



Palliative Care WA (Inc)

15 Bedbrook Place
Shenton Park WA 6008
ABN 13 107 780 017
Phone/Fax: 1300 551 704

Email: pcwainc@palliativecarewa.asn.au

Web: www.palliativecarewa.asn.au

Submission to the Western Australian State Budget For the year ending 30 June 2012

Palliative Care WA Inc acknowledges important investments in palliative care service provision in Western Australia in recent years but is conscious of several gaps which must be closed in order to help secure quality care at the end of life for all. The current areas of concern focus on metropolitan Perth and include:

- the availability of services to meet the needs of people with non-cancer terminal illnesses
- access to palliative care beds
- support for people living and dying in residential aged care facilities.

This document outlines additional investments in the 2011-12 State Budget that Palliative Care WA Inc believes are necessary to enhance access to quality care for those who are living with terminal conditions. It is essential 'new money' is allocated so that existing services and initiatives are not jeopardised or eroded, and so that important work planned for 2011-12 is able to go forward.

Proposal	2011-12 Expenditure	Nature of Expenditure
Increased specialist palliative care support for people with non-cancer terminal conditions in the community	\$500,000	recurrent
Improving quality care at the end of life for people living in residential aged care	\$500,000	recurrent
Increased number of palliative care beds in metropolitan Perth <ul style="list-style-type: none">▪ 5 beds at Bethesda Hospital▪ 10 beds Rockingham General Hospital	\$3,420,000	\$2,920,000 recurrent \$500,000 capital
Increase to funding for inpatient palliative care services provided by non-government organisations	\$70,000	research project – non-recurrent
total	\$4,490,000	\$3,920,000 recurrent \$570,000 non-recurrent

Palliative Care WA Inc also seeks, beyond 30 June 2012, resources for a number of important programs and initiatives which have been 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.

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

Proposal 1 – Increased specialist palliative care support for people with non-cancer terminal conditions in the community

Increased specialist palliative care support for people with non-cancer terminal conditions in Perth	
resources	\$500,000 per year
use	<ul style="list-style-type: none"> ▪ employment of community-based palliative care medical specialists by Silver Chain ▪ establishment of clinics in community settings – integrating nurse practitioners, medical specialists and allied health professionals – for ambulant complex patients ▪ supervision, mentoring and support of training medical specialists, Silver Chain Hospice Care Service GPs and training medical staff
benefits	<ul style="list-style-type: none"> ▪ avoidance of inpatient admissions through improved ability to proactively manage community-based clients with increasing acuity ▪ improved clinical practice, assessment and decision-making across the interdisciplinary care team ▪ better support for more clients to die in place of choice (home)

Palliative Care WA Inc calls for an increase in the capacity of community palliative care services in Perth.

Need

Palliative Care WA Inc is particularly concerned that people who have non-cancer terminal conditions, and who might benefit from access to specialist palliative care, are less likely to receive services they need. We are regularly furnished with anecdotal evidence that the quality of care provided to those with non-cancer terminal conditions is poor, particularly in the areas of pain and physical symptom management, care planning and coordination, carer support, terminal care and bereavement support.

The Western Australia Department of Health has recognised gaps in palliative care service provision for non-cancer populations. For example The *WA Chronic Obstructive Pulmonary Disease Model of Care* states:

*The current palliative care services tend to focus on patients with cancer and a short life expectancy. There is a need to become more focused on chronic diseases and the use of palliative care in a more holistic sense, particularly for improvement in the quality of life significantly prior to an “end stage”.*¹

Chronic illness is common in Australia – in 2005 the Australian Institute of Health and Welfare² found that 77% of people had at least one long term health condition, and that older people tended to have more conditions. The same report states that in 2004 major chronic diseases accounted for almost 50% of all deaths in Australia: the leading causes are heart disease and stroke. Silver Chain provides care to 12,000 people living with chronic conditions in Perth.

¹ *Chronic Obstructive Pulmonary Disease Model of Care* – WA Respiratory Health Network – 14 Jul 08 – page 20

² *Chronic Disease and Associated Risk Factors in Australia 2006* – Australian Institute of Health and Welfare - 2006

There is a clear consensus amongst palliative care clinicians, and increasing numbers of those who care for people with non-cancer chronic illness, that a palliative approach, and if needed, specialist palliative care services, are appropriate for people with non-malignant terminal conditions.³ People approaching death in this population report:^{4,5}

- deteriorating health status
- decreased independence
- social isolation for patients and carers
- increasing family burden
- limited availability of resources
- poor access to community services (including GPs)
- varying degrees of acceptance of their survival prospects
- depression
- anxieties and concerns for their future health and care options
- spiritual distress.

Crucially, people with terminal non-cancer conditions may have longer and less predictable trajectories compared to those who are living with terminal cancer.⁶ Because 'determining prognosis is more complicated in life-threatening, non-malignant disease,' clinicians caring for people dying from non-cancer illnesses may have a 'reluctance and/or inability to define palliative status and predict time to death,' and this reluctance seems justified by the science.⁷

Murtagh et al⁸ summarise the problem thus:

In those diseases with an 'entry-re-entry' pattern such as heart failure and chronic lung disease, decisions about when palliative care is appropriate are particularly difficult. Professionals, patient and family can all become accustomed to periods of severe illness, with subsequent dramatic improvement, which may bring a false perspective and detract from awareness of the overall decline... Recognition of dying is especially difficult. Which deterioration will be the one from which there is no recovery?

