

# Palliative Care

V I C T O R I A

Specialist health care and practical support

## Submission to the Senate Community Affairs Committee Inquiry into Palliative Care

"You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but to live until you die."

~ Dame Cicely Saunders

### Introduction

Palliative Care Victoria (PCV) is the peak body representing palliative care providers, consumers and their families and those with an interest in palliative care in Victoria.

PCV is a member of Palliative Care Australia (PCA) and has contributed extensively to the PCA submission. Therefore, this submission does not aim to address all of the terms of reference of the inquiry or to provide the depth of information contained in the PCA submission.

This submission complements the national PCA submission by highlighting:

- Victorian experiences and projects with potential national relevance;
- High priority issues raised in our consultations and interviews with key stakeholders; and
- Case studies that demonstrate the value of palliative care and some of the areas where improvement is needed.

### The Victorian Situation

The Victorian specialist palliative care system is well supported by the Victorian State Government and is perhaps the most comprehensive in the country.

In 2011-12 expenditure by the Victorian State Government on specialist palliative care services is around \$108 million. Please refer to [Appendix 1, Palliative Care Services in Victoria](#), which provides a comprehensive summary of current specialist palliative care service provision and funding breakdown in Victoria.

In August 2011, the Victorian Government released *Strengthening palliative care: Policy and strategic directions 2011-2015*. This provides a blueprint for development in relation to seven strategic priorities:

- Informing and involving carers
- Caring for carers
- Working together to ensure people die in their place of choice
- Providing specialist palliative care when and where it is needed

- Co-ordinating care across settings
- Providing quality care supported by evidence
- Ensuring support from communities.

This useful document provides a wealth of information and references that may be useful for the Inquiry. The Victorian policy and strategic directions for palliative care addresses the period to 2015 and sits within the broader Victorian Health Outcomes Framework 2012-22.

## Strategic Approach

Given the forecast significant increases in need for palliative care associated with changing demography and disease patterns, it is important the Senate Inquiry take a longer-term strategic focus for the next 20+ years in considering the issues and framing its recommendations.

Australia's expenditure on health in real terms has grown at an average of 5.3% per year, compared with average real growth in GDP of 3.1% per year.<sup>1</sup> This disparity, where health expenditure is rising faster than economic growth, is not sustainable. The National Health & Hospital Reform Commission concluded that:

- major reforms are needed to improve the outcomes from this health spending and to contain the upward pressure on health care costs; and
- evidence based investment in strengthened primary health care services, health promotion and prevention will help to contain future growth in spending.

In the context of life-threatening illness, this involves ensuring patients and their families have timely access to information and advice that helps them to make informed choices about treatment and palliative care options. This includes ensuring that patients and their families receive the support they need, when they need it and, wherever possible, at the preferred location.

This has implications for building community capacity in dealing with the issues of dying, death and bereavement. Alongside this, there are implications for developing the capacity of the broader health, aged care, and disability care sectors to provide appropriate care choices and services to people living with life-threatening illnesses and their families, with the support of specialist palliative care services.

## Sound Business Case for Investment in Palliative Care

Given this strategic context, international evidence indicates that there are compelling reasons for increased investment across Australia to ensure timely access to optimal palliative care services. This is outlined in *The Benefits of Palliative Care* at [Appendix 2](#). In summary, the evidence shows:

### 1. Palliative care contributes to more effective use of health resources

A range of studies has found that palliative care contributes to fewer hospitalisations and reduced use of acute hospital resources, when hospitalisation does occur. While this evidence is strongest in the case of patients with cancer, this reflects the fact that palliative care services have been focused predominantly on patients with malignant disease. However, there is growing recognition that it is also beneficial for patients with a range of chronic life-threatening conditions.

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<sup>1</sup> AIHW 2011. Health expenditure Australia 2009-10. Health and welfare expenditure series no. 46. Cat. no. HWE 55. Canberra: AIHW

## 2. Quality of life benefits for palliative care patients and their carers

Importantly, the international evidence also demonstrates that palliative care improves the quality of life of people with a terminal illness and the outcomes for carers.

