

Submission to the Health Reform Committee

The Organisation, Provision and Future Funding of Palliative Care in Western Australia

Presented by

Palliative Care WA (Inc)

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1. Introduction

Palliative Care WA (Inc), representing a broad base of palliative care interests in Western Australia, welcomes this opportunity to make a submission to the Health Reform Committee.

This document is intended to set before the Health Reform Committee current issues of concern to palliative care providers. It also proposes an agenda for future discussions regarding the appropriate levels of palliative care provision which the community will require, and how these needs can best be met, whilst encompassing nationally accepted standards and sustainability of funding.

Palliative Care WA (Inc) recognises that the remit of the Health Reform Committee is to “improve the quality of health services” and to “manage costs of the system to ensure sustainable growth in the health budget”¹. Providers of palliative care services in Western Australia share common objectives of offering highest standards of care, within a financially sustainable framework.

Representatives of Palliative Care WA (Inc) and those individuals who have assisted with preparation of this document look forward to future opportunities to participate in discussion with the Health Reform Committee about how these objectives might be reached.

2. Recommendations

Palliative Care Inc (WA) recommends that:

1. The strong foundation provided by existing partnerships within palliative care service provision be built on with a systematic approach to planning and funding (Section 3)
2. Robust trends modelling be undertaken to inform future planning for palliative care services at a population level (Section 4.1)
3. The Health Reform Committee make use of the expertise assembled in the Palliative Care Advisory Group, as convened by the Department of Health, to provide direct input into planning and policy in palliative care provision (Section 4.1)
4. The Health Reform Committee undertake a thorough review of current funding arrangements, with a view to formulating a transparent funding model based on premises agreed to by the stakeholders (Section 4.2)
5. The Health Reform Committee review comparative levels of funding made available for palliative care services in other Australian states and territories (Section 4.2)
6. Issues of long term underinvestment in specialist palliative care services be addressed before any capping is imposed upon health care funding in Western Australia (Section 4.2)
7. Any reforms of palliative care service provision be informed by current best practice and standards, and conform to nationally-accepted strategic guidelines (Section 4.3)
8. Stakeholders in the provision of palliative care be consulted in discussions regarding future planning for palliative care, with the joint objectives of improving quality of and access to services, within a financially sustainable climate.

3. Palliative Care in Western Australia – a brief overview

3.1 What is palliative care?

Palliative care is the specialised treatment of people with incurable illnesses. The major goals of palliative care are to provide comfort and care for terminally ill patients and their families, and to allow patients to die peacefully in the setting of their choice (often their own home) while receiving all necessary nursing, medical and social care. All dying patients and their families deserve access to age-appropriate high quality palliative care, irrespective of their ability to pay and their geographical location.

Palliative care is a comparatively new but now fully-accredited discipline which has arisen in response to clear patient need. An indication of the importance of this new specialty is the establishment of a Chapter of Palliative Care Medicine by the Royal Australasian College of Physicians in 2000.

Palliative care services embrace many aspects of care of terminally ill patients and their support networks. Equitable access to the level of required service, and seamless transfer between levels of provision, are requirements of a population-based model of care. The continuum of care offered ranges from primary palliative care at one end of the spectrum, to specialist palliative care services at the other².

Primary palliative care is provided by non-specialist palliative care providers. Its goals are to offer care and comfort to the dying patient. It can be provided by the patient's own family doctor, community and hospital based nurses and allied health professionals, and professionals in pastoral care, or may be offered by workers in other specialist areas of medicine, such as oncology, gerontology, nephrology and cardiology.

Specialist palliative care services provide care to those patients whose needs exceed the capacity and resources of primary care services, and are provided by a multidisciplinary team with specific expertise in palliative care. The skills base includes medicine, nursing, social work, pastoral care, physiotherapy, pharmacy and related specialties. In many cases it is sufficient for specialist services to provide advice and support to primary care givers, but some patients will require direct management by a specialist unit. It is vital that specialist expertise is accessible to all who need it.

Specialist palliative care provides the resource base for all areas of palliative care and its capabilities include the development of best practice service protocols, education and research. The availability of targeted education and training builds and strengthens local capability and, in its absence, there is heightened risk that patients requiring palliative care will not have a timely referral to appropriate services and that optimal care standards may not be met. The importance of research programmes at both clinical and service delivery levels in palliative care is widely recognised, and is necessary to ensure that best practice for palliative care patients is identified and adopted³.

Community education is vital to ensure that patients and their families are aware of the range of services to which they have an entitlement, and from which they should be free to select the options which best fit their individual needs.

3.2 Provision of palliative care services in Western Australia

Palliative care is available to patients in their homes, as outpatients, or as in-patients in hospices or hospitals. These services are provided by a range of skilled professionals and ancillary workers, and in some settings are supported by volunteers as well.