These difficulties seem to result in a widespread inability amongst doctors and other clinicians to discuss prognoses and preferences for end of life care with their patients (and their families), and to refer people to palliative care services when needed. Fitzsimmons et al, for example, noted the 'the expressed reluctance of some specialist clinicians to face the palliative care needs of their patients' with end stage non-cancer illnesses.⁴ (This is despite evidence that 'elderly, chronically ill patients are more satisfied with their primary care physicians and their care they deliver when advance directives are discussed.'⁹)

³ 'Palliative care beyond that for cancer in Australia' – Mitchell G et al – *Medical Journal of Australia* – July 2010 – vol 193 # 2 pages 124-126

⁴ 'The challenges of patients' unmet palliative care needs in the final stages of chronic illness' – Fitzsimmons D et al – *Palliative Medicine* – June 2007 – vol 21 # 4 pages 313-322

⁵ 'Patterns of social, psychological and spiritual decline toward the end of life in lung cancer and heart failure' – Murray S et al – *Jrnl Pain & Symptom Mngmnt* – October 2007 – vol 34 # 4 pages 393-402

⁶ 'Living Long in Fragile Health: The New Demographics Shape End of Life Care' – Lynn J – *Improving End of Life Care: Why Has It Been So Difficult* – Hastings Centre Report 35 – 2005 – no 6 pages 14-18

⁷ 'Prediction of appropriate timing of palliative care for older adults with non-malignant life-threatening disease: a systematic review' – Coventry et al – *Age and Ageing* – 2005 – 34: 218-227

⁸ 'Patterns of dying: palliative care for non-malignant disease' – Murtagh F et al – *Clinical Medicine* – 2004 – vol 4 # 1 – page 41

⁹ 'The effect of discussions about advance directives on patients' satisfaction with primary care' – Tierney W et al – *Jrnl General Internal Medicine* – 2001 – # 16: 32-40

There are several consequences of this reluctance:

1. advance care planning is not widely broached with patients with non-cancer life-threatening conditions and their families, or taken up (for example Knauft et al¹⁰ found only 24-32% of people with COPD discussed their end of life care preferences with their doctors, and cite studies which question the quality of communications that do occur in this area)
2. as detailed below, Rosenwax and McNamara's Western Australian research¹¹ shows people with non-cancer diagnoses do not access specialist palliative care services at the same rate as those with cancer, and as a result, are more likely to die in a hospital or other inpatient setting
3. people with non-cancer terminal conditions may be 'more likely to die with aggressive, technological care directed at preservation of life' and receive end of life care of poorer quality than the care received by people dying with cancer.¹²

The McNamara and Rosenwax study showed that 92% of people who died in Western Australia during the study period from 'selected non-cancer conditions' (including MND, heart, liver or renal failure, COAD, Alzheimer's HIV/AIDS and Huntington's) did not access any form of specialised palliative care service, despite being likely to suffer with various intense physical, emotional, social and spiritual problems. Lack of access to palliative care services predisposes people in this population to die in a hospital or other institution. (By comparison 68% of people in the McNamara and Rosenwax study who died from cancer received palliative care services.)

Increasing Department of Health emphasis on advance care planning for people with chronic conditions, as a result of the implementation of legislation permitting people to complete Advance Health Directives and Enduring Powers of Guardianship, will lead to growing demand for specialist palliative care services, as more consumers opt to forego futile curative treatments and instead set themselves alternative goals.

The proposal summarised here uses existing service infrastructure and proven systems, provided by an organisation trusted within the community.

The WA Neurodegenerative Conditions Coordinated Care Program (NCCCP) is run by MS Western Australia and funded by the Disability Services Commission to provide personal care, support for activities of daily living, assessment and care planning. We await evaluation outcomes for Palliative Ambulatory Service North, a service established in late 2010 which has the scope to provide consultancy support for people with terminal non-cancer conditions who are located in residential aged care facilities, secondary hospitals, correctional and mental health facilities. These initiatives are welcome but more needs to be done.

Great Britain has developed the Gold Standards Framework initiative which pays GPs to identify and assess those of their patients who might die in the next six to 12 months, and develop detailed holistic care plans for those patients and their carers and families. This has been described as 'systematic case finding and case planning'.¹³ Palliative Care WA Inc does not advocate for the adoption of the Gold Standards Framework in Western Australia, not least due to the number of 'issues that will impede uptake of systematic case finding and case planning in Australian general practice for people who may require palliative care in the foreseeable future' identified by Mitchell et al and others.