One of the key factors often cited in the literature, relevant to both the quality of life and health resource use benefits of palliative care, is that palliative care fosters timely conversations and informed choices about care goals and advance care wishes with patients and their families. This contrasts with the continuing use of futile and often expensive treatments (that may have adverse side effects), in the absence of those important conversations.

### **UK Strategy to invest in palliative care**

The United Kingdom reviewed its funding of palliative care in 2011 and proposes to fund new palliative care packages that would provide optimised care outside hospital settings. It is estimated that when fully implemented by 2021 this strategy would reduce hospital deaths by 60,000 a year. Increased effectiveness of health resources arising from this strategy is expected to fund palliative care provision to people with otherwise unmet palliative care needs - estimated at around 92,000 people currently. Pilots have been proposed to test these calculations but they are yet to report.<sup>2</sup>

While the UK system is not directly comparable to that in Australia, it faces similar issues and the UK developments signal the importance of investing in comprehensive palliative care services to address increasing needs in an effective and sustainable way.

## **Population Based Planning and Funding**

### **Equity of Access**

As a principle, people should be able to receive good quality services in the setting of their choice and ultimately die where they wish irrespective of their age, geography, cultural and social background. As the PCA submission shows there is great variation across the country in the nature and coverage of services. PCA has developed a population based planning guide for palliative care service provision in Australia and it would be desirable for this, or an updated version, to be considered as a basis for more equitable funding and access to palliative care services across Australia.<sup>3</sup>

Transitional arrangements to achieve greater equity of funding and access need to be considered. A good example is the Palliative Care Resource Allocation Model (PCRAM) recently developed and used by the Department of Health in Victoria. The PCRAM provides a formula for more equitable allocation of new funding based on the needs of the population within defined geographical catchment areas. PCRAM takes account of changes in the population, age structure, rurality and socio-economic status and can be used to address historical funding anomalies and facilitate greater equity in funding allocation and access to services over time. Victoria is also progressing the implementation of a service capability framework for palliative care services, which, amongst other things, articulates the roles and responsibilities of each service capability level (for inpatient, community and consultancy services respectively) to support patient care, service linkages, education and research within and across regions.

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<sup>2</sup> Palliative Care Funding Review - Funding the Right Care and Support for Everyone, Report to the Minister for Health, UK, July 2011

<sup>3</sup> Palliative Care Australia - A Guide to Palliative Care Service Development: A population-based approach

## Activity-Based Funding Concerns

The introduction of a national activity-based funding approach for a wide range of health services will impact on inpatient and community palliative care services in Victoria from 1 July 2013. It is still too early to assess the impact of this major change in funding, as much of the detail has still to be communicated, including the 'national efficient price' for palliative care to be determined by the National Health Pricing Authority.

We are concerned that activity-based funding may not adequately recognise the significant amount of work undertaken by palliative care services to support carers throughout the course of the patient's illness and during bereavement. Given that most patients wish to die at home and the majority of day-to-day care is provided by informal carers, the effort by palliative care services to support the needs of patients and carers is critical to the sustainability of home-based patterns of care, supplemented by respite, rather than relying mainly on an inpatient-based approach to palliative care provision.

It is also important that specialist palliative care consultancy services – both within acute settings and with other community-based health services – are not disadvantaged by the move towards activity-based funding, given their valuable role in promoting timely access to palliative care and the associated health resource utilisation and quality of life benefits.

We are also concerned that the introduction of activity-based funding will not act as a disincentive for health professionals to engage in conversations with patients and their carers about care options and goals and advance care wishes. These can be very time consuming and currently specialist palliative care services undertake much of the work because many health professionals do not feel well equipped to have these conversations. An adjunct issue is that activity-based funding for palliative care needs to recognise the significant amount of time spent in having these conversations with patients and their families.

### ***Recommendation 1***

- That Commonwealth and State Governments implement a population-based funding approach for the provision of palliative care services so as to provide equity of access across Australia;
- That palliative care services are adequately and appropriately funded given their capacity to drive more effective use of health resources, as well as improved quality of life benefits for patients with a life-threatening illness and their families; and
- That the National Health Pricing Authority monitor and evaluate the impact of the yet to be identified national efficient price for activity-based funding for palliative care services ensuring that the support provided to carers of patients with a life-threatening illness and the provision of specialist palliative care consultancy services are adequately funded and sustainable.

