's condition and liaise with the various health professionals. Workforce redesign to increase the availability of community support workers to assist families with personal care, domiciliary care (shopping, general cleaning) would provide meaningful support to families and carers and help ensure that patient's wishes to remain at home can be respected and achieved. Improved workforce productivity through the enhancement of assistant, support and supplementary workforce competence in end of life care, including the volunteer and informal workforces, would help ensure that more people could remain at home at the end of their life.

The availability of a general practitioner willing to provide the required care at the end of life is also a fundamental requirement if we are to support people to remain in their own homes as they approach and reach the end of life. This includes 24/7 support and a willingness to provide home visits – especially in the final weeks/days of a persons life. For a variety of factors fewer and fewer General practitioners are willing to provide this level of care. The development of nurse practitioner roles to support the care of people at the end of life would assist in meeting the gap between the need for GP services and their availability. Calvary Hunter Manning is developing and piloting a Nurse Practitioner model, funded by the Australian Government, Department of Health and Ageing, to support older Australians living in the Hunter Manning region as they approach and reach the end of life in either community or residential aged care settings.

There are particular concerns regarding the adequacy of the workforce in residential care settings. The registered nurse: resident ration can be as low as 1:100 – even where 40% of those residents are classified as 'high care'. As the needs of residents approaching the end of life become more complex, and as an increasing proportion of residents are classified as high care the validity of models of care and staffing establishments that are structured around 'homelike' care are called into question. The residential aged care facility of today could more appropriately be compared with the 'medical home' and should be staffed accordingly.

There has been much investment in education and training in residential aged care, primarily funded through the Department of Health and Ageing Palliative Care Program. But education alone will not improve care to residents who approach and reach the end of life in an aged care facility. Workforce issues within the aged care sector (including high rates of turnover and core competence gaps) result in less than adequate educational outcomes from this investment in the absence of parallel restructure and adequate resourcing.

Outside of specialist palliative care services (and even within some specialist palliative care services) people approaching the end of life do not always have access to multi-disciplinary care. In particular access to social work, bereavement support and pastoral care are less likely to be available for people who do not receive care through a specialist palliative care team, regardless of their need.

Funding to ensure that all sectors are able to participate in training and education related to end of life care relevant to their role must be factored into funding models across all sectors. This should incorporate funding for flexible approach to the delivery of vocational and professional education targeted to the needs of specific workforce roles. Interdisciplinary education, delivered within local and regional networks where participants will continue to

collaborate in a team care environment have been evaluated as effective in improving care outcomes[13]

Recommendations for workforce development

18. Build whole of workforce competence in end of life care using the Health Workforce Australia competency template
19. Adopt a specific focus on competence development within primary care and non-specialist settings
20. Develop and implement strategies to ensure the retention and development of an adequately qualified and skilled specialist workforce to enable access to all Australians based on need regardless of setting of care, location or geography.

Research

Research into end of life care has the potential to improve the quality of care for all people approaching the end of life and should form a part of the routine work of all health, aged and community services. While there has been some investment into collaborative clinical trials research there needs to be an equivalent emphasis on research that is focused on understanding the experiences and needs of people approaching the end of life, their families, carers and communities. This would include research that would examine the effectiveness of various models of care.

Adoption of a needs-based approach to palliative and end of life care focused on a reduction of existing disparities and inequity will require the generation of new research-based evidence to support service development and redesign. National palliative and end of life care research priorities should be articulated and form the basis of research funding rounds. These priorities must be integrated into clinical, health service and social research programs beyond the current reliance on palliative care specific research funding pools

Specialist palliative care services should have a recognised and resourced role in research leadership. This should include the resourced capacity to guide research translation across the health, aged and community care sectors.

Support is needed not only for research infrastructure but also for supporting emerging researchers and clinical staff to build a culture of enquiry within palliative care. Specific training for emerging researchers is required to build their competitiveness when applying for research project funding from competitive funding pools.

Recommendations for research

21. Adopt a national approach to the identification of national research priorities and align funding to these priorities.
22. Provide dedicated resources for the regular dissemination of research outcomes
23. Invest in the development of knowledge transfer methodologies to expedite translation of evidence into practice

[13] Cairns W, Yates P. (2003) Education and training in Palliative Care. *MJA*; vol. 179: S26-S28.

Conclusion

Little Company of Mary Health Care welcomes the opportunity to make this submission to the Community Affairs Committee – Palliative Care in Australia Committee. Calvary services, in partnership with State and Territory governments and the Commonwealth continue to seek ways to improve care for people approaching and reaching the end of life. We are also committed to continue to seek opportunities to contribute to the broader processes of system reform and re-design in the health, aged and community sectors to achieve our goals.

Our experience providing care across service and system boundaries and our long tradition of caring for the dying has allowed us to develop a unique insight into the challenges and opportunities that relate to the care of people approaching and reaching the end of life, their carers, families and communities.

We thank you for the opportunity to share these insights with the Committee.