¹⁰ 'Barriers and facilitators to end of life communication for patients with COPD' – Knauft E et al – *Chest* – 2005; 127 – page 2188-89

¹¹ 'Who receives specialist palliative care in WA – and who misses out' – McNamara B & Rosenwax L – *Palliative Medicine* – 2006 (20) 4 pages 439-445

¹² *ibid* Murtagh et al 2004

¹³ *ibid* Mitchell et al 2010

Proposal 2 – Improving quality care at the end of life for people living in residential aged care

Increased specialist palliative support care for people with terminal conditions living in aged care facilities in Perth	
resources	\$500,000 per year
use	employment of palliative care/aged care nurses and medical specialists by Silver Chain to work directly with aged care services in the provision of an ongoing program of support and education around the palliative approach and advanced care directives, and direct clinical consultation for aged care clients
benefits	<ul style="list-style-type: none"> ▪ better end of life care through improved clinical consultation processes and better access to medical and nursing specialists ▪ enhanced uptake of advance care planning amongst aged care clients through a better understanding of a palliative approach ▪ development of ongoing relationships between palliative care and aged care providers and implementation of an ongoing program of on-site education and support to aged care providers ▪ avoidance of inpatient admissions through improved ability to proactively manage residential aged care facility-based clients with increasing acuity ▪ improved clinical practice, assessment and decision-making across the interdisciplinary care team ▪ better support for more clients to die in place of choice (home)

Palliative Care WA Inc calls for improved support for people living with terminal conditions in residential aged care facilities in Perth.

Need

In 2009 there were over 20,000 residential and community aged care places funded by the Commonwealth, and 13,250 people living in residential aged care facilities in Western Australia. The numbers of people living in residential aged care facilities and the numbers of people who require high level care are both increasing steadily. Approximately 4,000 Western Australians (both permanent and respite residents) died in the care of a residential facility in the past year.¹⁴ Nearly 28% of Western Australia aged care residents are over 90 years old, but the deaths within this group account for over 40% of all deaths in residential care.¹⁵

The National Health and Medical Research Council-endorsed *Guidelines for a Palliative Approach in Residential Aged Care* notes that:

*... the majority of residents have dementia; they generally have co-morbidities that involve dealing with physical, psychological, emotional and social issues. The residents are generally highly dependent and require many medications...*¹⁶

Up to a quarter of aged care residents are admitted to a hospital each year¹⁷ and are more likely to present to a hospital emergency department, require hospital admission and die in hospital than other Australians.¹⁸ Improved primary care support for residential aged care facilities can influence the number of presentations to emergency departments in this population.¹⁹ Improved advance care planning is also likely to positively influence client satisfaction with care and minimise health service utilisation.²⁰

¹⁴ 4,000 deaths represent over 30% of all deaths in WA.

¹⁵ *Residential Aged Care in Australia 2008-09* – Australian Institute of Health & Welfare – 2010 – p 14

¹⁶ *Guidelines for a Palliative Approach in Residential Aged Care* – Dept of Health & Ageing – 2006 – p 4

¹⁷ 'Outcomes of hospital care in aged care residents' – Mudge A et al presentation World Congress of Internal Medicine – March 2010

¹⁸ 'Use of emergency departments by older people from residential care: a population based study' – Ingerfield S et al – *Age & Ageing* – 2009 vol 38 pages 314-18

¹⁹ 'Can transfers from residential aged care facilities to the Emergency Department be avoided through improved primary care services? Data from qualitative interviews' – Arendts et al – *Aust Journal on Ageing* – 2010 vol 29

²⁰ *Final evaluation of the Community Implementation of the Respecting Patient Choices Program* – January 2006 – Austin Health – page 6

While end of life care should be recognised as part of the normal scope of practice of residential aged care,²¹ many people dying in residential aged care will benefit from input, principally on a consultative basis, from a specialist palliative care service.

Palliative Care WA Inc notes:

- recent Commonwealth government initiatives aimed at improving the capacity of residential aged care services to provide quality care, and that these initiatives have not also enhanced the ability of state-government funded palliative care services to provide support to the aged care sector, despite increasing needs
- Silver Chain offers the Metropolitan Nurse Consultancy Service, which provides free specialist palliative care advice, information and training to meet the needs of individual residents – this service is, however, necessarily reactive because funding is allocated to an identified resident
- other Australian jurisdictions fund palliative care services to **pro-actively** engage their local aged care providers with the objective of developing relationships, awareness, staff capacity and organisational systems so that residents who have palliative care needs are readily identified and appropriately managed.²²

Ongoing targeted investments by the Government of Western Australia in supporting Commonwealth-funded aged care services to understand and meet the needs of dying residents and clients is an effective way of managing demand for acute hospital resources. Palliative Care WA Inc notes and welcomes state-funded capacity-building activities, conducted by the WA Palliative Care Network, in the aged care sector. We are also aware that the Silver Chain's Priority Response Assessment service, funded by the Government of Western Australia through the Friend in Need Emergency initiative, is emerging as a cost-effective way to minimise emergency department presentations by aged care residents.

This proposal highlights further strategic investment opportunities in the field of direct service delivery, and uses existing service infrastructure and proven systems.

