Palliative Care WA Inc
Western Australian State Election 2008

On 7 August 2008 the Premier called an election in Western Australia for Saturday 6 September 2008.

This document outlines the commitments Palliative Care WA Inc would like to secure from the parties contesting the election.

The priorities are:

1. **Ongoing development and implementation of the strategies in *Palliative Care in Western Australia – Final Report December 2007*, specifically:**

   Long-term funding for the Paediatric Palliative Care Service

   Improved access to specialist inpatient palliative care beds throughout Perth

   Improved coordination of palliative care service provision in all rural areas of Western Australia

   Ongoing support for indigenous palliative care

2. **Adequate provision for palliative and end of life care in the upcoming Australian Health Care Agreements**

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

Ongoing development and implementation of the strategies in *Palliative Care in Western Australia – Final Report December 2005*[1]

This Report lays out a strategy to create and sustain palliative care services which meet the palliative and end of life[2] care needs of Western Australia's changing and growing population. The strategy is consistent with the broader reform agenda adopted by the current Western Australian and Australian Governments, and has been endorsed by palliative care clinicians and other health care providers. The implementation of these strategies is currently being facilitated by the WA Palliative Care Network in the Department of Health, in conjunction with area health authorities.

The strategy needs ongoing material support to implement the recently adopted Models of Care and integrate a palliative approach into all other health models. The Palliative Care Network also needs ongoing support beyond 2009.

Within the *Report*, Palliative Care WA Inc has identified the following urgent and important priorities:

Long-term funding for the Paediatric Palliative Care Service

The Paediatric Palliative Care[3] Service is a statewide consultancy service which supports all health care providers who are caring for children with a life limiting illness. The Service was launched in May 2008. It is currently funded by charitable donations and headquartered at the Princess Margaret Hospital. There are already signs that the Service will make a real difference in the care of more than 100 children who die from a life-limiting illnesses each year in WA – the care needs of these patients, their families and carers are typically extremely complex. Specific benefits of the Service include:

- improved clinical decision-making for and with children with life limiting illnesses
- better communications between clinicians, patients and families
- better and more targeted pain and symptom management for patients
- capacity and confidence-building amongst specialist and generalist clinicians
- ongoing education, research and quality management.

This valuable service needs long-term public funding and support.

Improved access to specialist inpatient palliative care beds throughout Perth

Palliative Care in Western Australia – Final Report December 2005 projects the number of dedicated publicly funded inpatient palliative care beds in metropolitan Perth for the coming few years. Currently most of these beds are in central Perth (Nedlands, Claremont and Murdoch), and there are no beds in the middle and outer suburbs, areas where the population is growing rapidly, and where the situation for palliative care patients is urgent.

The commissioning of palliative care services with inpatient beds at the Joondalup Health Campus, Rockingham-Kwinana District Hospital, Peel Health Campus and Armadale-Kelmscott Memorial Hospital, consistent with the Reid Report[4], should be a priority.

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[1] access this report at http://www.healthnetworks.health.wa.gov.au/cancer/docs/Pall%20Care%20Report%20Final.pdf

[2] In this context, 'end of life' refers to the period of time marked by disability or disease that is progressively worse until death –from *Improving Care for the End of Life: A Sourcebook for Health Care Managers and Clinicians* – Lynn, Schuster and Kabcenell – Washington 2000

[3] The World Health Organisation defines paediatric palliative care as '…the active total care of the child's body, mind and spirit, and also involves giving support to the family [which] begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease [in order to] alleviate a child's physical, psychological, and social distress…'. – accessed 11 Aug 08 at http://www.who.int/cancer/palliative/definition/en/.