## The Right Service in the Right Setting

Within the context of the palliative care service planning framework outlined by PCA<sup>4</sup>, there is a need to ensure that patients and their carers receive the right support in the right setting. Ideally, general health, aged care and disability care services will have the capability to provide palliative care for people with a life-threatening illness who do not have complex needs. Specialist palliative care services will increasingly provide consultancy and support and focus on patients and carers with complex care needs.

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<sup>4</sup> Ibid

Victoria is working towards this approach. For example, all acute hospitals have access to specialist palliative care physicians who are skilled in symptom control, decision making, care for the dying, co-ordination of care and psychosocial care.

### **Proactive strategies to ensure care is providing in the right setting**

A range of initiatives are in place to improve the outcome for palliative care patients who present to Emergency Departments (EDs) and Intensive Care Units (ICU) or at outpatient clinics for chronic disease (such as renal failure and respiratory failure).

For example, Eastern Health has successfully developed a protocol for transferring palliative care patients from EDs and ICUs into the palliative care stream at any hour of the day or night seven days a week. The protocol has been trialed from March 2011 and since then they have taken across 38 patients from EDs to the palliative care stream. Not only have they improved the quality of patient care and the flow through the hospital but this initiative has resulted in more effective use of 172 bed days and associated operating costs in excess of \$100,000. The evaluation shows that 87 percent of the transfers have been appropriate: i.e. they have not had to transfer back to acute care.

#### Case study 1

Mrs MF was a 64 year old smoker with a known pancreatic cancer, struggling to care for herself at home. She was brought in to the ED by her family as they were concerned that she was no longer able to look after herself and was not eating. Mrs F hated being admitted to the oncology unit as it was impossible for her to smoke in the ward and smoking was one pleasure in her life. After a fast track transfer to palliative care, Mrs F was able to be cared for in a room overlooking a garden and to smoke safely outside. In addition, Mrs F's quality of life was improved by visits from volunteers, borrowing books from the library and massages. Mrs F died with her family present two weeks later. Had she been admitted to the acute system, she may have had three or four bed moves in that time.

### **Strengthening linkages between specialist palliative care and aged & disability care**

In the 2011 State Budget, the Victorian Government made funding available for all regions in Victoria to establish protocols and strengthen relationships between palliative care and aged care services. The impacts associated with this action are the development of state and regional palliative/aged care action plans and the development of joint resources to support the provision of end-of-life care in aged care services. The funding is based with the palliative care consortia in each region. It is envisaged that a link nurse position or similar will be based with a palliative care consultancy service as part of a multi disciplinary team and that the position work across each region (i.e. not specific to a health service). This expert advice will complement the existing training and support that specialist palliative care services currently provide to aged care in order to build their capacity. A similar approach is being established with residential disability services.

### **Increase Awareness and Understanding**

In November 2010, the Australian Health Ministers' Conference endorsed the *National Palliative Care Strategy*.

Promoting awareness and understanding is one of the four key areas addressed and includes the following goals.

- To significantly improve the appreciation of dying and death as a normal part of the life continuum.
- To enhance community and professional awareness of the scope of, and benefits of timely and appropriate access to palliative care services.

The National Strategy commits to five key action areas to advance achievement of these goals<sup>5</sup> but there is a need for more investment to achieve the desired outcomes.

A large ongoing national public education campaign is needed to increase understanding of palliative care and awareness of how to access these services in a timely manner. Utilising an empowering health promotion approach, the campaign would develop health literacy in relation to dying, death and bereavement. This would better prepare individuals and families are better able to deal with these issues and the broader community is better equipped to provide compassionate support.

The following case studies indicate the impact on patients, families and the health system when there is lack of awareness or understanding of palliative care services available and how to access them.