²¹ *Residential Aged Care and End of Life Position Statement* - Palliative Care Australia - www.palliativecare.org.au/Portals/46/PCAResidentialAgedCareandEndofLifePositionStatement.pdf

²² *Palliative Care Services Plan* – Govt of SA – 2009 – p 17

Proposal 3 – Increased number of palliative care beds in metropolitan Perth

Increased public inpatient palliative care capacity by December 2015 in Perth	
resources	<ul style="list-style-type: none"> ▪ \$800 per bed per day²³ ▪ in 2011-12: 5 beds at Bethesda: \$1,460,000 ▪ in 2011-12: 10 beds at Rockingham for six months: \$1,460,000 ▪ capital costs of \$500,000 to develop stage one of a new unit at Rockingham General Hospital
use	<ul style="list-style-type: none"> ▪ 5 additional beds in North Metro ▪ 10 additional beds in South Metro
benefits	<ul style="list-style-type: none"> ▪ quality care at the end of life for people who have complex needs which cannot be met in the community ▪ services closer to where people live, thus cutting travel time for families and friends (who are already dealing with the difficulties of life limiting illness) ▪ appropriate care for patients who would otherwise (inappropriately) occupy acute care beds in major hospitals

Palliative Care WA Inc calls for an additional 32 publicly funded palliative care beds in metropolitan Perth by December 2015.

These beds should be provided as close to possible where people live, consistent with the recommendations of the Reid Review.²⁴ The additional beds should be provided in addition to consultancy support for secondary hospitals currently piloted by the Palliative Care Network's Metropolitan Area Health Service Ambulatory Palliative Care Teams project.

Need

The following table shows Palliative Care WA Inc's estimates of Perth's population (assuming an annual 2.5% raw population growth rate²⁵) and bed numbers in 2010:

Dedicated palliative care beds in metropolitan Perth as at December 2010					
health region	populationπ	public beds	private beds	total beds	beds/100,000
North Metro~	931,715	20	20	40	4.29
South Metro^	816,718	17	5	22	2.69
totals	1,748,433	37	25	62	3.55

π population is based on a 2.5% annual growth rate over figures shown in the 2005 review
~ public beds: 14 at Bethesda and 6 at Kalamunda; private beds: 10 at Glengarry, 5 at SJOG Subiaco, 5 at Hollywood; Joondalup receives public funding but provides no dedicated beds
^ 20 at Murdoch (15 publicly funded), 2 publicly funded beds at Armadale

There is, particularly in the South Metro Area Health catchment, a serious shortage of palliative care beds (2.69 beds per 100,000 population compared to the Palliative Care Australia benchmark of 6.7 beds²⁶ or the KPMG benchmark of 5.9 beds²⁷).

The number of private palliative care beds available in Perth is difficult to measure accurately because several facilities offer palliative care within a comprehensive cancer centre (eg St John of God Subiaco and Hollywood Private Hospital) and are able to make more or less beds available within that facility depending on immediate demand. Additionally, some facilities are not able to always offer a specialist palliative care team to support palliative patients in their beds, and offer instead consultancy support to other care teams in their hospitals.

²³ PCWA has estimated this cost based on rates paid for comparable services elsewhere in Australia: as noted on page 9 of this Submission, bed day costs are confidential in WA

²⁴ *A Healthy Future for Western Australians: Report of the Health Reform Committee* – WA Dept of Health – March 2004 – page 15

²⁵ 3218.0 *Regional Population Growth, Australia*

www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/3218.02008-09

²⁶ *Palliative Care Service Provision in Australia: A Planning Guide (2nd Edn)* – Palliative Care Australia – 2005 – page 18

²⁷ *Subacute Care Benchmarking Study for the Department of Health and Ageing* – KPMG – Draft of September 2010 – page 71

Some providers report their agreements with private health funds do not always cover base costs of care provision, which can lead to a reluctance to admit people as private patients.

Palliative Care WA Inc believes that, consistent with the 2005 palliative care review's recommendation,²⁸ the minimum size for a palliative care unit is 10 beds, and that it is very difficult to develop and retain staff with the requisite expertise in any unit with fewer than 10 beds. (We note that the consensus in South Australia is that inpatient units should have 16 beds.²⁹) All specialist inpatient palliative care units should be appropriately staffed with the following palliative care team, as a minimum:

- palliative medicine specialist and senior registrar
- level 3 (clinical nurse consultant or similar) nursing direction
- level 2 clinical nurses
- dedicated social worker
- counsellors, chaplains, pastoral carers, volunteer coordinators, and other therapists
- palliative care volunteers.

Services should be supported to participate in the National Standards Assessment Program, a quality improvement program offered by Palliative Care Australia, which supports organisations to self-assess their services against the national *Standards for providing quality palliative care for all Australians*, identify strengths and weaknesses and plan to close any gaps.

Metro North

Palliative Care WA Inc proposes that an additional 15 public beds be made available in Metro North. In 2011-12 an additional five publicly-funded beds should be allocated to the current unit at Bethesda Hospital in Claremont, taking the number of public beds at this facility to 19. Funding for these five beds could then be reallocated to other sites as facilities become operational in future years.

We have had assurances from time to time that 10 public palliative care beds will be provided in a new dedicated unit at Joondalup Health Campus, although details about the date these beds will be available and their exact configuration and staffing support have been unclear. We are concerned that the new unit will not be staffed appropriately. In Palliative Care WA Inc's view the Joondalup Health Campus does not currently meet the national standards for even a Level 1 service.³⁰ The 10 public beds at Joondalup should be available and properly staffed by 2016.

