SVMHS

St Vincent’s Health Network NSW

Palliative Care in Australia – Senate Inquiry

St Vincent’s Health Network
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Submission to the Senate Inquiry on Palliative Care in Australia St Vincent's Health Network

The St Vincent's Health Network

The St Vincent's Health Network operates across the public health services provided by three Sydney facilities operated by St Vincent's Health: these include St Vincent's Hospital and the Sacred Heart Hospice at Darlinghurst and St Joseph's at Auburn.

Executive Summary

Australia, in part due to its attention to this important area of care from a policy and legislative perspective, was recently ranked second only to the UK on a 'Quality of Death Index' – an index developed to rank countries according to their provision of end-of-life care.[1] However, as a nation we cannot afford to become complacent, but need to recognise our limitations and focus on areas in need of improvement, particularly given our aging population, varying levels of income and social support and a wide array of cultural backgrounds and priorities.[1] Improving palliative care outcomes for patients and their carers (spouses, offspring, siblings, friends and neighbours) and reducing access disparity will continue to be a national priority.

In this submission we have addressed some "system-based" problems that impact on individuals who are nearing the end of life, and some approaches to consider, as a nation, aiming to achieve high quality and equitable palliative care. Our key suggestions are focused across three broad domains, as summarised below:

1. Positive policy environment

- Ongoing commitment to a National Palliative Care Strategy
- Strengthening the Commonwealths central leadership and coordination role
- Optimising the National Palliative Care Standards and funding nexus
- Supporting priority driven palliative care research

2. Community

- Better supporting carers in the community
- National approach to Advance Care Planning

3. Health Care Organisations

- Needs based approach to palliative care delivery
- Establishing integrated palliative care clinical networks
- Better supporting primary care
- Palliative care as a core element of all aged care services
- Building the health workforces' palliative care capacity

1. Suggested conceptual framework

We are committed to the concept that palliative care is the responsibility of the entire health, aged care and disability services system and all health professions. We acknowledge that ‘specialist’ palliative care services and providers are an essential component of the health care system but not the ‘only’ health professionals who ought to have palliative care capabilities.

The Chronic Care Model[2-4] (Figure 1) has been used as the conceptual model to identify the action required at the consumer, health professional and system levels to strengthen the provision of palliative care and end-of-life care in Australia. This model has previously been used by a diverse range of health care organisations to improve health care delivery to people with chronic and complex illnesses.[2 5-7] Given that the majority of people requiring palliative care in Australia are increasingly older people with chronic and complex conditions, this model provides a framework for identifying the action required at the local, state and national level to improve care outcomes.

