

# Palliative Care in Western Australia

Final Report December 2005



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# EXECUTIVE SUMMARY

## Background and Objectives of the Review

The Western Australian (WA) Department of Health, in consultation with the Palliative Care Advisory Group (PCAG), commissioned the WA Centre for Cancer and Palliative Care at Edith Cowan University to provide advice regarding the development of a statewide plan for the future configuration and delivery of palliative care services in WA. The specific objectives of the review were to:

- Outline current palliative care service provision in WA, including the relationships between services and service role delineation.
- Project future need for service delivery in metropolitan, rural and remote areas and identify future linkages and role delineations to improve and enhance service delivery.
- Identify options for coordinating future service delivery across the state.

## Accountability

The review was undertaken under the direction of the Palliative Care Advisory Group (PCAG). A sub-committee of PCAG, with other co-opted members, was appointed by Dr Neale Fong, the Director General for Health, to serve as a steering committee overseeing this specific project.

## Scope of Review

The review consisted of two phases:

- Phase I: focussed on metropolitan inpatient needs and issues and more particularly on bed allocation in the metropolitan area and the organisational framework, as a response to the Clinical Services Framework released by the Health Reform Implementation Taskforce (HRIT). The report from Phase I was completed in June 2005.
- Phase II: reviewed service provision issues for the following groups: rural and remote communities, people who require community-based services, people who require medium to long-term support, people with conditions other than cancer, people from indigenous communities and culturally and linguistically diverse backgrounds, older people, children and their families, consumers and carers.

## Philosophy underpinning the review

Every person in Western Australia with life-limiting illness has a fundamental right to a palliative approach to care. To enable this right to be met, issues regarding palliative care, specifically equity, access and affordability need to be considered for both current and future populations.

It is important to note, that in most instances a palliative approach to care can be provided in the community supported by knowledgeable health professionals. The community is the preferred place of care for most patients and admission to a specialised palliative care inpatient facility may only occur during brief episodes of care (i.e. respite, symptom management, terminal phase of illness). Recommendations offered in this report are provided within this broader context of palliative care, recognising that inpatient beds are only one aspect of a larger, well-linked system of palliative support.

## Definition of a palliative care unit (PCU)

A PCU is a facility from which both inpatient and outpatient specialist palliative care is provided and coordinated. A PCU has a multidisciplinary team of healthcare providers who are knowledgeable and skilled in all aspects of the caring process relating to palliative care and their discipline of practice (holistic care). A PCU is not limited to care for patients at the end-of-life nor those with a cancer diagnosis; rather it is available to patients and families throughout the illness (malignant and non-malignant causes) and bereavement experiences. In summary, PCUs provide a coordinated, integrated and patient-focused model of care, which includes respite and other supportive services to carers.

## RECOMMENDATIONS

Recommendations are grouped under three categories: A- Metropolitan Inpatient Bed Allocation; B- Organisational Framework; C- Special groups.

### A. Metropolitan Inpatient Bed Allocation

#### Recommendation 1: Total beds

Based on the current Palliative Care Australia (PCA) Benchmark of 6.7 beds per 100,000 population, the total number of private and public beds should be 117.3 beds by 2015/16. However, based on the projected benchmark of 8.4 beds per 100,000 population obtained from the analysis in this report, a total number of 148.2 beds would better meet the projected future needs of the significant ageing population in the metropolitan area, anticipated by the year 2015/16.

#### Recommendation 2: Public beds

The minimum recommended number of publicly funded palliative care beds is 32 beds in North Metropolitan Area Health Service and 36 beds in South Metropolitan Area Health Service, based on the current PCA benchmark of 6.7 beds per 100,000 population. This would serve the transitional period up to 2010, but would need to be increased by 2015 and beyond.

#### Recommendation 3: Location of PCUs

PCUs should be established at Joondalup, Swan Districts, Rockingham and Armadale to ensure that access to palliative care is equitable throughout metropolitan WA and that care is provided closer to home.

#### Recommendation 4: Number of beds in PCU

Each PCU should have a minimum of ten beds to ensure a critical mass of patients and trained professionals.

#### **Recommendation 5: Integration**

Each PCU should be an integral clinical service within a hospital and be housed within a purpose-designed unit to facilitate the implementation of a palliative approach across the hospital while retaining the valued ethos of care in traditional hospices within the unit itself. These services should be integrated into the wider clinical system to achieve the best outcomes for patients and families.

#### **Recommendation 6: Area Health Palliative Teams**

Each PCU should be part of an "Area Health Palliative Team" where the domiciliary team (Silver Chain or other community-based/primary health care services) and PCU team work together to provide a seamless care system (e.g. two Area Health Palliative Teams, one for North Metropolitan area and one for South Metropolitan area).

#### **Recommendation 7: Service Levels**

Each metropolitan area should have a mix of service levels to ensure adequate service provision in those areas. PCUs need to align with models of care outlined in the Clinical Services Framework Levels Definition and Palliative Care Australia Framework for service capability and role delineation (Appendices D and E).

#### **Recommendation 8: Consultative Service**

Tertiary hospitals should adopt a Specialist Palliative Care Consultative Service model to maximise access to palliative care services throughout the hospital, for all patients regardless of diagnosis.

#### **Recommendation 9: Data Collection for an Inpatient Database**

Mechanisms / measures are required for better identification of palliative care patients in hospitals. This needs to be developed by palliative care clinicians in collaboration with the Department of Health:

- To improve the identification/ coding for palliative care patients upon admission to hospitals thus ensuring that the appropriate type of episode of care is recorded on the inpatient databases.
- To improve statistical discharges and readmissions of patients (transfer from one specialty to another within a hospital) whose care becomes palliative, such that the care type is recorded as "Palliative" rather than "Acute" for the proportion of hospital stay that is palliative.

### **B. Organisational Framework: Palliative Care Network**

The Palliative Care Network will be a sub-network of the Cancer and Palliative Care Network. The Palliative Care Advisory Group (PCAG) will become the executive group of the Palliative Care Network. The Palliative Care Network will have an appropriate clinical leadership structure to guide its coordination and development.

## **Recommendation 10: Membership**

The Palliative Care Network will include palliative care providers (metropolitan and rural, public and private, including nurses, General Practitioners, specialists, allied health, chaplains and volunteers), Non-Government Organisations (NGOs), Area Health Services (AHS), Department of Health (DOH), and consumer representatives.

## **Recommendation 11: Model of Service Provision**

The Palliative Care Network will endorse models of service provision for palliative services as outlined in the Clinical Services Framework Levels Definition and Palliative Care Australia Framework for service capability and role delineation (Appendices D and E).

## **Recommendation 12: Standards**

The Palliative Care Network will recommend a set of principles using the Palliative Care Australia Standards (2005) as a guide for the delivery of a range of palliative care services across the state including respite and outreach care.

## **Recommendation 13: Formal Links**

The Palliative Care Network will formalise links amongst palliative care providers to ensure that all Western Australians, regardless of their geographic location, have access to information, advice, expertise and services from specialist palliative care services. This linkage role would also include liaison amongst palliative care providers and NGOs and those caring for conditions other than cancer.

## **Recommendation 14: Protocols and Pathways**

The Palliative Care Network will initiate discussions with other Clinical Networks to develop palliative care pathways and protocols to guide the preparation and smooth transition of persons from the curative to palliative phase of their illness. The pathways and protocols will include adequate information and preparation of individuals and their family for this change, the types of support that are available through this stage such as respite care (in-home and residential), access to affordable drug therapy, furniture and equipment.

## **Recommendation 15: Education, Training and Workforce Planning**

- The Palliative Care Network will strengthen relationships between the palliative care providers, including shared education / management, joint clinical meetings for peer review and policy development, shared volunteer training and coordination.
- The Palliative Care Network will develop partnerships in palliative care education (e.g. universities, hospitals, Divisions of General Practice, Western Australian Centre for Remote and Rural Medicine (WACRRM) and the Cancer Council of Western Australia) to avoid duplication and to highlight deficiencies or gaps in education.
- The Palliative Care Network will recommend strategies and priorities for workforce planning to address the shortage of trained palliative care staff to AHS and other service providers.
- The Palliative Care Network will provide a leadership role or catalyst to facilitate education in skills for the care of people with malignant and non-malignant diseases.
- The Palliative Care Network will review education, training and clinical standards including respite issues.



#### **Recommendation 16: Helplines**

- The Palliative Care Network will examine the most appropriate mechanism for developing a single palliative care helpline for health professionals. This helpline would be widely promoted and available to nurses, doctors and residential aged care service providers.
- The Palliative Care Network will examine the extent to which HealthDirect has information on palliative care for the general public.

### **C. Recommendations for Special Groups** *Rural and Remote Communities*

#### **Recommendation 17: Linkages and Coordination**

The Palliative Care Network will identify mechanisms to support rural and remote palliative care providers using various strategies such as Telehealth assisted technologies, telephone hotlines and visiting specialists. This support will include clinical and professional support as well as counselling and debriefing support.

#### **Recommendation 18: Regional Coordination**

It is recommended that the rural Area Health Services consider a coordinated approach to service delivery of palliative care including documented Service Level Agreements with NGOs and government organisations. Coordination would include:

- Workforce planning and development,
- Coordinating allied health services and respite services,
- Supporting and recruiting volunteers,
- Monitoring need for equipment and specialist services,
- Assessment and referrals for specialist service access, and
- Supporting residential aged care facilities (RACFs) to provide palliative care services.

#### **Recommendation 19: Education & Standards**

The Palliative Care Network will evaluate the current level of service, workforce resources and standards of palliative care available in the regions with respect to the Palliative Care Australia (PCA, 2005) Standards and therapeutic guidelines.

#### **Recommendation 20: GP Education**

The Palliative Care Network will facilitate palliative care education of General Practitioners by collaborating with the WA Divisions of General Practice, College of GPs and WACRRM.

#### **Recommendation 21: Particular Rural Issues**

The Palliative Care Network recommends that Area Health Services consider rural issues in Service Level agreements and funding, when contracting palliative care services. These issues include: Diseconomies of scale; occupational safety and health because of rural isolation; and cost to families (eg equitable access to drugs, gap payments and home aids).

### **Recommendation 22: Promotion of Telehealth Assisted Services**

The Palliative Care Network will support the promotion of Telehealth assisted services and the development of such options that decrease the need for patients and palliative care consultants to travel long distances for appointments and consultations.

### **Recommendation 23: Patient Assisted Travel Scheme (PATS)**

The Palliative Care Network, in partnership with the rural Area Health Services, will negotiate amendments to the PATS Guidelines and Policy Documents that reflect the transport and accommodation needs of cancer and palliative patients and to ensure that the amendments are informed by the Palliative Care Australia (PCA, 2005) Standards.

### *People who require community-based services*

#### **Recommendation 24: Service Provision for those Living Alone**

The Palliative Care Network in partnership with community-based health services will support the palliative care needs of people who are living alone with no carer through appropriate services; for example, through the establishment of alert-link systems, palliative care packages (similar to community aged care packages), pool of volunteers and paid carers, an-after hours support service / night sitting service and financial packages for in-house respite.

#### **Recommendation 25: Support for Community-Based GPs**

The Palliative Care Network in partnership with community-based health services will promote adequate funding of GPs' direct and indirect care (e.g., letter writing, telephone liaison, travel) for community-based palliative care patients to ensure that it is viable for GPs to undertake community palliative care.

### *People who require medium to long-term support*

#### **Recommendation 26: Linkage and Coordination**

The Palliative Care Network will provide a leadership role to ensure that all palliative care facilities are able to accommodate appropriately people with medium to long-term palliative care needs.

### *People with conditions other than cancer*

#### **Recommendation 27: Service Provision**

The Palliative Care Network will work with existing organisations of conditions other than cancer to develop an appropriate model of care to meet the needs of people with non-malignant diseases.

#### **Recommendation 28: Motor Neurone Disease**

The Palliative Care Network will work with the Motor Neurone Disease Association of WA to develop a case management approach with Care Advisors intensively case managing people with MND and liaising with palliative care providers. Furthermore, both home visiting and inpatient hospice palliative care providers with the knowledge and skills to manage MND patients are required.

### **Recommendation 29: Protocols and Pathways**

The Palliative Care Network will work with other clinical networks to develop pathways and protocols so that principles of a palliative approach can be offered to people with conditions other than cancer.

## ***People from Indigenous communities***

### **Recommendation 30: Linkages and Coordination**

The Palliative Care Network in consultation and partnership with Aboriginal Community Controlled Health Services (ACCHS), including the cultural and law centres, will facilitate forums / workshops with respect to linkages amongst palliative care, community care, and Indigenous-specific services for disseminating information on palliative care support services currently available in WA.

### **Recommendation 31: Communication strategies**

The Palliative Care Network in partnership and consultation with ACCHS and the Office of Aboriginal Health will develop protocols and communication pathways to foster best practice models for the provision of palliative care to Indigenous Australians. These pathways will include appropriate strategies, such as the use of Indigenous radio and other forms of media, which will require the allocation of adequate resources to develop appropriate messages.

### **Recommendation 32: Pathways and Protocols**

The Palliative Care Network in partnership and consultation with ACCHS will initiate discussions with other Clinical Networks to develop palliative care pathways and protocols to guide the preparation and smooth transition of Indigenous persons from the curative to palliative phase of their illness.

### **Recommendation 33: Indigenous Liaison**

The Palliative Care Network in partnership and consultation with the Area Health Services and other relevant existing services in rural and regional centres will design a culturally appropriate model of palliative care for Indigenous Australians, which take into account existing State and National standards and principles for working with Indigenous Australians.

### **Recommendation 34: Partnerships**

The Palliative Care Network will facilitate partnerships between Area Health Services and ACCHS to provide training and support for palliative care services.

### **Recommendation 35: PATS**

The Palliative Care Network, in partnership with rural area health services, will review the policy of PATS for indigenous people so as to respond to particular cultural issues such as the need to be returned to their communities when they die from the place they were receiving treatment.

## *People from Culturally and linguistically Diverse Backgrounds (CALD)*

### **Recommendation 36:**

The Palliative Care Network works collaboratively with Palliative Care Western Australia to address the need for information and support for people from CALD regarding palliative care.

## *Older people*

### **Recommendation 37: Linkages and Coordination**

The Palliative Care Network will facilitate forums / workshops with respect to linkages amongst palliative care, community care, and aged care providers for disseminating information on palliative care support services currently available in WA.

### **Recommendation 38: Education and Standards**

The Palliative Care Network will develop protocols and communication pathways to foster best practice models for the provision of palliative care to older persons, such as bereavement support models, advance care directives and standardised documentation templates.

## *Children and their families*

### **Recommendation 39: Service Provision**

Paediatric palliative care will be community-based and coordinated by dedicated multidisciplinary teams in consultation with the children and their families.

### **Recommendation 40: Coordination of Care**

The Palliative Care Network will facilitate identification of the most effective way to implement a case management approach for all children with chronic or life-limiting illnesses to provide children and their families with a coordinated palliative care service, including the provision of timely information and access to requisite resources.

### **Recommendation 41: Access**

It is recommended that families are able to self-refer to palliative care services.

### **Recommendation 42: Education and Standards**

The Palliative Care Network will develop protocols and communication pathways to foster best practice models for the provision of paediatric palliative care for all palliative care services (e.g., Silver Chain, hospices, respite facilities, hospital based personnel and rural and remote settings).

### **Recommendation 43: Linkages Between Services**

The Palliative Care Network will facilitate forums / workshops to ensure linkages amongst disability services, community-based palliative care, hospital-based palliative care, and other health care providers and families and to disseminate information on all paediatric palliative care support services that are currently available in WA.

#### **Recommendation 44: Respite**

The Palliative Care Network will recommend the development of suitable accommodation to enable respite for paediatric patients and their families. The existing respite care centre for children with special needs, eg Lady Lawley Cottage, could be extended to include a wing that specifically caters for children who are dying and their families.

### *Carers and Consumers*

#### **Recommendation 45: Education and Training of Service Providers**

The Palliative Care Network will facilitate the education and training of service providers in assessing and meeting carer's needs for support services and increased awareness of services available at an earlier point in time.

#### **Recommendation 46: Volunteer Support**

The Palliative Care Network will recommend a state or regional structure or model for volunteers to be regularly supported that incorporates ongoing education and training.

#### **Recommendation 47: Support Services**

The Palliative Care Network will support improved access to respite services and psychosocial and bereavement support.

#### **Recommendation 48: Partnerships**

Partnership between The Health Consumer Council and relevant peak bodies (for example The WA Cancer Council, the MND Association, PCWA) should facilitate the development of education packages on palliative care for consumers, which will be publicised and widely distributed to inform consumers of the range of palliative care services and how to access those services.

## PALLIATIVE CARE IN WESTERN AUSTRALIA:

### 1. BACKGROUND & OBJECTIVES

The Western Australian (WA) Department of Health, in consultation with the Palliative Care Advisory Group (PCAG), has commissioned the WA Centre for Cancer and Palliative Care at Edith Cowan University, to provide advice regarding the development of a statewide plan for the future configuration and delivery of palliative care services in WA. The specific objectives of the review were to:

- Outline current palliative care service provision in WA, including the relationships between services and service role delineation.
- Project future need for service delivery in metropolitan, rural and remote areas and identify future linkages and role delineations to improve and enhance service delivery.
- Identify options for coordinating future service delivery across the state.

### 2. SCOPE OF REVIEW

The review consisted of two phases:


- Phase I: focussed on metropolitan inpatient needs and issues and more particularly on bed allocation in the metropolitan area and the organisational framework, as a response to the Clinical Services Framework released by the Health Reform Implementation Taskforce (HRIT). The report from Phase I was completed in June 2005.
- Phase II: reviewed service provision issues for the following groups: rural and remote communities, people who require community-based services, people who require medium to long-term support, people with conditions other than cancer, people from indigenous communities and culturally and linguistically diverse backgrounds, older people, children and their families, consumers and carers.