Perth's eastern corridor and the hills area continue to develop and grow. Six palliative care beds are located at Kalamunda Hospital and these beds meet the needs of people living from south-western suburbs like Armadale, eastern suburbs, local hills communities and north-eastern suburbs like Midland. People who require inpatient palliative care at Swan District Hospital (or, in the future, Midland Health Campus) are often moved to Kalamunda Hospital. The unit at Kalamunda should be expanded to 10 beds and staffed accordingly to ensure safe and sustainable practice and to meet growing community needs by 2016.

Metro South

Palliative Care WA Inc also proposes that a net additional 18 public beds be phased in over time in the Metro South catchment area. We recognise this is a significant increase on current available bed stocks, which are currently located at St John of God Murdoch Community Hospice (13 public beds) and Armadale Health Service (2 public beds).

Palliative Care WA Inc suggests that a new palliative care unit be opened at Rockingham General Hospital. In the short term (2011-12) this unit could comprise 10 beds and occupy available vacant building space, but in order to meet the needs of this region and to ensure the unit is of sufficient scale to be sustainable and cost effective in the medium term, the unit should be expanded to twenty beds by 2016.

²⁸ 2005 Review – page 23

²⁹ *Palliative Care Services Plan* – Govt of SA – 2009 – page 15

³⁰ *A Guide to Palliative Care Service Development: A Population Based Approach* – Palliative Care Australia – February 2005 – page 39

Proposed palliative care beds in metropolitan Perth by January 2016					
health region	populationπ	public beds	private beds*	total beds	beds/100,000
North Metro~	1,054,151	34	20-25	59	5.60
South Metro^	924,042	35	5	40	4.33
totals	1,978,193	65	34	99	5.00

π population is based on a 2.5% annual growth rate over figures shown in the 2005 review
 * the number of private beds available is difficult to measure accurately because several facilities offer palliative care within a comprehensive cancer centre (eg St John of God Subiaco & Hollywood) and are able to make more or less beds available within that facility depending on immediate demand
 ~ public beds: 14 at Bethesda, 10 at Kalamunda and 10 at Joondalup; private beds: 10 at Glengarry, 5 at SJOG Subiaco, 5 at Hollywood
 ^ 20 at Murdoch (13 publicly funded), 20 publicly funded beds at Rockingham

Proposal 4 – Increase to funding for inpatient palliative care services provided by non-government organisations

Research to determine sustainable pricing of public inpatient palliative care beds provided by non-government organisations throughout Western Australia	
resources	\$70,000
use	six month project to accurately determine the sustainable pricing of inpatient palliative care services provided by non-government organisations to the Department of Health
benefits	<ul style="list-style-type: none"> ▪ sustainable non-government organisation-delivered inpatient palliative care services

Palliative Care WA Inc calls for an increase to the rate paid to non-government providers of inpatient palliative care services.

Need

Rates are negotiated between area health services and service providers. These agreements are commercial-in-confidence, and Palliative Care WA Inc does not have access to pricing details. We are, however, able to comment in general terms on the effects of insufficient rates.

Inpatient palliative care service providers routinely tell us that funding allocations are too low to cover the costs of quality care. Typically providers report annual funding is used up by April each year, leaving three months of services unfunded. Where possible, funding shortfalls are met by negotiating variations to existing agreements. In all cases providers risk having to fund care for public services from their own resources, which calls into question the medium and long-term sustainability of services. Palliative Care WA Inc notes that in 2009 Hollywood Private Hospital closed its long-established palliative care unit and relinquished a contract with North Metro Area Health Service to provide 4 publicly-funded beds, citing, amongst other reasons, the fact that the contract was not economically viable.

In addition, the structure of the existing funding agreements, which require providers to admit patients to their facilities in order to attract funding to cover fixed operating costs, acts as a perverse incentive for increased admissions. A 'block funding' system which assures each provider receives sufficient funds to run their service each year, based on fair prices and historical and projected demand and utilisation, would encourage providers to facilitate appropriate discharges to community settings, reduce the average length of stay, and free up inpatient resources for more people who need them.

An immediate priority is to run a cost study in order to better understand the real cost of providing inpatient palliative care consistent with the *Standards for providing quality palliative care for all Australians* in the Perth and regional marketplaces. We are also aware that the Palliative Care Network has worked with some metropolitan inpatient service providers to measure patterns of service demand and utilisation, a process which will help generate an accurate picture of the scale of the funding shortfall problem. Taken together, a cost study and the service demand information will inform the Department of Health of the specific funding reforms.

Appendix A: Background to Palliative Care

Palliative care improves the quality of life of people (and their families) who face problems commonly associated with terminal illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual.³¹

Palliative care can benefit people living with a wide range of illnesses and conditions (that is, not just cancer). Palliative Care Australia advocates for 'needs-based' service provision. This means that services should be provided in order to meet a person's needs. Service availability should not be determined by any particular prognosis, age, diagnosis, or location.