#### Case Study 2

Palliative Care Victoria received a phone call on a Saturday morning in December 2010 from a distraught relative who had taken her parent home to die the previous afternoon, against the hospital's advice. The situation had deteriorated rapidly. The patient was in considerable pain and the relative, who didn't know what to do, was unable to access the GP or have the patient re-admitted to the hospital ward. This avoidable situation arose because of a failure to discuss with the patient and carer their wishes regarding the goals and preferred location of care. As a result, the carer discharged the patient home without adequate supports in place.

#### Case Study 3

Palliative Care Victoria received a phone call in January 2011 from a daughter asking about the right to access palliative care for her mother, who was ill with terminal cancer in hospital. She had asked the Oncologist caring for her mother if she could care for her mother at home and had been told without any discussion "your mother's too sick for that". She had also expressed concern to a nurse at the hospital about the morphine being given to her mother via a syringe driver and had been told "it's what your mother needs, it's what she's getting." Both responses did not engage with the daughter's concerns and wishes or provide opportunities to discuss the patient's needs or preferences for end of life care.

*Beyond Blue* and *QUIT* are examples of two campaigns that raise awareness, improve access to services and provide health and economic benefits. The current investment in National Palliative Care Week is too small to have an enduring impact on awareness or access to services.

Investment in a more substantial and enduring national campaign is needed and would provide significant benefits for society given the evidence that palliative care results in quality of life benefits and more effective use of health resources. ***It also provides a strong foundation to facilitate advance care conversations and plans.***

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<sup>5</sup> Commonwealth Government – *Supporting Australians to Live Well at the End of Life* – National Palliative Care Strategy 2010

## ***Recommendation 2:***

That the Commonwealth provides adequate funding for the five action areas to promote greater awareness and understanding of palliative care, as outlined in *The National Palliative Care Strategy 2010*; and that this include, as a priority, a national campaign to raise awareness and understanding of palliative care and how to access it.

## **Increase Support for Carers**

One of the core values of palliative care is to provide a support system that helps the family and carers cope during a person's terminal illness and after the person's death.<sup>6</sup>

Regardless of the place of death, it is estimated that up to 90% of people in the terminal phase of a life threatening illness spend the majority of their time at home<sup>7</sup> and for most people this means with the significant support of carers.

Supporting carers increases their capacity to enhance the well-being of patients and carers and also recognises and sustains their remarkable economic contribution to health care.

### **National Carer Strategy**

The National Carer Strategy was developed in 2011. It is an integral part of the Australian Government's broader social inclusion agenda and it sits alongside and complements the National Disability Strategy. In conjunction with the Carer Recognition Act 2011, it forms part of the Australian Government's National Carer Recognition Framework.

### **Victoria**

Victoria recognises the crucial importance of providing appropriate and adequate support to carers and this continues to be a work in progress.

In the 2011 Victorian Budget, the \$34.4 million in new funding allocated over 4 years included \$500,000 additional funds to be added to existing flexible funding to support the specific needs of carers with costs of caring such as respite, equipment, and other out-of-pocket caring expenses. The funding also covers improved after-hours support for carers across all regions, drawing on the findings of several successful regional pilots and feedback from carers on the need for improved access to support outside usual business hours.

The Victorian Government funds the *Victorian Palliative Care Satisfaction Survey* (VPCSS) which invites feedback from adult patients, carers and bereaved carers in community and inpatient palliative care settings. This involves an annual survey conducted between mid February and mid May and the third survey is currently in progress. In the 2011 survey, the top five areas identified as priorities for improvement by carers were:

- Opportunities to talk with others about your own situation
- To minimise financial burden<sup>8</sup>
- The level of training provided to carers to carry out specific care functions such as massaging, moving or bathing the patient
- Planning ahead for funeral arrangements
- Support from volunteers<sup>9</sup>

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<sup>6</sup> Who Guide for Effective Programs – Cancer Control - 2007

<sup>7</sup> J Skilbeck, S Payne et al "An exploration of family carers' experience of respite services in one specialist palliative care unit," *Palliative Medicine* Vol19 no 6

<sup>8</sup> See Menzies Centre for Health Policy – "Travelling alongside: Patients', Carers' and health professionals' Experiences of the Calvary Health Care Bethlehem Model of Specialist Palliative Care." 2011 and the Bethany's Story Case study

