



**Palliative Care WA (Inc)**

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08 December 2011

Hon Dr Kim Hames MLA  
Minister for Health  
28<sup>th</sup> Floor  
Governor Stirling Tower  
197 St Georges Terrace  
PERTH WA 6000

Dear Minister

### **Submission to the Western Australian State Budget 2012-13**

I enclose Palliative Care WA Inc's Submission to the Western Australia State Budget for the year ending 30 June 2013.

This year we have identified three priority areas for investment:

#### Carers

Acknowledging the contribution to care made by friends and family carers, and the savings to the health system which result,<sup>1</sup> we propose a systematic approach to educating carers so that they can undertake this vital role sustainably and safely.

#### Palliative Care Volunteers

The management of palliative care volunteers is currently very variable across Western Australia. Our proposal outlines a best-practice strategy to help ensure palliative care services are able to attract, retain, train and recognise great volunteers. We know what practical support organisations need in order to run good programs,<sup>2</sup> and a palliative care volunteering development function within Palliative Care WA Inc will ensure they get it.

#### Advance Care Planning

The Barnett Government has already supported law reform permitting Western Australians to appoint their own Enduring Guardians and complete Advance Health Directives. This Submission details the best way to maximise the impact of that reform and give people some assurance their preferences for care will be respected.

Our proposals are each based on the evidence and are designed to offer value for money.

Andrew Allsop, the President of Palliative Care WA Inc, and I are available to meet with you and your team to discuss the ideas in this Submission. I can be contacted directly on 0412 412 532 to arrange a meeting.

Yours sincerely

Will Hallahan  
Executive Officer

Encl: Submission to the WA State Budget 2011-13  
cc: members of Parliament of WA

<sup>1</sup> Access Economics, Aug 2005: *The economic value of informal care* – p 15

<sup>2</sup> WA Govt Dept for Communities, May 2011: *Vital Volunteering 2011-16* – p 8



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## Submission to the Western Australian State Budget For the year ending 30 June 2013

Palliative Care WA Inc calls for new funds in the following areas:

- support for carers of those living with terminal illness
- support for palliative care volunteering
- introduction of an integrated system-wide advance care planning program.

It is essential 'new money' is allocated so that existing services and initiatives are not jeopardised or eroded, and so that important work already planned for 2012-13 is able to go forward.

Proposal	2012-13 Expenditure	Nature of Expenditure
Statewide roll-out of the Learn Now, Live Well Program	\$150,000	recurrent
Increased support for palliative care volunteering	\$400,000	recurrent
Integrated advance care planning program	\$1,000,000	recurrent
<b>total</b>	<b>\$1,550,000</b>	

### Other Items of Note

1. Palliative care service providers in Perth continue to report to Palliative Care WA Inc that demand for care is increasing year-on-year but that resource increases have not kept pace.
2. Palliative Care WA Inc seeks, beyond 30 June 2012, resources for a number of important programs and initiatives which were funded as part of the incoming Liberal-National Party government's 2008 state election commitment, including:
  - the Paediatric Palliative Care Service
  - implementation of the Liverpool Care Pathway in residential aged care facilities and hospitals in all parts of the state
  - ongoing development of palliative care service provision in rural Western Australia
  - support for secondary hospitals, mental health and correctional facilities and aged care services in Perth as part of the Palliative Care Area Health Teams initiative.
3. Operating funds for Palliative Care WA Inc have not been renewed since the three-year service agreement with the Department of Health expired on February 2011.

More information about each of the priority investments appears below, or contact Will Hallahan, Executive Officer, Palliative Care WA Inc, on 0412 412 532.

<b>Statewide roll-out of the Learn Now, Live Well Program</b>	
resources	\$150,000 per year recurrent funding
use	employment of community education specialist to deliver 60 modules of the Learn Now, Live Well program in metropolitan Perth and major rural centres each year
agency/s	Palliative Care WA Inc
benefits	<ul style="list-style-type: none"> <li>▪ education of 150 carers providing care in the community for people living with terminal illness</li> <li>▪ avoidance of inpatient admissions through improved ability of carers to provide safe, sustainable care at home</li> <li>▪ better support for more clients to die in place of choice (home)</li> </ul>

Carers in the community are critical to the operation of the entire system of end of life care.<sup>3</sup> The involvement of carers is the most important predictor of whether a person is able to die at home<sup>4,5</sup> but carers suffer harms as a direct result of undertaking this role.<sup>6</sup> Supporting carers, specifically resident carers and spouses, is necessary if more people are to be able to realise their personal goals of being cared for and dying at home.<sup>7</sup>

The Learn Now, Live Well Program is an evidence-based educational intervention tailored to Western Australian conditions. The program is designed to support the carers of people living with terminal illness in the community by improving their practical skills, awareness of community resources, confidence, and understanding of palliative care. It comprises six modules which can be offered as a complete program or individually:

- The Physical Side of Caring
- Knowing Your Medicines
- Symptom Control
- Nutrition and Exercise
- Pain
- Communication.

