WA Cancer and Palliative Care Network

Palliative Care Model of Care

2 April 2008

Government of **Western Australia**
Department of **Health**

Endorsed by SHEF April 2008. Reprinted September 2009 with minor edits. These changes do not affect the content of the original document. For details of those changes please contact palliativecare.cpcn@health.wa.gov.au.

Suggested Citation:

Department of Health, Western Australia. Palliative Care Model of Care. Perth: WA Cancer & Palliative Care Network, Department of Health, Western Australian; 2008.

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EXECUTIVE SUMMARY

Palliative care has primarily been provided to people with advanced cancer at the end of life. There is now international recognition of the need to extend the philosophy, the knowledge and skills developed in this specialty to provide access to care for all people with a life limiting illness. Every person, regardless of age or diagnosis, with a life-limiting illness has a fundamental right to access care that is underpinned by a palliative approach.

Western Australia has recognised specialist palliative care services, but service provision is currently not population based as most services are located within the North Metro Area Health Service region. The need for palliative care in Western Australia will increase as it is estimated that by 2016 the overall burden of disease will be greater due to the increased size and age of the population. Current service provision will not have the capacity to meet the predicted needs.

The Palliative Care Network has developed a model of care to address the identified gaps in current service delivery, the inequity of access to palliative care services and in particular the groups of people who are not well served by the current models of palliative care. The model of care has been developed in consultation with palliative care clinicians, key stakeholders and consumers and builds on the recommendations of "The Palliative Care in Western Australia, Final Report December 2005" (PC Report). The model aims to:

- provide services for patients with life limiting illness, regardless of diagnosis
- address the palliative care needs of patients and their families during their illness trajectory
- deliver care in any setting - hospital, palliative care unit, residential care or home
- identify partnerships between specialist palliative care services and primary care providers.

The Palliative Care Model is needs based, as advocated by Palliative Care Australia. It emphasises that the complexity of needs should not determine the setting of care. For example patients who are identified as having complex needs can be cared for in a community setting if they have appropriate support and expertise. The model identifies that health promotion strategies can be used to educate the public and primary health care providers of the social, psychological and spiritual impacts of living with a life limiting illness and the impact this has on the patient, family members and on the community in which they live.

A consistent approach to palliative care referral across Western Australia is paramount and referral earlier in the illness trajectory may be appropriate. Referral to palliative care services is not exclusively for medical input and physical symptoms but can be to address psychological, emotional, social and spiritual support needs. The model identifies a group of patients with ongoing illness and intermittent needs that currently miss out on essential services. It also recognises that a palliative approach to care delivered by the primary care provider may address the needs of patient with non complex needs. In contrast the more intensive care of people with complex needs will require the expertise of a specialist palliative care team if patient needs exceed the skills of the primary carer.

Primary care providers can partner with specialist palliative care teams/services to provide the best possible care according to the needs of each individual. Fundamental to this partnership is the role of specialist palliative care services in strengthening the skills of primary care providers by providing education, mentorship and professional development.

The PC Report (2005) has made specific recommendations relating to the development and coordination of specialist palliative care services in metropolitan Perth and in rural and remote WA. By coordinating the functions of normally separate services including alignment of practices, processes, protocols and systems, it is anticipated that this will result in improved outcomes and efficiencies for the patient and family as well as the services involved.

Strategies for application of the palliative care model in Western Australia are discussed. The Palliative Care Network will work strategically with the Department of Health and Area Health Services: North, South and Country, to develop and implement a coordinated approach to the integration of palliative care across the state.

The relationships between tertiary, secondary and primary services in the North and South metropolitan health regions are detailed. In particular, the need for tertiary services to have the capacity and resources to provide leadership, outreach advice, episodic care and consultancy to secondary and primary care services in both metropolitan and rural locations.

The Palliative Care Network would remain as the central link with stakeholders to promote quality and equitable service provision statewide. It is proposed that Area Health Palliative Teams would function at an operational level to provide seamless care systems for patient transition between palliative care units, consultative services and domiciliary care. Supporting community based services and rural care would be an additional function.

A Rural Model of Palliative Care to address the specific needs of rural and remote communities is currently being developed and will under go further consultation. Likewise the specific needs of paediatric patients will also be addressed.

The Palliative Care Network proposes that the key recommendations made are implemented in phases according to the resource, further planning and development needs.

1. INTRODUCTION

The traditional concept of palliative care has been based on the Hospice model of care developed in the United Kingdom in the 1960s. Care is provided by specialist multidisciplinary teams, often in purpose built facilities, primarily to people with advanced cancer at the end of life. There is now world wide recognition of the need to extend the philosophy, knowledge and skills developed from this traditional Hospice model to provide access to care for all people, with a life limiting disease. This has evolved into the concept of palliative care.

The current challenge is to develop an appropriate palliative care model, in line with international and national best practice, for application in any health care setting and reflecting the responsibility of all health care professionals to provide high quality care that meets the Palliative Care Australia's Standards. This model also needs to reflect the role of specialist palliative care services in not only providing care to patients with complex needs but in effectively providing support to primary care providers.

2. METHODOLOGY – THE DEVELOPMENT OF A PALLIATIVE CARE MODEL OF CARE

The development of a palliative care model builds on a review of palliative care in Western Australia (WA) commissioned by the Department of Health in 2005. The review was overseen by the Palliative Care Advisory Group to the Director General of Health and culminated in “The Palliative Care in Western Australia, Final Report December 2005”[1] (PC Report), a population based review of palliative care needs, which makes recommendations for a model that integrates palliative care provision across the state. It advocates that service provision is coordinated with linkages established between specialist palliative care services and primary care providers, across metropolitan rural and remote regions and with special needs groups. The vision for the future is to provide equitable access to palliative care statewide. This will be according to each individual’s level of need, will be for all people living with a life limiting illness and will ensure timely support for their families and carers. The care provided should be consistent with the informed wishes of the person.

The WA Palliative Care Network has the brief of implementing the recommendations of the PC Report and has led the model development work by:

- reviewing national and international models of palliative care
- conducting a workshop, held in May 2007, with invited clinicians to initiate discussion about a palliative care model
- working with a rural palliative care group to develop a rural model
- establishing a Paediatric Palliative Care Working Group that conducted an Australasian review of paediatric palliative care models
- consultation with other WA Health Networks and health care providers
- distribution of a draft paper, followed up by a presentation and discussion at the Palliative Care Network Meeting held 9 November 2007, attended by 70 people from around the state
- distribution, in February 2008, of an updated draft discussion paper for comment: to palliative care clinicians across the state, WA Health Networks and to others who expressed interest in response to a notice in the February 2008 Net News
- seeking comment from the Cancer Council WA consumer advocacy group
- receiving support from Palliative Care WA (Appendix).

The Palliative Care Network Advisory Committee is accountable for the final model of care.

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[1] Department of Health Western Australia, 2005a, Palliative Care in Western Australia Final Report December 2005, Department of Health Western Australia, Perth.

3. THE CURRENT STATE OF PLAY

3.1 Definition of Palliative Care

The World Health Organisation (2006)[2] has in recent years refined the definition of palliative care to reflect the reality that people with life threatening illness may have palliative care needs throughout their illness trajectory:

Palliative care is an approach that aims to improve the quality of life of patients and their families facing the problems associated with life-threatening illness. This is achieved through the prevention and relief of suffering by means of the early identification, impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems.

Palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten nor postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patients illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

3.2 Burden of Disease

The burden of disease is difficult to quantify accurately from an epidemiological perspective. McNamara, Rosenwax, Holman and Nightingale (2004[3]) conducted a population based, retrospective cohort study of deaths in WA between 1st July 2000 and 31st December 2002 to estimate the population of Western Australian's requiring palliative care services. In their study they developed the following categories of palliative care constituencies and associated statistics for WA within the nominated time period (Table 1).

