Victorian Healthcare Association

SUBMISSION

Palliative Care in Australia

2 March 2011

1. Introduction

This submission outlines the Victorian Healthcare Association's response to the Australian Senate Community Affairs Committee inquiry into *Palliative Care in Australia*.

The Victorian Healthcare Association (VHA) agrees to this submission being treated as a public document and the information being cited in the Committee's report.

1.1. Contact details

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1.2. The Victorian Healthcare Association

The VHA is the major peak body representing the public healthcare sector in Victoria. Our members include public hospitals, rural and regional health services, community health services and aged care facilities. Established since 1938, the VHA promotes the improvement of health outcomes for all Victorians, from the perspective of its members.

1.3. Prefacing comments

Over the next 40 years, the number of people aged 85 years and over (the main users of aged care services) is expected to increase four-fold[1]. Occurring simultaneously is the shift in disease patterns. Currently approximately 85 per cent of people will die after a chronic illness, not after a sudden event, and this is expected to increase in the coming years, creating a demand for end of life care.

Although the advances in medical technology that enable us to live much longer have been welcomed, the fact is that the mortality rate for all of us remains at 100 per cent. However, what has changed over the past few decades is the way death is handled in our society.

International research suggests that up to 90 per cent of people with a life-threatening illness would prefer to die at home, or in a home-like environment[2]. The capacity to meet a person's wish to die at home is important as it allows them to spend time with their families and friends and maintain their own routines and preferences in a safe and familiar environment. Despite this preference however, only 26.5 per cent of Victorians die at home, while 56 per cent died in hospital[3]. According to the Australian Institute of Health and Welfare, the average length of stay in hospital for palliative care was 12.5 days per admission. This is nearly four times longer than the average 3.2 days spent in hospital for all admissions[4].

When a person with a serious and life threatening disease is asked what kind of care they want, their preferences include a sense of control, pain and symptom management, concern for family burden, an opportunity to strengthen relationships with loved ones and avoidance of prolongation of the dying process[5]. This range of services can only be provided with coordinated palliative care across Australia.

According to the Victorian Department of Health (DH), the demand for palliative care is growing at 4.6 per cent per annum[6] yet there are many barriers in the current system that prevent people from receiving quality, seamless palliative care. Episodic care with different providers and settings results in a lack of continuity of care and the absence of a multidisciplinary approach necessary to meet the physical, emotional and social needs of a patient. Inequities and inconsistencies in access to care can lead to avoidable hospitalisations or lead to the inability of people to access appropriate pain and symptom relief.

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2. The VHA Response

a. The factors influencing access to and choice of appropriate palliative care that meets the needs of the population

There are many facets to the provision of palliative care in Australia that influence access to and choice that meets the needs of the population. The rising rates of chronic disease, the changing needs and expectations of populations and the impact of an ageing population have all exacerbated the demand for palliative care services over the last few decades. Workforce challenges, fragmented funding arrangements and scarce resources have made the capacity to meet ongoing demand with supply problematic. Consequently, there are sub-populations who often miss out.

The provision of palliative care must be appropriate to a person's needs at the right time and in the place of their choice. Palliative care must be available to all who require it, irrespective of location, income, age, social and cultural background, diagnosis or prognosis. However, inequities in access exist for those of Aboriginal descent, from a culturally and linguistically diverse background, who are elderly, or who live in a rural and remote area.

Having the choice to die at home is not available to many patients in rural and remote settings. Professional isolation, the tyranny of distance and inflexible funding structures have contributed to limited availability of suitably trained specialist physicians, nurse and GPs, which impacts on the choice to die 'in place'. This is further compounded by the lack of access to after hour GP services and after hour pharmacy services to relieve pain.

The VHA believes this should be addressed through a population health approach to planning. Health services should no longer operate merely to service those that "walk in the door", seeking immediate medical care. While there has been great momentum for chronic disease management and prevention programs over the past couple of years, there remains an emphasis on acute episodic care in the Australian healthcare system. Consequently, the lack of knowledge regarding appropriate service availability causes marginalised groups to approach the health system when it is too late. Health services have a role to be a key stakeholder of community viability, actively targeting groups across the spectrum, including those most vulnerable or at risk.

The capacity of service providers to adequately use population health approaches to planning needs to be developed to avoid fragmentation in addressing local community needs in regards to palliative care provision. The VHA/Monash University Population Health Approaches to Planning Project provides an evidence-based strategy for profound change and system improvement. The VHA believes that investment is required to support the ongoing training for the workforce and boards of health and community sectors. This will develop the capacity to better plan and deliver appropriate palliative care for the entire population.