The development and initial deployment of Learn Now, Live Well was funded by the Commonwealth Department of Health and Ageing between 2003 and 2006. A formal evaluation of the initiative found that, amongst participants, there was 'a reduction in care isolation... increased carer confidence over time... an increase in access to the support available to carers' and that the program was suitable for those caring for people with a range of conditions.<sup>8</sup>

Palliative Care WA Inc is aware that the Palliative Care Network at the Department of Health has funded the Cancer Council WA to research the status of the Learn Now, Live Well Program in Western Australia. Our understanding is that the Program is not currently offered anywhere in the state. The strategy developed by the initial project team, which aimed to sustain the program using a train-the-trainer approach to recruit facilitators from amongst health care professionals at different organisations,<sup>9</sup> has not succeeded.

Palliative Care WA Inc, as the community organisation committed to securing better end of life care for all Western Australians, is the logical delivery agency for Learn Now, Live Well.

<sup>3</sup> Palliative Care Australia, 2005: *A Guide to Palliative Care Service Development* – p 27

<sup>4</sup> Maida V, 2002: 'Factors that promote success in home palliative care: a study of a large suburban palliative care practice' – *Jrnl Palliative Care* – vol 18 pp 282-286

<sup>5</sup> Viser et al, 2004: 'The end of life: informal care for dying older people and its relationship to place of death' – *Palliative Medicine* – vol 18 # 5 pp 468-477

<sup>6</sup> Palliative Care Australia, 2004: *The hardest thing we have ever done: Full Report of the National Inquiry into the Social Impact of Caring for Terminally Ill People*

<sup>7</sup> Gott et al, 2004: 'Older people's views about home as a place of care at the end of life' – *Palliative Medicine* – vol 18 # 5 pp 460-467

<sup>8</sup> White K et al, 2008: 'Learn Now, Live Well: an educational programme for caregivers' – *International Journal Palliative Nursing* – vol 14 # 10 pp 497-501

<sup>9</sup> Auret K et al, 2006: *Caring Communities Program: Final Report of the Learn Now Live Well Project* – p 4

<b>Increased support for palliative care volunteering</b>	
resources	\$400,000 per year recurrent funding
use	<ul style="list-style-type: none"> <li>▪ 7 x 0.2 FTE managers of volunteers positions in regional health services</li> <li>▪ 5 x 0.5 FTE managers of volunteers positions in inpatient palliative care units with more than 10 publicly-funded beds</li> <li>▪ 1.5 FTE coordinators of volunteers position at Silver Chain</li> <li>▪ 0.5 FTE Palliative Care Volunteering Development Project Officer at PCWA</li> </ul>
agency/s	<ul style="list-style-type: none"> <li>▪ all publicly-funded community and inpatient palliative care services</li> <li>▪ Palliative Care WA Inc</li> </ul>
benefits	<ul style="list-style-type: none"> <li>▪ well-managed palliative care volunteer programs in all areas of the state</li> <li>▪ assurance palliative care volunteers operate in safe and effective ways</li> <li>▪ increased focus on recruiting and retaining palliative care volunteers</li> </ul>

Palliative care volunteers provide practical help to people living with advanced illness, their carers and families, working in both community and inpatient settings. The work is very diverse and includes providing respite for carers and companionship for clients, helping with shopping and getting to appointments, writing clients' life stories, and providing complementary therapies approved by the palliative care service.

Recent overseas studies have shown that the use of palliative care volunteers is associated with increased survival times for terminally ill people<sup>10</sup> and greater satisfaction with services.<sup>11</sup> A systematic review of health volunteering by Casiday et al identified a range of benefits, including a 'salubrious effect' on the volunteers themselves.<sup>12</sup>

Casiday et al also noted that 'how well the volunteers are trained, managed, supported and matched with clients' are amongst critical factors in establishing a 'healthy outcome' from volunteering. The Victorian Department of Human Services published *Palliative Volunteer Standards* in 2007 which highlight the central role of designated managers of volunteers in attaining quality outcomes in palliative care volunteering.<sup>13</sup> Managers of volunteers are responsible for the recruitment, orientation, training, performance management and retention of volunteers and the development and implementation of program plans, policies and procedures and risk management strategies. This role requires high level management skills and wide experience due to the issues volunteers in health care are likely to confront.<sup>14</sup>

The Silver Chain Hospice Care Service in Perth has the largest number of palliative care volunteers and employs a manager of volunteers. There are active volunteer programs at each of the inpatient palliative care facilities around the state and community volunteers in some country areas. Palliative Care WA Inc understands Department of Health service agreements do not specifically provide for manager/coordinator of palliative care volunteer positions. Services either use their own funds or clinical staff time to sustain these roles.