- *Minimal palliative care constituency*

  Using a literature review and focus group data, ten conditions that most require palliative care were identified to form the minimal palliative care constituency. Between 1st July 2000 and 31st December 2002, this constituency accounted for 50% (13 453) of all deaths in WA. The ten conditions include cancer (54%); heart failure (19%); renal failure (9%); Chronic Obstructive Pulmonary Disease (9%); Alzheimer's Disease (4%); Liver failure (3%); Parkinson's Disease (0.1%); Motor

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[2] http://www.who.int/cancer/palliative/definition/en/

[3] McNamara, B. Rosenwax, L., D'Arcy Holman, C. & Nightingale, E, 2004, Who receives specialist palliative care in Western Australia – and who misses out, The University of Western Australia Uniprint, Perth.

Neurone Disease (0.1%); Human Immunodeficiency Virus/Acquired Immunodeficiency Disorder and Huntington's Disease (<0.1%).

Eighty per cent of this constituency were aged 65 years or older and one in 50 was Aboriginal.

- *Mid-range palliative care constituency*

  This constituency includes all people hospitalised in the 12 months prior to their death for the same condition which was documented as the underlying cause of death on their death certificate. Using this estimation, 14 919 people (55.5% of all deaths) were included. The causes of death that did not comprise the 10 conditions in the first constituency were mostly cerebral vascular accidents, pneumonia, respiratory failure, myocardial infarct, septicaemia, ruptured aneurysm and cardiac arrest (McNamara et al 2006[4]).

- *Maximal palliative care constituency*

  The broadest estimation method included all but deaths that were sudden in the time period. Using this method, the constituency included 89.4% (24 032) of all deaths.

Table 1: Palliative Care Constituency and WA Deaths Statistics

Palliative Care Constituency	Number of deaths in Western Australia between 1st July 2000 and 31st December 2002	Percentage of all deaths in Western Australia between 1st July 2000 and 31st December 2002
Minimal	13 453	50.0 % [Cancer 54%; Heart failure 19%; Renal failure 9%; COPD 9%; Alzheimer's Disease 4%; Liver failure 3%]
Mid-range	14 919	55.5 %
Maximal	24 032	89.4 %

Incidence

The incidence and prevalence of the ten conditions outlined by McNamara et al (2004) that would most require palliative services can be established through state and national data. Where data is available, it has been outlined below.

- *Cancer*

  According to the report of the Western Australian Cancer Registry[5], 9151 new cases of cancer were recorded in WA in 2005 (356 per 100 000 males; 261 per 100 000 females). In the same period, 3432 deaths due to cancer were recorded (127 per 100 000 males; 78 per 100 000 females).

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[4] McNamara, B. Rosenwax, L., D'Arcy Holman, C. & Nightingale, E, 2006, *A method for defining and estimating the Palliative Care population*, Journal of Pain and Symptom Management, Vol 32, No 1, pp 5-12.

[5] Threlfall TJ, Thompson JR (2007). ***Cancer incidence and mortality in Western Australia, 2005.*** Department of Health, Western Australia, Perth. Statistical Series Number 81**.**

- *Heart failure*

  According to the National Health Survey 2004-05, 263 000 people (1.3% of the population) in Australia have oedema and heart failure (Australian Bureau of Statistics 2006[6]). Heart failure is likely to be noted as an *associated* cause of death rather then the underlying cause of death. It is usually associated with kidney failure, Coronary Heart Disease (CHD), diabetes or chronic lower respiratory disease (AIHW 2006). In 2003, the leading cause of death in Western Australia was Coronary Heart Disease (Ischaemic Heart Disease). It was also the leading cause of disease burden Disability Adjusted Life Years (DALY) for both males and females in the same year [11,816 DALY (10.1% of total DALY) for males; 8,250 DALY (7.8% of total DALY) for females] (Draper, Unwin, Serafino, Somerford & Price 2005[7]).

- *Alzheimer's Disease*

  The Australian Institute of Health and Wellbeing (AIHW) estimates that 171 000 people aged 65 years or older have or had dementia in 2004. Alzheimer's disease is generally responsible for approximately 70% of dementia cases (AIHW 2006[8]). In WA, Dementia was one of the ten leading causes of disease burden in 2003 [3 344 DALY (2.9% of total DALY) for males; 6 200 DALY (5.9% of total DALY) for females) (Draper et al 2005).

- *Renal Failure*

  In 2004 in Australia, 1 912 people commenced treatment for end-stage kidney disease (ESKD) and 7 952 were undergoing dialysis. Aboriginal and Torres Strait Islanders are overrepresented in the overall population of people with chronic kidney disease and ESKD (AIHW 2006).

- *Chronic Obstructive Pulmonary Disease*

  Chronic Obstructive Pulmonary Disease (COPD) was one of the 20 leading causes of disease burden in WA. It accounted for 4 417 DALY (3.8% of total DALY) for males and 2 894 DALY (2.7% of total DALY) for females in 2000 (Draper et al 2005). In Australia, it is estimated that 3.5% of the population (665 000 people) have COPD (based on the 2001 National Health Survey)(AIHW 2006).

- *Parkinson's Disease*

  In 2000, Parkinson's Disease accounted for 1165 DALY (1.0% of total DALY) for males and 1336 DALY (1.3% of total DALY) for females. It was one of the 20 leading causes of diseases burden in WA (Draper et al 2005).

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[6] Australian Bureau of Statistics, 2006, National Health Survey: Summary of Results, 2004-05, ABS, Canberra
Viewed online 5th December 2007
http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4364.02004-05?OpenDocument

[7] Draper G, Unwin E, Serafino S, Somerford P, Price S (2005). Health Measures 2005: A report on the health of the people of Western Australia. Department of Health Western Australia, Perth.

[8] Australian Institute of Health and Wellbeing (AIHW), 2006, Australia's Health 2006, AIHW, Canberra
Viewed on line 5th December 2007
http://www.aihw.gov.au/publications/index.cfm/title/10321

Population Trends

In the 2001/2002 period, the PC Report 2005 identified 2,225 metropolitan separations for public patients involving palliative care activity. The majority of these (52%) were tertiary hospitals and the remaining 48% were from non-tertiary hospitals (16.4%) and hospices (31.6%) (Department of Health Western Australia, 2005b).

It was estimated that by 2016 the overall burden of disease will be greater due to the increased size and age of the population in WA. While the burden attributable to cardiovascular and chronic respiratory disease is expected to reduce, an increase is anticipated in other diseases such as cancer, neurological disorders and diabetes. The report also emphasises the population growth within the Perth metropolitan area and the implications for the provision of palliative care in WA. Current service provision will not have the capacity to meet the predicted needs (Department of Health Western Australia, 2005b).

The PC Report (2005) also emphasises the population growth within the Perth metropolitan and the implications for the provision of palliative care in Western Australia, as current service provision will not have the capacity to meet the predicted needs. The Report projects separations, bed-days, beds and beds per 100,000 population up to the financial year 2015/16 for the north and south metropolitan areas. 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. 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).

According to McNamara and Roxenwax (2007[9]) over half of Western Australians died in hospital, but as people age there is an increasing tendency to die in their usual place of residence, which may be a private residence or an aged care facility. People who accessed community-based specialist palliative care had a seven times higher chance of dying in their usual place of residence. Importantly, this information is provided, not just for cancer deaths, as has been the practice to date, but for a range of other painful and life-limiting conditions considered amenable to palliative care.

3.3 Current Service Provision

Western Australia has a recognised palliative care health professional community that has aspired to raise the profile of palliative care as a health care specialty by promoting best practice standards and ensuring that specialist services meet accreditation requirements for the development of future specialists.