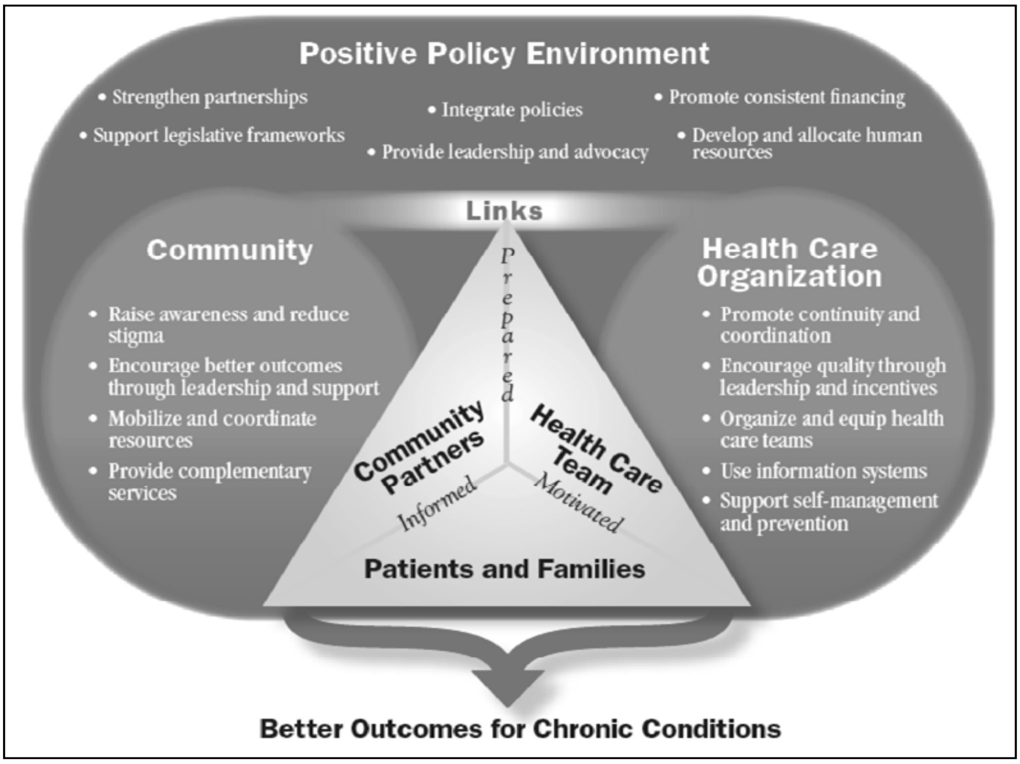

Figure 1: The Chronic Care Model[2-4]

2. Positive policy environment

Policy initiatives are fundamental to making long-term system changes that can result in improvements in access and quality of palliative care delivery.[8] Ensuring that expenditures in this area of health care are appropriately and equitably distributed is also crucial and policy will guide such distribution of funds. All of these elements are important within a national agenda aimed towards maintaining quality care where it exists but also moving towards optimisation of care across the nation for those nearing the end of life.

2.1. Ongoing commitment to a National Palliative Care Strategy

The Commonwealths' ongoing commitment to a National Palliative Care Strategy[9] is essential to achieving greater integration of palliative care services across all sections of the Australian health care system. Ensuring that the National Strategy is underpinned by targeted funding and jurisdictional buy-in is critical to ensuring the delivery of high quality, clinically effective palliative care across care settings (e.g. in community, aged care, acute care and inpatient palliative care settings).

2.2. Strengthening the Commonwealths' central leadership and coordination role

The complexity of advancing an end-of- life reform agenda in Australia in a strategic, coordinated and timely manner demands a centralised approach. We suggest strengthening the leadership and central coordination of palliative care at the Commonwealth to accelerate the end-of-life reform required across the acute care, aged care and primary care sectors to ensure that best evidence based palliative care and end of life care is provided when and where it is needed.

Given the complexity of this reform agenda, consideration ought to be given to creating a Commonwealth Agency with the authority and funding required to implement the '*Supporting Australians to live well at the end of life: National Palliative Care Strategy*'[9]; to facilitate a National Advance Care Planning agenda; to highlight and suggest strategies to address disparities; and to focus on opportunities to strategically improve the quality of end-of-life care provided to all of those individuals in Australia who are approaching the end of life, across all care settings.

We strongly believe that the Commonwealth should also continue to support and maintain a robust national peak organisation, such as Palliative Care Australia, to promote palliative care in the community and to continue to represent the interests and aspirations of all who share the ideal of quality care at the end-of-life.

2.3. Optimising the National Palliative Care Standards and funding nexus

The Commonwealth is ideally placed, through the funding it provides to aged care, primary care and the jurisdictions through the Council of Australian Governments (COAG), to ensure that the palliative care is delivered in accordance with the '*Standards for providing quality palliative care for all Australians'.*[10] Adherence to these standards ought to be required by all agencies/services/organisations receiving designated palliative care funding.

Due consideration needs to be given to integrating the palliative care standards [10] into the Aged Care and other Accreditation Agency Standards to help ensure that the palliative care needs of older people in residential aged care are better met.

2.4. Supporting priority driven palliative care research

An ongoing investment in priority driven palliative care research is required to ensure that Australia has the highest quality palliative care.

2.4.1 Ongoing commitment to successful research initiatives

The Commonwealth's investment in a strategic palliative care research agenda during the first half of this decade has produced some remarkable outcomes. The creation of the Palliative Care Clinical Studies Collaborative (PaCCSC) has fostered the research infrastructure necessary to undertake a number of Phase 3 and 4 clinical medical studies across 13 palliative care sites in Australia. Building this evidence base is essential for ensuring the quality use of medications in palliative care populations and informing the listing of these medications on the Pharmaceutical Benefit Scheme (PBS). This collaborative research group has demonstrated what can be achieved through fostering sharing and transfer of expertise, recruitment across multiple sites, and ensuring dissemination of findings through the networks involved. It is collaborative research models like this that are required to accelerate the palliative care research agenda in Australia.