[4] see Recommendation 41 of *A Healthy Future for Western Australians – Report of the Health Reform Committee* – Mar 04 at http://www.health.wa.gov.au/HRIT/publications/docs/Final_Report.pdf

Improved coordination of palliative care service provision in all rural areas of Western Australia

Western Australians from country areas typically have poor access to the specialist palliative care support they need. Most palliative care in the bush is provided by primary health providers, but many lack ongoing support and as a result more complex patients receive suboptimal care or are transferred to Perth, where they die remote from their homes and communities. A regional palliative care coordination model has been shown to improve care for patients and their families, and build confidence and capacity amongst other health care providers and within the broader community. Recent consultations by the WA Palliative Care Network have shown that health professionals and communities across country Western Australia would welcome the introduction (in some cases the consolidation) of this model.

The Western Australian Country Health Service should get extra resources to create and sustain a regional palliative care coordination model in all areas of the state.

Ongoing support for indigenous palliative care

Indigenous Western Australians have worse health outcomes and higher mortality rates than non-indigenous people. At the same time, Indigenous people do not often access palliative care services, even when their care needs are complex. Palliative Care WA Inc calls for tandem strategies to improve access for this group:

- consumer awareness and education – this strategy should be designed to reach Indigenous Western Australians in a range of ways and to promote understanding and acceptance of available palliative care services within their communities
- provider awareness and education – this strategy, which builds on recent Australian Government initiatives, should be designed to educate health care providers at all levels so that their services cater for the palliative care needs of Indigenous Western Australians.

Adequate provision for palliative and end of life care in the upcoming Australian Health Care Agreements

End of life care is a critical healthcare issue, and we must do better to support people who are dying, their families, carers and communities. Ongoing health system reform is necessary if we are to cope with the growing population of older Australians with multiple chronic conditions who 'live long in fragile health'[5].

It is essential that the next round of Australian Healthcare Agreements include palliative and end of life care provisions which take into account new understandings of the ways in which people live and die, recent changes within the health system, and projections of need for end of life care in the future. Palliative Care WA Inc has identified a number of opportunities which can help ensure Western Australians have better access to quality end of life care which accords with their needs and preferences:

- investments in needs-based service provision frameworks (as laid out in *Palliative Care in Western Australia – Final Report December 2005*), and in particular more resources to ensure community-based care meets growing demand, especially for people living for several years with significant impairment as the result of multiple chronic conditions which will eventually lead to death
- ongoing investments in educating the entire healthcare workforce in end of life care issues and a palliative approach to care
- implementation of the advance care planning regime laid out in the *Consent to Medical Treatment (Acts Amendment) Bill 2006* within Western Australia, and coordination with advance care planning processes in other jurisdictions around the country
- improving continuity of care by better integrating existing resources and systems across all levels of government and the private sector.

[5] 'Living Long in Fragile Health – The New Demographics Shape End of Life Care' in *The Hastings Centre Special Report November 2005* by Dr J Lynn – accessed 11 Aug 08 at http://www.allhealth.org/BriefingMaterials/JoanneLynn-LivingLonginFragileHealth-756.pdf

Appendix 1 – 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.[6]

Appendix 2 – About Palliative Care WA Inc

Palliative Care WA Inc is a not-for-profit association incorporated under the *Associations Incorporation Act 1987*.

The objectives of Palliative Care WA Inc include:

- promoting the principles of hospice palliative care for terminally ill people and their families among health care professionals, service agencies, government and the general public
- encouraging and supporting the development of palliative care programs in Western Australia
- providing a resource for information and communication amongst hospice and palliative care groups
- assisting in the development and maintenance of policies and standards of care and guidelines for health care program planning and implementation
- advocating for the maintenance of appropriate training programs for health care professionals
- cooperating with kindred groups and voluntary organisations through encouragement of symposia, conferences and workshops to promote the objectives of the Association
- establishing and maintaining committees working in particular areas, including but not limited to, clinical services, education and the dissemination of information.

Palliative Care WA Inc is a founding member of Palliative Care Australia.

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[6] accessed Aug 08 at http://www.who.int/cancer/palliative/definition/en/