Currently specialist palliative care in Perth is provided using three key models of care (Table 2):

- *Hospital consultancy services*
- *Hospice and palliative care units with designated palliative care beds*
- *Community services (Silver Chain Hospice Care Service provides end of life care to over 550 palliative care patients, at any one time, throughout the Perth Metropolitan region).*

Service provision is currently not population based. Most inpatient services are located within the North Metro Area Health Service (NMAHS) region. Private organisations contracted to provide public patient care are the main service providers. It should be noted

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[9] McNarnara, B. & Rosenwax, L. (2007) Factors affecting place of death in Western Australia. Health & Place. 13: 2, p356-367.

that two major palliative care providers, St John of God Hospital (Subiaco) and Glengarry Hospital only provide privately funded palliative care.

Funding models influence current service provision. For example, private organisations that provide inpatient palliative care are contracted for a set number of public patient bed days per year. If the bed day quota is used before the end of the financial year there is potential for patients to remain in the tertiary hospital or community setting inappropriately. Likewise funding to Silver Chain Hospice Care Service limits the service provided to patients who have progressive disease with active symptoms and those requiring end of life care.

Table 2: Current Perth Metropolitan Palliative Care Services

Service Type	North Metropolitan Area Health Region		South Metropolitan Area Health Region	
Inpatient with designated Palliative care beds	Bethesda Hospital Hollywood Hospital Glengarry Hospital Kalamunda Hospital	CS Level 4-5 CS Level 4-5 CS Level 4 CS Level 2	St John of God Murdoch Community Hospice	CS Level 4-5
Hospital Consultancy Service	Sir Charles Gairdner Hospital Palliative Care Service (CS Level 5-6) St John of God Subiaco King Edward Memorial Hospital (weekly consultation visits only)		Royal Perth Hospital Palliative Care Service (CS Level 5-6) Fremantle Hospital (CS Level 3)	
Domiciliary Service	Silver Chain Hospice Care Service		Silver Chain Hospice Care Service Peel Community Palliative Care	

3.4 Quality of Care

The PC Report (2005) highlights the gaps in current service delivery, the inequity of access to palliative care services and in particular the groups of people who are not well served by the current models of palliative care. Table 3 identifies and explains gaps.

Referral of patients to specialist palliative care services is variable, as each service throughout the state determines their own referral criteria. For example some services require a medical referral, wherefore other services may accept self referral from patients and their families.

The PC Report (2005), in line with recommendation 41 of the Reid Report[10], makes recommendations for palliative care to be government funded and for new inpatient services at the general hospitals at Rockingham, Joondalup, Armadale Kelmscott and Midland to ensure that access to palliative care is equitable throughout the metropolitan region. These should have a minimum of ten beds to ensure a critical mass of patients and staff with expertise, to be located in a ground floor environment with easy on site access to investigatory and treatment technologies.

Specialist palliative care has primarily focused on providing ongoing care for people with cancer at the end of life. This approach has denied access to people with life threatening illness who would benefit from input from skilled health professionals who understand the

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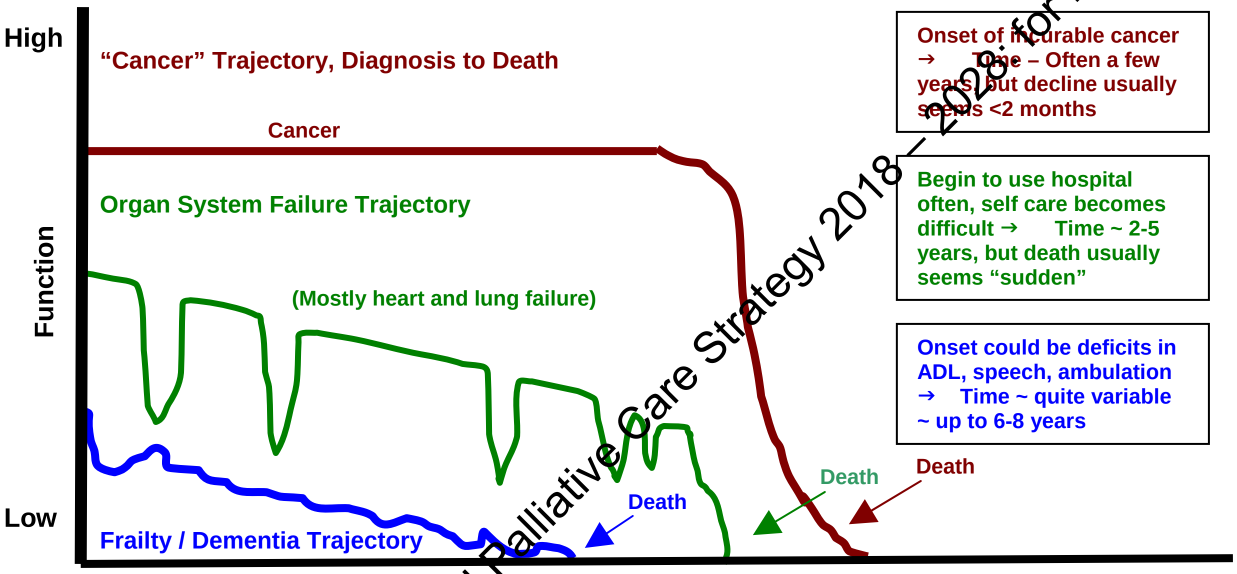
[10] http://www.health.wa.gov.au/hrit/publications/docs/final_report.pdf - 2060k - [pdf] -

holistic scope of palliative care. This scope is best illustrated by Figure 2: Domains of Palliative Care.

The “end of life” only approach to palliative care impacts at consumer level as from their perspective, accepting palliative care is essentially different to seeking treatment with the aim of wellness, as it can be viewed as taking away hope. “Fighting illness” is symbolically tied to achievement and to not giving up. It is acknowledged that the transition to palliative care offered only at the end of life can be difficult for patient, family and health care professionals, especially if the health team is still “treating and do not want to give up”. On a practical basis for consumers, navigating access to palliative care can be difficult as it is determined by prognosis, residential location, local services, the treating medical team and the admission criteria used by the palliative care service.

Figure1: Illness Trajectories[11]



The challenge for specialist palliative care services is to extend the skills and knowledge learnt from the cancer experience to cater for the <u>needs of the non malignant disease group</u> of patients. Figure 1 illustrates that non malignant disease groups have different illness trajectories to cancer with patients having a lower level of functioning associated with the burden of disease, including distressing symptoms, over a longer period of time yet traditionally having little access to specialist palliative care services.

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[11] Prognostic Indicator Guidance to aid identification of adult patients with advanced disease, in the last months/years of life, who are in need of supportive and palliative care. vs 2.25- Gold Standards Framework Programme England 2005