A research report by Calvary Health Care Bethlehem has highlighted significant financial pressures on patients with a life threatening illness and their carers. Participants in the study kept track of out of pocket expenses on health care professionals (not refundable or gap), community services, medications and transport. On average these costs were around \$185 per fortnight. For some participants this was 20% of their household's income.<sup>10</sup> Issues identified were the use of the calendar year to determine eligibility for access to the PBS safety net, as this can disadvantage families who face high costs in a short period that spans the end of one calendar year and the start of another. Access to flexible funding can assist in addressing needs that are not readily accommodated by programs such as the PBS and that are not specifically geared to the special needs of palliative care patients.

### ***Recommendation 3:***

That the National Carer Strategy, the National Palliative Care Strategy and the National Disability Strategy are appropriately and adequately resourced so that the wellbeing of carers and their capacity to continue to provide care are supported through access to adequate and appropriate flexible funding, respite, practical support, financial assistance and holistic care.

## **Develop Workforce Capacity to Provide Palliative Care**

Victoria has embraced the Commonwealth funded Program of Experience in the Palliative Approach (PEPA) which is designed to improve the skills, confidence and expertise of health practitioners who care for people who are dying and their families. This includes general practitioners, nurses, allied health and Aboriginal health workers.

PEPA has three core components:

- supervised clinical placements build workforce capacity and enhance links between specialist and generalist health care professionals;
- workshops provide an introduction to the palliative approach; and
- post placement support activities provide professional development, networking and education opportunities.

PEPA and reverse PEPA (palliative care health professionals supervised placement in acute care and other specialist areas such as aged care) should continue on an on-going basis as it builds capacity across sector boundaries, particularly within aged care. Victoria has used it particularly successfully with Aboriginal Health Workers.

Health Workforce Australia is undertaking some broad planning in an attempt to ensure that Australia will have the medical workforce it requires in terms of numbers and skill areas. Victoria also has some quality workforce initiatives that could usefully operate alongside the macro workforce strategies and these may have national application.

### **Victorian Palliative Care Medicine Training Program (VPMTP)**

The VPMTP was established to provide co-ordinated state-wide training in palliative medicine. It aims to build and sustain a high quality palliative medicine workforce including specialist palliative care physicians, doctors from general practice and other specialities. More information is available from <http://centreforallcare.org/index.php/education/vpmtp/>

### **Victorian Palliative Care Nurse Practitioner Collaborative (VPCNPC)**

The VPCNPC has been operating since 2009 to assist with the development, support and mentorship of Palliative Care Nurse Practitioners.

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<sup>9</sup> Victorian Palliative Care Satisfaction Survey – Statewide Report, June 2011

<sup>10</sup> Menzies Centre for Health Policy – “Travelling alongside: Patients’, Carers’ and health professionals’ Experiences of the Calvary Health Care Bethlehem Model of Specialist Palliative Care.” 2011

## Post-Graduate Palliative Care Scholarships

Medical, nursing and allied health professionals, with a minimum of an undergraduate health related degree, either currently working in the area of palliative care or who wish to develop their capacity to provide palliative care are eligible for funding. Over the past 5 years 144 Postgraduate Palliative Care Scholarships have been allocated to the value of \$346,000.

## **Develop and Sustain Palliative Care Volunteerism**

Canada and the UK are currently investing in the development and sustainability of palliative care volunteering at a much greater level than Australia.<sup>11</sup>

A 2005 Victorian palliative care workforce study<sup>12</sup> showed that palliative care volunteers at that time made up 60% of the combined palliative care labour workforce. Since then, there has been continued growth in the involvement of volunteers in palliative care provision in Victoria, as outlined in the *Volunteers in Victorian Palliative Care Fact Sheet (Appendix 3)*. Palliative care volunteers contribute to all the palliative care domains - physical, spiritual, social and emotional. Following extensive training they increase and enhance the range of supports palliative care services can offer to their clients.<sup>13</sup> Managers of Volunteers perform a vital role in developing and supporting volunteer services.<sup>14</sup>

The Victorian Government provided new ongoing funding in the 2011 Budget for the development and implementation of a Palliative Care Volunteering Strategy in Victoria. This recognises that volunteering in palliative care needs to be promoted, nurtured and sustained through effective recruitment, training and development, management and evaluation strategies. The development of a 3 year strategy for 2013-15 has commenced and will be completed by the end of 2012. It may be a useful reference for the development of a national strategy. Palliative Care Victoria is currently updating the Palliative Care Volunteer Training Resource Kit, which is used interstate and internationally to train volunteers working in palliative care.