### 3. PHILOSOPHY UNDERPINNING THE REVIEW

Every person in Western Australia with life-limiting illness has a fundamental right to a palliative approach to care. To enable this right to be met, issues regarding palliative care, specifically equity, access and affordability need to be considered for both current and future populations.

A palliative approach aims to improve the quality of life for people with a life-limiting illness, and for their families, by reducing their suffering through early identification, assessment and treatment of pain, physical, cultural, psychological, social, and spiritual needs.[1]

Underlying the philosophy of a palliative approach is a positive and open attitude towards death and dying. The promotion of a more open approach to discussions of death and dying between health care professionals and their clients / patients and their families facilitates identification of the individual's wishes regarding end-of-life care.



A palliative approach is not confined to the end stages of an illness. Instead, a palliative approach provides a focus on active comfort care and a positive approach to reducing an individual's symptoms and distress, which facilitates the individual's understanding that they are being actively supported through this process.[1]

Surveys of patients with advanced illnesses consistently report that, if given the choice "up to 80% of patients with cancer would prefer to die at home"[2] supported by family and friends. The percentage realising their preference is much smaller because there are a number of limiting factors including carer fatigue, fear, anxiety, lack of technical expertise to provide complex medical care, limited support networks, cultural expectations, and other factors.

The impetus for the beginning of the palliative care movement in Australia nearly a quarter of a century ago was largely to respond to the prevalence of excessively burdensome treatments, unnecessary suffering and inappropriate hospitalisation of those with illnesses that had no hope of a cure. These pioneers wanted to reclaim the notion that death is indeed part of life, and when death becomes inevitable that it be returned to its rightful place amongst family and friends and the place of the dying person's choice. Therefore, a palliative approach should be provided in the setting preferred by the individual and his / her family, such as at home, whenever this is possible.

Therefore it is important to note, that in most instances a palliative approach to care can be provided in the community supported by knowledgeable health professionals. The community is the preferred place of care for most patients and admission to a specialised palliative care inpatient facility may only occur during brief episodes of care (ie, respite, symptom management, terminal phase of illness). Recommendations offered in this report are provided within this broader context of palliative care, recognising that inpatient beds are only one aspect of a larger, well-linked system of palliative support.

#### 4. MEMBERSHIP AND TERMS OF REFERENCE

This review was undertaken under the direction of the Palliative Care Advisory Group (PCAG). A sub-committee of PCAG, with other co-opted members, was appointed by Dr Neale Fong, the Director General for Health, to serve as a steering committee overseeing this specific project. Steering committee members are highlighted with an asterisk in the list below.

##### PCAG Members

- Professor Linda Kristjanson - The Cancer Council of WA Chair of Palliative Care and Chair of the Palliative Care Advisory Group (PCAG)\*
- Dr Anil Tandon - Palliative Care Specialist, SCGH and Cottage Hospice\*
- Mrs Eleanor Roderick - Chief Executive Officer, Murdoch Community Hospice\*
- Mr Steve Carmody - Manager, Silver Chain Nursing Association\*
- Mrs Amanda Leigh - Director, Cancer Council Cancer Services\*
- Mr Gareth Griffiths - Palliative Care Nurse, SCGH\*
- Dr Scott Blackwell - General Practitioner\*
- Mr Clory Carrello - Department of Health, WA\*
- Mr Kingsley Burton / Ms Liza Houghton - Department of Health, WA\*
- Dr Phil Claringbold - Oncology Department, Fremantle Hospital

- Dr Doug Bridge- Palliative Care Physician, Royal Perth hospital
- Mr Clive Deverall - President, Palliative Care WA
- Ms Michelle Kosky - Executive Director , Health Consumers Council
- Rev Terry McAuliffe - Chaplain, Silver Chain Nursing Association
- Dr Marianne Phillips - Paediatric Oncologist and Palliative Care Specialist, Princess Margaret Hospital
- Dr Sarah Pickstock - Medical Director, Hollywood Palliative Care Unit
- Ms Penny Tuffin - Clinical Pharmacist, RPH and Cottage Hospice
- Ms Helen Walker - Manager, Cancer Council Palliative and Supportive Care Professional Development Centre
- Ms Donna Wilson - Social Worker, Hollywood Palliative Care Unit
- Ms Susan Kay - South West Area Health Service
- Ms Amelia Foster / Dr Jenny Dodd - WA Country Health Services

## Co-opted Members

- Dr Lorna Rosenwax - Faculty of Medicine and Dentistry, University of Western Australia
- Associate Professor Samar Aoun - Project Manager, WA Centre for Cancer and Palliative Care, ECU
- Mrs Jayne Walton, Research Assistant, WA Centre for Cancer and Palliative Care, ECU

## Terms of Reference of PCAG


- To advise the Director General and through him the Minister for Health on palliative care issues.
- To advise on strategic service development to ensure equitable access and to promote integrated models of care.
- To advise on palliative care research topics to inform models of efficient and effective service delivery.
- To advise on resourcing priorities for palliative care to ensure an optimal mix and distribution of services.
- To ensure a continuing commitment to quality and appropriate standards.
- To advise on education, training and support matters.
- To ensure maximum possible collaboration with government and the non-government sectors.
- To work effectively with the WA Aged Care Advisory Group on matters of mutual concern for older people in the community.

## 5. METHODOLOGY

The methods for this review included the following:

1. Broad call for submissions to ensure that the views of the wider community were received. Specific comments or experience regarding challenges in delivering palliative care services and suggestions for improvement were sought (total of 13 submissions, Appendix A).



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2. Interviews with key experts and stakeholders in the community were held and this consisted of two rounds of consultations involving 80 service providers in the first round and 67 service providers and consumers in the second round (Appendix A). Specific understanding of the contextual issues is important in constructing an integrated state-wide palliative care service, delivered within a range of settings across disease groups and along the continuum of care. Consultations were also made in regard to current and future service levels and role delineation. Consultations with rural and remote stakeholders were performed via videoconferencing.
  3. Quantitative data collection and analysis of current service activity and utilisation (separations and bed days) was undertaken including geographic distribution of need, trends in utilisation over the last five financial years and projection of service utilisation to 2015.
  4. Literature review of the prevailing models of palliative care services in Australia and overseas. These included needs and programs for special groups such as children, individuals with non-malignant conditions, people living in rural and remote communities and individuals from minority cultural groups (Appendix F).

## 6. POPULATION BASED NEEDS ASSESSMENT

### 6.1 Data Collection

The initial assessment of "Palliative Care" services was based on discharge summaries from the Department of Health's Hospital Morbidity Data System (HMDS). This central database incorporates a subset of the information contained on TOPAS. Although palliative care episodes are meant to be identified on the system as having a "Palliation" care type, this is not reflected in the tertiary hospital's HMDS data, namely for the three hospitals: SCGH, RPH and Fremantle.

To rectify the problem, both TOPAS and Palliative Care departmental data were sought from most tertiary hospitals. All consultants who provided care to a patient during a hospital stay were available from additional fields in TOPAS, over and above the admission and separation doctors reported on the discharge summaries. By identifying all separations involving "Palliative Care" consultants and estimating the proportion of these episodes that involved palliation, more accurate statistics are expected for each tertiary hospital.

Thus tertiary cases were identified based on the Palliative Care Services (PCS) departmental data, using patient identifiers (UMRN) and admission dates to match the entries to records on the Hospital Morbidity Data System, and referral dates to ascertain the proportion of each episode that involved palliative care. All cases that didn't match automatically were checked manually for potential links. The majority of the non-matches relate to services that occurred at a time when the patient was not admitted to hospital or services that could take place in an outpatient setting. This is evident from the very high number of non-matches relating to "same-day" PCS events.

In summary, the revised Palliative Care figures for the tertiary hospitals were obtained from entries from the PCS databases, which were matched to records on the central Hospital Morbidity Data System, which contains summary records extracted from TOPAS. Thus, the patient identifier (UMRN) and admission date were used to match database entries between the two sources. The referral date on the PCS record was also used (when available) to determine the "Palliative Care"

length of stay. However, all other fields required in the analysis were those recorded on the Hospital Morbidity Data System. They include the separation date, as well as sex, age, postcode/SLA and other demographic details used in the presentation of cross-tabulations and in the assessment of projections according to population changes.

It is worth noting that a large number of separations considered to be palliative care cases have been allocated to other specialty groups in the overall statewide model developed for Health Reform Implementation Taskforce (HRIT). The outputs, used to perform the following analysis, have been produced by the Epidemiology Branch of the Department of Health (WA). Although this does not provide a complete picture of palliative care activity in Western Australia, it provides the most accurate assessment available at this time given the existing issues in coding for palliative care admissions, which has been highlighted as being an issue throughout Australia.

### 6.2 Palliative Care Activity and Trends

Table 1 presents the palliative care activity for the Perth metropolitan area. The table highlights the following:

- In 2003/04, approximately 55% of separations for palliative care services were from tertiary hospitals, 30% for public patients from hospices/private palliative care units and 15% from non-tertiary hospitals.
- Between 2001/02 and 2003/04, palliative care separation activity has increased for both hospices and non-tertiary hospitals by about 5%, with the highest increase in the tertiary hospitals at about 17%. Overall, there was an increase of 11% in three years.
- The palliative care activity could not be segregated from other specialties through the Hospital Morbidity Data System & TOPAS for Princess Margaret Hospital and King Edward Memorial Hospital and were therefore not included in Table 1.

Table 1: Metropolitan Separations for Public Patients 2001/02 - 2003/04

	2001/02	2002/03	2003/04	% change 2001/2-2003/4
Fremantle Hospital	306	383	383	
Royal Perth	407	439	479	
SCGH	445	505	488	
<b>TOTAL TERTIARY</b>	<b>1,158</b> <b>(52.0%)</b>	<b>1,327</b> <b>(55.5%)</b>	<b>1,350</b> <b>(54.6%)</b>	<b>16.6% increase</b>
Armadale	15	22	14	
Bentley	5	4	3	
Joondalup	39	65	83	
Kalamunda	34	45	39	
Murray district	38	13	13	
Osborne park	19	37	22	
Peel	172	151	195	
Rockingham	31	20	3	
Swan district	11	16	9	
<b>TOTAL NON-TERTIARY</b>	<b>364</b> <b>(16.4%)</b>	<b>373</b> <b>(15.6%)</b>	<b>381</b> <b>(15.4%)</b>	<b>4.8% increase</b>
Cottage hospice	355	355	363	
Hollywood	62	82	85	
Murdoch com. hospice	286	252	293	
	703	689	741	
<b>TOTAL OTHER (hospices)</b>	<b>(31.6%)</b>	<b>(28.8%)</b>	<b>(30.0%)</b>	<b>5.4% increase</b>
<b>TOTAL</b>	<b>2,225</b>	<b>2,389</b>	<b>2,472</b>	<b>11% increase</b>

Source: Palliative Care Review Project, May 2005

Table 1 is compared to Table 2, which outlines the palliative care activity reported in the Clinical Services Consultation report released by the HRIT.

It is noted that there are significant differences between the activity reports in each of the tables, such as the difference in the level of palliative care activity undertaken in the tertiary sector, which could impact on service planning. Where 3% of separations were deemed to have come from tertiary hospitals and the trend was showing a decrease (Table 2), the revised proportion is now 55% and the trend showing a reasonable increase (Table 1). *It is therefore proposed that Table 1 replaces Table 2 for the purpose of future palliative care service development.*

**Table 2: Separations 2001/02 to 2003/04**

	2001/02	2002/03	2003/04	Average annual rate of change
Fremantle Hospital	63	33	22	-40.9%
Princess Margaret Hospital	0	1	3	-
Royal Perth Hospital	32	4	3	-69.4%
Royal Perth Hospital Shenton Park	0	1	1	-
Sir Charles Gairdner Hospital	6	7	15	58.1%
<b>TOTAL TERTIARY</b>	<b>101</b>	<b>46</b>	<b>44</b>	<b>-34.0%</b>
Armadale Kelmscott Memorial Hospital	15	22	14	-3.4%
Bentley Hospital	5	4	3	-22.5%
Joondalup Health Campus	33	55	76	51.8%
Kalamunda Community District Hospital	34	45	37	4.3%
Murray District	38	13	13	-41.5%
Osborne Park Hospital	19	37	22	7.6%
Peel Health Campus	149	128	156	2.3%
Rockingham / Kwinana District Hospital	31	20	3	-68.9%
Swan District Hospital	11	16	9	-9.5%
<b>TOTAL NON-TERTIARY</b>	<b>335</b>	<b>340</b>	<b>333</b>	<b>-0.3%</b>
Cottage Hospice	355	355	331	-3.4%
Hollywood Private Hospital	62	82	84	16.4%
Mercy Hospital	0	0	1	-
Murdoch Community Hospice	286	252	293	1.2%
<b>TOTAL OTHER</b>	<b>703</b>	<b>689</b>	<b>709</b>	<b>0.4%</b>
<b>TOTAL</b>	<b>1139</b>	<b>1075</b>	<b>1086</b>	<b>-2.4%</b>

Source: Clinical Services Consultation 2005, p215

Key features summarised from other outputs (periods considered were 1999/00, 2000/01, 2001/02, 2002/03, 2003/04:

- A large number of separations considered to be palliative care cases have been allocated to other specialty groups in the overall statewide model developed for HRIT. Hence the Service Related Group (SRG) allocation of tertiary hospital separations, over the 5 year period, is as follows: 32% Medical Oncology, 8% Respiratory Medicine, 6.5% Haematology, 5% Diagnostic GI Endoscopy, 5% Non Subspecialty Surgery, 4% Neurology, 4% Palliation and 35% a number of other specialty groups. Only 4% of cases included for the tertiary hospitals were previously recognised as palliative care.
- For the five periods combined, males accounted for slightly more separations (55%vs 45%) and beddays (53% vs 47%) than females.

- For the five periods, 68% of separations and 72% of beddays for palliative care services were accounted for by patients aged 65 years and over.
- Among indigenous people, the proportion of palliative care separations and beddays involving patients aged 45-64 years was nearly twice as high as in the non-indigenous population: separations (48% vs 26%) and beddays (45% vs 23%), in the five financial years combined.

**Table 3: Palliative care hospitalisations (public and private) in North and South Metropolitan areas for 1999/00 - 2003/04: Metropolitan Hospitals(a) and Residents(b)**

<b>Palliative Care Separations</b>	<b>99/00</b>	<b>00/01</b>	<b>01/02</b>	<b>02/03</b>	<b>03/04</b>	<b>Total</b>
North Metropolitan Hospitals	1,762	1,883	1,939	2,095	2,123	9,802
North Metropolitan Residents	1,275	1,319	1,355	1,446	1,438	6,833
South Metropolitan Hospitals	787	901	1,023	1,053	1,070	4,834
South Metropolitan Residents	1,162	1,313	1,474	1,542	1,587	7,078
<b>Palliative Care Bed-Days</b>	<b>99/00</b>	<b>00/01</b>	<b>01/02</b>	<b>02/03</b>	<b>03/04</b>	<b>Total</b>
North Metropolitan Hospitals	19,585	21,648	21,559	22,747	21,988	107,527
North Metropolitan Residents	14,565	16,244	15,866	16,168	15,525	78,368
South Metropolitan Hospitals	8,076	9,310	9,638	9,506	9,472	46,002
South Metropolitan Residents	11,952	13,323	14,015	14,728	14,426	68,444
<b>Estimated Palliative Care Beds (c)</b>	<b>99/00</b>	<b>00/01</b>	<b>01/02</b>	<b>02/03</b>	<b>03/04</b>	<b>Total</b>
North Metropolitan Hospitals	63	70	69	73	71	69
North Metropolitan Residents	47	52	51	52	50	51
South Metropolitan Hospitals	26	30	31	31	31	30
South Metropolitan Residents	39	43	45	47	46	44

- (a) Metropolitan hospital figures include all inpatient activity (for Metropolitan and non-Metropolitan patients) at public and private establishments within the Area Health Service.
- (b) Metropolitan resident figures include all inpatient activity at a WA hospital (metropolitan/non-metropolitan; public/private) for residents of the specified Area Health Service.
- (c) Bed estimates are based on 85% occupancy.

Table 3 presents trends in the corrected activity in the last five financial years for north and south metropolitan areas separately, based on two different counts. The hospitals' separations include all patients admitted to hospitals in that particular area but who may live in the area or elsewhere. The residents' count considers hospital activity for all patients who lived in a particular area and were admitted to a WA hospital. There were more patients using north metropolitan palliative care services than there were palliative care patients who live in that area, while the situation was reversed in the south metropolitan area. Therefore, the estimated palliative care bed requirements (public and private) based on service utilisation was 69 in the north metropolitan area and 30 in the south metropolitan area. When location of residence was considered, the estimated bed requirements (public and private) was 51 for north metropolitan residents and 44 for south metropolitan residents. This supports the need for additional palliative care beds in the south metropolitan area.

### 6.3 Projections of Utilisation of Palliative Care Services

Projection of separations, beddays, beds and beds per 100,000 population up to the financial year 2015/16 for the north and south metropolitan areas are presented in Appendix B.

The projections in Appendix B were derived from average palliative care age-specific rates for the financial years 2000/01-2003/04, applied to annual population estimates up to 2015/16. Despite slightly higher numbers of separations among south metropolitan residents compared to their north metropolitan counterparts, bed and bed-day requirements for south metropolitan residents are expected to remain consistently lower than corresponding north metropolitan requirements throughout the projection period. This trend reflects current hospital utilisation patterns. Differences in clinical care and administrative practices may possibly account for the higher separation counts but lower average lengths of stay for south metropolitan residents.