Palliative Care Australia notes:<sup>15</sup>

*The resources needed to support volunteers are substantial. Their time is free, but not the infrastructure to support them.*

The proper resourcing of the management of palliative care volunteers is an urgent necessity if palliative care services across the state are to:

- comply with Department of Health policy<sup>16</sup>
- provide satisfying experiences to their volunteers
- (most importantly) provide safe, effective volunteer support services to those living with terminal illness, their carers and families.

<sup>10</sup> Herbst-Damm & Kulik, 2005: 'Volunteer support, marital status and the survival times of terminally ill patients' – *Health Psychology* – vol 24 # 2 pp 225-229

<sup>11</sup> Block E et al, 2010: 'Got volunteers? Association of hospice use of volunteers with bereaved family members' overall rating of the quality of end-of-life care' – *Jrnl Pain & Symptom Management* – vol 39 # 3 pp 502-506

<sup>12</sup> Casiday R et al, Jul 2008: *Volunteering and health: What impact does it really have? Summary Report to Volunteering England* – p 3

<sup>13</sup> Victorian Govt Dept Human Services, 2007: *Strengthening Palliative Care: Palliative Care Volunteer Standards* – p 6

<sup>14</sup> Volunteering Australia & National Health & Medical Research Council, Apr 2003: *Working with volunteers and managing volunteer programs in health care settings* – p 1

<sup>15</sup> Palliative Care Australia, Sep 2003: *Palliative Care Service Provision in Australia: A Planning Guide* – p 30

<sup>16</sup> WA Department of Health, March 2011: *WA Health Volunteer Policy* ([www.health.wa.gov.au](http://www.health.wa.gov.au) accessed 30 Nov 11)

<b>Integrated advance care planning program</b>	
resources	\$1M per year recurrent funding
use	<p>WA Advance Care Planning Program:</p> <ul style="list-style-type: none"> <li>▪ development and dissemination of program materials</li> <li>▪ training and support of Advance Care Planning Consultants (normally fractional appointments, joint clinical roles)</li> <li>▪ roll-out and ongoing support of advance care planning processes in primary, secondary and tertiary care settings</li> <li>▪ public information and education program</li> <li>▪ information and communications technology improvements</li> <li>▪ program management, research and evaluation.</li> </ul>
agency/s	all community and inpatient health services funded by the WA Department of Health
benefits	<ul style="list-style-type: none"> <li>▪ systematic approach to advance care planning</li> <li>▪ more people with realistic and actionable advance care plans</li> <li>▪ better outcomes for people at the end of life and for our health system</li> </ul>

Most people die an expected death<sup>17</sup> and are in a position to outline their preferences for place and type of care in advance. Typically people use advance care plans to refuse or limit burdensome or futile medical treatments<sup>18</sup> and to make clear that they do not want to be cared for in a hospital. The plans can provide valuable guidance for clinical decision-makers.<sup>19</sup> The advance care planning process is associated with high levels of satisfaction with care.<sup>20</sup> The respectful implementation of advance care plans predicts decreased likelihood of disordered grief reactions amongst bereaved carers and family members.<sup>21</sup>

Take-up of advance care planning is very low in Western Australia despite the proclamation in early 2010 of legislation<sup>22</sup> permitting people to create Advance Health Directives and appoint Enduring Guardians. Barriers to advance care planning include:

- reluctance of doctors to discuss end of life and advance care planning issues with their patients<sup>23</sup> and insufficient time for doctors, patients and their families to discuss the issues<sup>24</sup>
- poor community understanding and uncertainty about the legal status of advance directives<sup>25</sup>
- low levels of training amongst health care providers and the absence of integrated systems to capture plans and provide clinicians with information when they need it.

Integrated advance care planning programs such as the Respecting Patient Choices Program have evolved to overcome these barriers and the evidence they are effective is mounting up.<sup>26</sup> Such programs are implemented across entire healthcare organisations and have a particular focus on managing change successfully within each organisation.<sup>27</sup> We have listed, in Appendix A, the essential aims and characteristics of any such program.