Additional funding is only one answer to the challenges in access and availability of choice to appropriate palliative care. Cultural change and enhanced training and education are also vital to remove the stigma of palliative care being equivalent to terminal care. There continues to be a lack of understanding both within the community and health professional groups around the benefits of palliative care being a simultaneously delivered adjunct to disease-focused treatment[7]. Consequently, the belief that palliative care is terminal care deters clients and healthcare providers from the option of early referral. Early referral to palliative care allows for better care management and coordination that reduces inappropriate and avoidable hospitalisation.

The benefits of early palliative care were identified in a randomised, controlled trial that offered palliative care in addition to standard oncologic care for patients with newly diagnosed metastatic non-small-cell lung cancer. In comparison with the standard care group, this intervention group displayed better quality of life and lower rates of depression[8]. The results

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of the study emphasise the necessity to shift the paradigm of believing palliative care is only delivered in the terminal stages of care.

VHA Recommendation:

- Adopting a population health approach to planning to provide early referral of palliative care that meets the needs of the population.

b. The funding arrangements for palliative care provision, including the manner in which subacute funding is provided and spent

While palliative care attracts substantial resources from charitable donations and volunteer labour, the ways in which governments allocate funds and pay for services will inevitably play a major part in shaping the course of care.

It is imperative that appropriate funding arrangements acknowledge the priorities of providing palliative care and do not overlook patient preferences. However, the current funding arrangements and other monetary factors, such as patient co-payments and accommodation, skews palliative care provision towards bed-based options in a hospital as opposed to services provided 'in place'.

The introduction of activity based funding (ABF) in hospital-auspiced palliative care from 1 July 2013 is still yet to be articulated. The current Palliative Care Resource Allocation Model (PCRAM) weights funding based on a number of variables including rurality and low socio-economic status. It is unclear whether the application of ABF will include a similar weighting structure. This is of particular concern for block funded small rural hospitals in Victoria that may be unable to provide the same level of services under ABF as under the PCRAM if the extra costs inherent are not taken into account.

VHA members have expressed some concern regarding the implications of moving these palliative subacute services into an ABF model as it places restriction on the capacity to truly cater for patient needs. The transition of subacute services into ABF must allow the mobility of funds into programs that are in the home and community, not just in hospitals. Home and community based programs provide specialised, patient-centred medical care and care coordination that are enabled by block funded grants.

Each year more funding is allocated to increase the number of aged care packages within the community to enable elderly people to remain at home. However, these packages do not in any away enable aged and community care services to prepare and provide generalist palliative care for a person.

Currently in Victoria, palliative care reflects a substantial discrepancy in funding. The provision of palliative care is seen as increasingly necessary in residential aged care (RAC) facilities but as it is still funded as 'general care' in RAC, it is not adequately resourced. One VHA member has reported the huge difference between the cost per day for an acute palliative bed of approximately $1300.00 and the subsidy payment for palliative care provided in an RAC facility of approximately $163.00 per day.

As length of stay in a RAC facility is likely to be short (almost one-quarter of people admitted into permanent RAC died within just over 7 months of being admitted and one half died within 14 months[9]), the predominant need is for care, not accommodation. However, there is inequity between older people entering a RAC facility for end of life care that are charged a daily accommodation charge and being in a hospital or palliative care unit where no accommodation charge applies.

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Any funding reform needs to consider the specific needs of people to ensure that there is no inequitable burden on them or their families depending on which setting they choose for palliative care.

VHA Recommendation:

- Appropriate and flexible funding arrangements must acknowledge the priorities in providing palliative care in both bed and community based care models. The emphasis of funding must ensure the effective provision of care in the right place at the right time.

c. The efficient use of palliative care, health and aged care resources

The provision of palliative care resources in Australia is not as efficient as it should be. Building the capacity to care for people at home according to their wish makes economic sense. International research also suggests that palliative care can reduce costs by reducing hospital admissions and use of acute beds, length of stay and pharmacy costs[10].

A study conducted in Spain indicated that appropriate community palliative care services have the capacity to improve health system efficiency without compromising client care[11]. The success of the community health service (CHS) model in Victoria is due to the integration of workforce multidisciplinary teams and partnerships among organisations that mitigate the social determinants of health. This is in alignment with the CHS principle of focusing on the client rather than the client's specific requirement at the static point in time. Clients that registered with community palliative care were five times more likely to be admitted directly to a designated palliative care bed rather than clients who were not. This reduces the number of presentations to the emergency department and subsequently reduces demand for acute beds[12].