Bed rates per 100,000 population remain almost identical for north and south metropolitan residents throughout the projection period. Currently, the north and south metropolitan residents utilise 6.8 and 6.9 beds per 100,000 (respectively), a mix of private and public beds. This reflects the Palliative Care Australia (PCA) current benchmark of 6.7 beds per 100,000 (see section below). By the year 2015/16, it is projected that the north metropolitan area will need a total of 79 beds (based on 8.4 beds per 100,000) and south metropolitan a total of 70 beds (based on 8.5 beds per 100,000).

### 6.4 Palliative Care Australia (PCA) Benchmark

The following statement is taken from the PCA 2003 report on "Palliative Care service provision in Australia: A planning guide" (Page 18).

*Previous crude estimates of the requirement for palliative care beds were thought to be based on models from the UK, which not only excluded patients with a non-malignant disease from hospices, but also were based on a different culture and health system. Australian experience over more than 20 years has allowed appropriate refinement. It is estimated that in a population of 100,000, 295 patients will require an average of 7 inpatient palliative care beddays each year. Based on an occupancy level of 85%, a **minimum** of 6.7 designated palliative care beds is recommended per 100,000 population.*

*The minimum levels specified above will need to be supplemented with additional resources in rural and remote areas, in lower socio-economic areas and for people with more complex needs eg HIV/AIDS or MND. These recommendations are for specialist palliative care inpatient beds and assume that as patients are stabilised they will return to more appropriate levels of care-discharge to home under community palliative care providers, transfer to an aged care facility or other sub-acute clinical environments.*

### 6.5 Geographic Distribution of Need

Appendix C (two maps) presents the distribution of deaths from malignant and non-malignant cases that potentially needed palliative care services, July 2000 to December 2002, by postcodes of residence in North and South Metropolitan areas separately. The data used to plot the maps is based on the minimal palliative care constituency which is defined in terms of the presence of any of 10 tracer conditions as a cause of death (McNamara et al, 2004). These conditions are: neoplasm (59.5%), heart failure (21.0%), renal failure (9.8%), chronic obstructive pulmonary disease (9.6%), Alzheimer's disease (4.0%), chronic liver failure (4.0%), Parkinson's disease (1.3%), motor neurone disease (0.9%), HIV/AIDS (0.1%) and Huntington's disease (0.1%). At least 40% of deaths requiring palliative care are due to non-neoplastic conditions (Table 4).

For south metropolitan area, the density of cases appears to be in the Peel area, Rockingham, Armadale and Bentley. For the north metropolitan area, the higher density of cases appears to be in Kalamunda, Swan District, Osborne Park and Joondalup. This distribution supports the approach of making palliative care beds available outside the central metropolitan area, particularly, as recommended in the Health Reform Report (Reid report), in areas such as Joondalup, Swan, Armadale and Rockingham.

**Table 4: Number of deaths caused by the ten tracer conditions grouped under neoplasms, non-neoplasms and both, for the metropolitan area (total of 10,454 deaths, July 2000- December 2002)**

Conditions causing death	North Metropolitan		South Metropolitan	
	Number	%	Number	%
Neoplasms	2995	56.7	2861	55.3
Non-neoplasms	2037	38.6	2082	40.3
Neoplasms and Non-neoplasms	250	4.7	229	4.4
Total	5282	100	5172	100

Source: Data was compiled from the NHMRC 2004 report by B. McNamara, L. Rosenwax, D. Holman and E. Nightingale "Who receives specialist palliative care in WA and who misses out".

## 6.6 Levels of Care and Role Delineation

All stakeholders who participated in interviews were consulted about the current and future levels of care and role delineation of their services and other services. Appendix D presents a consensus of the different opinions. It was agreed that the current level of care and role delineation do not quite fit the PCA framework and there are no formal links, only informal ones. However, it was acknowledged that this is where services should be moving to in the future, particularly in terms of roles, linkages and resource profiles. This activity was taken before the release of the Clinical Services Consultation report, where 6 levels of care were presented (see Appendix E). Appendix D attempts to match the six levels to those of the PCA framework.

Table 5 presents PCAG's suggestions for levels of care in 2015/16, where each metropolitan area will have a mix of service levels ranging from 2 to 6. The two tertiary hospitals and PMH would be level 6, the proposed palliative care units in the four general hospitals would be level 4, and the two hospices would be 5 or 6. Descriptions of levels of service are in Appendix E.

According to the Clinical Services Framework, it is anticipated that Royal Perth and Fremantle hospitals will be relocated to form the new Fiona Stanley Hospital. Therefore, their projected level of service appears as nil in Table 5.

Based on the geographic distribution of population need (section 6.5) and the Health Reform Report, there is a need to reallocate palliative care beds to better match population distribution, needs, and future trends. Therefore, the projected level of service of Cottage Hospice appears as nil in Table 5, as these beds have been reallocated (see Table 8).

**Table 5: Current and projected levels of palliative care services in the metropolitan area, as suggested by PCAG (based on the Clinical Services levels of care listed in Appendix E).**

Location of service	Name of service	Current service level	Projected Clinical service level by 2015
NORTH	Cottage Hospice	5	NIL
	Hollywood Palliative Care Unit	5	6
	Fremantle Hospital	3	NIL
	Joondalup Health Campus	2	5
	Osborne Park Hospital	2	2
	Royal Perth Hospital	5	NIL
	Sir Charles Gairdner Hospital	5	6
	Swan District Hospital	2	4
SOUTH	Armadale Kelmscott Memorial Hospital	3	4
	Fiona Stanley Hospital	N/A	6
	Kalamunda Hospital	2	2
	Murdoch Community Hospice	5	5
	Peel Health Campus	2	4
	Rockingham Kwinana District Hospital	2	4
STATE WIDE	King Edward Memorial Hospital	NIL	NIL
	Princess Margaret Hospital	4	6

Note: Table 5 is proposed to replace the table on level of service, page 219, of the Clinical Services Report

## 6.7 Population Based Bed Allocation

Table 6 presents the current bed allocations for the metropolitan area, the funded public beds and all beds including private. Currently public beds make up 52% of all beds. The total number of public and private beds available is close to the PCA benchmark (92.5 compared to 100.7), however the current South Metropolitan beds are half those in North Metropolitan (29.1 compared to 63.4) and much below the benchmark for South Metropolitan (47.0). Although North Metropolitan population exceeds South Metropolitan population by about 100,000, North Metropolitan deaths exceed South Metropolitan deaths by only 110. Again this supports the need for additional palliative care beds in the South Metropolitan area.



Table 6: Current bed allocations

	Public & Private Beds	Public Beds Only (indicative funding)
<b>NORTH METROPOLITAN (a)</b>		
Cottage Hospice	26.0	13.7
Hollywood PCU	20.0	3.6
Joondalup Health Campus	4.0	1.1
Swan District Hospital	5.5	5.5
Other public beds*	7.9	7.9
■ Tertiary hospitals		
■ General hospitals		
<b>Total North Metropolitan beds</b>	<b>63.4</b>	<b>31.8</b>
<b>PCA Benchmark**</b>	<b>53.7</b>	
<b>SOUTH METROPOLITAN (b)</b>		
Murdoch Community Hospice	20.0	11.0
Armadale Hospital	0.9	0.9
Rockingham/Kwinana	2.3	2.3
Peel	5.0	1.5
Other public beds*	0.9	0.9
■ Tertiary hospitals		
■ General hospitals		
<b>Total South Metropolitan beds</b>	<b>29.1</b>	<b>16.6</b>
<b>PCA Benchmark**</b>	<b>47.0</b>	
<b>TOTAL METROPOLITAN</b>	<b>92.5</b>	<b>48.4</b>
<b>PCA Benchmark**</b>	<b>100.7</b>	

Notes:

- \* "other public beds" means indicative publicly funded palliative care inpatient beds in hospitals
  - in North Metro: Bentley, Kalamunda, RPH, SCGH, Osborne Park
  - in South Metro: Fremantle and Murray District
- \*\* PCA estimation of 6.7 beds per 100,000 population is based on an occupancy level of 85%. PCA justifies this estimate as follows: Previous estimates were based on UK models, which are of a different culture and health system and excluded patients with a non-malignant disease. It is estimated that in a population of 100,000, 295 patients will require an average of seven inpatient PC beddays each year, average length of stay per episode is about 14 days.
- (a) North Metropolitan current population (2003) = 801,298 and Deaths in 2.5 year period was 5,282
- (b) South Metropolitan current population (2003) = 701,296 and Deaths in 2.5 year period was 5,172

Table 7 presents the total beds (public and private) that match the population in the two metro areas, currently and by 2015.

**Table 7: Current and projected population and bed allocation (based on PCA’s 6.7 beds/100,000\*) by local government authorities and Health Districts. Area of hospital is highlighted in each region.**

Metropolitan regions by health districts	2005		2015	
	Population	PC beds	Population	PC beds
<b>NORTH METROPOLITAN</b>				
North West (Upper and Coastal Health Districts) Wanneroo, <b>Joondalup</b>	262,254	17.5	322,372	21.5
North East (Hills, Valley and Midlands Health Districts) Kalamunda, Mundaring, <b>Swan</b>	181,384	12.1	212,057	14.2
North Central (Perth City, Lower, and Central Health Districts) Perth, Vincent, Cambridge, Subiaco, <b>Nedlands</b> , Mosman Park, Peppermint Grove, Stirling, Bayswater, Bassendean	379,863	25.4	389,257	26.0
<b>Total North Metropolitan</b>	<b>823,501</b>	<b>55.0</b>	<b>923,686</b>	<b>61.7</b>
<b>SOUTH METROPOLITAN</b>				
South East (Armadale and Bentley Health Districts) <b>Armadale</b> , Gosnells, Serpentine-Jarrahdale, Canning, Belmont, Victoria Park, South Perth	335,252	22.5	373,737	25.0
South West ( Fremantle and Rockingham-Kwinana Health Districts) Cockburn, Kwinana, <b>Rockingham</b> , Fremantle, Melville	316,133	21.2	371,110	24.9
Peel (Peel Health District) <b>Mandurah</b> , Murray, Waroona	70,475	4.8	85,318	5.7
<b>Total South Metropolitan</b>	<b>721,860</b>	<b>48.5</b>	<b>830,165</b>	<b>55.6</b>

Source: ABS projected population estimates for WA. Data downloaded from the Epidemiology Branch website, June 2005.

\* Using the current PCA estimation of 6.7 beds per 100,000 population, 103.5 beds are required in 2005 and 117.3 beds will be required in 2015 (public and private beds). However, if the projected benchmark of 8.4 to 8.5beds/100,000 is used for the year 2015, the total number of beds required to service the population will increase to 148 beds (77.6 beds in North Metropolitan and 70.6 beds in South Metropolitan).



## 6.8 Recommended Bed Allocation in the Metropolitan Area

Table 8 compares the suggested bed allocation for public beds as presented in the Clinical Services Report (column 2), and those public beds endorsed by PCAG (column 3). A scenario for bed allocation is suggested by PCAG based upon geographical distribution, level of service provider, PCA benchmarks and projected trends for palliative care activity: 32 public beds in North Metropolitan and 36 public beds in South Metropolitan by the year 2015/16. The total of 68 public beds is nearly similar to the total of 66 beds allocated in the Clinical Services (CS) report.

It is anticipated that the 68 public beds will be topped up by 49.3 private beds to make up the benchmark of 117.3 total beds, which takes into account the needs of all palliative care cases (malignant and non-malignant conditions): 29.7 private beds in North Metropolitan and 19.6 private beds in South Metro. It has also been recommended through the stakeholder consultations that a palliative care unit should not be less than 10 beds to be viable. Therefore it is hoped that private beds will make up the number to ten beds or more in areas where the suggested public beds in Table 8 are below the recommended level. However, the split into public and private beds still needs to be addressed (see notes (d) and (e) below Table 8).

**Table 8: Suggested future bed allocation by PCAG compared to bed allocation in clinical services report and PCA benchmarks, by year 2015/16. (Please read in conjunction with notes)**

Year 2015/16	Public beds as suggested by Clinical Services Report	PCAG suggestions for public beds
<b>NORTH METROPOLITAN</b>		
PMH	-	consultative
KEMH	-	consultative
SCGH (central tertiary)	19 (a)	consultative
Hollywood PCU	-	10
Swan	6	10
Kalamunda	1	-(c)
Joondalup	15	12
<b>Total North Metropolitan public beds</b>	<b>41</b>	<b>32</b>
<b>PCA benchmark 61.7 total beds*</b>		
Private beds needed to reach benchmark in North Metropolitan= 29.7 (d)		
<b>SOUTH METROPOLITAN</b>		
Fiona Stanley Hospital	17 (b)	consultative
Murdoch Com Hospice	-	15
Rockingham	4	8
Armadale	4	8
Peel	-	5
<b>Total South Metropolitan public beds</b>	<b>25</b>	<b>36</b>
<b>PCA benchmark 55.6 total beds*</b>		
Private beds needed to reach benchmark in South Metropolitan= 19.6 (e)		
<b>Total Metropolitan Public</b>	<b>66</b>	<b>68</b>

**Notes:**

- (a) in second column, SCGH beds include those currently at Hollywood PCU and Cottage Hospice.
- (b) in second column, Fiona Stanley Hospital beds include those currently at Murdoch Community Hospice and transfer from RPH.
- (c) Kalamunda is in catchment area of Swan District Hospital.
- (d) The most recent estimates of planned and existing North Metropolitan Private beds are a total of 31.4 beds: SJOG Subiaco (5 beds in the future) and Glengarry Hospital (10 beds currently) and Hollywood PCU (16.4 beds currently). Without any increases in private beds, these together with the recommended public beds would achieve the PCA benchmark for 2015/16.
- (e) The current number of South Metropolitan is 9 private beds at Murdoch Community Hospice. Although we would anticipate some increase in the number of private beds in the South Metro, we have planned for the recommended benchmark by allocating a slightly larger number of public beds to this area.

\* based on current estimate of PCA 6.7beds/100,000.

It is worth noting that the total beds benchmark of 61.7 in North Metropolitan and 55.6 in South Metropolitan are based on the minimum PCA estimate of 6.7beds/100,000, which is applicable to the current situation. Should the projected beds per population for the year 2015 be used, the total number in North Metropolitan would increase to 77.6 beds based on 8.4beds/100,000 and the total number in South Metropolitan would increase to 70.6 beds based on 8.5beds/100,000 (these projected ratios were provided by the Epidemiology Branch, see section 6.3), a total of 148.2 beds (Table 9). The projected benchmarks take into account the 50% increase in the population aged 60 years and over between the years 2005 and 2015, compared to a rather steady increase of 5-8% in the population aged less than 60 years, for the same period (Table 9).

Therefore, the 68 public beds and the 49.3 private beds (total 117.3) are a conservative estimate, and would serve the transitional period up to 2010, but would need to be increased by 2015 and beyond.

**Table 9: Projected population change for the under 60- and over 60- years old people in the two metropolitan areas, and the difference in bed allocation based on the projected benchmark that accounts for the ageing of the population.**

	2005	2015	% change 2005- 2015
60+ yrs- North Metropolitan	133,072	200,102	50
60+ yrs- South Metropolitan	124,929	183,554	47
<60 yrs- North Metropolitan	690,429	723,584	5
<60 yrs-South Metropolitan	596,931	646,611	8
<b>Total beds based on current PCA 6.7/100,000</b>		<b>117.3</b>	
Beds - North Metropolitan		61.7	
Beds- South Metropolitan		55.6	
<b>Total beds based on projected 8.4- 8.5/100,000*</b>		<b>148.2</b>	
Beds-North Metropolitan		77.6	
Beds- South Metropolitan		70.6	

\*The projected benchmark has been provided by the Epidemiology Branch of the Health Department in the analysis reported in section 6.3 of this report and charts in Appendix B.

## 7. PHASE I: RECOMMENDATIONS FOR METROPOLITAN BED ALLOCATION

The following recommendations are based on an analysis of all qualitative data collected from consultations with key stakeholders, quantitative data and the literature review. These recommendations build on the previously suggested recommendations in the report on the Evaluation of the State Palliative Care Plan (2000).

### Definition of a palliative care unit (PCU)

A PCU is a facility from which both inpatient and outpatient specialist palliative care is provided and coordinated. A PCU has a multidisciplinary team of healthcare providers who are knowledgeable and skilled in all aspects of the caring process relating to palliative care and their discipline of practice (holistic care). A PCU is not limited to care for patients at the end-of-life nor those with a cancer diagnosis; rather it is available to patients and families throughout the illness (malignant and non-malignant causes) and bereavement experiences. In summary, PCUs provide a coordinated, integrated and patient-focused model of care, which includes respite and other supportive services to carers.

### *Recommendations for metropolitan bed allocation:*

#### **Recommendation 1: Total beds**

Based on the current Palliative Care Australia (PCA) Benchmark of 6.7 beds per 100,000 population, the total number of private and public beds should be 117.3 beds by 2015/16. However, based on the projected benchmark of 8.4 beds per 100,000 population obtained from the analysis in this report, a total number of 148.2 beds would better meet the projected future needs of the significant ageing population in the metropolitan area, anticipated by the year 2015/16.

#### **Recommendation 2: Public beds**

The minimum recommended number of publicly funded palliative care beds is 32 beds in North Metropolitan Area Health Service and 36 beds in South Metropolitan Area Health Service, based on the current PCA benchmark of 6.7 beds per 100,000 population. This would serve the transitional period up to 2010, but would need to be increased by 2015 and beyond.

#### **Recommendation 3: Location of PCUs**

PCUs should be established at Joondalup, Swan Districts, Rockingham and Armadale to ensure that access to palliative care is equitable throughout metropolitan WA and that care is provided closer to home.

#### **Recommendation 4: Number of beds in PCU**

Each PCU should have a minimum of ten beds to ensure a critical mass of patients and trained professionals.