For the majority of Western Australians who die their needs, and those of their carers and family, will be adequately met by their existing health care providers and treating specialists using a palliative approach. These people may not need input from a specialist palliative care service, but it is essential that palliative care services are resourced to form and sustain supportive relationships with these existing health care providers, and that all health care professionals who provide care and support to people at the end of life have appropriate training and education.

A smaller group of people will have occasional problems which are beyond the capacity of their existing health care providers to address. This group will benefit from consultative support from a specialist service. The smallest population of people and their families will need ongoing direct care from a specialist service, due to the extent of their problems.

Specialist palliative care services are provided in the following settings:

- the community – this is the setting where most people spend most of their time when they are living with terminal illness, and the preferred place of death for most Australians
- tertiary hospitals – palliative care is provided on a consultancy basis in all areas of the state's major hospitals
- inpatient palliative care units/hospices – these are dedicated facilities which provide high intensity care for people with complex problems.

Most people who have a terminal illness spend most of their time in the community, typically at home with family, friends, colleagues and neighbours. Sustaining care at home depends on a few significant factors, the most important of which include having a number of carers available to help out, and early referral to a palliative care service.^{32, 33} More attention is needed to help ease the burden on informal caregivers,³⁴ specifically resident carers and spouses, if more people are to be able to realise their personal goals of being cared for and dying at home.³⁵

A systematic review of the international evidence found high quality evidence that 'patients who died at home not only had more homecare input but also more frequent home visits. This effect was found to be more significant in the last weeks of life.'³⁶

Palliative Care WA Inc calls for a health system which is sensitive to the needs of dying people and their families, and which is able to provide quality care to all at the end of life. We recognise that specialist palliative care services cannot, and should not, provide all care to all people at the end of life. Our policies identify the need for development and reform in a number of areas including primary care (eg general practice), and community care, residential aged care, and acute hospital care. Ongoing palliative care education for all people who care for those at the end of life is essential.

³¹ *Definition of Palliative Care 2002* – World Health Organisation – www.who.int/cancer/palliative/definition/en/

³² 'Factors that promote success in home palliative care: a study of a large suburban palliative care practice' – Maida V - *J Palliative Care* 2002; 18: 282-286

³³ 'The end of life: informal care for dying older people and its relationship to place of death', Viser et al, *Palliative Medicine* – July 2004 – vol 18 # 5 pages 468-477

³⁴ *The hardest thing we have ever done* by Palliative Care Australia

³⁵ 'Older people's views about home as a place of care at the end of life' – Gott et al – *Palliative Med* July 2004 vol. 18 no. 5 460-467

³⁶ 'Factors influencing death at home in terminally ill patients with cancer: a systematic review' – Gomes & Higginson – *British Medical Journal* 2006 4;332(7540):515-21

Appendix B: Palliative Care Service Provision in Western Australia

All people in this state deserve quality care at the end of life. Palliative Care WA Inc notes this view is supported by the Western Australia Legislative Assembly's Education and Health Standing Committee.³⁷

There were 12,752 deaths in Western Australia in 2008.³⁸ Based on causes of death data in Australia, we estimate that up to 70% (>8,900) of these deaths were 'expected', that is, the person had (perhaps well in advance) a clear diagnosis of the condition that led directly to their death. It is the experiences of those who die expected deaths, and their carers, families and communities, that Palliative Care WA Inc seeks to improve.

Australians say consistently that they would prefer to die at home and not in a hospital or other institutional setting,³⁹ but the statistics show that in most states and territories less than 20% do so.⁴⁰ McNamara and Rosenwax demonstrated that:⁴¹

- the number of people who die at home in Western Australia is higher than the national average (35.8% of people died in their normal place of residence in 2000-2002)
- older people are more likely to die in their usual place of residence
- those who accessed community-based specialist palliative care had a seven times higher chance of dying in their usual place of residence.

Specialist palliative care services are provided by both government (via the Department of Health) and non-government organisations. A summary of publicly funded service provision appears at Appendix C. Non-government providers mostly hold service agreements with their local area health service, although Silver Chain is contracted on a statewide basis.

Services have developed in the metropolitan area since the 1980s and in most country regions in the last twenty years. The emergence of services in rural areas was marked by considerable variation in terms of timing, models, resources and effectiveness.

There are three main models of specialist service provision in Western Australia:

- community-based services – palliative care clinicians (nurses, doctors, social workers, counsellors and chaplains) and volunteers work as an interdisciplinary team visiting people at home
- consultancy services – mostly located in major hospitals, consultancy services provide advice, education and support to other health care providers as the need arises
- inpatient services – care is provided in hospices or palliative care units, normally such facilities are part of a larger hospital campus.

Interdisciplinary practice is a central element of specialist palliative care, and established services are able to offer support from volunteers, social workers, counsellors and pastoral care workers, although access to physiotherapists, occupational and music therapists, all of whom are able to make valuable contributions to the care of people at the end of life, can be problematic. The coordination of volunteers in Western Australia palliative care services is currently unfunded.

Silver Chain Hospice Care Service holds a service agreement with the Department of Health to provide community based palliative care services throughout Perth. Silver Chain is one of the largest community palliative care service providers in Australia, supporting upwards of 530 people at any one time.⁴² Silver Chain reports that 65% of clients in their Hospice Care Service die at their usual place of residence. Data from Silver Chain's June 2010 family and carer satisfaction survey shows that 98.33% of respondents were either satisfied or very satisfied with the service.