The enablers for an efficient use of health resources arise from good governance. Victoria's devolved governance model has enabled local boards of governance to bring a community perspective to strategic decisions about health service structure and how to meet local demands with limited resources. These decisions should be based on the broad understanding of the social determinants of health and the wide range of health and community services available to address identified community needs. This has been a major strength of the Victorian health system.

The opportunity exists for significant improvement and more efficient use of resources in order to provide more seamless palliative care services that can be 'wrapped around a client'. This notion of 'patient centred care' shifts the system approach from a disparate group of independent entities into a dynamic and complex whole, requiring participating units to recognise their interdependence and interact accordingly.

For this reason, most Victorian public hospitals have rebranded themselves as 'public health services' to emphasis the integration of the acute, subacute, aged and community services to best match the client profile. Barwon Health is an example of a health service in Victoria that operates community palliative care, a hospital-based palliative care consultancy team, a palliative care unit, community nursing, outpatients medical and nursing review clinics. The amalgamation of these services minimises the barriers between service providers, enables the sharing of patient information, and provides timely coordination across services – all of which improves the patient journey.

VHA Recommendation:

- Good governance, at a local community level, is essential to provide an integrated and co-ordinated use of palliative care, health and aged care resources.

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d. The effectiveness of a range of palliative care arrangements, including hospital care, residential or community care and aged care facilities

Effectiveness in palliative care arrangements arises when health service consumers can have access to a flexible system with services closer to home with a range of choices. Greater investment and appropriate funding mechanisms need to be in place to support the' triangle of care' so that the right care is provided at the right place and at the right time.

The Victorian DH proposes a 'triangle of care' for an integrated framework in palliative care provision to meet the needs of patients through the final stages of their illness. The framework encompasses community-based or home care, inpatient hospice care (hospice units), and acute hospital support[13]. The triangle of care may be provided through different service structures, or the one organisation, depending on the services available within different communities. All palliative care clients should have access to the three settings according to their support or clinical care needs.

Hospices play an integral part in the 'triangle of care' by providing respite care and symptom management in a cost-effective manner. The hospice enables patients to access medical, nursing and psycho-social support while still allowing patients to return to their homes. By controlling their symptoms, it reduces the number of unnecessary emergency department admissions. However, as many operate on a charity basis and provide services free of charge, the continuous financial pressure threatens the capacity to perform day to day operations of the hospice.

Specifically, the VHA sees a need for a particular focus on assistance to rural and regional RAC services. Victoria has the highest proportion of Public Sector Residential Aged Care Services (PSRACS) of any Australian jurisdiction. This is an important factor to the viability of rural health services, where the majority of these residential care beds are co-located. Enabling these services to provide high quality palliative care is likely to allow a greater number of residents to remain in a RAC facility until the end of life. In rural areas especially, this can mean that residents are able to remain in their community and close to family and friends who are able to maintain contact with them more easily than if they were to be moved.

Continuity of care depends on the integration and coordination of service and organisations involved in a person's care. The 'triangle of care' provides an effective structured framework that should allow patient to move with ease from one service type to another, however, this will not be viable without a flexible funding arrangement that fosters collaboration and partnership.

VHA Recommendation:

- In achieving 'patient centred care', palliative care services should be funded as a strategy rather than a stand-alone activity to enable the mobility of funds to suit the needs and wishes of the patient.

e. The composition of the palliative care workforce

Australians and their health workforce are ageing rapidly like all other developed nations. Approximately 70 per cent of the total palliative care workforce is over 40 years of age; almost 35 per cent is over 50 years of age[14]. This is problematic as over the next 20 years the number of workers retiring will lead to an inadequacy to meet the demand for health services by an ageing and growing population. It is estimated that the demand for health services will necessitate a workforce growth at twice the pace of the non-health related workforce.

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The nationwide shortage of healthcare professionals will have a profound impact on the composition of an adequate specialist workforce that is critical in the provision of palliative care.

Palliative care in Australia is delivered by a range of professionals from GPs and community nurses to large tertiary referral specialist palliative care services. However, Australia currently has about half the palliative care medicine specialists it needs under the current referral pattern[15]. The situation is worse in rural and regional areas in Australia where the lack of professional support, locum coverage and sense of personal isolation has affected all health workforce recruitment.

A multidisciplinary team is essential in providing appropriate palliative care that includes medical, nursing, allied health, chaplaincy/spiritual care, and also grief counselling and bereavement support for families and carers. The development of multidisciplinary teams requires enhanced learning and training for clinicians and support staff so that they are able to provide the necessary physical, emotional and spiritual needs for the person's end of life care.