#### **Recommendation 5: Integration**

Each PCU should be an integral clinical service within a hospital and be housed within a purpose-designed unit to facilitate the implementation of a palliative approach across the hospital while retaining the valued ethos of care in traditional hospices within the unit itself. These services should be integrated into the wider clinical system to achieve the best outcomes for patients and families.

#### **Recommendation 6: Area Health Palliative Teams**

Each PCU should be part of an "Area Health Palliative Team" where the domiciliary team (Silver Chain or other community-based/primary health care services) and PCU team work together to provide a seamless care system (e.g. two Area Health Palliative Teams, one for North Metropolitan area and one for South Metropolitan area).

#### **Recommendation 7: Service Levels**

Each metropolitan area should have a mix of service levels to ensure adequate service provision in those areas. PCUs need to align with models of care outlined in the Clinical Services Framework Levels Definition and Palliative Care Australia Framework for service capability and role delineation (Appendices D and E).

#### **Recommendation 8: Consultative Service**

Tertiary hospitals should adopt a Specialist Palliative Care Consultative Service model to maximise access to palliative care services throughout the hospital, for all patients regardless of diagnosis.

#### **Recommendation 9: Data Collection for an Inpatient Database**

Mechanisms / measures are required for better identification of palliative care patients in hospitals. This needs to be developed by palliative care clinicians in collaboration with the Department of Health:

- To improve the identification/ coding for palliative care patients upon admission to hospitals thus ensuring that the appropriate type of episode of care is recorded on the inpatient databases.
- To improve statistical discharges and readmissions of patients (transfer from one specialty to another within a hospital) whose care becomes palliative, such that the care type is recorded as "Palliative" rather than "Acute" for the proportion of hospital stay that is palliative.

## 8. PHASE I: RECOMMENDATIONS FOR ORGANISATIONAL FRAMEWORK

The Palliative Care Network will be a sub-network of the Cancer and Palliative Care Network. The Palliative Care Advisory Group (PCAG) will become the executive group of the Palliative Care Network. The Palliative Care Network will have an appropriate clinical leadership structure to guide its coordination and development.

### **Recommendation 10: Membership**

The Palliative Care Network will include palliative care providers (metropolitan and rural, public and private, including nurses, General Practitioners, specialists, allied health, chaplains and volunteers), Non-Government Organisations (NGOs), Area Health Services (AHS), Department of Health (DOH), and consumer representatives.

### **Recommendation 11: Model of Service Provision**

The Palliative Care Network will endorse models of service provision for palliative services as outlined in the Clinical Services Framework Levels Definition and Palliative Care Australia Framework for service capability and role delineation (Appendices D and E).

### **Recommendation 12: Standards**

The Palliative Care Network will recommend a set of principles using the Palliative Care Australia Standards (2005) as a guide for the delivery of a range of palliative care services across the state including respite and outreach care.

### **Recommendation 13: Formal Links**

The Palliative Care Network will formalise links amongst palliative care providers to ensure that all Western Australians, regardless of their geographic location, have access to information, advice, expertise and services from specialist palliative care services. This linkage role would also include liaison amongst palliative care providers and NGOs and those caring for conditions other than cancer.

### **Recommendation 14: Protocols and Pathways**

The Palliative Care Network will initiate discussions with other Clinical Networks to develop palliative care pathways and protocols to guide the preparation and smooth transition of persons from the curative to palliative phase of their illness. The pathways and protocols will include adequate information and preparation of individuals and their family for this change, the types of support that are available through this stage such as respite care (in-home and residential), access to affordable drug therapy, furniture and equipment.



### **Recommendation 15: Education, Training and Workforce Planning**

- The Palliative Care Network will strengthen relationships between the palliative care providers, including shared education / management, joint clinical meetings for peer review and policy development, shared volunteer training and coordination.
- The Palliative Care Network will develop partnerships in palliative care education (e.g. universities, hospitals, Divisions of General Practice, Western Australian Centre for Remote and Rural Medicine (WACRRM) and the Cancer Council of Western Australia) to avoid duplication and to highlight deficiencies or gaps in education.
- The Palliative Care Network will recommend strategies and priorities for workforce planning to address the shortage of trained palliative care staff to AHS and other service providers.
- The Palliative Care Network will provide a leadership role or catalyst to facilitate education in skills for the care of people with malignant and non-malignant diseases.
- The Palliative Care Network will review education, training and clinical standards including respite issues.

### **Recommendation 16: Helplines**

There are currently three helplines operating in WA for advice and support on palliative care service provision: the first helpline is based at Silver Chain Hospice Care, the second one is based at Sir Charles Gairdner Hospital (SCGH) and the third one is the Residential Care Line, based also in SCGH, caters for staff in residential aged care facilities.

- The Palliative Care Network will examine the most appropriate mechanism for developing a single palliative care helpline for health professionals. This helpline would be widely promoted and available to nurses, doctors and residential aged care service providers.
- The Palliative Care Network will examine the extent to which HealthDirect has information on palliative care for the general public.

## **9. PHASE II: SPECIAL GROUPS NEEDING PALLIATIVE CARE**

### **Introduction**

Not all individuals require the same or consistent levels of care through the disease trajectories and the plan of care needs to be tailored to the needs of individuals and their families. For instance, a different skill set and modality of care will be required for paediatric patients; non-malignancy clients have differing needs in the early stages of disease progression to when they become increasingly dependent on airway and mobility support. Other palliative care clients have episodes of intensive short-term care requirements. By way of example, the first 24-hours of care are especially intensive as are often the end of life or terminal stage and bereavement phases of the palliative episode. Even the setting where palliative care is required impacts upon the service delivery; for example, people living in rural and remote areas have less access to specialist palliative care services than do metropolitan-dwelling people.

The following nine special groups have been targeted in the two rounds of the consultation process (Appendix A).

- Rural and Remote Communities
- People who Require Community-Based Services
- People who Require Medium to Long-Term Support
- People with Conditions Other than Cancer
- People from Indigenous Communities
- People from Culturally and Linguistically Diverse Backgrounds (CALD)
- Older People
- Children and their Families
- Carers & Consumers

## 9.1 Rural and Remote Communities

### Background

Poor access to specialist palliative care services was the probable reason for the findings that rural terminally ill patients were less likely to receive a palliative approach.[3,4] Those people who were Indigenous, female, older than 84 years, living in outer rural or remote areas and socially disadvantaged were the most at risk of all the individuals living in rural and remote areas.[4]

The following issues have been highlighted in consultations in rural and remote areas:

- Diseconomies of scale: funding needs to recognise the additional costs of rural and remote service provision and funding jurisdictions issues ie Commonwealth -Medicare, PBS, Capital Grants, Aged Care and State Department of Health services.
- Cost to families: rural areas do not have out-patient clinics. Therefore, financial and social welfare issues are more prevalent ie Medication costs, loss of earnings, self employment issues, accessing medications, health professional costs- GP, PBS, home aids, allied health. All these have been identified by rural palliative care clients as key issues.
- Occupational safety and training: OSH is a significant issue for rural home based and out of hours services due to distances and isolation, for example travel, vehicle failure, unreliable telephone access, to name a few.
- Counselling, professional support and debriefing support: Rural staff often care for the dying who are known and are a part of their community. Carers and clients should have access to professional services. Telemedicine may be an option.

A review of the Western Australian Country Health Services (WACHS) in 2003, acknowledged many difficulties that health care services face in rural and remote settings such as workforce shortages, lack of sustainable planning and at times, inflexible approaches to service delivery.[5] A framework for the delivery of country health services was developed, which focuses on a 'whole of community' approach via a regional network model. This approach recommends building upon existing health services such as Telehealth assisted technologies, workforce attraction and retention strategies and continued investment into health service infrastructure to develop a regional focus for health care service provision.[5]

The following rural and remote recommendations are made with regard to the Regional Network Model[5] for the provision of palliative care in country health services.

## *Recommendations for Rural and Remote Communities*

### **Recommendation 17: Linkages and Coordination**

The Palliative Care Network will identify mechanisms to support rural and remote palliative care providers using various strategies such as Telehealth assisted technologies, telephone hotlines and visiting specialists. This support will include clinical and professional support as well as counselling and debriefing support.

### **Recommendation 18: Regional Coordination**

It is recommended that the rural Area Health Services consider a coordinated approach to service delivery of palliative care including documented Service Level Agreements with NGOs and government organisations. Coordination would include:

- Workforce planning and development,
- Coordinating allied health services and respite services,
- Supporting and recruiting volunteers,
- Monitoring need for equipment and specialist services,
- Assessment and referrals for specialist service access, and
- Supporting residential aged care facilities (RACFs) to provide palliative care services.

### **Recommendation 19: Education & Standards**

The Palliative Care Network will evaluate the current level of service, workforce resources and standards of palliative care available in the regions with respect to the Palliative Care Australia (PCA, 2005) Standards and therapeutic guidelines.

### **Recommendation 20: GP Education**

The Palliative Care Network will facilitate palliative care education of General Practitioners by collaborating with the WA Divisions of General Practice, College of GPs and WACRRM.

### **Recommendation 21: Particular Rural Issues**

The Palliative Care Network recommends that Area Health Services consider rural issues in Service Level agreements and funding, when contracting palliative care services. These issues include: Diseconomies of scale; occupational safety and health because of rural isolation; and cost to families (eg equitable access to drugs, gap payments and home aids).

### **Recommendation 22: Promotion of Telehealth Assisted Services**

The Palliative Care Network will support the promotion of Telehealth assisted services and the development of such options that decrease the need for patients and palliative care consultants to travel long distances for appointments and consultations.

### **Recommendation 23: Patient Assisted Travel Scheme (PATS)**

The Palliative Care Network, in partnership with the rural Area Health Services, will negotiate amendments to the PATS Guidelines and Policy Documents that reflect the transport and accommodation needs of cancer and palliative patients and to ensure that the amendments are informed by the Palliative Care Australia (PCA, 2005) Standards.

## 9.2 People who require Community-Based Services

### Background

There is a growing recognition within the palliative care sector and in health planning that there is an emerging unmet need for palliative care services for groups within the community who have a progressive terminal disease other than cancer that have not accessed hospice services (i.e. end-stage respiratory, heart, renal and other diseases, non-malignancies in children, neuro-degenerative diagnoses).[4] There is an imperative that new models of care and population based solutions be developed to enable access for these people to quality palliative care. This plan needs to be flexible and individually tailored to meet patients and their families' needs.

The clear implication is that community services will be required to accommodate this increased service commitment and that resources (both material and human) will need to be reallocated into service provision. The need for an expanded and up-skilled palliative workforce is a natural consequence of accommodating this broader palliative care population.

Community-based palliative care services understand that:

- Keeping people at home is consistent with client choice
- Keeping people at home is more cost effective

### *Home alone issues*

Community and home-based palliative care services will be facing increasing challenges in service provision due to an ageing population, an increase in the number of people living alone who require care, a decrease in the availability of family caregivers and a preference to be cared for and die at home. This scoping study has explored the issues of palliative care patients living alone, from a client and service provider perspective, and has provided evidence-based information to assist with service planning for this growing population.[6] The study has also identified a set of recommendations (refer to Recommendation below).

### *General Practitioner issues (specific to community based services)*

Attracting General Practitioners (GPs) to participate in palliative care at the community level is dependent on goodwill and the particular GPs' alignment with the philosophy of palliative care. GPs in community palliative care provide care at no cost to the patient, because of the current Commonwealth funding arrangements. However, these funding arrangements do not include extra patient contact-related services, which GPs undertake in their own time, such as letter writing, telephone liaison and frequent travel to patients' homes. Unlike an in-patient setting, GPs are not supported to do some of this ancillary work by resident medical officers and other staff. Therefore, consideration should be given to supporting GPs working in community palliative care through adequate funding of their direct and indirect care for clients.

### *Recommendations for People Who Require Community-Based Services*

#### **Recommendation 24: Service Provision for those Living Alone**

The Palliative Care Network in partnership with community-based health services will support the palliative care needs of people who are living alone with no carer through appropriate services; for example, through the establishment of alert-link systems, palliative care packages (similar to community aged care packages), pool of volunteers and paid carers, an-after hours support service / night sitting service and financial packages for in-house respite.

### **Recommendation 25: Support for Community-Based GPs**

The Palliative Care Network in partnership with community-based health services will promote adequate funding of GPs' direct and indirect care (e.g., letter writing, telephone liaison, travel) for community-based palliative care patients to ensure that it is viable for GPs to undertake community palliative care.

## **9.3 People who require Medium to Long-Term Support**

### **Background**

A small, but significant number of people require palliative care for medium to long-term periods. Medium term palliative care is usually longer than six weeks but less than 16 weeks. Long-term care refers to those people who require palliative care for more than 16 weeks.

There are three main groups of people who require medium or long-term care. The first group are those who are older and frail with a primary diagnosis of a slow-growing cancer and in some instances, a secondary diagnosis of dementia. This group generally requires high-level care, which can be provided in-home or in residential care; hence, their care needs can be met.

The second group are mentally alert young people who have been diagnosed with a localised cancer. This group will often have high needs with a reasonable length of life. These people can be complex to work with in terms of their adjustment to their disease, longevity, physical needs, social needs and for some, angst at not being able to remain at home or in the hospice. Medium to long-term stay in a hospice is often not available for this person and residential care is inappropriate due to their age.

The third category consists of patients who have non-malignant diseases, such as Motor Neurone Disease. Many people with non-malignant diseases are young and have high physical needs and like the previous group they have complex care needs. Medium to long-term stay in a hospice is often not available for this person and residential care is inappropriate due to their age, and because of extreme pain, or pain control devices, which cannot be managed, in high level care.

### ***Recommendation for People Who Require Medium to Long-Term Support***

### **Recommendation 26: Linkage and Coordination**

The Palliative Care Network will provide a leadership role to ensure that all palliative care facilities are able to accommodate appropriately people with medium to long-term palliative care needs.

## **9.4 People with Conditions Other Than Cancer**

### **Background**

The terminal trajectory or decline of cancer is relatively consistent and documented; however, the last phases of disorders such as neurodegenerative disorders, congestive heart failure, liver disease, chronic obstructive pulmonary disease or failed organ transplant are difficult to track and predict.[7] This does create a dilemma for specialist palliative care services in determining admission priorities to support services and specialist facilities. Additionally, people with non-malignant diagnoses may not be included in specialist palliative services because discomforts might not be considered to be as significant as in cancer and because the prognosis is uncertain.[8] Some evidence exists to support these views; for example less than 10% of people who died of non-malignant conditions had access to specialist palliative care services, compared with 66% of people who died of malignant conditions.[4]

A recent Australian study examined the four main neurodegenerative diseases and found that most people requiring palliative care preferred to remain at home as long as possible, or to move into an appropriate residential care facility of their choosing.[9] If they do move into residential care, they want their carers to be adequately trained and knowledgeable regarding neurodegenerative diseases. The study also highlighted the need for a case manager to coordinate services for people with neurodegenerative diseases. The Motor Neurone Disease Association of WA (MNDAWA) supports this case management approach. However, currently the Association only has two part-time Care Advisors (38hrs/week) to handle a caseload of 120 members, when at any one time, a third to a half of members require active intervention and follow-up due to the rapidly progressive course of this disease.

### *Recommendations for People with Conditions Other Than Cancer*

#### **Recommendation 27: Service Provision**

The Palliative Care Network will work with existing organisations of conditions other than cancer to develop an appropriate model of care to meet the needs of people with non-malignant diseases.

#### **Recommendation 28: Motor Neurone Disease**

The Palliative Care Network will work with the Motor Neurone Disease Association of WA to develop a case management approach with Care Advisors intensively case managing people with MND and liaising with palliative care providers. Furthermore, both home visiting and inpatient hospice palliative care providers with the knowledge and skills to manage MND patients are required.


#### **Recommendation 29: Protocols and Pathways**

The Palliative Care Network will work with other clinical networks to develop pathways and protocols so that principles of a palliative approach can be offered to people with conditions other than cancer.

## **9.5 People from Indigenous Communities**

### **Background**

The Indigenous population of WA consists mainly of Aboriginal people; however, there are small numbers of Torres Strait Islanders.[10] Therefore, the terms 'Aboriginal' or 'Indigenous' when used in this document, refer to both Aboriginal and Torres Strait Islanders. Despite documents supporting that Indigenous Australians have the right to good health,[11,12] Indigenous Australians have significantly higher mortality rates compared with non-Indigenous Australians.[13,14] It is also common for Indigenous Australians to be diagnosed when they are already in the terminal stage, which has implications for palliative care provision.[14,15] Palliative care service statistics suggest very low rates of utilisation by Indigenous Australians.[13] However, usage rates increase slightly when the service is solely for Indigenous Australians, such as Indigenous residential aged care facilities.[13] Such low rates of service provision may be indicative of the cultural needs of Indigenous Australians, which differ significantly from any non-Indigenous Australian cultures. The development of culturally appropriate services will encourage and make accessible services that otherwise would not have been utilised by the Aboriginal population.[10]



Although Indigenous Australian culture is very diverse, there are some general concepts such as the notion of community and the centrality of land and familial obligations.[12,15] For example, many Indigenous Australians want to die in their own communities and will make care decisions that enable them to do this.[13] Additionally, some Indigenous Australians have a strong preference for care to include traditional healers.[16] Therefore, any models developed for Indigenous Australian palliative care need to be sufficiently flexible so that their choice to die in their country and their choice to involve traditional healers can be supported.[13] Such an approach also would require enhancing existing partnerships with primary health care providers, community health services, families and the communities.

A recently completed care needs study has identified Indigenous palliative care needs around several areas: socio-economic contexts, communication, traditional issues, access to palliative care services, planning and delivery of care, settings of care, workforce issues, information, and training and education.[13] The study suggests that Aboriginals are under-represented as clients in palliative care services although their mortality burden is actually higher than the non-Aboriginal population.