The Palliative Care Outcomes Collaborative (PCOC) funded by the Commonwealth is another initiative that is helping to reduce the disparities in care outcomes through the voluntary use of standardised validated clinical assessment tools to benchmark and measure outcomes in palliative care. Participation in PCOC enables palliative care service providers to improve practice and meet the *Standards for Providing Quality Palliative Care for all Australians*. [10]

An ongoing commitment by the Commonwealth to the many successful ventures created as a result of their targeted palliative care research investment is required to ensure that these achievements continue to grow and inform the delivery of best evidence based palliative care.

2.4.2 Research aligned to the National Palliative Care Strategy

In addition to addressing the need for clinical trials of palliative medications, focusing the national research agenda on the National Palliative Care Strategies four broad priority areas is an important consideration. These areas are i) Awareness and understanding; ii) Appropriateness and effectiveness; iii) Leadership and governance; and iv) Capacity and capability,.[9]

2.4.3 Fostering translational palliative care research

Translational research requires a commitment to work collaboratively across policy, health service provision and research to improve care outcomes for patients and their care givers. Greater emphasis ought to be placed on supporting the rapid translation of research findings into clinical practice. Research implementation occurs within the context of strong evidence, an environment receptive to change and skilled facilitators to drive the change process. Achieving translation requires a commitment at national, state and local heath network levels to address patient, provider and system issues, whilst building sustainable processes to facilitate the translation of palliative care evidence into practice.

3. Community

Engaging consumers in funding and policy reform is required to ensure that there is more effective commissioning of community health care services, including palliative care services and Home and Community Care, that directly support carers through the provision of hands on care and respite services in the community setting.

3.1. Better supporting carers in the community

The vast amount of community palliative care is provided by informal carers with support from care workers and visiting health professionals. If we are to increase the number of days that people spend receiving care at home then consideration needs to be given to increasing the investment in the delivery of personal care, nursing care and home care. There is an urgent need to address delays and disparities in access to such services as well as inadequacy in the available services (respite, home assistance etc). The Home and Community Care Program in its current format is inadequately configured to meet the needs of people with a life limiting illness living at home and their care givers in a timely manner.

3.2. National Framework for Advance Care Planning

We support the National Framework for Advance Care Directives Senate submission lodged by The Clinical Technical and Ethical Principal Committee of the Australian Health Ministers Advisory Council.

4. Health care organisation

There is growing acknowledgement of the need to ensure access to palliative care to people with life limiting illnesses other than cancer. Despite this realisation, the vast majority of specialist palliative care services continue to predominately service people with cancer, while people with other life limiting illnesses frequently have unmet palliative care needs. Identifying and applying the drivers for change that will facilitate the care of all those in need is critical at the National, State and Local level with efforts directed to reorientating health care services to address these populations needs.

4.1. Needs based approach to palliative care delivery

We endorse the National Health and Hospitals Reform Commission (NHHRC) recommendation for a needs based approach to palliative care delivery. This approach acknowledges that patients have different needs that may change over time and ensures people can access the right care in the right setting.[11]

'*A guide to palliative care service development: A population based approach*'[12] provides an overview of the actions required to ensure access to palliative care based on identified need. The Commonwealth has a key role in promoting a population based approach to palliative care service delivery across the care continuum and ensuring greater adherence to the principles of this approach to care by primary, aged, acute care and specialist palliative care services.

4.2. Establishing integrated palliative care clinical networks

As part of this reform agenda, we suggest that consideration be given to the establishment of national palliative care clinical networks (some of which may need to operate across jurisdictional boundaries). These networks would need to cover all areas of Australia and serve to establish formal links with specialist palliative care services into primary care practice, aged care facilities, community agencies and, where appropriate, link urban services to specific regional, rural and remote areas that may be lacking access to specialised palliative care expertise.

Where palliative care resources do exist in rural and regional Australia, ensuring that palliative care is networked through a regional nexus could be one approach to ensuring palliative care networks are well anchored in the local systems and have the local supports needed to be truly effective. In some instances such a “nexus” site could for example, be a Regional Cancer Centre and in others the regional hospital may fill this need.

Strengthening the Medical Outreach Assistance Program to support the linking of rural services to established city-based services would begin to, at the very least, provide a “stop-gap” solution to an immediate need while longer term strategies are put in place to address the lack of palliative care access in many regional, rural and remote settings. There is also scope to consider extending the Medical Outreach Assistance Program to include the input of palliative care specialist nurses and allied health professionals, where these disciplines are lacking within more remote parts of the network.

Such networks would need to extend beyond addressing the needs of people with cancer to *all* with a palliative care need. Reducing duplication, promoting better utilisation of existing palliative care resources, and reducing inequities could be a central goal in the establishment of these clinical networks and would serve to address a population based approach to palliative care service delivery.