The VHA welcomes the development of innovative workforce designs to meet the demand for healthcare professionals in palliative care over the next decade. This strategy must clearly identify the cost of maintaining a professional workforce and ways to maximise the use of skilled medical professionals, who are in short supply. Work demarcation needs to be addressed in order to move away from professional 'silos' towards a workforce based on capability and competency. For example, an experienced patient care worker trained in the activities of daily living and with some drug competencies, could provide routine home nursing in consultation with a registered nurse.

A workforce redesign involves creating new categories of healthcare workers that complement trained health professionals and relieve them of the routine and time-consuming elements of their profession. The Grampians Region in Victoria recognised that with its population of over 200,000 and only two physicians, it had less than the recommended ratio of palliative care specialist physicians (1.5 EFT per 100,000) . This was further exacerbated by the significant distance between each population group. By sharing resources, such as information and tasks directed towards a shared goal, the Victorian Rural Palliative Care Nurse Practitioner (PCNP) Project emerged. The aim of the project was to identify the service gaps within the Grampians Region and to employ the PCNP model to extend and enhance service provision rather than duplicate or replace existing service. Access to an advanced level of expertise from a PCNP within the region aimed to improve equity of specialist service provision for rural patients and assist in providing services in a more timely and cost effective manner. The project is an example of the necessity to implement similar models of advance scope of practice roles in building a responsive, skilled and appropriate workforce that meets the needs of the local community.

The broader definition of the palliative care workforce must also include voluntary and unpaid carers. Volunteer workforce contributions include support of patient and patients' families or carers, alternative therapies (massage, aromatherapy, diversional therapy etc) and fundraising for palliative care services. In 2010, carers in Australia contributed an estimated 1.32 billion hours of care[16]. It is anticipated that the caretaker ratio – the number of people to provide care to the number of people most likely to require care – will diminish from 2.5 to less than one over the next 50 years[17].

VHA Recommendation:

- Modernisation in workforce models is needed, including expanding the scope of practice for healthcare workers, increasing skills and partnering between health agencies. The focus should be to achieve efficient and patient-centred care outcomes.

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f. The adequacy of standards that apply to the provision of palliative care and the application of the Standard for Providing Quality Care to all Australians

The VHA recognises the need to promote excellence and quality care across all healthcare settings that is continuously monitored and reported. This includes the measurement of health outcomes, access and system performance so that high level of care provider expertise is consistent across all sectors. This has potential benefits in providing standard quality measures, benchmarking across the country and, ideally, identifying the impact in supporting palliative care provision to older Australians.

At present, there are 13 Standards for Providing Quality Palliative Care for all Australians as set by Palliative Care Australia for all different care settings. Services and providers are encouraged to adopt the Standards on a voluntary basis to support quality management and improvement activities.

As these Standards are not obligatory, it provides little opportunity for health services to benchmark against their peers. Benchmarking can be a powerful tool in identifying the capacity to reach productivity and be a flag in identifying health services needing help to improve. This can be achieved via the appropriate implementation of indicators. The VHA believes that any formalised development of indicators must occur with the intent of continuous quality improvement, rather than solely punitive or financial outcomes.

Health service administrators rely on data analysis and comparison of inputs, operational procedures and outcomes to operate their services more efficiently. Many healthcare agencies are using internal resources to collect and provide data but the data is not analysed or disseminated in a way that improves their services. The VHA believes health services should not be required to submit data unless they receive meaningful benchmarking information in return. This 'information in/information out' approach will ensure the measures and their implementation contribute to the improvement of health services and outcomes that benefit the Australian population.

The VHA supports the integration of these indicators within existing organisational planning and evaluative frameworks and not seen as a stand-alone activity that providers can choose to either to opt in or out. This would be best driven by a framework that is articulated in accreditation standards.

VHA Recommendation:

- Formalise the assessment process to ensure that all services are meeting standards as assessed by an independent body rather than a self-assessment done on a volunteer basis.

g. Advance care planning

The discussion around future care needs at the end of life is a difficult one. There is a tendency for health professionals to avoid the subject particularly when end of life care is further complicated by communication and cognitive problems relating to old age and the emotions that families endure when their loved ones are ill and possibly dying[18]. However, health professionals need to recognise the wariness of generalising end of life treatment as there is sometimes a discrepancy between people's views as relatives of a seriously ill person and what they would want if they themselves were dying[19]. Thus there is a need to initiate and promote discussion about end of life care for all people.