Various types of communications already exist that are able to reach Aboriginal communities such as Indigenous radio stations and other forms of media. The Office of Aboriginal Health (OAH) is also proactively developing health promotion messages to Indigenous people using a range of mediums. It would be appropriate to partner with these existing communication services to communicate with Indigenous people regarding palliative care.[10,17]

The contracting of Aboriginal Community-Controlled Health Services (ACCHS) to deliver palliative care should be considered. In many rural and remote areas, the ACCHS are the only service providers and as they operate on a very limited budget it would not be feasible for them to assume other responsibilities without access to more resources. Therefore, training is not the only requirement, but the resources to engage suitable staff to provide those services.[13]

Because there are existing documents that outline criteria for cultural respect regarding newly developed health service provision,[10,17] it would be prudent to consider these prior to the implementation of any of the following Indigenous recommendations.

### ***Recommendations for people from Indigenous communities***

#### **Recommendation 30: Linkages and Coordination**

The Palliative Care Network in consultation and partnership with Aboriginal Community Controlled Health Services (ACCHS), including the cultural and law centres, will facilitate forums / workshops with respect to linkages amongst palliative care, community care, and Indigenous-specific services for disseminating information on palliative care support services currently available in WA.

#### **Recommendation 31: Communication strategies**

The Palliative Care Network in partnership and consultation with ACCHS and the Office of Aboriginal Health will develop protocols and communication pathways to foster best practice models for the provision of palliative care to Indigenous Australians. These pathways will include appropriate strategies, such as the use of Indigenous radio and other forms of media, which will require the allocation of adequate resources to develop appropriate messages.

## **Recommendation 32: Pathways and Protocols**

The Palliative Care Network in partnership and consultation with ACCHS will initiate discussions with other Clinical Networks to develop palliative care pathways and protocols to guide the preparation and smooth transition of Indigenous persons from the curative to palliative phase of their illness.

## **Recommendation 33: Indigenous Liaison**

The Palliative Care Network in partnership and consultation with the Area Health Services and other relevant existing services in rural and regional centres will design a culturally appropriate model of palliative care for Indigenous Australians, which take into account existing State and National standards and principles for working with Indigenous Australians.

## **Recommendation 34: Partnerships**

The Palliative Care Network will facilitate partnerships between Area Health Services and ACCHS to provide training and support for palliative care services.

## **Recommendation 35: PATS**

The Palliative Care Network, in partnership with rural area health services, will review the policy of PATS for indigenous people so as to respond to particular cultural issues such as the need to be returned to their communities when they die from the place they were receiving treatment.

## **9.6 People from Culturally and Linguistically Diverse Backgrounds (CALD)**

### **Background**

In general, CALD patients and their carers experience additional layers of disadvantage [18]:

- Culturally and linguistically challenging environments,
- Lack of experience and knowledge of how the system works,
- Disruption to the family as a result of migration,
- Diminished support networks and lack of appropriate services.

People with limited proficiency in English face extreme difficulty in accessing information in comprehensive and understandable community languages. This results in restricted access to services for the person requiring care or carers themselves including respite. Recently, carer support kits became available in 13 community languages through the Commonwealth Carer Resource Centres. Each kit includes eight fact sheets on topics relating to caring, an emergency care kit and a card to list medications. Brochures about palliative care in Australia are available in 20 languages. The content provides a culturally sensitive explanation of palliative care, together with a brief description of services available [19]. However, the provision of written material does not address the problem entirely.

## **Recommendation 36:**

The Palliative Care Network works collaboratively with Palliative Care Western Australia to address the need for information and support for people from CALD regarding palliative care.



## 9.7 Older People

### Background

Older adults with support needs are cared for in three main settings, acute care (hospital and/or hospice), residential care, and within the community. In community settings, relatives and other unpaid caregivers usually provide care to older persons.[20] Several care services are available to support community care for older persons. These services can meet the needs of individuals with high or low care needs, and provide additional supports such as personal care or therapy.[21]

Although people generally prefer to die in their home, this is not always feasible, particularly for older persons with dementia and other comorbid disorders.[15] Therefore, residential aged care facilities fulfil the important role in the last months or years of many of Australia's aged population[15] with more than 80% of permanent residents remaining in such care until they die.[22] This care setting, along with hospices, has assumed greater responsibility for older persons who are dying. [23]

Meanwhile the residential care system is catering for an increasing proportion of high dependency residents. Over the past three years, the proportion of permanent residents categorised as 'high care' shifted from 58% to 63%-a significant rise for a relatively short period of time.'

Currently there is a Residential Care Line which is a helpline providing support and advice for staff in Residential Aged Care Facilities with coverage seven days a week. It is proposed that this helpline be extended to cover palliative care issues in these facilities.

The following recommendations are made against a backdrop of significant changes in the aged care environment, including changes to the aged care funding tool in 2006, increasing requirements to meet aged care accreditation standards related to palliative care, and increased programs to support the provision of palliative care in community settings.

### *Recommendations for Older People*

#### **Recommendation 37: Linkages and Coordination**

The Palliative Care Network will facilitate forums / workshops with respect to linkages amongst palliative care, community care, and aged care providers for disseminating information on palliative care support services currently available in WA.

#### **Recommendation 38: Education and Standards**

The Palliative Care Network will develop protocols and communication pathways to foster best practice models for the provision of palliative care to older persons, such as bereavement support models, advance care directives and standardised documentation templates.

## 9.8 Children and Their Families

### Background

There is an increasing recognition that the palliative care needs of children and their families require special consideration to ensure that an appropriate model and approach is available for all children with life-limiting or chronic illnesses and their families.[24,25] To date, there is no funded paediatric palliative care specialist service in the State.

In Western Australia (WA), approximately 450 children under the age of 15 years require palliative or supportive care at any time, the majority of these children require care for non-malignant chronic disabilities that involve sustained and complex care needs.[25] A recent study was undertaken to identify and consider the development of a palliative care service in WA for children and their families.[25] The authors' of the study suggested that any such model would need to be based upon the following key principles of care:[25]

- Care must be community based, linked and integrated with Princess Margaret Hospital in collaboration with community services such as Disability Services Commission, Silver Chain and Lady Lawley Cottage.
- Care must be coordinated by a dedicated multidisciplinary team in consultation with the children and their families.

Additionally, the model should be amenable to home-based care and requires flexible and responsive respite support, particularly for those children with non-malignant diseases.[25] A free-standing respite service was not considered the most appropriate; instead further development of existing services such as Lady Lawley were recommended. Appropriate infrastructure support was also suggested to ensure the provision of quality and effective palliative care and support for sick children, their families and health professionals.[25]

For larger regional areas close to Perth, it might be appropriate to develop outreach support with metropolitan specialist palliative care services including paediatric palliative care, when it becomes available through Princess Margaret Hospital (PMH). Members of the rural paediatric palliative care teams could spend time working with the PMH paediatric team in reciprocal arrangements to promote discussion and education in palliative care for children and their families.

For those areas where it is not geographically appropriate to develop an outreach support, there remains a need for metropolitan specialist palliative care services to provide support and education and training to nominated rural and remote palliative care providers via existing Telehealth assisted technologies.

The most effective model is a case management approach for all children with chronic or life-limiting illnesses to provide children and their families with a coordinated palliative care service, including the provision of timely information and access to requisite resources.[25]

### ***Recommendations for children and their families***

#### **Recommendation 39: Service Provision**

Paediatric palliative care will be community-based and coordinated by dedicated multidisciplinary teams in consultation with the children and their families.

#### **Recommendation 40: Coordination of Care**

The Palliative Care Network will facilitate identification of the most effective way to implement a case management approach for all children with chronic or life-limiting illnesses to provide children and their families with a coordinated palliative care service, including the provision of timely information and access to requisite resources.

#### **Recommendation 41: Access**

It is recommended that families are able to self-refer to palliative care services.

#### **Recommendation 42: Education and Standards**

The Palliative Care Network will develop protocols and communication pathways to foster best practice models for the provision of paediatric palliative care for all palliative care services (e.g., Silver Chain, hospices, respite facilities, hospital based personnel and rural and remote settings).

#### **Recommendation 43: Linkages between Services**

The Palliative Care Network will facilitate forums / workshops to ensure linkages amongst disability services, community-based palliative care, hospital-based palliative care, and other health care providers and families and to disseminate information on all paediatric palliative care support services that are currently available in WA.

#### **Recommendation 44: Respite**

The Palliative Care Network will recommend the development of suitable accommodation to enable respite for paediatric patients and their families. The existing respite care centre for children with special needs, eg Lady Lawley Cottage, could be extended to include a wing that specifically caters for children who are dying and their families.

## **9.9 Carers and Consumers**

### **Background**

Palliative Care Australia launched in 2003 a National Inquiry into the Social Impact of Caring for Terminally Ill People, in order to plan strategies to enhance support for informal carers for the terminally ill [26]. A comprehensive literature review and public submissions indicated that the role of supporting a dying relative has adversely affected the wellbeing of many family carers: physical, mental, emotional and economic aspects of life of carers. In general, carers reported unmet needs for information and communication, service provision and support from health and community services and community recognition. More specifically, carers reported a need to access adequate and flexible resources, fairer remuneration, more respite care, better training and equipment, counselling and bereavement support, personal and home help and improved access to the paid workforce. Evidence collected by the National Inquiry reinforced the importance of policy responses and resource allocations that are focused on helping carers perform a vital and important role into the future, particularly as carers are increasingly replacing skilled health workers in the delivery of unfamiliar complex care for the terminally ill.

At the local level, these unmet needs were reiterated in focus groups conducted in the South West with 26 consumer participants, mainly carers and volunteers, and the consumers' roundtable in Perth.

### ***Recommendations to support Carers and Consumers***

#### **Recommendation 45: Education and Training of Service Providers**

The Palliative Care Network will facilitate the education and training of service providers in assessing and meeting carer's needs for support services and increased awareness of services available at an earlier point in time.

## **Recommendation 46: Volunteer Support**

The Palliative Care Network will recommend a state or regional structure or model for volunteers to be regularly supported that incorporates ongoing education and training.

## **Recommendation 47: Support Services**

The Palliative Care Network will support improved access to respite services and psychosocial and bereavement support.

## **Recommendation 48: Partnerships**

Partnership between The Health Consumer Council and relevant peak bodies (for example The WA Cancer Council, the MND Association, PCWA) should facilitate the development of education packages on palliative care for consumers, which will be publicised and widely distributed to inform consumers of the range of palliative care services and how to access those services.

## 10. CONCLUSION

Overall there is support for the existing model of palliative care in Western Australia that is essentially community-based with multidisciplinary teams linking with hospices and acute care hospitals, the latter operating on a consultative model of care. Calls to address the shortage of inpatient palliative care in the northern and eastern corridors have been addressed in this report. The first phase of this report has specifically responded to questions about allocation of beds in the metropolitan area, and provided an analysis of current service activity/utilisation (Separations and Bed days), geographic distribution of need, trends in utilisation over the last 5 financial years and projection of service utilisation to 2015.

This review also presents a benchmark for all public and private palliative care services in terms of levels of service, role delineation, linkages and resource profile. This benchmark will define and formalise relationships between services for future workforce planning and providing the appropriate mix of service levels, to meet the different needs of palliative care patients in the future.

While acknowledging that many fundamental aspects of palliative care apply to all populations, settings, and types of service provision, the second phase of this report highlighted the different needs of nine special or minority groups. Other special groups not mentioned in this report include prisoners, refugees, detainees and the mentally-ill and it is recommended that their needs be addressed by the Palliative Care Network.

Therefore, this review provides the palliative care community with a quantitative and qualitative analysis of service provision within a consultative framework, which can be used to plan services that are appropriate to the needs of the population in WA. The proposed Palliative Care Network will play a lead role in implementing the recommendations, coordinating and planning for statewide services to address the palliative care needs for cancer and non-cancer related conditions.

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## APPENDICES

**Appendix A: Participants in consultation process**

**Appendix B: Projections based on average activity**

**Appendix C: Two maps on distribution of deaths in metropolitan areas**

**Appendix D: Feedback from Stakeholders on current and future level of service**

**Appendix E: Clinical Service Framework Level Definitions**

**Appendix F: Literature Review**

## Appendix A: Participants in consultation process

The qualitative data has been collected from rural and metropolitan key stakeholders in WA, public and private.

The first round of consultations consisted of 13 submissions, 20 interviews, 6 videoconferences, 1 teleconference and 3 group interviews, involving a total of 93 service providers in the consultation process.

Type of service	Submissions	Interviews		Special needs consultations
		Metropolitan	Rural & Remote	
Allied Health Professionals	1		2	
Community-based services		4	8	
Consumers		9		
Cultural and linguistically diverse backgrounds				1
General Hospitals		6	4	
Health services (other than PCU or Tertiary hospital)	6		22	
Hospices	2	4	2	
Indigenous				1
Palliative care unit			4	
Peak body	1	3	1	1
Residential aged care facility	1		1	4
Tertiary hospitals	2	3		
<b>Total</b>	<b>13</b>	<b>29</b>	<b>44</b>	<b>7</b>

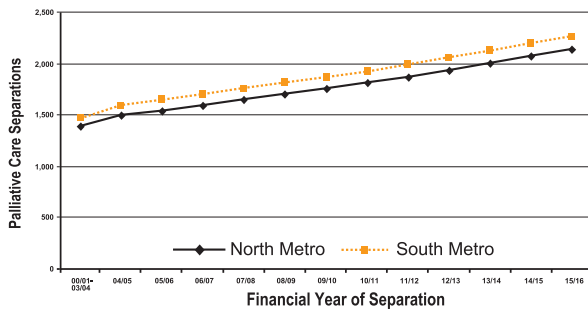
A second round of consultations was conducted with

- 21 stakeholders from the two rural area health services, WACHS and SWAHS
- Special groups' stakeholders: Aged care - 7; Community based - 8; Medium term - 7; Non-malignant conditions - 12; and Paediatrics - 12

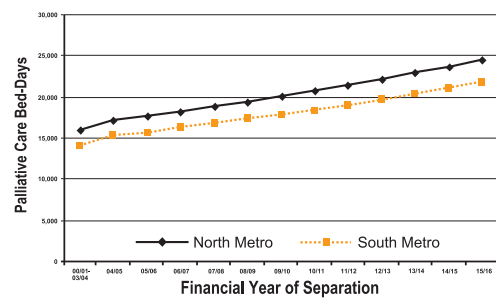


## Appendix B: Projections for North and South Metropolitan areas based on average activity

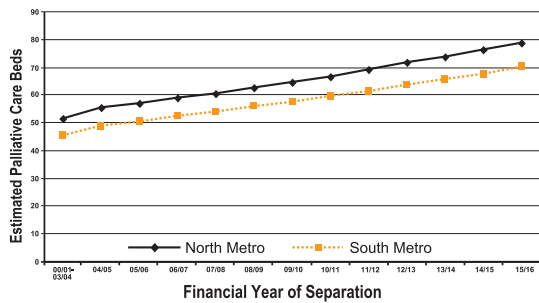
**WA Palliative Care Hospitalisations  
Separation Projection for North and South Metro  
Residents (2004/05-2015/16)**  
(Based on Average Rates for 2000/01-2003/04)



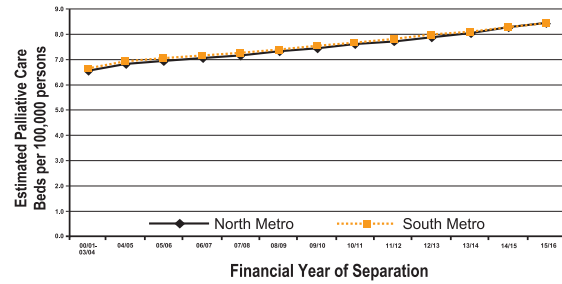
**WA Palliative Care Hospitalisations  
Bed-Day Projection for North and South Metro  
Residents (2004/05-2015/16)**  
(Based on Average Rates for 2000/01-2003/04)



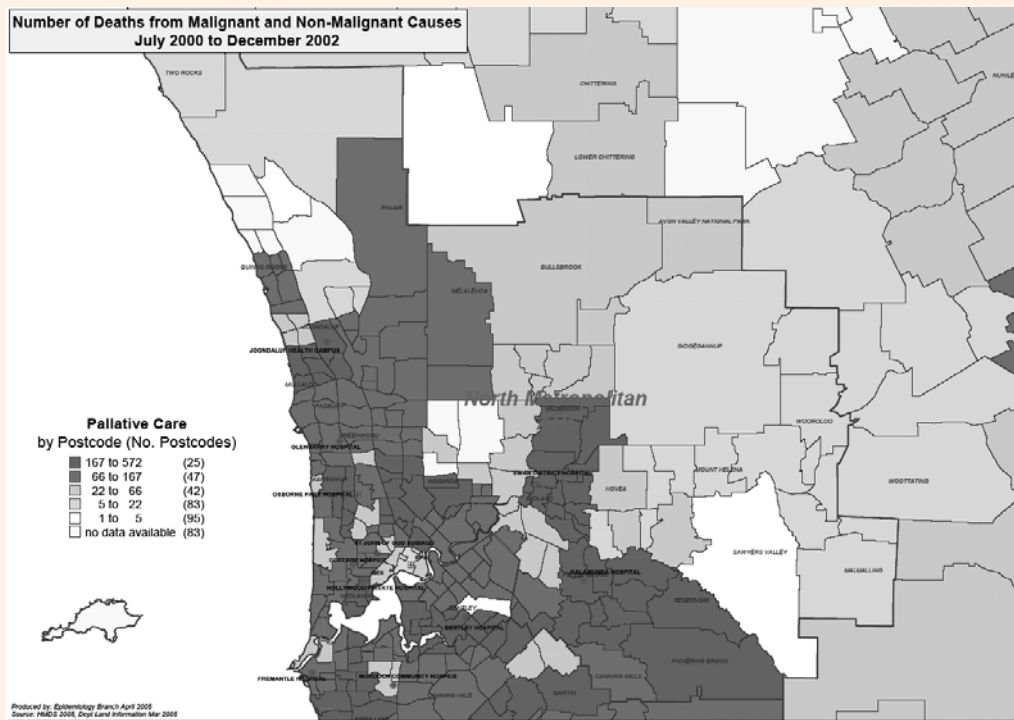
**WA Palliative Care Hospitalisations  
Estimated Bed Projection for North and South Metro  
Residents (2004/05-2015/16)**  
(Based on Average Rates for 2000/01-2003/04)