³⁷ *Destined to Fail: Western Australia's Health System* – Legislative Assembly Education and Health Standing Committee – Finding 122 – vol 2 page 407

³⁸ 33020DO001_2008 Deaths, Australia, 2008 – Australian Bureau of Statistics – www.abs.gov.au

³⁹ 'Factors predictive of preferred place of death in the general population of South Australia' – Foreman L, Hunt R, Luke C, Roder D – *Palliative Medicine* – 2006 20(4) pp 447-453

⁴⁰ *Place of death of people with cancer in NSW* – Tabor B et al – October 2007 – Cancer Institute NSW

⁴¹ 'Factors affecting place of death in Western Australia', McNamara B & Rosenwax L, *Health & Place* vol 13, issue 2, June 2007, pages 356-367

⁴² *Destined to Fail* – page 408

In regional and rural areas of Western Australia community-based care is provided by the WA Country Health Service. Services offered by local hospitals, GPs and community health services in each region are coordinated by a specialist nurse, who works with local health authorities and other providers (eg GPs) to ensure a consistent standard of care and the alignment of processes, protocols and systems across each region.⁴³

Some publicly-funded inpatient specialist palliative care services are provided by non-government organisations In Perth (Bethesda and St John of God Murdoch Community Hospice), Bunbury (St John of God) and Geraldton (St John of God). Local charities support hospice units in country centres including Northam, Busselton and Albany. Inpatient services for private patients are available at Glengarry Hospital, St John of God Subiaco and Hollywood Private Hospital.

Educational services are provided at little or no cost to both specialist and primary health care clinicians and volunteers by the Cancer Council WA's Professional Development Centre under a Department of Health service agreement. Services, with only limited resources, provide education about palliative care in their local areas.

Specialist palliative care services for children and adolescents are offered by the Child and Adolescent Health Service at Princess Margaret Hospital. The Paediatric Palliative Care Service, which caters for the needs of children with non-cancer terminal conditions, is funded through the 2008 election commitment. This funding stream finishes on 30 June 2012 and Palliative Care WA Inc calls for continuing funding of Paediatric Palliative Care Service beyond this date.

Palliative Care WA Inc received a three year grant of \$87,500 (ex GST) from February 2008 to February 2011. At the time of writing, Palliative Care WA Inc had not received confirmation funding would be recommitted after 30 June 2011.

Budget papers show Government of Western Australia funds are allocated for palliative care in the current and coming years thus:⁴⁴

2010-11 estimate	2011-12 estimate	2012-13 estimate	2013-14 estimate
\$23,689,000	\$25,221,000	\$26,735,000	\$27,765,000

The palliative care allocations in 2010-11 represent 0.45% of the total gross cost of health expenditures (\$5,567,888,000) in Western Australia.

The Australian Government funds the National Palliative Care Program, which is designed to meet the goals of the *National Palliative Care Strategy*, last published in 2000 but currently under review. The National Palliative Care Program has funded, in recent years, a wide range of research, educational, equipment, quality improvement, resource development and health promotion initiatives, many of which have been effective in Western Australia. The Australian Government does not fund direct palliative care service provision through this program.

⁴³ *Rural Palliative Care Model in Western Australia* – WA Cancer & Palliative Care Network – October 2008

⁴⁴ *2010 Budget Papers – Health* – page 280 –Govt of WA, www.ourstatebudget.wa.gov.au/

Appendix C: Recent Developments in Palliative Care in WA

The Department of Health commissioned a review into future palliative care service provision needs in Western Australia which was presented in 2005.⁴⁵ The philosophy underpinning the review was that every person in Western Australia with a life limiting illness has a fundamental right to a palliative approach to care. The review team applied population-based needs assessment methods to project the number of palliative care beds needed in metropolitan Perth and propose the distribution of those beds within the city:

2005 Review	actual: 2005		projected: 2015	
	population	beds	population	beds
North Metro	823,501	55.0	923,686	61.7
South Metro	721,860	48.5	830,165	55.6
totals	1,545,361	103.5	1,753,851	117.3

In the review, the total number of beds needed by 2015 ($n = 117.3$) is based on Palliative Care Australia's benchmark of 6.7 beds for every 100,000 people⁴⁶. The total number of beds includes private beds.

The 2005 review also makes recommendations about a range of other things:

- data collection
- the creation and operation of the Palliative Care Network
- training and education for palliative care and primary care clinicians
- meeting the needs of people in rural areas, those living alone, Aboriginal Western Australians, children and the broader 'well' community.

Since 2007 the Palliative Care Network has been working steadily to implement the recommendations of the 2005 Report. In 2008 the incoming Liberal government committed \$14M over 4 years for palliative care services development, which was a significant boost. In particular, investments have been made in the following areas:

- development of comprehensive models of service provision for metropolitan, rural, indigenous and paediatric palliative care (although we note in some rural areas recruiting skilled staff to key positions has proven difficult)
- creation and funding of Metropolitan Area Health Service consultancy teams which aim to support those providing care to people at the end of life in secondary hospitals and other health services
- research into and implementation of referral pathways and evidence-based treatment protocols
- working closely with WA Country Health Service, additional support for rural palliative care service provision including funding for Regional Palliative Care Coordinators and additional clinical staff in all areas of the state
- paediatric palliative care
- improving care at the end of life in aged care services.

