

4 August 2009

The Members
Education and Health Standing Committee
Legislative Assembly
Parliament of Western Australia
11 Harvest Terrace
WEST PERTH WA 6008

Dear Members

Review of Western Australia's Current and Future Hospital and Community Health Care Services

Palliative Care WA Inc is the peak body representing all Western Australians who seek to secure better care and support for those dealing with problems often associated with dying, death, and bereavement. As such, we concern ourselves with the quality, safety, appropriateness and accessibility of all health services which provide care to people at the end of life.

In this context, Palliative Care WA Inc has welcomed the findings of *A Healthy Future for Western Australians* (the Reid Report), the thrust of which is consistent with the service development policy framework published by our national peak body, Palliative Care Australia. The recommendations to minimise unnecessary hospital admissions and expand care in the community were welcomed because we know that, given the opportunity, many people with a life-limiting or terminal illness will choose not be admitted to an inpatient facility when they are dying.¹ The corollary is that if plans and assessments are substandard, or providers lack resources, skills and confidence, avoidable admissions and long hospital stays are all too common.

Palliative Care WA Inc also welcomed Recommendation 41 in *A Healthy Future for Western Australians* which calls for the building of purpose-built inpatient palliative care facilities at Perth's general hospitals, facilities which would integrate with community-based services.

A key outcome of the health reform implementation following the Reid Report was the commissioning by the Department of Health and the then Palliative Care Advisory Group of a report entitled *Palliative Care in Western Australia* which was completed in late 2005. This led to the formation of the Palliative Care Network as part of the Western Australia Cancer and Palliative Care Network. The Network has achieved much and plans a lot more, and its work should be supported on an ongoing basis.

I have enclosed with this letter a two-page paper which addresses the Inquiry's terms of reference in more detail.

Palliative Care WA Inc's representatives would be very pleased to meet with you at any time to further discuss these issues. Please contact me at this office to arrange a meeting.

Yours sincerely



Will Hallahan
Executive Officer

¹ '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

Are population needs taken into account in assessing, planning, implementing and evaluating palliative care services?

As a member of Palliative Care Australia, we subscribe to several key policies which promote needs-based service provision to support those approaching the end of their life.² Our model recognises that:

- end of life care is, and should be, part of the normal scope of practice for all primary health care workers
- some people will need access to inpatient care at the end of life – using appropriately resourced acute and sub-acute beds
- not all people will need input from a specialist palliative care service at the end of life
- many will benefit from improved community care models which aim to provide more acute-care type services outside of hospitals.

The notion of a large and growing 'end of life population', comprising the majority of Australians who will 'live with a set of conditions that are, taken together, progressively worsening and eventually fatal'³ is critical, because it is this population which, if not well managed, will cause the greatest logistical problems in an unreformed health system. Many of the clinicians providing care to this population, and the patients themselves, do not realise they could benefit from a palliative approach to care: some will continue to receive care in hospitals which could be provided at home, and many who would benefit from input from a palliative care service will not be referred. We have no real sense of the exact size of this group of consumers, which hampers our ability to accurately evaluate the impact of palliative care services on improving end of life care outcomes in the entire community.

The Western Australia Palliative Care Network has, until now, published three models of care:

- *Palliative Care Model of Care* (April 2008) – this is mainly concerned with the provision of services in metropolitan Perth, but foreshadows models of care for other areas and groups
- *Rural Palliative Care Model in Western Australia* (October 2008) – this document provides details of the configuration of services in the country
- *Paediatric and Adolescent Palliative Care Model of Care* (First Draft April 2009).

Each of these documents considers population needs. The palliative care sector was fortunate to have access to an important study from 2004 entitled *Who receives specialist palliative care in Western Australia – and who misses out?*⁴ which expanded our concept of the range of people who could benefit from input from a palliative care service beyond a 'traditional' palliative care population (of people dying with cancer or a similar condition). More work is needed through time, however, to understand the exact end of life care needs of the entire population.

Compliance with and any departure from *A Healthy Future for Western Australians and WA Health Clinical Services Framework 2005-15*.

On the whole, the development of palliative care services in the last few years has complied with the findings of the Reid Report and the Clinical Services Framework. It is important to note that since the Reid Report (and 2005's *Palliative Care in Western Australia* report), our understanding of population needs has evolved, as has the health system, so that some of the reports' recommendations have been adapted.