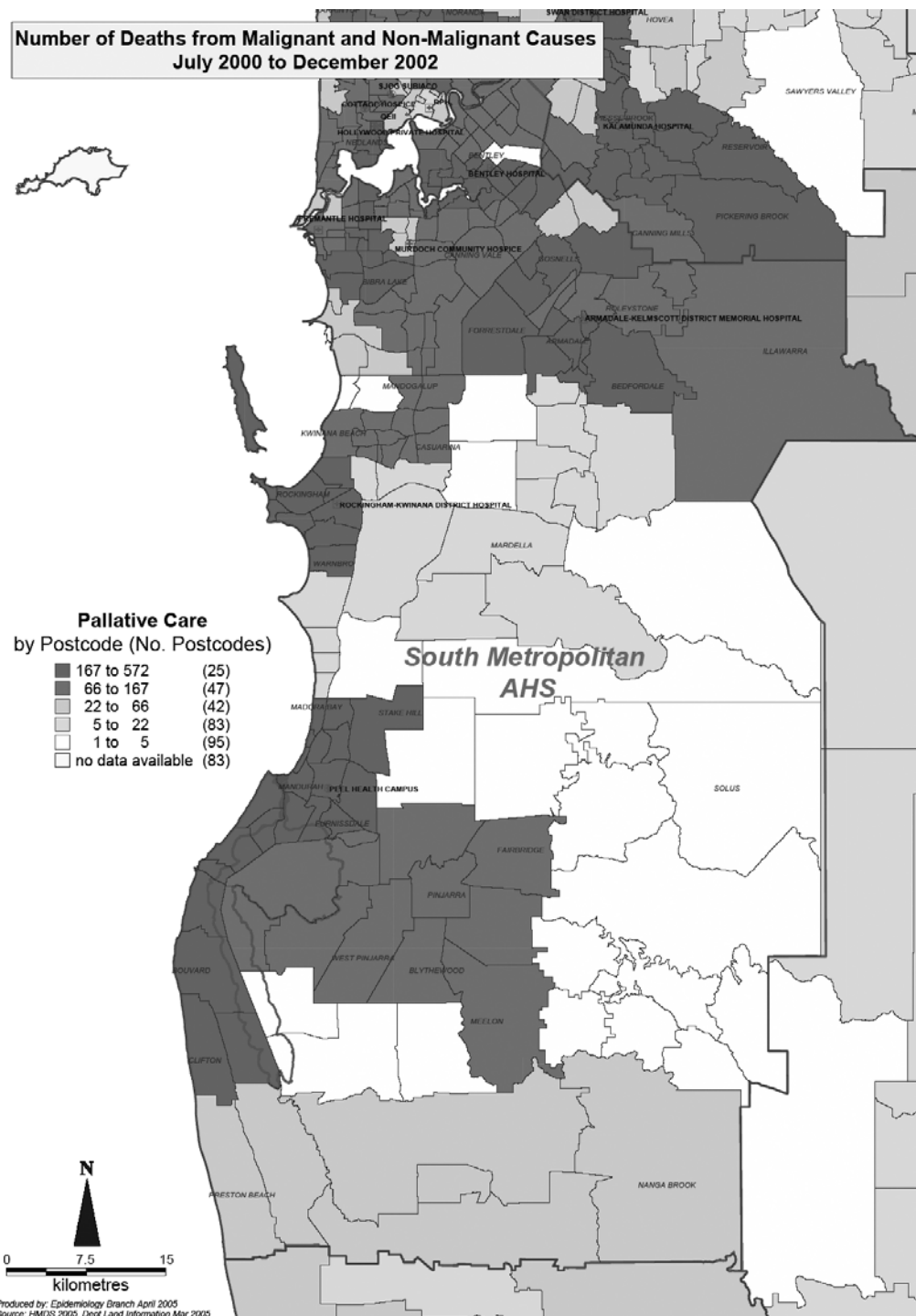
**WA Palliative Care Hospitalisations  
Projection of Bed per 100,000 for North and South  
Metro Residents (2004/05-2015/16)**  
(Based on Average Rates for 2000/01-2003/04)



## Appendix C: North Metropolitan Area Health Service - Numbers of deaths from malignant and non-malignant causes July to December 2002



## Appendix C: South Metropolitan Area Health Service - Numbers of deaths from malignant and non-malignant causes July to December 2002



Appendix D: Feedback from Stakeholders (public and private) on current and future level of service based on the PCA framework. The Clinical Services (CS) framework has 6 service levels for hospitals and is matched to PCA framework in the table below.

Level of service CURRENT	Level of service FUTURE	Capability / role delineation (PCA Framework)	Typical resource profile (PCA framework)
<p><b>Primary care</b> (CS levels 1&amp;2)</p> <p><i>Rockingham-Kwinana H</i></p> <p><i>Swan District</i></p> <p><i>Osborne Park</i></p> <p><i>Kalamunda</i></p> <p><i>Bentley</i></p>	<p><b>Primary care</b> (CS levels 1&amp;2)</p> <p><i>Osborne Park</i></p> <p><i>Kalamunda</i></p> <p><i>Bentley</i></p>	<p><b>Role</b> Clinical management and care coordination including assessment, triage, and referral using a palliative approach for patients with uncomplicated needs associated with a life limiting illness and/or end of life care.</p> <p><b>Linkage</b> Has formal links with a specialist palliative care provider for purposes of referral, consultation and access to specialist care as necessary.</p>	<p>General medical practitioner, nurse practitioner, registered nurse, generalist community nurse, aboriginal health worker, allied health staff.</p> <p>Specialist health care providers in other disciplines would be included at this level.</p>
<p><b>Specialist Palliative Care</b></p> <p><b>Level 1</b> (CS level 3)</p> <p><i>Joondalup H.</i></p> <p><i>Armadale H.</i></p> <p><i>Fremantle</i></p> <p><i>Peel Health Campus</i></p>	<p><b>Specialist Palliative Care</b></p> <p><b>Level 1</b> (CS level 3)</p>	<p><b>Role</b></p> <ol style="list-style-type: none"> <li>1. Provide palliative care for patients, primary carers and families whose needs exceed the capability of primary care providers.</li> <li>2. Provides assessment and care consistent with needs and</li> <li>3. Provides consultative support, information and advice to primary care providers.</li> </ol> <p><b>Linkage</b></p> <ol style="list-style-type: none"> <li>1. Has formal links to primary care providers and level 2 and/or level 3 specialist palliative care providers to meet the needs of patients, carers and families with complex problems.</li> <li>2. Has quality and audit program.</li> </ol>	<p>Multi - disciplinary team including medical practitioner with skills and experience in palliative care, clinical nurse specialist/consultant, allied health staff, pastoral care and volunteers. A designated staff member if available, coordinates a volunteer service.</p>

<p><b>Specialist Palliative Care</b></p> <p><b>Level 2</b> (CS level 4)</p> <p><i>Cottage Hospice</i></p> <p><i>Murdoch Community Hospice</i></p> <p><i>Hollywood</i></p> <p><i>Glengarry</i></p> <p><i>SJOG Subiaco</i></p> <p><i>Silver Chain</i></p> <p><i>PMH</i></p> <p><i>Peel Comm. Service</i></p>	<p><b>Specialist Palliative Care</b></p> <p><b>Level 2</b> (CS level 4)</p> <p><i>Cottage Hos.</i></p> <p><i>Murdoch Com Hospice</i></p> <p><i>Silver Chain</i></p> <p><i>Joondalup HC</i></p> <p><i>Peel HC</i></p> <p><i>Armadale</i></p> <p><i>Swan District</i></p> <p><i>Rockingham-Kwinana</i></p> <p><i>Peel Comm. Service</i></p>	<p><b>Role</b></p> <ol style="list-style-type: none"> <li>As for level 1, able to support higher resource level due to population base (eg regional area).</li> <li>Provides formal education programs to primary care and level 1 providers and the community.</li> </ol> <p><b>Linkage</b></p> <ol style="list-style-type: none"> <li>Has formal links with primary care providers and level 3 specialist palliative care services for patients, primary carers and families with complex needs.</li> </ol>	<p><b>Resource Profile</b></p> <p>Interdisciplinary team including medical practitioner and clinical nurse specialist/ consultant with specialist qualifications. Includes designated allied health and pastoral care staff.</p>
<p><b>Specialist Palliative Care</b></p> <p><b>Level 3</b> (CS levels 5&amp;6)</p> <p><i>SCGH</i></p> <p><i>RPH</i></p>	<p><b>Specialist Palliative Care</b></p> <p><b>Level 3</b> (CS levels 5&amp;6)</p> <p><i>Hollywood PCU</i></p> <p><i>SCGH/ RPH</i></p> <p><i>Fiona Stanley</i></p> <p><i>PMH</i></p> <p><i>SJOG Subiaco</i></p> <p><i>Glengarry</i></p>	<p><b>Role</b></p> <ol style="list-style-type: none"> <li>Provides comprehensive care for the needs of patients, primary carers and families with complex needs.</li> <li>Provides local support to primary care providers, regional level 1and/or level 2 services including education and formation of standards.</li> <li><i>Has a comprehensive research and teaching role.</i></li> </ol> <p><b>Linkage</b></p> <ol style="list-style-type: none"> <li>Has formal links with local primary care providers and with specialist palliative care providers level 1 and 2,</li> <li><i>and relevant academic units including professional chairs where available.</i></li> </ol>	<p>Interdisciplinary team including medical director and clinical nurse consultant/ nurse practitioner and allied health staff with specialist qualifications in palliative care.</p>

## Appendix E: Clinical Service Framework Level Definitions - Palliative Care Services

Level	Description
1	<ul style="list-style-type: none"> <li>Care is carried out by GPs (potentially visit) with or without the assistance of RNs depending on the type of patient care needed.</li> </ul>
2	<ul style="list-style-type: none"> <li>Management by GPs and generalist nurses</li> <li>24 hour coverage</li> <li>Linkage with community based services provided by Silver Chain Nursing Association</li> </ul>
3	<ul style="list-style-type: none"> <li>Inpatient care by accredited GP or specialist physician.</li> <li>24 hour cover clinical nurse with experience in palliative care services.</li> <li>Outpatient care by visiting general physician and possibly palliative care specialist</li> <li>Linkage with community based services provided by Silver Chain Nursing Association.</li> </ul>
4	<ul style="list-style-type: none"> <li>Palliative care inpatient beds managed medical practitioner specialising in palliative care</li> <li>Access to specialist SRN</li> <li>Seamless linkage to Silver Chain Nursing Association who provide community based palliative care</li> <li>Undergraduate and postgraduate teaching role</li> </ul>
5	<ul style="list-style-type: none"> <li>Inpatient care by resident palliative care physician</li> <li>Registrar/RMO</li> <li>Regional referral role</li> <li>Access to specialist SRN</li> <li>Undergraduate teaching and some research role</li> <li>Integrated community/ hospice consultative service under direction of palliative care physician</li> <li>Links with oncology, radiotherapy, anaesthetics, psychiatry, pain clinic and rehabilitation</li> </ul>
6	<ul style="list-style-type: none"> <li>Full range of palliative care services with palliative care specialist providing consultancy to other units referral hospitals</li> <li>Emergency services available</li> <li>State wide referral role</li> <li>Undergraduate and postgraduate teaching role</li> <li>Has staff with conjoint appointment with hospice</li> <li>Access to specialist SRN</li> </ul>

Source: Clinical Services Consultation report, 2005

## Appendix F: LITERATURE REVIEW

### Abstract

The literature review of palliative care service provision indicates that there are various models of care operating throughout Australia and overseas, which are practiced in a range of settings such as hospitals, stand-alone inpatient units, hospices, residential institutions, and in the home and community. It appears that the various models of palliative care have developed, in part, as a consequence of the setting of care. Models also reflect the use of available resources within those settings.

Many of these models are based upon expert opinion rather than being evidence based; consequently, there are considerable variations in fundamental determinants to service provision such as minimum bed numbers per palliative care units and per populations. Despite these differences, there are similar areas of concern, such as meeting the needs of children, older persons and those with non-malignant disorders such as neurological disorders. Recent reviews have been conducted within Australia looking at these groups and suggestions for improvements have been made to ensure that there is equitable access to palliative care services within Australia.

In general, the most appropriate model was a four level integrated approach of primary, secondary, tertiary, and specialist care, with each increasing level reflecting the patients more complex needs (e.g. symptom management, psychosocial needs). This integrated approach to palliative care service provision was based on the premise that all levels of service should have formalised links and networks and/or partnerships with service providers from each of the four service levels.

The purpose of this report is to provide an overview of the issues surrounding palliative care. This review examines recent reports that address these issues in palliative care settings, both in Australia and overseas.

### AUSTRALIAN MODELS OF PALLIATIVE CARE

Although different models of palliative care have developed throughout Australia, all are described as palliative care services. It is possible that, due to a range of resources, activities, and interpretations within these various models, the practice of palliative care therefore, is not consistent. However, because palliative care is considered an essential component of health care provision, it should be easily accessed when required and a minimum standard of care should be provided irrespective of where the service is located (Palliative Care Australia, 2003).

In general, palliative care services in most states and territories have palliative care beds in a small number of metropolitan hospitals and a network of palliative care coordinators and community-based services. These services usually operate as part of the State or Territory Government's regional health delivery structure. Additionally, in most metropolitan centres there are separate palliative care units within hospitals or hospices, which are often run by private service providers.

The community-based services either include, or coordinate access to, services to deliver palliative care in the home; services such as palliative care nurses, social workers, bereavement / grief counsellors and home help. Some regional hospitals also have limited palliative care beds, usually in surgical or acute wards.

### Palliative Care Australia’s model of palliative care

Palliative Care Australia (2005) recently released a *Guide to Palliative Care Service Development: a population based approach*, which includes a collaborative integrated model based upon needs of the patient, primary carer and family needs. The primary care provider works with a designated specialist palliative care service, and makes referrals based upon the level of need. The model appears to be an appropriate model that is responsive to the Australian context in which palliative care service provision is required.

Palliative Care Australia (2005) suggests that there should be three levels of specialist palliative care services in addition to primary care providers as follows:

Resource Level	Description	Appropriate setting
1	Has formal links with level 2 and level 3 services and shares responsibility for a designated subpopulation of Level 2 services.	This service level is appropriate for metropolitan regions and small towns.
2	Has formal links with level 2 and level 3 services and shares responsibility for a designated subpopulation of Level 2 services.	This service level is appropriate for metropolitan and regional centres.
3	Has formal links with level 2 services and responsibility for a designated population.	This service level is appropriate for metropolitan and large regional centres.

Palliative Care Australia has also determined appropriate standards for palliative care (Palliative Care Australia, 2004b) and has established national benchmarks (Palliative Care Australia, 2003) for staffing levels and beds within community-based, acute hospital, and palliative care designated beds per 100,000 population. These standards and planning guidelines are based on the premise that palliative care service provision requires an interdisciplinary team framework.

### Victorian model of palliative care

The Victorian Government Department of Human Services (2004) model of palliative care is an integrated service system. Regional consortia of specialist palliative care providers have been established to facilitate the integration of care to persons requiring a palliative approach and their carers and families.

The consortia is responsible for developing regional plans for how palliative care services are delivered across their regions to strengthen relationships between palliative care providers and to improve care for patients.



Across a region, the consortia will develop formal links between hospitals and health services to ensure all health services have access to a full range of palliative care services to meet the needs of the person requiring palliative care and their family and carers.

The different levels of palliative care services are as follows:

Level	Description	Requisites
1	These services include smaller community hospitals accessing specialist community-based palliative care services as required. Level one services might have designated palliative care beds.	At a minimum specialist palliative care requires a palliative care nurse with access to a palliative care physician or a sufficiently trained medical practitioner who has formal links with a palliative care physician. The staff must have access to grief and bereavement services.
2	This service requires onsite specialist palliative care that includes a palliative care physician or sufficiently skilled medical practitioner who has formal links with a palliative care physician and a palliative care trained nurse. This service is available for consultation Monday to Friday in normal business hours.	Access to staff experienced in providing grief and bereavement services is all essential.
3	Designated palliative care beds are available and where possible, meet the minimum standards required for a hospice setting. For example, metropolitan and regional hospitals with large dedicated palliative care inpatient units where staff are employed onsite and are available 24 hours, 7 days per week.	A palliative care team is required that includes a palliative care physician or sufficiently skilled medical practitioner who has formal links with a palliative care physician, palliative care trained nurse, and staff experienced in providing grief and bereavement services. This level of service directly accepts patients from community-based specialist palliative care providers. A 24 hour secondary consultation service is also provided.

**Tasmanian model of palliative care**

The Tasmanian proposed model is based on an integrated palliative care service delivery, which is determined by the needs of the patient. Specialist palliative care will be provided when the patient has multiple or complex needs due to a life-limiting illness whether malignant or non-malignant. Patients will be provided with multidisciplinary assessments, consultations, and/or management of physical, psychosocial, cultural, Indigenous, and/or spiritual symptoms. Grief and bereavement services will be available to the individual and his/her family during the course of illness and post-death. Specialist services will also be responsible for the education of and professional development of primary and secondary care providers.