A national strategy to support palliative care volunteerism across Australia is needed if we are to keep pace with the growing need for palliative care. It is also an important part of building compassionate communities that support people throughout the life cycle.

### ***Recommendation 4:***

That the Commonwealth fund the development and implementation of a National Palliative Care Volunteer Workforce Strategy, with particular emphasis on:

- Recruitment, retention and retirement
- Standards
- Training and development of volunteers and managers
- Funding and resources
- Data collection

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<sup>11</sup> Dimbleby Marie Curie Cancer Research Fund 2010/11, *Call for Research Proposals on the use of Volunteers at the end of Life*, UK, <http://www.mariecurie.org.uk/en-gb/healthcare-professionals/research/Funding-for-research/>

<sup>12</sup> Department of Human Services, (2006). *Palliative Care Workforce- A Supply and Demand Study*, p 2

<sup>13</sup> Doyle, D.; Hanks, G. W. C. & MacDonald, N (1998) *Oxford textbook of Palliative Medicine* (2<sup>nd</sup> ed.). Oxford: Oxford University Press

<sup>14</sup> Commonwealth of Australia and Volunteering Australia, 2003, *Working with Volunteers and Managing Volunteer Programs in the Health Care Setting*, p9.

- Collaborative partnerships

## Improving Access to Palliative Care

### Aboriginal & Torres Strait Islander Communities

In Victoria the number of people accessing palliative care services from an Aboriginal and Torres Strait islander (ATSI) background was much smaller than the state's demographics would suggest. The numbers were particularly low given that ATSI people have a lower life expectancy, higher infant mortality rate and high levels of chronic disease.

In 2007 the Victorian Government made funding available for 3 years to the Victorian Aboriginal Community Controlled Health Organisations (VACCHO) to raise the numbers using the services and to improve the service's cultural awareness. That project was very successful and is now ongoing. The project's results are outlined in [Appendix 4](#). Consideration could be given to implementing similar models in other states.

### Culturally & Linguistically Diverse Communities

An evaluation of the impact of the *Victorian Strengthening Palliative Care Policy 2004-2009* found that a similar situation was occurring with CALD communities and there was a need for more specific engagement with them to improve their awareness of and utilization of palliative care services.<sup>15</sup> Victoria already has in place a *Cultural responsiveness framework: guidelines for Victorian health services* which is a tool to strengthen the capacity of health services to respond to the needs of CALD patients. However, there was a need for a more targeted strategy to promote awareness of and access to culturally competent palliative care services.

Victoria is currently developing a *Palliative Care Cultural Diversity Strategy* involving collaborative leadership, research and broad engagement with key stakeholders. The aims are:

- To increase knowledge about and use of palliative care services by people from culturally and linguistically diverse backgrounds living with a life threatening illness and their families.
- To develop the capacity to provide palliative care services which are inclusive of, and responsive to, the needs of people from culturally and linguistically diverse backgrounds.

The research component of the project is nearing completion with a report due in April. The early findings confirm the need for more specific engagement with CALD communities to raise awareness and understanding of palliative care. Survey results indicate that palliative care services would welcome access to more structured education to support the provision of culturally competent palliative care to CALD patients and their families. The Victorian Palliative Care Cultural Diversity Strategy could be a useful reference for the development of a national strategy.

### ***Recommendation 5:***

That a national strategy be developed to improve the access of special needs groups to palliative care services and to further develop the cultural competence of palliative care services

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<sup>15</sup> Victorian Government Department of Human Services, 2009, *Strengthening Palliative Care Policy 2004-2009 Evaluation Report*, p 46.