Palliative Care WA Inc notes the Palliative Care Network is investigating this area. We are confident that the Network will find that the only certain way to improve advance care planning participation and outcomes for our community is to adopt and adequately resource a system-wide solution based on the evidence.

<sup>17</sup> Australian Bureau of Statistics, May 2011: 3303.0 - Causes of Death, Australia, 2009 – [www.abs.gov.au](http://www.abs.gov.au)

<sup>18</sup> Kass-Bartelmes & Hughes, 2003: 'Advance care planning: Preferences for care at the end of life' – *Research in Action* – Agency for Healthcare Research & Quality – issue # 12 – pp 5-15

<sup>19</sup> Camhi S et al, 2009: 'Deciding in the dark: Advance directives & continuation of treatment in chronic critical illness' – *Critical Care Medicine* – vol 37 # 3 pp 919-25

<sup>20</sup> Tierney W et al, 2001: 'The effect of discussions about advance directives on patients' satisfaction with primary care' – *Journal General Internal Medicine* – vol 16 pp 32-14

<sup>21</sup> Detering et al, 2010: 'The impact of advance care planning on end of life care in elderly patients: randomised controlled trial' – *British Medical Journal* – 340:c1345

<sup>22</sup> Parliament of WA, 2008 – *Acts Amendment (Consent to Medical Treatment) 2008*

<sup>23</sup> Murray S et al, 2006: 'Advance care planning in primary care' – *British Medical Journal* – 333:868-69

<sup>24</sup> Bloomer M et al, 2010: 'End of life care: the importance of ACP' – *Aust Family Phys* – vol 39 # 10 p 734

<sup>25</sup> Shanely C et al, 2009: 'Understanding how ACP is approached in the residential aged care setting: A continuum model as an explanatory device' – *Australasian Journal on Ageing* – vol 28 # 4 pp 212

<sup>26</sup> Detering et al, 2010: *ibid*

<sup>27</sup> Austin Health, Jan 2006: *Final evaluation of the community implementation of the Respecting Patient Choices Program* – p 4

**Appendix A****Integrated Advance Care Planning Program**

<b>Essential Aims</b>	<b>Essential Characteristics</b>
<ul style="list-style-type: none"> <li>▪ support in the community and health system for ongoing values-directed care planning discussions involving consumers, their families and health professionals</li> <li>▪ transformed systems to support advance care planning across a range of institutional settings</li> <li>▪ sufficient material resources to ensure the integration of advance care planning into clinical practice and culture</li> <li>▪ the involvement of communities and the wider public</li> <li>▪ excellent education and applied research to support the process</li> </ul>	<ul style="list-style-type: none"> <li>▪ comprehensive (system-wide), integrated, and equitably available to all Western Australians and especially those at the end of life or living with chronic or life limiting illnesses</li> <li>▪ effective and efficient in a variety of settings and for a range of patient populations</li> <li>▪ based on the best available evidence</li> <li>▪ tending to promote healthy ways of living, dying and grieving and build community capacity to cope with death as a part of life</li> <li>▪ consistent with any advance care planning program guidelines developed at the national level</li> <li>▪ above and beyond any initiative to provide health professionals and the broader community with introductory information about the <i>Western Australian Consent to Medical Treatment Act 2008</i></li> <li>▪ focussed on improving the quality of care at the end of life (not the rate of completion of advance health directives)</li> </ul>

## Appendix B

### World Health Organisation Definition of Palliative Care<sup>28</sup>

Palliative care is an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patients illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

### About Palliative Care WA Inc

The aims of the Palliative Care WA Inc are to:

1. be a representative community organisation which seeks to improve the quality of care and support available to all Western Australians at the end of life
2. promote the principles and practices of palliative care with the intention of enhancing the broader community's capacity to provide care and support at the end of life
3. advocate for appropriate services and benefits for Western Australians confronting issues and problems commonly associated with the end of life
4. advocate for appropriate palliative care education and training for all who provide care and support to people at the end of life
5. promote the aims of the Association through cooperation and collaboration with stakeholders in palliative and end of life care
6. act as a coordinating body and information resource for organisations and service agencies which provide care at the end of life and which promote the principles and practices of palliative care
7. establish and maintain committees which are active in areas including, but not limited to, clinical services, standards and quality, education and community capacity building.

Palliative Care WA Inc is a not-for-profit association incorporated under the Western Australian *Associations Incorporation Act 1987*. We support and are subject to the *WA Carers Charter*.

Palliative Care WA Inc is a founding member of Palliative Care Australia and a member of the WA Seniors Alliance.

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<sup>28</sup> accessed Nov 11 at <http://www.who.int/cancer/palliative/definition/en/>