Home-based palliative care services are well developed in metropolitan and rural towns, offered by Silver Chain Hospice Care Services and other non-government providers. Around the clock care is offered by teams which include nurses, hospice care doctors (who are mainly general medical practitioners), care aides, chaplains, counsellors and volunteers. In-patient services are offered at Hollywood Private Hospital, The Cottage Hospice, the Murdoch Community Hospice and St John of God Healthcare Bunbury. Consultative services are provided by Royal Perth Hospital, Sir Charles Gairdner Hospital, Hollywood Private Hospital and Fremantle Hospital.

Palliative care services are provided in rural and remote regions of the state mainly at the primary care level. In-patient services in rural centres range from the well-developed to limited, and home-based palliative care services are offered in some areas following a variety of service delivery models. A group of Perth-based palliative care specialists are available on call to provide advice to rural general practitioners. While aiming to offer the best care to all, country service providers are faced with the challenges of distance and isolation, attaining the appropriate skills mix to provide high quality care, difficulties in planning due to a variable workload, and the inability to benefit from economies of scale.

Providers of paediatric and adolescent palliative care are faced with a different set of challenges, including meeting the protracted access requirements often accompanying childhood illness, location of suitable accommodation, and assembling the specific age-appropriate range of expertise required in supporting the families of dying children and teenagers.

Palliative care funding comes from a variety of sources, including the Department of Health of Western Australia, the Commonwealth Departments of Health and Aged Care and Veterans' Affairs, private health insurers, charitable organisations such as the Cancer Foundation of Western Australia, St John of God Healthcare and Silver Chain Nursing Association, and groups and individuals from within the wider community.

All providers share common goals of excellence in the care which they offer. One of the greatest strengths of palliative care provision in Western Australia has been the strong partnerships which have evolved between government and non-government

organisations, due in large part to the personal commitment and motivation of individuals involved.

Future provision of palliative care will require a more systematic approach to planning and funding, promoting a new era of service delivery to a wider range of metropolitan and rural communities.

4. Issues which Palliative Care WA (Inc) wishes to raise

4.1 Need for trends modelling

Palliative Care WA (Inc) commends the intention of the Health Reform Committee, as stated in its *Interim Report*, to undertake robust trends modelling “in the areas of demographics, demand trends, supply trends, and epidemiological trends”.

Only by a thorough investigation into population health trends can future requirements for palliative care be planned in terms of facilities and workforce requirements. Palliative Care Australia has formulated planning guidelines for the appropriate minimum levels of specialist palliative care staffing needed to service the population⁴. Palliative Care WA (Inc) advocates that these guidelines be used to inform workforce planning.

Broad changes in population demographics are placing direct pressure on the provision of palliative care in Western Australia. These include well-documented features, such as:

- ?? an ageing population with the concomitant increase in disease incidence (both cancer and non-malignant conditions); and
- ?? the increase in the numbers of people who live alone, who lack traditional family infrastructure, or who, themselves ill, live with an elderly or ill partner.

In addition to these overall changes, there are a number of specific issues currently evolving which are affecting the ability of palliative care providers to meet demand:

- ?? the growing recognition that palliative care has much to offer patients of all ages with diseases other than cancer, such as neurological conditions, renal disease, cardiac disease, respiratory disease and muscular dystrophy
- ?? patients with non-malignant terminal illnesses have less predictable prognoses; they may live longer, have multiple admissions to inpatient care, and need a different range of nursing, medical and ancillary health capabilities, leading to difficulties in planning care⁵

- ?? advances in medical knowledge (such as chemotherapy) have resulted in longer life expectancies for many disease sufferers, with the result that as these patients reach their final stage of life they are older, suffer a greater acuity of symptoms, and require lengthier access to as well as a more intensive level of palliative care⁶
- ?? the shortfall in appropriate accommodation for adults aged under 60 who are unable to be supported at home, need access to longer term palliative care, and do not qualify for placement in (nor should be accommodated by) an aged care facility.

Palliative Care WA (Inc) also wishes to remind the Health Reform Committee that it has access to the expertise assembled in the Palliative Care Advisory Group, convened by the Department of Health. Members of this group have the experience, the skills and the willingness to provide direct input into planning and policy in palliative care provision based on current research and best practice.

4.2 Sustainability

It is noted that the Health Reform Committee has a brief to restrict future growth in health expenditure to 6% per annum for “short term expense limits” (2003/4 and 2004/5) and 4.5% per annum in the following years. Palliative Care WA (Inc) believes that issues of long term underinvestment in specialist palliative care services must be addressed before any capping is imposed upon health care funding in Western Australia.

Palliative Care WA (Inc) requests that the Health Reform Committee investigate the levels of funding made available for palliative care services in other Australian states and territories, as provided by the various Departments of Health, the Department of Veterans Affairs, and health insurers. It is the strongly held view of Palliative Care WA (Inc) that services in Western Australia are funded at a significantly lower level than elsewhere in Australia.

An area of major and ongoing concern is that the funding model currently applied to in-patient palliative care is flawed.