Table 3: Current Gaps in Service Delivery

Current Gaps	Issue
Referral Pathway	Referral to palliative care criteria and processes are not consistent
Inpatient services are not population based	Palliative Care inpatient services are primarily based in the North Metropolitan Health Region
End of Life Pathway for care of the dying	Acknowledgement by health professionals that a patient is dying will prompt timely communication with patients and families, prevent futile treatments and promote appropriate care of the dying. The use of an End of Life Pathway, for example the Liverpool Care Pathway for the Dying Patient, (LCP) has been demonstrated to improve care of the dying[12]
Older and in residential care	Residential Aged Care Facilities can access limited support from palliative care services. Currently palliative care medical consultation is not accessed
Indigenous palliative care	Services limited and not targeted to needs
Paediatric palliative care	WA is the only mainland state in Australia that does not have a designated Paediatric Palliative Care Service
Patients with life limiting illness without any current physical symptoms, emotional psychological or spiritual needs or functional limitations that require physical assistance yet have expected rapid progression of the illness	Difficult to access community palliative care due to current focus on end of life and presence of physical symptoms
Patients with life limiting illness resulting in distress for patient and or the family with the need for psychological, emotional or spiritual support or intervention	Difficult to access community palliative care due to current focus on end of life and presence of physical symptoms
Patients with life limiting illness without symptoms but with functional limitations requiring physical assistance	Difficult to access community palliative care due to current focus on end of life and presence of physical symptoms
Patients with life limiting illness with slow or fluctuant progression and prognosis of longer than 3 months	Difficult to access medium to long term care particularly for younger patients.
Patients with life limiting illness with long standing co-morbidities, and receiving community aged care packages, where a palliative care referral may impact on their continued access to suitable services	Some patients may have to relinquish the services provided by the "Aged Care Package" to be referred to community palliative care services
Patients with life limiting illness who live outside of existing palliative care service boundaries in both metropolitan and rural areas	Difficult to access specialist palliative care expertise according to patient needs due to rigid boundaries e.g. Services only provided to certain postcodes
Patients with life limiting illness in rural and remote communities	Access to specialist palliative care expertise, according to patient needs, is variable
Lack of consistent palliative care data	No strategy to collect data to reflect palliative care practice. PCOC, the national quality improvement program dataset is voluntary
Training positions for future palliative care health professionals	Palliative care must maintain services with a critical mass of patients and expertise to ensure continued accreditation for Physician, GP and ongoing health professional training Fremantle Hospital Palliative Care Service, although a tertiary hospital, does not currently meet the criteria for Physician training. *(Appendix 5)*

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[12] Ellershaw, J. & Wilkinson S. (2003) Care of the dying. A pathway to excellence. Oxford: Oxford University Press.

Figure 2: Domains of Palliative Care[13]

The holistic scope of palliative care is highlighted by the following Domains of Palliative Care:

DISEASE MANAGEMENT
- Primary diagnosis
- Secondary diagnoses or co-morbities (e.g. dementia, psychiatric diagnoses, substance use, trauma)
- Prognosis
- Adverse events (eg. side effects/ toxicities)
- Allergies

PHYSICAL
- Pain and other symptoms *
- Level of consciousness, cognition
- Function level of safety, aides, falls risk
  - Needs and implications for care
  - Motor (eg. mobility, swallowing, excretion)
  - Senses (e.g. hearing, sight, smell, taste, touch)
  - Physiologic (e.g. breathing, circulation, sexual)
- Nutrition and hydration
- Wounds
- Habits (e.g. alcohol, smoking)

PSYCHOLOGICAL
- Personality, strengths, behaviour, motivation.
- Impact of illness on patient and family
- Depression, anxiety
- Emotions (e.g. anger, distress, hopelessness, loneliness)
- Fears (e.g. abandonment, burden, death)
- Control, dignity, independence, self image
- Conflict. Guilt, stress, coping
- Psychological or psychiatry assessment/treatment required

LOSS & BEREAVEMENT
- Loss
- Grief (e.g. acute, chronic, anticipatory)
- Bereavement planning & Referral pathway
- Ongoing support for complicated grief.

PATIENT AND FAMILY

Characteristics

Demographics (e.g. age, gender, race, contact information)

Culture (eg. ethnicity, language, cuisine)

Personal values, beliefs, practices, strengths

Developmental state, education, literacy

Disabilities

SOCIAL
- Cultural values, beliefs, practices
- CALD needs
- Relationships, roles with family, friends, community
- Isolation, abandonment, reconciliation, support systems
- Privacy, intimacy, sexuality
- Routines, rituals, recreation, vocation
- Financial resources, expenses – welfare needs.
- Legal (e.g. powers of attorney for business, for healthcare, advance directives, last will/testament, beneficiaries)
- Family caregiver support
- Guardianship, custody issues
- Special needs - indigenous

END OF LIFE CARE
- Use of Pathways Protocols to guide care
- Preferred place of death
- Anticipation and management of physiological changes in the last hours of life. Identification of patient/family/staff.
- Responsive care for patient and family
- Advanced care planning
- Organ donation
- Preparation for expected death
- Information giving and responsive care.
- Rites, rituals
- Pronouncement, certification of death
- Care of family at time of and following death eg. privacy, involvement in care.
- Arrangements for the body eg. mortuary viewing
- Funerals, memorial services.

PRACTICAL
- Comprehensive discharge planning
- Activities of daily living (e.g. personal care, household activities)
- Dependents, pets
- Special needs
- Rural & remote
- Telephone access, transportation

SPIRITUAL
- Meaning, value
- Existential, transcendental issues
- Values, beliefs, practices
- Pastoral and spiritual support
- Rites, rituals, symbols, icons.

** See Appendix 1 for symptom details.*

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[13] Adapted with permission from: Canadian Hospice Palliative Care Association. (2002).A model to guide hospice palliative care: Based on national principles and norms of practice. Ottawa, ON.

4. MODEL OF CARE

A **Palliative Care Model** is proposed to:

- *provide services for patients with life limiting illness, regardless of diagnosis*
- *address the palliative care needs of patients and their families during their illness trajectory*
- *deliver care in any setting - hospital, palliative care unit, residential care or home*
- *identify partnerships between specialist palliative care services and primary care providers.*

4.1 Principles

The principles that underpin this Palliative Care Model are:

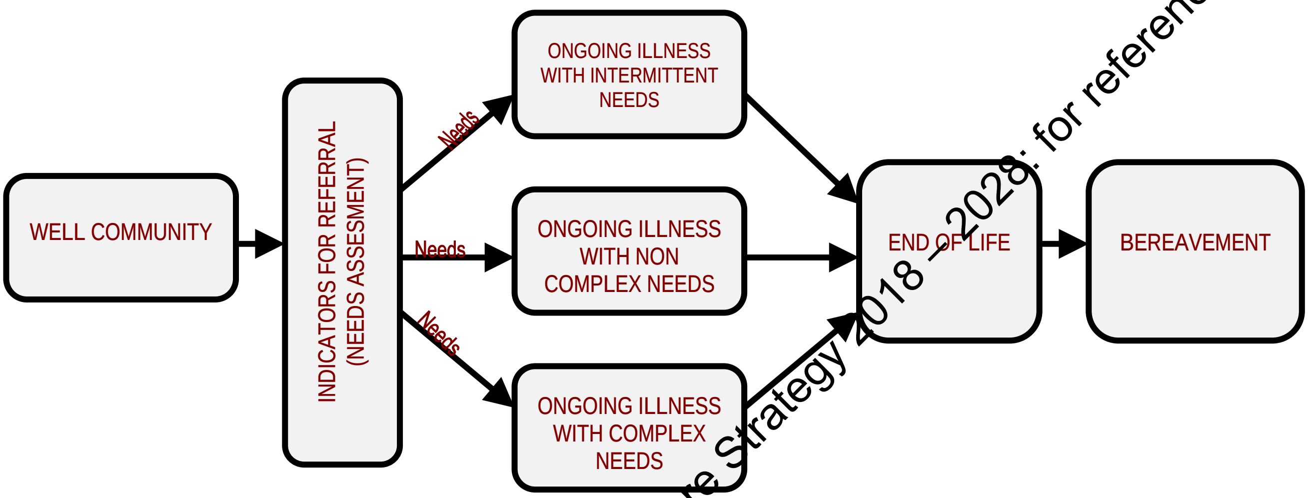
- *A life-limiting illness is an illness that can be reasonably expected to cause the death of a patient within a foreseeable future.*
- *The patient and family are the unit of care given that: the person's illness affects not only the person who is unwell but also the family and any difficulties experienced by the family will in turn have impact on the person who is unwell.*
- *Palliative care is multidisciplinary and is an integral part of the health care system. Every person with a life-limiting illness has a fundamental right to access care that is underpinned by a palliative approach.*
- *There is a formal process of assessment, informed consent inclusive of boundaries of care and decision making around advance care plans. For example orders for "not for resuscitation".*
- *Quality of life can be enhanced by access to physical, psychological, emotional, social and spiritual support provided in a culturally appropriate manner.*
- *People with a life-limiting illness, and their families, will have access to information about options for future care so that they are able to actively participate in decision making about treatment, care and end-of-life issues.*
- *People with life limiting illness will have access to quality care to meet their needs. This care is delivered by trained staff who are supported by specialist palliative care services.*
- *People with life limiting illness have the right to spend as much time as possible in their own home and community, therefore out patient follow-up will be provided where possible in local community settings, or by using Telehealth and other technologies, to avoid unnecessary travel and burden to patients and families.*
- *Patients and families need to experience a seamless service system, with smooth and timely transitions from one service to another.*

  This includes:

  - **Timely referral** to a palliative care service (preferably not in crisis)
  - Effective **communication** with the patient and family and between services
  - Speedy and **straightforward admission** to appropriate inpatient care when required
  - Speedy and **straightforward transfer** from acute care to an appropriate palliative care service setting if this is required
  - **Continuity** of health care provision across the various care settings
  - Coordination and integration of services across all settings with other medical, health or community care providers.