A summary of the model is as follows:

Level	Service delivery	Specialist palliative care role
1	Primary Palliative Care	Training and professional development of primary and secondary care providers
2	Consultation-Liaison	Consultation and advice for primary and secondary care providers
3	Shared Care	Shared care with other with other primary and secondary care providers
4	Direct Care	Direct care including community and inpatient by the specialist service

The level of care required is determined by an initial assessment of the patient and it is anticipated that patients will move between the four levels at varying times during the trajectory of their illness.

## Northern Territory model of palliative care

The Northern Territory (NT) strategy for palliative care is an integrated model of palliative care service provision that is shared by family/partners, health services and community organisations (Northern Territory Government Department of Health and Human Services, 2004). The model is based upon the Tasmanian model of palliative care (Eager, Gordon, Quinsey, & Fildes, 2004) and Palliative Care Australia's (2004a) draft policy *Meeting the Needs of People who are Dying Through Population Based Service Planning*. The model requires that primary care providers are supported and educated to provide palliative care to their patients. Formalised partnerships and role delineation between primary and secondary care givers are required to ensure that service provision is integrated.

The integrated palliative care service model considers that the patient, their family and carers are the core focus of care. Additionally the model incorporates culturally appropriate palliative care practices for Indigenous persons that are based upon the *Indigenous Palliative Care Service Delivery: A Living Model* (McGrath, Watson, Derschow, Murphy, & Rayner, 2004).

The integrated service delivery model is as follows:

Level	Service delivery	Specialist palliative care role
1	Primary Care	Training and professional development of primary care providers
2	Consultation Liaison	Consultation and advice for primary care providers
3	Episodic Input	Episodic input with other primary care providers
4	Ongoing Input	Ongoing input including community and inpatient by the specialist service

# INTERNATIONAL MODELS OF PALLIATIVE CARE

## Canadian model of palliative care

In 2002, Canada, 75% of deaths occur in hospitals (including hospices) and long-term care facilities with the remaining 25% occurring at home.

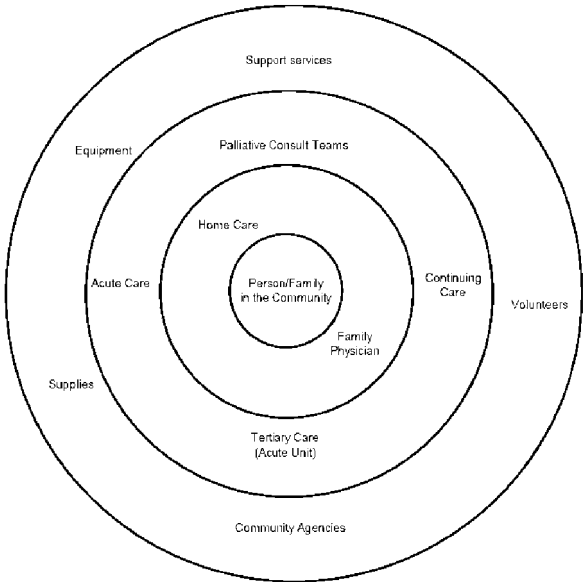
The Canadian Hospice Palliative Care Association (CHPCA) (Ferris et al., 2002) developed a consensus-based model of palliative care to provide a standardised approach to palliative care service provision in 2002. This model advocated the use of norms of practice rather than standards of practice because norms were considered to be less specific or rigid providing a higher level of practice to which organisations could aspire.

The model is a 'seamless' or integrated service of palliative care provision. The needs of the patient and his/her family determine the level of palliative care required and thus the site of care. Acute and tertiary level services are available when needed, allowing persons to choose settings such as home and palliative hospice when stable. The model focuses on the ability to provide options for site of care other than acute care.

A person who requires palliative care services can be identified in any setting and referred through a single access number. The model involves several service levels, primary, acute, and tertiary and incorporates the differing needs of regional areas and metropolitan locales (see the following diagram for a visual representation of the model).

The model focuses on the family physician and palliative home care providing the majority of palliative care. If the person is unable or unwilling to remain at home, but does not require acute care services, the family physician can refer to a palliative care consultant, a community liaison nurse or palliative consultation team (at the Cross Cancer Institute) for assessment for palliative hospice care. If a person requires acute care services for acute palliative needs or diagnostic work that cannot be completed on an outpatient bases, any hospital can admit and request a palliative care consultation for symptom assessment and management. The consultant works with the discharge site to ensure that all necessary information is shared.

REGIONAL PALLIATIVE CARE MODEL



In regional areas, the Palliative Care Program Council was established in 2001 with the key areas of responsibility being quality improvement, utilisation management, health technology assessment, service delivery planning, research and education, and physician workforce planning.

Regional palliative care program offices (RPCO) have been established, which are generally located at community hospitals. These offices:

- Coordinate the delivery of care in the region
- Provide consult teams (physicians/nurses) to assist primary caregivers in providing care to palliative persons and families at home, in continuing care, community hospitals and other health care institutions in the region.
- Identify and advocate for funding needs
- Provide education in palliative care for professionals and the public.
- Coordinate research with the Divisions of Palliative Care Medicine.
- Provide education and support for palliative care volunteers.
- Identify, coordinate and encourage development of bereavement services.
- Identify and plan for the future direction of palliative programs

A request for admission to the tertiary palliative care unit (TPCU) for management of severe symptoms can originate from any care setting. The TPCU primary aim is to treat persons with the most complex palliative physical and psychosocial issues. The average length of stay for 2001 to 2002 was 23 days. A palliative care consultant will assess the person and refer to the unit if symptoms cannot be managed at the present setting. If the person is in another region, the tertiary unit will work directly with the attending physician and nursing staff to assess and arrange admission.

The palliative care consultants utilise a single assessment form and common symptom assessment tools to ensure that the most appropriate care setting is chosen. They travel throughout regional areas to see patients referred by any setting. The consultants are on call to provide support to the primary caregivers 24 hours, 7 days per week. Consultants have access to an emergency drug box, which can be sent to a home if required.

Grief and bereavement support is available on an ongoing basis for persons and their families and for the staff who provide care.

Currently Canada does not have national indicators to measure palliative care service provision.

### **United States of America (USA) Model of Palliative Care**

In 2003, more than 25% of academic medical centres and 950 hospitals (20% of US total) indicated that they provided access to a palliative care program, including hospices. Nearly a third of the USA's hospices are hospital-based, and many hospital, nursing home and home-care agency palliative care programs have been initiated and supported by hospice professionals.

The locations of death in 2003 for US individuals were home (25%), nursing home (25%), hospital or hospice (50%). For those individuals who died in a hospice, 50% had non-cancer diagnoses. Due to regulatory and insurance restrictions to palliative care, a smaller proportion of paediatric deaths (10%) are cared for in a hospice. Recently, however, paediatric hospice programs have grown, particularly for larger hospices, in response to community demand.

The USA considers that the model of palliative care (for end-of-life care) is best met by the provision of hospice care. For those requiring comprehensive services at an earlier period in life, a range of emerging palliative care programs are situated in acute hospital, hospice, home care, nursing home and community settings. Common organizational delivery models for palliative care programs inclusive of hospice programs include:

- Consultation service team (usually in a hospital, office practice setting, nursing home or home setting), consisting of physician, nurse and/or social work evaluations.
- Dedicated inpatient unit (acute and rehabilitation hospital, nursing home) or combined with freestanding inpatient hospice.
- Combined consultative service team and inpatient unit (hospital and nursing home).
- Combined hospice program and palliative care program (hospital, nursing home and some freestanding hospice inpatient facilities).
- Hospital- or private practice-based outpatient palliative care practice or clinic.
- Hospice-based palliative care at home.
- Hospice-based consultation in outpatient settings.

**United Kingdom (UK) Model of Palliative Care**

The United Kingdom (UK) model of palliative care (Doyle, 1998) is based upon the notion that palliative care follows the patient. As any patient moves between home, hospital, and specialist palliative care unit he/she always has access to specialist palliative care. All that is required is for the general practitioner or hospital physician/surgeon to call in the specialist in palliative care, whether that is a nurse or a doctor.

Ordinary professional carers	Places of care for patients in need of palliative care	Specialists in palliative care
General practitioners Community nurses Nursing home nurses Community physiotherapists Community occupational therapists Social workers Clergy	Home, day hospice, nursing home	Specialist nurses Palliative 'home care team' staff Physiotherapists in palliative care Occupational therapists in palliative care Others
Consultants      Social workers Junior doctors    Chaplains Nurses              Others Therapists	Hospital	Specialist palliative care physicians Specialist palliative care team OR consultancy from hospice OR palliative care unit
	Hospital palliative care unit, Hospice/specialist palliative care unit	Palliative care specialists of all disciplines

The principle of the above model is that palliative care follows the patient. When the person resides at home the primary care providers are the ordinary day-to-day professional carers such as the general practitioner, community nurses, and therapists. The patient may move between his/her home, a nursing home, and a day centre, but the primary care providers are always the same. These providers can be assisted if required by the specialists in the right column. If the patient is admitted to hospital, the staff there also have palliative care specialists to help and advise them. If admission to a specialist palliative care service unit is required, even if the patient leaves to return to hospital, home, or nursing home, palliative care specialists are on hand.

### **IMPORTANT ASPECTS OF PALLIATIVE CARE SERVICE PROVISION IN AUSTRALIA**

In general, the most appropriate palliative care model was a four-level integrated approach of primary, secondary, tertiary, and specialist care, with each increasing level reflecting the patients more complex symptom management needs. This integrated approach to palliative care service provision was based on the premise that all levels of service should have formalised links and networks and/or partnerships with service providers from each of the four service levels.

Particular consideration of each model's applicability to Indigenous populations and service provision for rural and remote locations was also undertaken. Of the models that incorporated an integrated multi-level approach to palliative care, the Canadian model was deemed to be the most appropriate for, and most transferable to, the Australian context. The type and level of palliative care required, and thus the site of care is determined by the needs of the patient and his/her. The model involves several service levels, primary, acute, and tertiary and incorporates the differing needs of regional areas and metropolitan locales. A person who requires palliative care services can be identified in any setting and referred through a single access number.

### **Summary of models of care**

Palliative care is practiced in a range of settings such as hospitals, stand-alone inpatient units, hospices, residential institutions, and in the home and community. It appears that the various models of palliative care have developed, in part, as a consequence of the setting of care. Models also reflect the use of available resources within those settings. For example, a social worker may not be part of a palliative care team, but is likely to be included in a hospital-based team having been seconded from the general staff of the larger facility. If resources allow, a social worker may be part of an interdisciplinary palliative care team in a stand-alone facility and work solely within that unit. It is likely that not only will the composition of palliative care teams differ according to the setting, but also many other factors will vary according to resources and needs of the particular service.

Although models of care may vary throughout Australia and overseas, a review of recent reports indicates that there are many similar issues that need further consideration to ensure that palliative care is accessible to all persons, such as minimum bed numbers, involvement of General Practitioners, and special needs groups (e.g. children, older persons). Each of these issues is discussed below.

## Minimum bed numbers

Many palliative care reports stated that there were a minimum number of beds that were required to provide a cost-effective palliative care service. For example, Wales considered that the minimum number was eight, whereas Australia, England, and the USA considered ten beds to be the minimum. These differences are likely to exist because none of the estimations have been evidence-based.

The number of beds per population was also discussed in many reports, again with varying results. For example, New Zealand used the UK benchmark of 5.1 palliative care beds per 100,000 population, whereas Australian palliative care services used Palliative Care Australia's (2005) benchmark of 6.7 per 100,000 population. A review of seven European countries palliative care beds to population in 2000 also found that the number of beds per population varied considerably (Clark, ten Have, & Janssens, 2000, p. 484):

Country	Beds	Ration of beds to population
United Kingdom	3196	1 : 17 866
Belgium	358	1 : 28 212
Sweden	298	1 : 29 530
Spain	812	1 : 49 261
Germany	989	1 : 82 812
Netherlands	119	1 : 131 092
Italy	30	1 : 1 913 333

The discrepancy in the number of beds per population is likely due to the way in which palliative care services developed in each country. For example, the Netherlands and Italy have the lowest numbers of beds per population and both did not commence specialist palliative care services until the early to mid 1990s, which meant that these two countries were ten to thirty years behind the other countries that were reviewed.

Requisite minimum bed numbers are not the only accommodation issue that palliative care services need to address; long-term and medium-term patients who require palliative care are a group of patients for whom it can be rather difficult to place in appropriate care settings.

## Long-term and medium-term patients

A retrospective study of the needs of WA medium-term patients was conducted during July 1, 1999 to June 30, 2000. Medium term patients were considered to be those with a predicted life expectancy of one to three months, whereas long-term patients had a predicted life expectancy of greater than three months (Bridge, 2001). Whether medium or long term, this group of terminally ill patients require prolonged episodes of care, which results in problems specific to this group such as providing appropriate palliative care when most services of this nature cater for short term patients.

The total number of deaths from all causes that were reported during the data collection period by the three tertiary hospitals for adults was 2,308, of whom 54 patients had a length of stay of greater than 60 days. Almost 1,000 inpatients were referred to palliative care services within these hospitals. Of these, 179 patients were transferred to a hospice, 546 went home (private residence), and 246 died in hospital.

Also during the study period, 120 inpatients of the three hospices were reviewed by an Aged Care Assessment Team after an average interval of 21 days, and 4 had been assessed at home. Eighty-eight were assessed for a nursing home, hostel or community package (73, 12, 3 respectively). Fifty-seven assessed patients were eventually discharged to these destinations, including 35 to a nursing home and 11 to a hostel. These “longer stay” hospice admissions occupied approximately 5,500 bed days, which is equivalent to 28% of the 68 dedicated hospice beds at 80% occupancy.

The hospices had an informal policy of accepting short-term patients for a notional 14-day length of stay. This impression was strengthened by the Health Department of Western Australia (HDWA) guidelines, which directed hospices to aim for an average length of stay of 10 - 14 days. This guideline contradicted patients and families expectations, which was that care would be provided for an indefinite period of time in a hospice (however, this same expectation did not apply if the patient was receiving palliative care in a hospital). The author concluded that these expectations create resistance to transfer from a hospice to another care facility such as a nursing home.

The researchers concluded that palliative care patients with a prolonged course utilise a large portion of both hospital and hospice resources. Of all patients who died in an adult tertiary hospital only around 10% had been referred to a palliative care team. It was recommended that options to improve access to appropriate facilities for longer-term palliative care patients be developed.

Long and medium term patients are not the only group for whom there are specific issues relating to the provision of palliative care. Other groups that are difficult to service include children or older persons, and people from Indigenous backgrounds. Even the type of disorder (e.g. neurological disorders) that a person has potentially impacts upon the adequacy, availability and appropriateness of the services that they might or might not receive.

### Children


A recent report (Australian Government Department of Health & Ageing, 2004b) reviewed models of paediatric palliative care across different life-limiting illnesses, families and communities, taking into account cultural and geographical differences. Although accurate data for the number of children and adolescents who require palliative care is currently unavailable in Australia, it is estimated that in comparative countries such as the UK, there are approximately 20,000 children who have a terminal illness, most of whom will require palliative care at some time in their disease trajectory.

The aim of the report was to provide an evidence-based best practice framework to meet the needs of children, families and communities by integrating a palliative approach to care. However, no single model was appropriate for paediatric palliative care model; therefore, a highly flexible model was determined that considered availability of existing resources and programs, avoided duplicating services, and built on what was currently available.

At the centre of this flexible model were the needs of the child, family and the community. The care can be delivered at any setting and the key elements of the program are tailored to meet the needs of the child and family, with packages of care being added or removed according to changes in the child’s condition.

Due to a lack of best practice, evidence based guidelines could not be determined. Despite this limitation, the authors of the report made the following suggestions for improvements:



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1. A national paediatric palliative care reference group be formed.
  2. National clinical practice guidelines and protocol that meets the needs of children and families be developed for palliative, end-of-life and bereavement care.
  3. Information programs and other resources that will help families and clinicians to support an integrated family-centred model of paediatric palliative care should be developed.
  4. A national paediatric palliative care database should be developed.
  5. Specific funding for paediatric palliative care should be provided at state and federal levels.
  6. Funding support for national research priorities such as protocols for bereavement support should be provided.
  7. Resources to educate and train staff involved in providing paediatric palliative care in community-based agencies to achieve an integrated services model are required.
  8. Service improvements should be evaluated by developing a national standard for measuring performance in accordance with evidence-based best practice.

### **Aged care**

A project was undertaken with the aim of providing evidence based guidelines for best palliative care practice relating to residential aged care facilities, which included consideration of psychosocial, cultural, Indigenous, spiritual and physical issues (Australian Government Department of Health & Ageing, 2004a). Despite a lack of empirical evidence relating to palliative aged care, eighty-three guidelines were determined, which were based on the following assumptions that a palliative approach:

- is appropriate for the care of older persons who are dying from a terminal illness or due to the process of ageing
- should be provided in a resident's familiar surroundings
- requires a multidisciplinary approach to care
- enhances the dignity and quality of life of residents
- requires the completion of an advance care plan to ensure the resident and his / her families preferences for care are documented
- requires the careful assessment and management of the resident's physical, psychological, social, cultural, Indigenous, and spiritual support needs
- is enhanced when appropriately screened and matched volunteers act as a companion and confidant to the resident and his / her family

The following suggestions for improvement were also made:

- A palliative approach should be available to residents in the settings of their own choice such as nursing homes.
- Aged care team members require appropriate training and education to enhance their provision of a palliative approach in residential aged care.