As one example of this, funding provided to the Cancer Foundation Cottage Hospice has been based on occupied bed-days and care levels have been compared, inappropriately, with secondary/tertiary medical and surgical clinical areas, rather than comparable specialist, intensive palliative care services⁷. There has been neither acknowledgement of best-practice palliative care service models and quality standards within the funding model; nor a true reflection of real cost within the contract currency (occupied bed days). Funding to the Cottage Hospice currently assumes a subsidy from the Cancer Foundation of WA in excess of \$500,000 per annum, an expectation which the Foundation has met with reluctance, in the interests of keeping this important facility open. Subsidisation at this level is no longer sustainable within the competitive charitable environment in which the Foundation must operate. Compounding matters across the state, the artificially low

level of Departmental funding provided to the Cottage Hospice has since become the baseline for funding offered to other providers of in-patient palliative care. Those providers which do not have access to back up resources such as those of the Cancer Foundation are penalised by this assumption.

It is also implied within the current funding model that the cost of service provision within the charitable or “private sector” is higher than if the same service were provided by the public sector. Palliative Care WA (Inc) would like this view re-examined in the light of the national standards for palliative care service delivery, which apply equally across public and non-profit sectors (see Section 4.3 below). Palliative care is intensive and complex. A funding model is now required that acknowledges the realistic strategic costs of palliative care to the health care budget and the value of these services to the community.

Other matters of concern include the annual re-negotiation of contracts, which is time-consuming for all parties, militates against long term planning, and has caused uncertainty for providers by not being finalised prior to the commencement of the financial year. While longer-term financial planning is to be welcomed, the Department of Health’s recent proposals for non-government providers to accede to three year contracts are based on the unsound funding model described above, and fail to take into account external and unavoidable cost pressures, such as the CPI and wage agreements. It may be that a workable solution lies somewhere in between, with a long-term commitment to provide funding, forming the basis for annual negotiation around certain services.

The ability to negotiate workable, appropriate contracts is a key factor in providing proper and financially sustainable palliative care services throughout Western Australia. Increasing tension over contracting arrangements between the Department of Health as purchaser, and community-based charitable provider organisations has the potential to erode strategic relationships between purchaser and provider, to the detriment of palliative care provision across the Western Australian community. Palliative Care WA believes that this would be both regrettable and counter-productive to achieving a sustainable palliative care service model.

Providers of palliative care welcome the opportunity to discuss with the Health Reform Committee options for strengthening the current funding model and contracting arrangements.

4.3 Standards of Care

There is a wealth of excellent Australian documentation available about optimal service delivery for palliative care which has been produced by the Commonwealth (for example *National Palliative Care Strategy – A National Framework for Palliative Care Service Development, 2000*), the State Government (*Palliative Care – The Plan for Western*

Australia, 1997) and the peak body for palliative care, Palliative Care Australia (*Standards for Palliative Care Provision, 1999*). In the absence of paediatric palliative care standards in Australia, the provision of paediatric and adolescent palliative care should currently follow standards developed in the United Kingdom.

It is assumed that the Health Reform Committee is aware of these documents and supports their objectives. Palliative Care WA (Inc) does not propose to reiterate in this brief submission what has been well-documented elsewhere. It is important to state, however, that any reforms of palliative care service provision must be informed by current best practice and standards, and conform to nationally-accepted strategic guidelines.

Standards for accreditation of palliative care services, formulated by Palliative Care Australia⁴ and to be applied in conjunction with the Australian Council of Health Care Standard's Evaluation and Quality Improvement Programme (EQuIP) are now in place. The Commonwealth Department of Health and Aged Care has made clear its objective of introducing National Minimum Standards in palliative care service provision, and then evaluating all providers³. Conformity to accepted standards is not an option for quality providers of palliative care – whether they be in the government or non-government sector – but a requirement.

All palliative care providers contributing to this submission share the common objective of offering the highest standards of care, and look forward to working closely with appropriate state and commonwealth authorities to ensure that palliative care services in this state are appropriately resourced, soundly-structured, optimally staffed and properly delivered to all who have need of them.

5. References

- ¹ Government of Western Australia (2003). Health Reform Committee. *Initial Report through Minister for Health and the Treasurer to the Expenditure Review Committee*. Perth: Government of Western Australia.
- ² Palliative Care Australia (2002). *Palliative Care Service Provision in Australia: A Planning Guide*. Canberra: Palliative Care Australia.
- ³ Commonwealth Department of Health and Aged Care (2000). *National Palliative Care Strategy. A National Framework for Palliative Care Service Development*. Canberra: Commonwealth Department of Health and Aged Care.
- ⁴ Palliative Care Australia (1999). *Standards for Palliative Care Provision*. Third Edition. Canberra: Palliative Care Australia.
- ⁵ Health Department of Western Australia (1997). *Palliative Care. The Plan for Western Australia*. Perth: Health Department of Western Australia.
- ⁶ Bridge D (2001). *Medium term palliative care patients in tertiary hospitals* (Unpublished report). Dr Doug Bridge, Palliative Care Physician, Royal Perth Hospital.
- ⁷ Franther Consulting Services (1998). *Hospice and Palliative Care Provided by the Cottage Hospice – Report on the Current and Proposed Funding System for the Cottage Hospice for the Health Department of Western Australia*. Perth: Franther Consulting Services.