- Coordination can be achieved in a variety of ways and will depend on local circumstances. Each team should identify the other teams/services with which they interact most frequently and should develop plans to promote coordinated care. These plans might include:
  - establishing joint out-patient or community-based clinics
  - undertaking joint ward rounds/case review
  - participating in multidisciplinary meetings that include people from different services.

Figure 3: Palliative Care Needs



4.2 Palliative Care Needs

The Palliative Care Model will be needs based, as advocated by Palliative Care Australia[14] (PCA). *Figure 3: Palliative Care Needs* illustrates the variation in patient needs throughout the illness trajectory. Needs and illness trajectories can be unpredictable as often the experience of caring for people with chronic non malignant disease is that they may be near death on more than one occasion and yet revive. A palliative approach to care is appropriate. It is emphasised that the complexity of needs does not determine the setting of care. For example patients who are identified as having complex needs can be cared for in a community setting if they have appropriate support and expertise. The stages in the above diagram are further explained:

4.2.1 Well Community

There is a role for a health promotion approach in the provision of palliative care. Both health promotion and palliative care models demand consideration of not only the physical (e.g. symptoms) but also the social, psychological and spiritual impacts of living with a life limiting illness. Health promotion strategies can be utilised to educate the public and primary health care providers regarding the impacts of these different factors on the patient and family members, and on the community in which they live. A health promotion approach also supports early intervention and offers the means by which to manage issues at policy, local or individual levels.

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[14] Palliative Care Australia. (2005). *A Guide to Palliative Care Service Development: a Population based approach*. *A National Consensus Document*. Deakin West: Palliative Care Australia

4.2.2 Indicators for Palliative Care Referral

A referral to a palliative care service, or the decision to take a palliative approach to care, should be based on criteria that are applied to each person's situation, with the **onus on palliative care services to undertake a full holistic assessment of each patient so that there is consent to care based on need.** It has been identified that a consistent approach to palliative care referral across WA is paramount. Referral to palliative care services is not exclusively for medical input but can be to address psychological, emotional, social and spiritual support needs.

4.2.3 Ongoing Illness

Palliative care service provision will be variable according to the patient and family needs. The patient's care needs can be broadly classified into three categories in recognition that a palliative approach to care delivered by the primary care provider may address the needs of patient with non complex needs. In contrast the more intensive care of people with complex needs will require the expertise of a specialist palliative care team.

1. Ongoing Illness with intermittent needs

The patients in this category will be identified as having a life limiting illness with a poor long-term prognosis and with all or some of the following characteristics:

- **a.** no current physical symptoms, emotional psychological or spiritual needs or functional limitations that require physical assistance, but with expected rapid progression of the illness
- **b.** patient or family distress with need for psychological, emotional or spiritual support or intervention
- **c.** no symptoms but with functional limitations requiring physical assistance
- **d.** slow or fluctuant progression and prognosis of longer than 3 months.

2. Ongoing Illness with non complex needs

The characteristics of patients in this category include:

- **e.** symptoms that are easily controlled according to palliative care protocols
- **f.** social, emotional, psychological, spiritual and family needs that are managed by the existing primary care provider team
- **g.** consultation with a specialist palliative care service may be required for the management of specific problems or advice only.

3. Ongoing illness with complex needs

The characteristics of patients in this category include:

- **h.** symptoms that remain uncontrolled despite the use of palliative care protocols
- **i.** social, emotional, psychological, spiritual and family needs that require intervention by a specialist interdisciplinary team with qualifications and expertise in palliative care.

4.2.4 End of life Care

There is recognition that the patient may die in the near future (months, weeks or days) and the individual needs of the patient and family will be identified and addressed. Patients should be offered the choice of care setting. For example discharge home.

In the **last few days of life** an End of Life Pathway guides care of the dying patient.[15]

4.2.5 Bereavement Care

A bereavement risk assessment is conducted prior to the death of the patient and bereavement care follow-up provided to the significant family according to identified best practice.

Unmet Needs:

A 55yr old male patient with Glioblastoma Multiforme and significant disability following aggressive resection was receiving community palliative care services. When an MRI scan showed no recurrence of tumour he was deemed no longer eligible for the service, despite a predicted poor long term prognosis. When the community palliative care withdrew services the hospital bed was also removed. The patient was unable to sleep in a normal bed so his wife purchased a second hand hospital bed without electronic controls. This impacted significantly on his comfort as he was no longer able to position himself independently. One month after being discharged from the community palliative care service a follow-up MRI showed likely tumour recurrence. *(Source: Medical Consultant)*

Mr J: Diagnosis Ca bowel with liver metastases was discharged from a tertiary hospital and referred to the community palliative care service. When his symptoms became controlled and his condition stabilised he was discharged from the service with no offer of follow up. Six months later Mr J. was readmitted acutely to hospital. His general condition had deteriorated greatly; he had gross ascites and associated pain. On admission, Mr J expressed great concern that he could no longer be the primary carer at home for his sister who was also disabled by illness. As well as coping with his own deterioration, he had been providing care to his sister without any additional community support. *(Source: Palliative Care Consultancy Hospital Service)*

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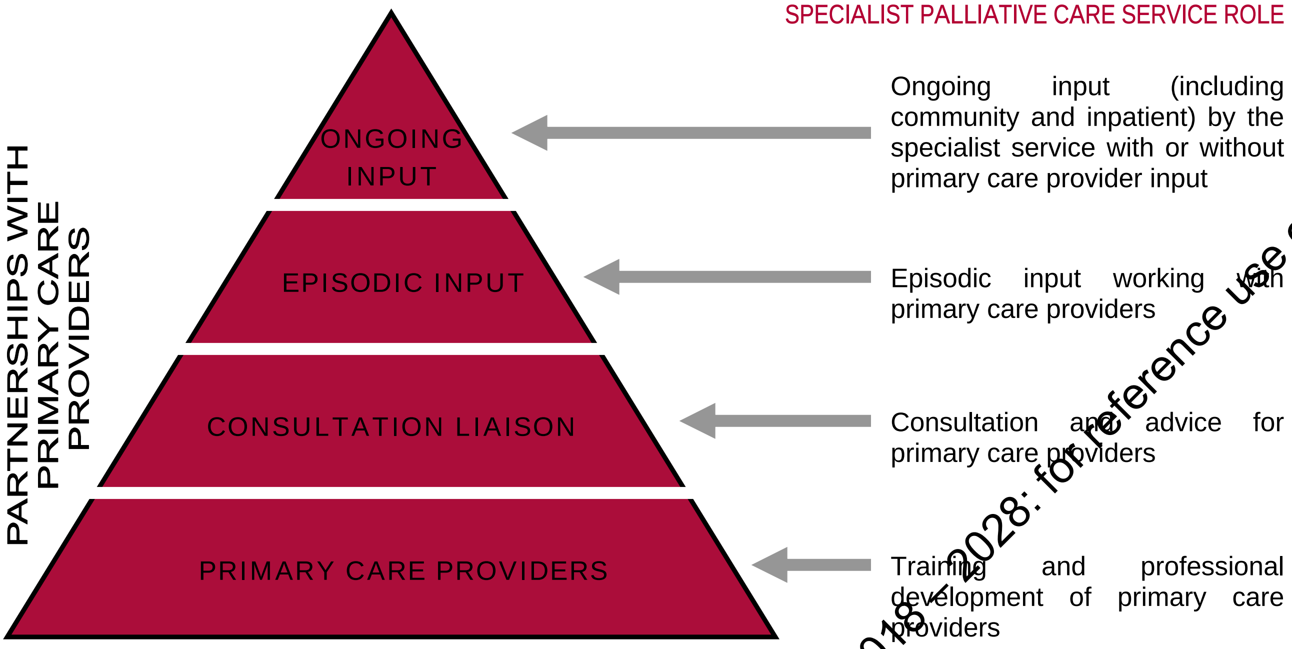
[15] Currently the Palliative Care Network is conducting a pilot study in four Perth palliative care services to trial the use of the Liverpool Care Pathway for the Dying Patient (LCP), with view to adapting it for use in Western Australia as an End of Life Pathway.