Better integration of available resources would help to overcome the diseconomies of scale which might otherwise make discrete services unsustainable and improve local palliative care service delivery. Ensuring that palliative care clinical networks are embedded into Medicare Locals, the National Health and Hospitals Network, and the numerous agencies providing community and domiciliary nursing and home care services would be essential to their success.

4.3. Better supporting primary care

If community palliative care is to be optimised primary care must be the mainstay of this care and appropriate incentives need to be provided through Medicare Locals to actively engage interested General Practitioners (GPs) in the delivery of palliative care and in the development of any clinical networks. Establishing local or network models of community palliative care that involve specialist GPs who express an interest in, and willingness to increase their palliative care capabilities and work collaboratively with local palliative care services will strengthen the delivery of community based palliative care, especially access to timely medical care at home and aged care. At this time for an established GP to seek opportunities for training in this field is challenging with numerous practical, financial and geographical disincentives to them undertaking this activity. Novel approaches to addressing this problem are needed.

In addition to the development of approaches to supporting greater GP engagement in palliative care, funding needs to be made available if we are to better support Practice Nurses to play a more active role in the delivery of a palliative approach to care. There is tremendous potential for Practice Nurses to play a very significant role in identifying and helping to address the unmet palliative care needs of patients and their carers, as well as integrating advance care planning conversations and documentation into routine practice. That stated, there are disincentives to this area being advanced and these need to be addressed.

4.4. Palliative care as a core element of all aged care services

The Commonwealth is strongly encouraged to ensure that a palliative approach underpins all future residential ageing polices and funding formulas to ensure the delivery of best evidence based care for older people living in Australian aged care facilities.[13] Palliative care needs to be viewed as core business of all residential aged care facilities.

As previously described (Refer 1.3) there is a need for the Palliative Care Standards to be linked into the Residential Aged Care Accreditation Standards '.

In addition, the 'Guidelines for a Palliative Approach in Residential Aged Care'[14] also need to be updated.

The issue of advance care planning and not for resuscitation orders are inherently problematic within the aged care sector, especially in the context of cognitive impairment. It is likely that a complex interplay of individual values and beliefs, as well as policy, legal and regulatory issues are conspiring to limit the exploration and documentation of residents' end-of-life care preferences in a systematic manner.[15]

4.5. Building the health workforces' palliative care capacity

The ability to provide a palliative approach to care is underpinned by all graduate health professionals having core palliative care capabilities, which requires an ongoing commitment to strongly encouraging and supporting the tertiary education system to embed this content into all relevant undergraduate curricula as well as most specialist training schemes (e.g. training schemes for GP, ED, ICU, Geriatric Medical and surgical specialties). It is important that medical, nursing and allied health schools and post graduate training bodies are aware of, and address, this need.

There is a need to integrate aged and palliative care principles across all areas of the nursing, medical and allied health curricula, particularly within a context of population ageing.[16] In addition, the fact that palliative care is an evolving field, alongside the changing nature of the workforce over time, highlights the important need for a coordinated approach to the development and support of continuing professional development educational opportunities and packages relating to palliative care for all health professionals, but in particular GPs, community nurses, aged care nurses and care assistants. Learning opportunities and/or packages need to be readily available to those in the public health system as well as those in aged care and other environments.

Maintaining and strengthening the capacity of local services along with that of the health workforce is a key element of establishing an integrated network palliative care system. There is a growing needs for skill enhancement and diversification, extended roles and new scopes of practice for many health care professionals, particularly those working in acute care services, community nursing and residential aged care, potentially resulting in the creation of palliative care as a sub-specialty within these areas. An ongoing commitment by the Commonwealth to support innovation and develop capacity building programs is important.

5. Summary

There are many opportunities to build upon the existing initiatives and programs to support the delivery of best evidence based palliative care to more Australians. Reconfiguring the health care system to deliver a need's based approach to care, with the flexibility to respond to individual patients and carers differing needs over time, whilst also ensuring they have access to the right care in the right setting is urgently required. Achieving this requires a commitment and investment in making it happen at the national, state and local level. The Commonwealth is ideally placed to provide the leadership and incentives to make this vision a reality.

The St Vincent's Health Network would like to thank the Senate Community Affairs Committees for the opportunity to make this submission to the inquiry into palliative care in Australia and looks forward to hearing the outcomes of this process.

6. Contact

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