We welcomed funding committed by the Liberal Party during the 2008 state election campaign which is being used to implement the rural and paediatric models of care mentioned above, and to advance several important projects managed by the Palliative Care Network which will tend to improve continuity of care and access to services in all sectors, both central Reid Report themes.

² *A guide to palliative care service development: A population based approach* – Palliative Care Australia – February 2005 and *Standards for providing quality palliative care for all Australians* - Palliative Care Australia – May 2005

³ 'Living long in fragile health – The new demographics shape end of life care' – Dr J Lynn in *Improving End of Life Care – Why Has It Been So Difficult? Hastings Centre Report Special Report 35 no 6* – 2005 – available at www.rand.org

⁴ *Who receives specialist palliative care in Western Australia – and who misses out?* – McNamara, Rosenwax, Holman and Nightingale – University of WA – 2004

Palliative Care WA Inc notes that implementation of the Reid Report and health reform process recommendations is often dependent on area health services and private health care providers, and we do not have strong links with those organisations, so it is hard to access accurate information about progress against agreed targets.

Recommendation 41 of *A Healthy Future for Western Australians* reads:

*Purpose build facilities to provide inpatient, day and ambulatory palliative care hospice services should be incorporated into the four designated general hospitals. These services should form an integrated network with existing community-based palliative care services, including supporting end of life care in residential aged care facilities.*⁵

We have had assurances, via the Palliative Care Network, that Level 5 palliative care services⁶ and a dedicated palliative care unit will be available at Joondalup Health Campus, although a completion date is hard to nail down. The project appears to be running late. Swan Districts palliative care services are being provided at Kalamunda Hospital – this unit has stability and is increasing its capacity, but Palliative Care WA Inc is concerned that many people who access Swan Districts Hospital for the care of their chronic conditions may be without regular structured palliative input and support, while those admitted for palliative care at Kalamunda may need transfers to access acute services.

Palliative Care WA Inc has heard very little from the South Metropolitan Area Health Service about progress against Recommendation 41 in *A Healthy Future for Western Australians*: the development of integrated palliative care services at Fiona Stanley, Rockingham and Armadale.

Outstanding needs and gaps in the health system

Advance Care Planning

Respecting the healthcare wishes of people at the end of life brings numerous and far-reaching benefits for patients, their carers, families and communities, for clinicians and the healthcare system. Palliative Care WA Inc welcomes the *Acts Amendment (Consent to Medical Treatment) Act 2008* as a core component of what might eventually become a comprehensive advance care planning regime in Western Australia.⁷ We know that substantial changes at a systems level – which in turn can affect organisational culture – will be needed if advance care planning is to be widely taken up in Western Australia.⁸ Thoughtful implementation of the new law will be critical.

Ensuring Quality Care at the End of Life for Aged Care Residents

Overall, there is ongoing difficulty supporting aged care facilities caring for their residents at the end of life. Low levels of confidence and undeveloped end of life care skills often lead aged care facility staff to transfer dying residents to hospital, these are often avoidable admissions. The underlying problem seems to be that palliative care services, which are funded by the state, are not contracted to provide full palliative care support and services to aged care facilities that have registered nursing staff on duty around the clock. We note that this is not a marked problem in other jurisdictions.

Silver Chain Hospice Care Service has a 24 hour Palliative Nurse Consultancy Service designed to assist facilities increase their capacity through a time-limited episode of education, care planning and complex problem resolution.

Ramifications of the *Royal Perth Hospital Protection Bill 2008*

Palliative Care WA Inc is concerned, that, through time, the cost of updating and maintaining Royal Perth Hospital as a major tertiary treatment centre will divert resources from the ongoing health reform process. Any such hospital should have a level 6 palliative care service, as shown on page 46 of the Clinical Services Framework, and workforce planning should reflect this.

⁵ *A Healthy Future for Western Australians – Report of the Health Reform Committee – March 2004 – Recommendation 41 – page 66*

⁶ *WA Health Clinical Services Framework 2005-15 – WA Dept of Health – September 2005 – page 46*

⁷ *Advance Care Planning in WA: A Position Statement – Palliative Care WA Inc – March 2009 – available at www.palliativecarewa.asn.au/policy.php* - enclosed with this submission

⁸ *State of the Science Review of Advance Care Planning Models – Street AF & Ottmann G – LaTrobe Uni, Bundorra, 2006 – pages 50-52*