4.3 Palliative Care Partnerships



SPECIALIST PALLIATIVE CARE SERVICE ROLE

Ongoing input (including community and inpatient) by the specialist service with or without primary care provider input

Episodic input working with primary care providers

Consultation and advice for primary care providers

Training and professional development of primary care providers

Figure 4: Palliative Care Partnerships

Adapted from Palliative Care in Tasmania: current situations and future directions.[16] *and from the Northern Territory Integrated Service Model*[17] *with permission from the Northern Territory and Tasmania DoH)*

Figure 4: "Palliative Care Partnerships" is proposed as a model to demonstrate the relationships required between specialist palliative care services and primary care providers.

PCA (2005)[18] advocates for a population based approach to palliative care based on the complexity of need. To adequately meet the needs of all people requiring palliative care, primary care providers in all health care settings will assume a role in caring for people with life limiting illness. Figure 5: "The Process of Providing Palliative Care" highlights the palliative care therapeutic process that should guide the interactions between health professionals, patient and families. Primary care providers can partner with specialist palliative care teams/services to provide the best possible care **according to the needs of each individual**. Fundamental to this partnership is the role of specialist palliative care services in strengthening the skills of primary care providers by providing education, mentorship and professional development. Palliative care, appropriate to the needs of patients and families, could be delivered in one or more of the following ways:

- People may be cared for in a **primary health care setting** using a palliative approach, with a general practitioner providing medical support.

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[16] Eagar, K., Gordon, R. Quinsey, K. and Fildes, D. (2004) Palliative Care in Tasmania: current situation and future directions. Centre for Health Service Development, University of Wollongong.

[17] http://www.nt.gov.au/health/comm_health/palliative/strategic_development_plan/palliative_care_strategy.pdf

[18] Palliative Care Australia. (2005). *A Guide to Palliative Care Service Development: a Population based approach*. *A National Consensus Document*. Deakin West: Palliative Care Australia

- People may remain under the primary care of other specialties and will be able to access **once only** or **episodic consultation** with members of an interdisciplinary specialist palliative care team in a supportive role.
- **Ongoing specialist palliative care** may be available with the primary health care team providing the supportive role.
- **Specialist palliative care** may be required to take on the **overall care** of the person based on the complexity of care required.
- To meet the needs of **rural patients**, consultation may be provided by **visiting** specialist palliative care team members or through the **use of technologies** such as Telehealth.
- **Advice** may be provided to medical practitioners, nurses and other health care professionals via telephone advisory services: e.g. The 1300 55 86 55 Palliative Care Medical Outreach Service.

The process of care should remain flexible and be responsive to variation in the patient's level, and type of need, as well as the ability of individual services to meet that need at any given time during the course of the illness.

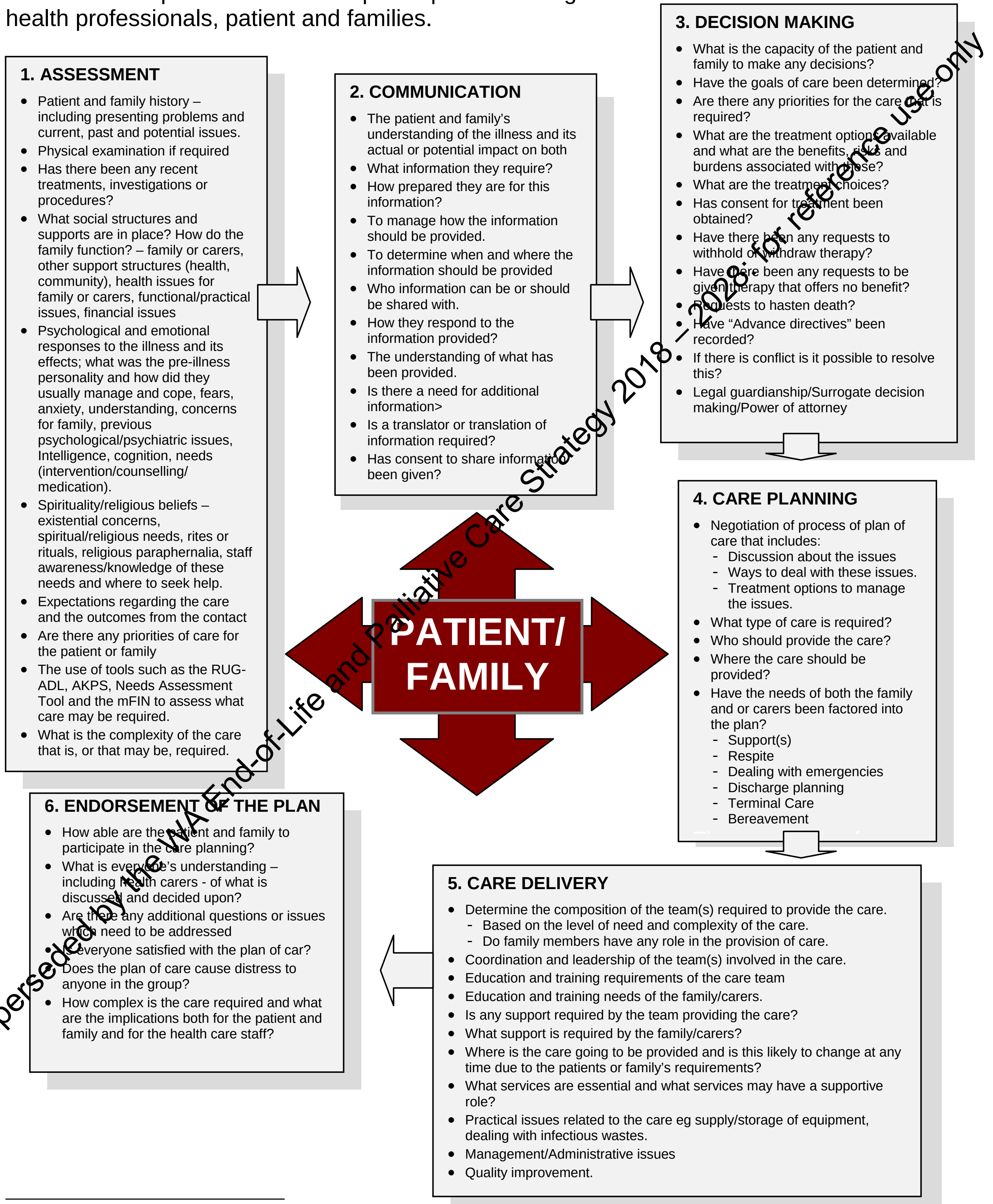
Consumer Perspectives:

My husband was diagnosed with cancer by a specialist. He was then referred to a surgeon and told he was inoperable. He was then referred to a radiation oncologist. No one took responsibility for his pain. The specialists did not communicate with each other. It was horrific for the family to sit back and watch this. He died two months later and the memories I have of him are of him climbing the walls in pain. He died at home, which is what he wanted, but not one of the specialists referred him to Silver Chain. A friend told us to hassle the doctor to get a referral. He went through 3-4 weeks of agony and he only lived 2 months. *(Widow of a Cancer Patient – Consumer Focus Group.)*

The whole family takes on the journey. It was family friends who put us onto pain management. The hospital we were being seen at didn't know the pain specialist we saw existed. You need a holistic view. You lose control of your life. You should help patients to maintain their dignity. *(Widower of a Cancer Patient- Consumer Focus Group.)*

Figure 5: The Process of Providing Palliative Care

The need for palliative care often goes unrecognised as there are misconceptions about the skills and expertise that can be offered by the specialist palliative care team, even as early as the diagnosis of the patient's illness. The following framework[19] details the steps involved in the palliative care therapeutic process that guides the interactions between health professionals, patient and families.



1. ASSESSMENT

- Patient and family history – including presenting problems and current, past and potential issues.
- Physical examination if required
- Has there been any recent treatments, investigations or procedures?
- What social structures and supports are in place? How do the family function? – family or carers, other support structures (health, community), health issues for family or carers, functional/practical issues, financial issues
- Psychological and emotional responses to the illness and its effects; what was the pre-illness personality and how did they usually manage and cope, fears, anxiety, understanding, concerns for family, previous psychological/psychiatric issues, Intelligence, cognition, needs (intervention/counselling/ medication).
- Spirituality/religious beliefs – existential concerns, spiritual/religious needs, rites or rituals, religious paraphernalia, staff awareness/knowledge of these needs and where to seek help.
- Expectations regarding the care and the outcomes from the contact
- Are there any priorities of care for the patient or family
- The use of tools such as the RUG-ADL, AKPS, Needs Assessment Tool and the mFIN to assess what care may be required.
- What is the complexity of the care that is, or that may be, required.

2. COMMUNICATION

- The patient and family's understanding of the illness and its actual or potential impact on both
- What information they require?
- How prepared they are for this information?
- To manage how the information should be provided.
- To determine when and where the information should be provided
- Who information can be or should be shared with.
- How they respond to the information provided?
- The understanding of what has been provided.
- Is there a need for additional information>
- Is a translator or translation of information required?
- Has consent to share information been given?

3. DECISION MAKING

- What is the capacity of the patient and family to make any decisions?
- Have the goals of care been determined?
- Are there any priorities for the care that is required?
- What are the treatment options available and what are the benefits, risks and burdens associated with these?
- What are the treatment choices?
- Has consent for treatment been obtained?
- Have there been any requests to withhold or withdraw therapy?
- Have there been any requests to be given therapy that offers no benefit?
- Requests to hasten death?
- Have "Advance directives" been recorded?
- If there is conflict is it possible to resolve this?
- Legal guardianship/Surrogate decision making/Power of attorney

PATIENT/ FAMILY

4. CARE PLANNING

- Negotiation of process of plan of care that includes:
  - Discussion about the issues
  - Ways to deal with these issues.
  - Treatment options to manage the issues.
- What type of care is required?
- Who should provide the care?
- Where the care should be provided?
- Have the needs of both the family and or carers been factored into the plan?
  - Support(s)
  - Respite
  - Dealing with emergencies
  - Discharge planning
  - Terminal Care
  - Bereavement

5. CARE DELIVERY

- Determine the composition of the team(s) required to provide the care.
  - Based on the level of need and complexity of the care.
  - Do family members have any role in the provision of care.
- Coordination and leadership of the team(s) involved in the care.
- Education and training requirements of the care team
- Education and training needs of the family/carers.
- Is any support required by the team providing the care?
- What support is required by the family/carers?
- Where is the care going to be provided and is this likely to change at any time due to the patients or family's requirements?
- What services are essential and what services may have a supportive role?
- Practical issues related to the care eg supply/storage of equipment, dealing with infectious wastes.
- Management/Administrative issues
- Quality improvement.

6. ENDORSEMENT OF THE PLAN

- How able are the patient and family to participate in the care planning?
- What is everyone's understanding – including health carers - of what is discussed and decided upon?
- Are there any additional questions or issues which need to be addressed
- Is everyone satisfied with the plan of car?
- Does the plan of care cause distress to anyone in the group?
- How complex is the care required and what are the implications both for the patient and family and for the health care staff?

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[19] Adapted with permission from: Canadian Hospice Palliative Care Association. (2002).A model to guide hospice palliative care: Based on national principles and norms of practice. Ottawa, ON.