Advance care planning (ACP) can assist in the shift from a disease-focused approach to an emphasis on the needs of the patient and their families. It encompasses the principles of "comfort, choice, dignity, empowerment and peace of mind"[20]. ACP provides an opportunity for an individual to proactively make choices and decisions about what is important to them

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and by involving their families, they become more aware of the issues surrounding their end of life planning.

Recently there have been awareness campaigns to promote organ donation, such as the need to register decisions and initiating discussion to know each other's wishes, particularly within the family. A similar campaign is needed for ACP for discussion, understanding and acceptance of each family member's decision. This needs to occur irrespective of where in the life stage a person is – healthy and active, recently diagnosed, chronically ill, or at the end of their life. This is particularly important as in some cases, illness and incapacity is sudden and unforeseen, leaving no capacity for care planning. It also enables the capacity to express health care preferences, nominate a surrogate decision-maker and complete an Advance Care Directive (ACD) prior to chronic illness and the early onset of dementia.

While ACP takes a holistic approach in the discussion of a person's life goals, values and personal views and choices about their outcomes of care, an ACD is a legal document that is intended to ensure a patient's preference can be honoured during any period of temporary or permanent impaired decision-making capacity, not only at the end of life.

Legislation regarding treatment choices, the refusal of treatment and the power to appoint substitute decision makers is specific to each state and territory. In Victoria, ACP occurs in an ad hoc manner across various health services, underpinned by the Medical Treatment Act 1988 and the Guardianship and Administration Act 1986. The problem emerges when people move interstate for example to be closer to their family. The lack of case law in Australia provides little direction on the legality of an ACD and how an ACD may be followed in practice[21]. There is a clear need for the development of nationally consistent legislation to ACD across all jurisdictions in Australia.

There are good reasons to be interested in ACP, even in the face of criticism. The fact that most Australians have not made an ACD does not mean they do not want the *right* to make one. The problem is that half of us will not be a position to make our own decisions when near death and our family will most likely be unaware of our views.

VHA Recommendation:

- Nationally consistent ACD legislation across all jurisdictions.
- Public awareness campaigns that promote the necessity of having an ACP (irrespective of age) and to inform family members of these choices.

h. The availability and funding of research, information and data about palliative care needs in Australia

Over the past decade, there has been a surge in the amount of palliative care evidence, through increased research. However to be truly valuable, this empirical evidence needs to be available and used by all involved in providing care to people as they approach the end of their life. Translating theory into practice isn't a simple task. Palliative care providers are spread across many health and community settings, hindering the communication process to share valuable knowledge and experience.

The VHA recognises the role of information and communication technology (ICT) in making health services more efficient and effective in promoting the health and wellbeing of Australians. Initiatives, such as the personally controlled electronic health record (PCEHR) have the potential to enhance the interoperability between health and local government ICT systems to allow better sharing of assessment and treatment information of palliative care client. This may avoid assessment duplication and enable clients to seamlessly navigate through the service provider world. Information sharing initiatives can facilitate the growth of

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strong multidisciplinary teams that are able to effectively manage the gamut of complex health needs of clients.

Increasing web-based information sharing strategies, such as forums, enable service providers to share valuable knowledge including good models of practice, innovation, lessons learnt and mistakes made, which can contribute to a more efficient and effective delivery of palliative care services. It must be acknowledged, however, that implementation of ICT strategies to support access and distribution to information will take time and need to be well planned and well resourced. This includes the consideration of the barriers associated in the implementation and execution, such as insufficient broadband capacity in some rural locations and a lack of supportive funding models.

VHA Recommendation:

- Investment to enable the implementation of ICT strategies to support access and distribution of information among service providers and staff.

3. Conclusion

During this period of health reform in Australia, it is essential that the choices made in the health care system provide the support to integrate care across the health care continuum. To optimise palliative care service delivery in Australia, reform is crucial at the patient, provider and service level.

At a system level, policy frameworks are required to promote integrated models of care that consistently meets, and perhaps exceeds, safety and quality requirements. This will not be possible without necessary funding and resourcing that fosters appropriate and tailored care. At the provider level, there is a need to promote multidisciplinary care and communication strategies. For patients and their families there is a need to accentuate the importance of ACP and provide timely information about the benefits of palliative care and supportive care services.

The philosophy and principles of palliative care must include the respect for the right of each patient to make informed choices about their own care, including the type and site of care, and the right to die with dignity and without unnecessary intrusions. This must be upheld in the most cost-efficient, the most effective and at the highest quality pathway possible.

Please contact me on (03) 9094 7777 to clarify any information in this submission.

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