## Children and Young People

The needs of children and young people with a life threatening illness and their families are considerable. There are also some important differences compared to adult palliative care: the number of children dying is small; many conditions are extremely rare with diagnoses specific to childhood; the time scale of children's illnesses is variable and can be prolonged; most clinical trials involve adult populations so treatment regimes may require modification having regard to the developmental stage of the child.

Many children and young people with palliative care needs also have multiple disabilities. The risk, or certainty, of death in childhood or young adulthood and their changing and often complex care needs add a degree of complexity and urgency to their care and associated family support. The disability service system is not equipped to meet all their needs.

Co-ordination of a plethora of care and support services is daunting and often falls on the shoulders of the parents. Effective case management is critical to ensuring that care meets the continuously changing needs of the child and family. This is not uniformly available.

Palliative care is a small but critical area of the health sector and paediatric palliative care is smaller again in a resource intensive field. One of the key findings of the Commonwealth's *Paediatric Palliative Care Service Model Review 2004* was a proposal to establish a *Paediatric Palliative Care Reference Group* to "develop the evidence based national, definitions, standards and policies that are required to implement integrated paediatric palliative care models, including developing information, education and research strategies aimed at improving delivery." Those in the field took up the challenge and formed the reference group without any resources or Government support. Resourcing is needed so that further progress can be made on outstanding work particularly in the areas of neonatal and ante natal palliative care, services for young adults and data collection.

Three case studies attached as [Appendix 5](#) graphically demonstrate the plethora of issues that these families face such as co-ordination of services, costs of caring, sibling issues, and the transition from the paediatric to the adult system.

### ***Recommendations 6-9:***

- That sufficient funding is available into the future to ensure that children with life threatening conditions and their families have equitable access to quality information and responsive and appropriate palliative care services; including case management where required.
- That the *Australasian Paediatric Palliative Care Reference Group* be resourced via national funding to support the development and implementation of a national paediatric palliative care strategy; including issues associated with neonatal and antenatal palliative care.
- That the Commonwealth funds a research project to explore the palliative care needs of young adults and the appropriate service responses.
- That the Commonwealth Government funds a project to design a data collection system for paediatric palliative care.

## Recipients of Aged Care Services

Currently 13% of all deaths occur in residential aged care facilities<sup>16</sup> and if Australia follows US trends this could increase to 50% by 2020. Most aged care facilities are currently unable to offer appropriate palliative care. However, a recent Australian study has demonstrated that with proper support and appropriate training that good palliative care can be provided in this setting.<sup>17</sup>

The recent Productivity Commission Inquiry *Caring for Older Australians* has recognised that there are currently large systemic problems with the financing and operation of aged care and that the current models are not sustainable to meet future demand. In relation to palliative care they concluded that 'there is a strong case for residential and community care providers to deliver excellent palliative and end of life care' because it is less expensive and a more appropriate environment. However, they identified a number of problem areas that needed to be resolved first – a primary one being an increase in nursing hours.

As part of the reform process the Productivity Commission recommended a cost of care study to set subsidies that reflect the real cost of care. The implementation a palliative approach and appropriate care must be part of this study and the resultant subsidies.

Growth of aged care services for older people with chronic and complex conditions will also need to be complemented by an expansion of the capacity and competence of primary health care services to provide generalist palliative care, both for people living in the community and in aged care homes. This service delivery needs to be supported by increased collaboration and networking with expanded specialist palliative care services.

### ***Recommendations 10-15:***

- Specialist palliative care services should be funded to provide clinical and education support to residential care facilities in their region and this should be reflected in the specialist palliative care standards.
- Community aged care clients with complex palliative care needs currently receiving HACC or packaged care should be eligible to receive specialist palliative care consultancy support across the country and this should be reflected in funding agreements.
- The Commonwealth Government should provide adequate funding for systemic linkages between aged care and palliative care providers in order to embed an ongoing relationship.
- The Commonwealth Government should provide funding for the national rollout of the evidence based Palliative Approach Toolkit<sup>18</sup> to support aged care facilities to provide a palliative approach. A similar product should be developed to support the community care guidelines.
- That aged care subsidies include funding to cover the provision of palliative care.
- That the Commonwealth funds a project to look at how the quality improvement framework supporting the *National Palliative Care Standards* can be reflected in *Aged Care Accreditation*.