Funding for many of these initiatives should be extended past 30 June 2012.

Palliative Care WA Inc welcomed the \$14M election commitment in 2008, and supports the work of the WA Palliative Care Network.

⁴⁵ *Palliative Care in Western Australia: Final Report December 2005* – Palliative Care Advisory Group, WA Dept of Health – www.healthnetworks.health.wa.gov.au/cancer/docs/Pall%20Care%20Report%20Final.pdf

⁴⁶ *Palliative Care Service Provision in Australia: A Planning Guide (2nd Edn)* – Palliative Care Australia 2005, page 18

Changes to the *Guardianship and Administration Act 1990* which enable people to complete their own advance care directives took effect in February 2010. Education for the general community is conducted by the Office of the Public Advocate, while health professionals receive training from the Department of Health. Palliative Care WA Inc, long an advocate in favour of advance care planning, welcomed the new legislation and provides education to both health care professionals and in the general community.

The National Partnership Agreement on Hospital and Health Workforce Reform (NPA) was established by the Council of Australian Governments in early 2009.⁴⁷ Under Schedule C of the NPA Western Australia was allocated \$48.608M for the period 2009-13 for 'subacute care', which for the purposes of this agreement includes palliative care. The *Subacute Care Western Australia Implementation Plan 2008-13* is the document which explains how the \$48.608M will be spent in this state. The funds are allocated to rehabilitation, psycho-geriatrics, palliative care and geriatric evaluation and management, but the Plan says:

*the palliative care sector has been the recipient of significant injections of State Government and Commonwealth funding over the past four years to increase service capacity. In this context, a limited approach will be taken to provide services where gaps remain. It is recommended that there will be a small proportion of funds relative to other sectors allocated to palliative care.*⁴⁸

By our calculation, and based on our best information, palliative care has received less than 2% of the total NPA allocation for subacute care in Western Australia.

Palliative Care WA Inc notes that the health reform agreed by Australian governments in April 2010 leaves open the question of whether responsibility for community palliative care should be transferred to the Commonwealth.⁴⁹ Palliative Care WA Inc is of the view that the Government of Western Australia should retain management of community palliative care services.

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www.ahwo.gov.au/documents/COAG/National%20Partnership%20Agreement%20on%20Hospital%20and%20Health%20Workforce%20Reform.pdf

⁴⁸ page 6

www.federalfinancialrelations.gov.au/content/national_partnership_agreements/HE003/implementation_plans/WA_subacute_care.pdf

⁴⁹ *National Health and Hospitals Network Agreement* – COAG – April 2010 – page 26

Appendix C – Publicly Funded Palliative Care Services in WA

all entries in *italics* are non-government organisations

area/region	community services	consultancy services	inpatient services
North Metro Area Health Service	<i>Silver Chain Hospice Care Service</i>	Sir Charles Gairdner Hospital Palliative Care Service	<i>Bethesda Hospital</i> (14 publicly funded beds)
	<i>Palliative Ambulatory Service North</i> (HQ at Bethesda Hospital)		Kalamunda Hospital (6 publicly funded beds)
			<i>Joondalup Hospital</i> (2 publicly funded beds)
South Metro Area Health Service	<i>Silver Chain Hospice Care Service</i>	Royal Perth Hospital Palliative Care Service	<i>St John of God Murdoch Community Hospice</i> (13 publicly funded beds)
	Peel Community Palliative Care	Fremantle Hospital Palliative Care Service	
	<i>Palliative Ambulatory Service South</i> (to commence operations in 2011)		Armadale Hospital (2 publicly funded beds)
WA Country Health Services	Regional Palliative Care Services in all regions		
	in Bunbury: <i>St John of God Bunbury</i>		in Bunbury: <i>St John of God Bunbury</i>
	non-palliative care specialists and primary health care providers offer end of life care in most country towns		in Geraldton: <i>St John of God Geraldton</i>
			Kalgoorlie Hospital Palliative Care Unit
			Albany Hospital Hospice Unit
		Northam Hospital Hospice Unit	
Statewide		Paediatric Palliative Care Service	Princess Margaret Hospital Paediatric & Adolescent Haematology/Oncology Service within the Total Care Unit
		<i>Silver Chain Rural Nurse Consultancy Service</i>	
		WA Combined Palliative Care Outreach Service	

World Health Organisation Definition of Palliative Care

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.⁵⁰

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*.

Contact our office or visit www.palliativecarewa.asn.au/about_wa.php to view the Palliative Care WA Inc Constitution.

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

Palliative Care WA Inc
15 Bedbrook Place
SHENTON PARK WA 6008
Phone/Fax: 1300 551 704
Email: pcwainc@palliativecarewa.asn.au
Internet: www.palliativecarewa.asn.au

⁵⁰ accessed Aug 08 at <http://www.who.int/cancer/palliative/definition/en/>