### **Indigenous Australians**

A study was recently conducted that reviewed Indigenous specific services or initiatives in palliative care in Australia and identified the needs of Aboriginal and Torres Strait Islander people requiring palliative care and their families (Sullivan et al., 2003). The aim of the study was to provide a culturally appropriate and accessible approach to palliative care services, irrespective of the location in which Aboriginal and Torres Strait Islander peoples resided. Despite some limitations to the study (e.g., poor response rates and of those received few had Indigenous clients), the project team suggested the following improvements:

- Continued promotion of the issues involved in palliative care for Aboriginal and Torres Strait Islander clients, especially among both mainstream palliative care providers and Aboriginal and Torres Strait Islander health providers.
- The need for Aboriginal and Torres Strait Islander people to be able to access culturally appropriate health services is a fundamental issue that service providers and policy makers must act upon.
- Mainstream service providers should not assume that Aboriginal people will, or will not, be able to access palliative care services through an Indigenous health service and must make sure that their own services are appropriate and accessible, and / or that they are working in partnership with Indigenous organisations to deliver the best possible care.

### **Non-malignant conditions**


The need to provide palliative care for people with non-malignancies is increasingly being recognised. (Kristjanson, White, & Wollin, 2004) The sub-heading of 'non-malignancies' incorporates many different diseases such as neurodegenerative disease, renal failure, chronic heart failure. To assist in reviewing the literature regarding non-malignant conditions, this section discusses neurodegenerative diseases separately from other non-malignant conditions.

### **Neurodegenerative Diseases**

A recent study provided the first empirical evidence on the needs and service use of those people with neurological disorders such as MND (Kristjanson et al., 2004). This study highlighted the need for improved coordination of care between service providers such as medical specialists, GPs, associations and organisations affiliated with these diseases, health services, and home care agencies. Nurse specialists and case managers were reported to be effective in coordinating service provision. The findings also highlighted the need for a partnership between the organisations involved with service provision (both government and volunteer) for the effective planning, delivery and monitoring of supportive and palliative care.

Palliative care for people with Motor Neurone Disease (MND) is now provided in current policy initiatives, but not for other neurodegenerative conditions such as Multiple Sclerosis (MS), Parkinson's Disease (PD), and Huntington's Disease (HD).

Motor Neurone Disease (MND), Multiple Sclerosis (MS), Huntington's Disease (HD) and Parkinson's Disease (PD) are progressive neurodegenerative diseases that primarily occur in adulthood. The diseases are incurable. MND leads to progressive muscle weakness and wasting, spasticity and speech and swallowing problems. It tends to have a rapid, unremitting and fatal trajectory. The incidence of MND is approximately 1.8 per 100,000 per year. MS causes profound disability associated with fatigue, muscle weakness, and balance and coordination problems during a variable illness trajectory. Approximately 10,000 people are known to have MS in Australia. The incidence of HD is 1 per 10,000. HD is an inherited and fatal brain disorder manifested by worsening involuntary movements, psychiatric difficulties and cognitive changes occurring over a number of years. PD is not a life limiting illness but causes increasing disability over a period of years. The incidence of PD is between 1 and 2 per 1,000 people.



The key characteristics of these neurodegenerative diseases are that progressive degeneration occurs as a primary event long before symptoms develop and that it is selective, at least initially, for a particular neuronal pool. (Williams, 2002) Few health agencies offer health service provision for specific neurodegenerative diseases because they can cut across several subspecialties such as dementia, Parkinson's disease, motor neurone disease, or cerebellar degenerations. It is important for sub-classifications to exist for research, management and more targeted treatment but problems exist with terminology, because a person may be labelled with one condition such as Parkinson's disease and also have dementia as an additional feature.

People with these neurodegenerative diseases wished to remain at home with their family for as long as is possible, or to move into residential care in their facility of choice.

The national survey showed the financial impact of these disorders with nearly 40% of patients giving up work or retiring early as a result of their illness. The majority of patients were living with their partner or another family member. The median time from diagnosis to survey was seven years. About 40% of patients and carers reported using one to three items of equipment. More than 45% of patients reported needing assistance with domestic tasks such as shopping, transport or maintaining finances. Community rehabilitation, home care and respite were the most commonly used services.

The authors of the study made the following suggestions for improvement:

- Improved financial support such as increased pension, better subsidies on medication, equipment and support services, modifications for car and home and funding for support organisations.
- More respite and other home support for carers (eg, housekeeping and social and recreation activities for family caregivers).
- Transport such as affordable transport and door to door service, better taxi service to help with independence.
- Availability of and access to allied health services such as social workers, physiotherapists and dieticians.
- More contact with service providers and access to Associations through frequent home visits or regular phone contact.
- Services reaching rural areas.
- More information about the conditions and the support services available for patients and carers and developments in treatment/ cure/ research.
- Education of service providers and improvement in their attitude.
- Dedicated facilities/ programs for these special conditions.

### ***Investigator's Conclusions***

The study highlighted the need for improved coordination of care between the various service providers. Better information, more effective communication and the capacity to remain at home as long as possible were all issues for patients and carers.

The authors concluded that palliative and supportive care, including respite care, should be offered to all individuals with life threatening or chronic illnesses with complex care needs, and to their families, by specifically trained, skilled multidisciplinary teams.

### **Non-malignant conditions (other than neurodegenerative diseases)**

The terminal trajectory or decline of cancer is relatively consistent and documented; however, the last phases of disorders such as congestive heart failure, liver disease, chronic obstructive pulmonary disease or failed organ transplant are difficult to track and predict. This creates a dilemma for specialist palliative care services in determining admission priorities to support services and specialist facilities.

Patients with non-cancer diagnoses may not be included in specialist palliative services because discomforts are not as great as in cancer and because the prognosis is uncertain.

One study that considered various non-malignancies aimed to correlate changes in bio-impedance measurements (eg whole body mass, bone mass) with social or environmental changes in order to understand the effects of these influences on disease progression.

### **Key Findings**

- The level of depression evident in all patients interviewed. This depression appears to revolve around two time frames - immediate concern for their clinical status and/or distress about long-standing unresolved life grievances. Importantly, the degree of depression in the patient correlates with the degree of depression the partner/carer observes in the patient and relationships are appearing between the Edmonton Symptom Assessment Scale and the Geriatric Depression Scale
- The issues around addressing depression are made more complicated by the question of when or how palliative care approaches are introduced for those patients with a chronic or progressive illness who are still being managed in a curative environment
- A superficial interrogation of the data shows significant trends in the major variables, the progression through illness and the arrival at the end point of life
- Of particular importance is the examination of the interrelationships between the key psychological and physical measures and the specialists' estimate of survival and a determination of which factors currently influence that decision
- In cardiac and respiratory groups introducing palliative care as management may appear premature at times
- At present it is difficult to answer the question "where does the trajectory start?" The in-depth analysis of the full data set may provide more information, and
- Demands of different ethics committees often make the utilisation of uniform procedures / processes across the institutions difficult.

### ***Investigator's Conclusions***

For patients who are chronically ill with a severity of disease progression that deems them palliative or pre-palliative, preliminary psychological assessment may be useful to determine if more comprehensive psychological supports are needed.

### ***Implications for policy and / or practice***

The interim analysis shows that depression is a serious and significantly unattended issue. Depression revolves around two time frames - the patient's immediate concern about their clinical status and/or distress about long-standing unresolved life grievances.

## Renal Conditions

Renal dialysis and transplantation have been the subject of research and social review; however, the issues around dialysis abatement (either not to initiate or to cease dialysis) have not been well examined (Ashby, Kellehear, Holdsworth, & Brooks, 2004). The decision to withhold or withdraw from dialysis is usually very difficult and the process is uneasy for patients, families and carers, and at times the renal unit staff. Dialysis discontinuation is becoming more common as the dialysis population increases and becomes older with more significant co-morbid conditions.

The study aims were to provide:

1. Descriptive and systematic data on the social impact of these decisions and processes on patients, families and social networks
2. A re-examination of professional procedures in dealing with patients, particularly concerning disclosure and clinical decision-making and its timing and impact on patients and their families
3. A review of institutional policies with respect to the location and type of care appropriate to such patients, and
4. Demographic and clinical data concerning patients who cease or elect not to start dialysis, and therefore die of renal failure.

The patient experience is crucial to the decision-making around withdrawing or withholding renal dialysis. This study suggests that for many patients the burdens of treatment may outweigh the benefits.

The interview data suggests that withdrawing from treatment may be more difficult and more likely to be made by the patient alone than the decision to withhold from treatment.

Medical uncertainty was a recurrent theme for the participants and indicates that an evidence base to guide practice is still developing.

### *Investigator's Conclusions*

This research shows that potential improvements in practice require a strategy that will fully integrate the advances of palliative care into the processes of renal dialysis abatement. Collaborative management earlier in the illness trajectory may offer opportunities to support patients and enable gentler transitions from dialysis to palliative care.

The uncertainties and complexities faced by renal patients during end-of-life care indicate that further research is needed to develop an evidence base to support care practices.

### *Implications for policy and / or practice*

The research highlights the need for collaborative management of patients by nephrology and palliative care earlier in the illness to enable support for decision-making and appropriate transitions in care planning. This needs to be supported by policy changes to renal management of end-of-life care.

Joint management between palliative care services and renal services has the potential to promote well being and chronic pain management during dialysis as well as at the end-stage.

There is the relative absence of broadly-based community and professional discussion of the relationship between renal failure and death.

### Chronic heart failure

Chronic heart failure (CHF) is a major public health issue for Australia. It is primarily a condition of ageing and is increasing due to an ageing population and success in the treatment of hypertension, acute myocardial infarction and valvular disorders (Davidson et al., 2003; Davidson et al., 2002).

Chronic disease with an inevitable terminal outcome creates health management issues for professionals who must balance acute and palliative aspects of care within a context of an unpredictable trajectory of illness. At the moment the evidence base for managing such patients is limited. Understanding how patients with CHF are managed in the health system and the particular concerns of patients, families and health professionals could inform policy, service delivery and patient care.

The aim of the study was to examine the systems of end-of-life care in the Australian CHF population and to examine the impact of this process upon health professionals, carers and significant others.

### Key Findings

The model of care for the dying has been completed and incorporated as part of the revised Cardiac Society of Australia and New Zealand/National Heart Foundation Guidelines to be released in March 2005.

A number of key findings were identified by the study:

- There is evidence of clear socio-economic differential in outcomes nationally for heart failure
- There is a need to consider issues related to cultural and ethnic diversity in care delivery
- There is a need for funding and policy support to facilitate palliative care provision in heart failure
- Palliative care issues need to be included in undergraduate and postgraduate curricula
- There is a need to clarify medico-legal considerations in respect to CHF management and advance care directives
- There is a need for a model of clinical supervision in cardiology practice
- There is a need for reliable Australian epidemiological data
- There is a need for education and consumer awareness on the role of Advance Care Directives in heart failure management
- There is a need for the development of administrative and patient management information systems, and
- Cardiology clinicians need education and support surrounding “difficult conversations” involving prognosis and outcome.

### *Investigators' Conclusions*

This research has shown that implementing palliative care principles in CHF is complex and multifaceted. There are implications for policy, professional education, consumer awareness and basic and clinical science. They can be summarised as follows:

- There is a need for education of cardiology clinicians in palliative care and of palliative care clinicians in heart failure management
- Models of care need to be dynamic, flexible and responsive to the individual needs of patients and their families rather than diagnosis
- The issue of access to consumables such as oxygen therapy needs to be examined
- There needs to be information for health professionals and consumers regarding palliative care and heart failure
- Better tools and information and data systems are needed to assist the research agenda in this area
- There is a need for culturally appropriate care
- There needs to be further work on the current funding models. Funding solutions are needed to integrate palliative care principles into the disease trajectory. This would also complement the development of appropriate configurations of service delivery, and
- There is evidence of inferior outcomes in rural and remote Australia.

The active program of dissemination has also promoted the awareness of palliative care nationally and internationally in this field.

#### ***Implications for policy and / or practice***

The implications can be summarised in four areas:

1. Development of expertise and knowledge
2. Issues around funding and models of service delivery
3. Recognition of the importance of the patient including their cultural and carer circumstances, and
4. Development of pharmacological and basic science activities.

The research work has contributed to the revised set of Cardiac Society of Australia and New Zealand National Heart Foundation Guidelines.

### **General Practitioners**

A recent report identified the gaps or barriers in the education, training and support opportunities that existed for General Practitioners (GPs) in palliative care (Australian Government Department of Health & Ageing, 2003). The needs were identified from the perspectives of GPs and significant others, such as the target populations of Indigenous and Transcultural communities, rural and remote communities, patients in home-based, and residents in RACFs.

The authors of the report suggested that GPs were central to the provision of palliative care and initiatives or models of care should be designed accordingly. The most appropriate model was considered to be a community-based palliative care approach with a reduction in the patient's dependence for care upon specialist palliative care services and that focused upon the dying patient's right to be cared for and to die in the setting of their own choice, which was generally their home. The following suggestions for improvement were made:

- Palliative care training should be routinely introduced into undergraduate medical curricula.
- Palliative care will be specifically included in the national training program for intern training to encourage local hospital employing junior staff to teach palliative care within the hospital's educational program.

- Vocational training for GPs should reflect the needs of the prevailing palliative case load of the district and include the needs of groups that are disadvantages such as Indigenous communities or RACF residents.
- A minimum palliative care skill set be promoted to all GPs, which should be nationally standardised.
- Additional funding to support the GP in providing community-based palliative care such as 24-hour medical cover, bereavement support services.
- Provide sufficient appropriate electronic information for carers.
- Develop an auspice to oversee piloting of models for GP involvement in palliative care.
- Provide sufficient funding to ensure baseline standards for liaison between GPs, public hospitals and discharge planning for palliative patients.

## CONCLUSION

The literature review of palliative care service provision indicates that there are various models of care operating throughout Australia and overseas. Many of these models are based upon expert opinion rather than being evidence based; consequently, there are considerable variations in fundamental determinants to service provision such as minimum bed numbers per palliative care units and per populations. Despite these differences, there are similar areas of concern, such as meeting the needs of children, older persons, and Indigenous Australians, as well as those with non-malignant disorders such as neurological disorders. The role of the General Practitioner is considered integral in many models of palliative care; however, General Practitioners may require additional education and supports to ensure that they are able to adequately meet this expectation. Recent reports have been conducted within Australia looking at these varying issues and suggestions for improvements have been made to ensure that there is equitable access to palliative care services within Australia. These reports make an excellent contribution to understanding the varying settings for palliative care; however, more research is required in specialist areas such as aged care before clear guidelines for the practice of palliative care in any setting can be developed.



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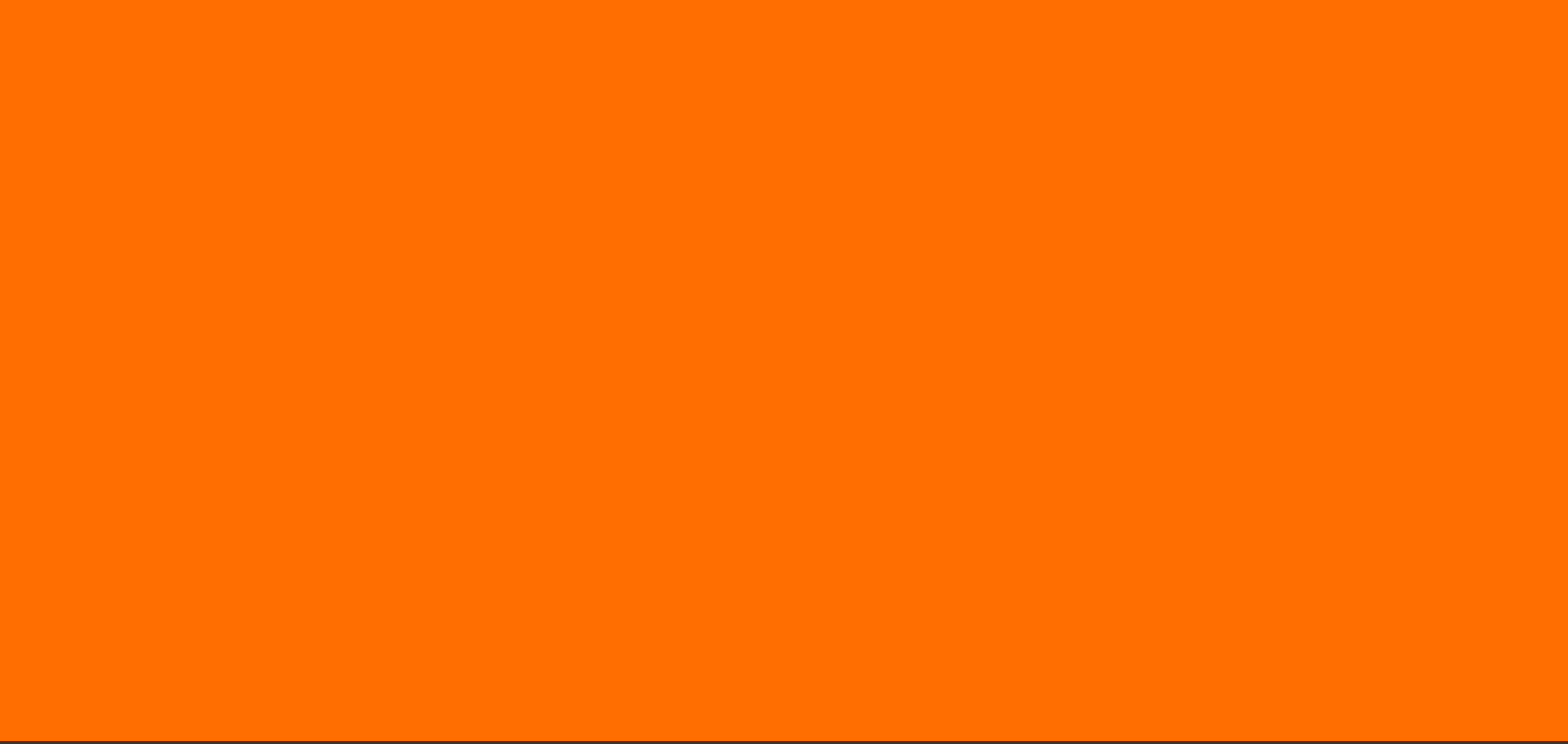
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