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<sup>16</sup> Sheenan, D and Schirm, V 2003, 'End of Life Care of Older Adults', *American Journal of Nursing*, Vol 103, p 48-58

<sup>17</sup> Parker D, Hughes K et al, A comprehensive evidence based palliative approach in residential aged care, Report to the Department of Health & Ageing 2011

<sup>18</sup> [www.uq.edu.au/bluecare](http://www.uq.edu.au/bluecare)

## Medication Management

Palliative Care Victoria has received a number of complaints from family members of relatives receiving residential aged care and staff of those facilities regarding poor pain assessment and management. This has been reinforced by feedback from some specialist palliative care services providing support to aged care facilities. An effective medication management system involves GPs, Pharmacists and facility staff, both nurses and personal carers.<sup>19</sup>

While there is currently no policy impediment in Victoria for nurses to delegate the administration of medications to personal care workers in aged care services, their duty of care requires them to ensure that the staff have the requisite competencies before delegating performance of this function.

### ***Recommendations 16-19:***

- The *Assist Clients with Medication* unit must become a mandatory core component of the Certificate III & IV in aged care and home and community care and a competency gained by all aged care workers.
- Residential care facilities should be required to have a functioning Medication Advisory Committee and this should be reflected in the aged care accreditation standards.
- That the Lead Clinician Group work, in collaboration with Aged Care, Pharmacy and other peak bodies and professional advisory councils, should systematically review relevant practice guidelines to improve the interface between all professionals, who work to support and care for older people across community and residential care and health settings.
- That the Council of Australian Governments, working through the Australian Health Ministers' Advisory Council, establish a working party to consider adopting uniform national model legislation in relation to drugs, poisons and controlled substances across Australia's states and territories.

## Standards

PCA developed the national palliative care standards. These are widely used by an increasing number of specialist palliative care services who are now undertaking a self-assessment against the standards under the voluntary National Standards Assessment Program.

However, there is also a need to promote high standards of palliative care across all health, aged care and disability care services. The National Safety and Quality Health Standards (NSQHS) exist to protect the public from harm and to improve the quality of health service provision. They provide a quality assurance mechanism that tests whether relevant systems are in place to ensure minimum standards of safety and quality are met, and a quality improvement mechanism that allows health services to realise aspirational or developmental goals.

Accreditation is an important driver for safety and quality improvement and Australia's health accreditation processes are highly regarded internationally. Standards are integral to the accreditation process as they determine how and against what an organisation's performance will be assessed. The NSQH standards have been designed for use by all health services. Health service organisations can use these standards as part of their internal quality assurance mechanisms or as part of an external accreditation process.

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<sup>19</sup> Aged & Community Services Australia was commissioned by Health Workforce Australia to collaboratively review the current medication management system and to draft a roadmap for reform. That report is yet to be released.

Given the expectation that increasing numbers of people will die in a wide range of health, aged care and disability care settings, it would be appropriate for the NSQHS to include a standard on care of the dying person and their family. This would drive a stronger focus on this aspect of care via their various accreditation and continuous quality improvement processes.

***Recommendation 20:***

That a standard on the care of the dying person and their family be developed and included in the National Safety and Quality Health Standards.

## **Definitions**

The lack of consistency in the use of terminology (eg palliative care, palliative approach, end-of-life care) across the country is creating confusion among bureaucrats, providers and academics. Consistency and accuracy are critical for data collection, planning and policy development. The Senate Inquiry provides an opportunity to initiate work that would result in an agreed national set of terms for data collection and research, and an agreed common language for use in community awareness raising and capacity building. These revisions should refocus end of life care from an individualised, private and medicalised approach to a more communal and social approach emphasising relationships, community participation and strengthening community capacity. PCA developed a glossary of terms in 2008 which now needs to be revisited and refined.

***Recommendation 21:***

That the Senate Committee develops a national set of terms for adoption in all jurisdictions.