Figure 6: Model of Care Matrix

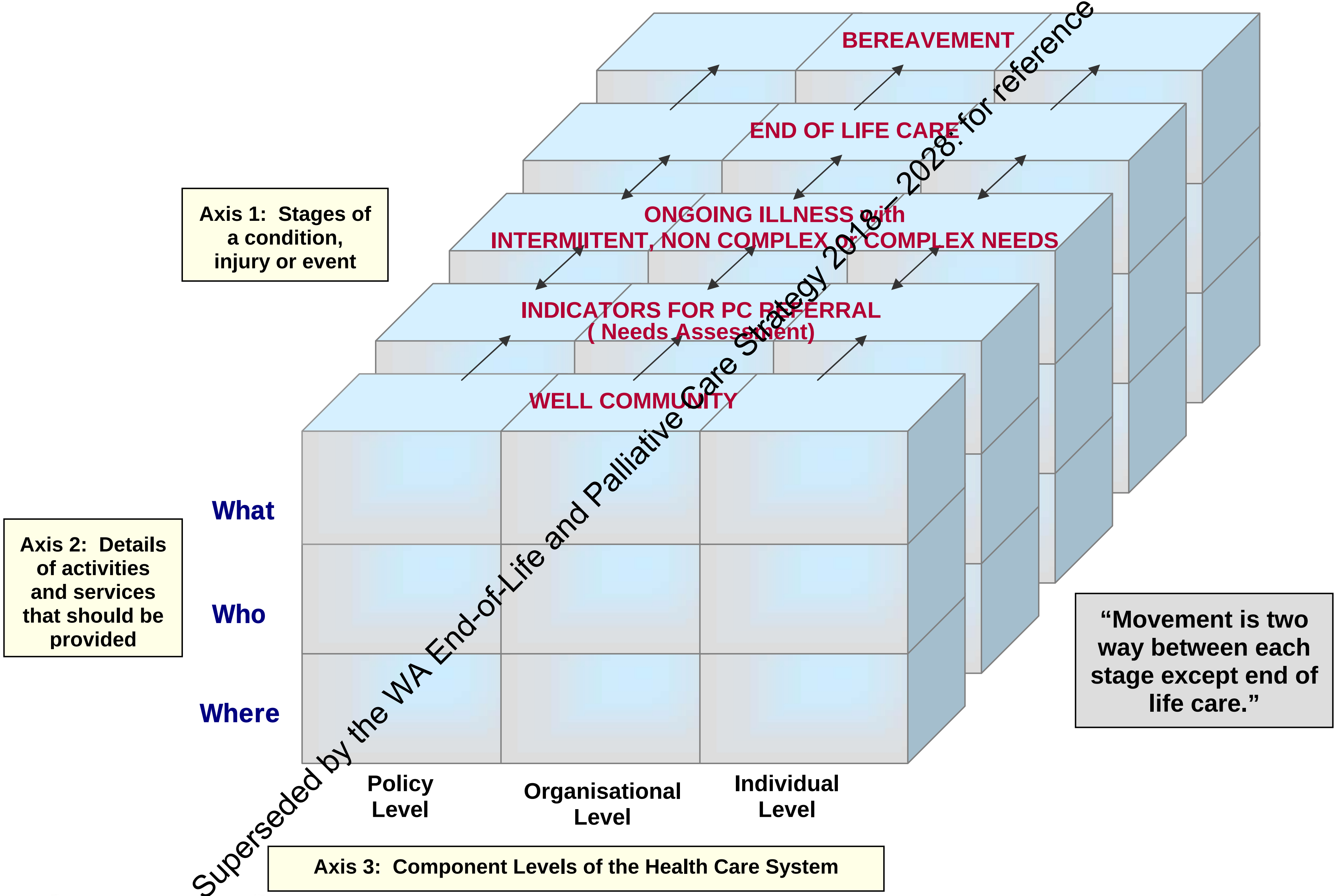


Table 4: The Model of Care Matrix

1. Well Community			
	What should be provided?	**Who should provide it?**	**Where should it be provided?**
Policy Level	Australian Health Care Agreements 2003-2008 • Commitment to the implementation of the "National Palliative Care Strategy" community awareness "Palliative care in WA. Final Report Dec. 2005" WA Health Work Life Balance Policy	State Government Australian Government *(National Palliative Care Program)*	General Community • Health professional training at all levels
	Legislation: Medical Treatment for the Dying Bill • Advance Care Planning	State Government GP Networks Aged Care Facilities	Across the WA health care system • Acute tertiary and secondary care settings • Primary care • Community care • Aged care Community Awareness
Organisational level	Implementation at state level of "The National Palliative Care Strategy" *Goal 1. Awareness and understanding:* • To improve community and professional awareness and understanding of, and professional commitment to, the role of palliative care practices in supporting the care needs of people who are dying and their families of care. • Health promoting Palliative Care	Health Services – Public & Private, NGOs GP Networks Palliative Care Australia Palliative Care WA Carers WA Palliative Care Network Education Department Universities	Professional Awareness Across the WA health care system • Tertiary and secondary care settings • Primary care • Community care • Aged care • Medical/nursing/allied health curriculum Community Awareness • Local Governments • Community Service Organisations • NGOs • Primary care – GP practices • Schools • Workplaces
Individual Level	• Patient and family information relating to awareness and understanding of palliative care • Advice on palliative care options	All health professionals	• Primary Care - General practice • Community care • Aged care • Tertiary and secondary care settings

2. Ongoing Illness

	What should be provided?	Who should provide it?	Where should it be provided?
Policy Level	Australian Health Care Agreements 2003-2008 Implementation of the National Palliative Care Strategy • Goal 2: Quality and effectiveness • Goal 3: Partnerships in care • Access to quality palliative care • “Standards for providing quality palliative care for all Australians” (4th edn., PCA 2005) • “Palliative care in WA. Final Report Dec. 2005” • Referral/Admission/Discharge Policies • Endorsed Protocols & Pathways • Guidelines for a Palliative Approach in Residential Aged Care.	State Government Service Level Policy	Across the WA health care system – NMAHS, SMAHS, WACHS • Primary care • Community care • Aged care • Acute tertiary and secondary care setting Formal links rural/metro

2a. Ongoing Illness – with intermittent needs			
	What should be provided?	**Who should provide it?**	**Where should it be provided?**
Organisational Level	Palliative Care Support • Referral pathway • Holistic palliative care needs assessment • Information and education according to diagnosis & prognosis • Clinical protocols & pathways • Symptom management advice • Quality Improvement programs – e.g. PCOC National Data collection • Access to after hours number and support • Intermittent support contact e.g. Via telephone or community outpatient visit/appt	Community Palliative Care Support Service - Nursing - GP - Allied health - Volunteers	Health care providers Public/Private/NGOs Palliative Care Services • Community • Home/outpatient/GP practice • Telephone support
Individual level	• Full assessment on referral • Carer training and information • Information about accessing help as required e.g. after hours call number • Service access according to assessment	Community Palliative Care Support Service	Health care providers Public/Private/NGOs • Inpatient – prior to discharge • Community home care

2b. Ongoing Illness – with non complex needs

	What should be provided?	**Who should provide it?**	**Where should it be provided?**
Organisational Level	Multidisciplinary palliative care - according to the patient needs: e.g. palliative approach with access to specialist palliative care consultancy /advice • Referral pathway • Holistic palliative care needs assessment • Care planning • Clinical protocols & pathways • Symptom management • Bereavement Risk Assessment Psychosocial support • Counseling support • Spiritual support • Information and education for patient & families according to diagnosis & prognosis • Access to respite • Ongoing palliative care education and support for primary care providers • After hours "on call" backup for health professionals	Multidisciplinary non palliative care specialists/generalists with consultancy and advice from specialist palliative care. • Primary Care Providers - Primary care - Regional hospitals - Hospital specialties e.g. Cardiac, Renal, Respiratory, Neurology • Medical Consultants • GPs • Nursing • Allied Health • Volunteers	Health care providers Public/Private/NGOs • Tertiary & secondary health services • Community services • Primary care • Telehealth • 1300 PC Medical Specialist Outreach Advisory
Individual Level	• Full assessment on referral and ongoing • Patient and Carer education and information e.g. "Live Well, Live Now" • Appropriate timely communication and information for both patient and family • Family Meetings • Timely clinical management • Psychosocial and spiritual support • Culturally appropriate care • Information about accessing after hours call number	Health care professionals - As above	Health care providers Public/Private/NGOs • Tertiary & secondary health services • Community services • Primary care • Telehealth • 1300 PC Medical Specialist Outreach Advisory

2c. Ongoing Illness – with complex needs

	What should be provided?	Who should provide it?	Where should it be provided?
Organisational Level	Multidisciplinary palliative care - according to the patient needs with ongoing access to specialist palliative care • Referral pathway • Holistic palliative care needs assessment • PC Specialist team • Care planning • Clinical protocols & pathways • Bereavement Risk Assessment Psychosocial support • Counseling support • Spiritual support • Access to PC Unit/Hospice beds • Access for procedures e.g. radiology & anesthetics • Access to other specialists e.g. Anesthetist, Oncologist, Psychiatrist • Culturally appropriate support • Discharge/transfer planning • Specialist equipment	Specialist Palliative Care Teams • PC Medical - Consultants - Registrars - General Practitioners • Nursing - CNCs - Nurse Practitioners - RNs - Enrolled nurses - Patient Care Assistants • Allied Health - Social Work - OT - Physio - Dietitian - Speech pathology - Chaplaincy - Counseling • Volunteers • Other specialists on referral	Health care providers Public/Private/NGOs Specialist Palliative Care Services (Tertiary/Secondary) • Inpatient • Community - e.g. Silver Chain Hospice home care • Consultancy - e.g. Hospital
Individual Level	• Ongoing assessment • Appropriate timely communication and information for both patient and family • Family Meetings • Carer Education e.g. Learn Well; Live Now” • Timely clinical management • Psychosocial and spiritual support • Culturally appropriate care • After hours contact information	Specialist Palliative Care Teams • As above	Health care providers Public/Private/NGOs Specialist Palliative Care Services (Tertiary/Secondary) • Inpatient • Community - e.g. Silver Chain Hospice home care • Consultancy - e.g. Hospital

3. End of Life Care

	What should be provided?	Who should provide it?	Where should it be provided?
Policy Level	1. *Legislation: Medical Tx for the Dying Bill* 2. Aust. Health Care Agreements 2003-2008 Implementation of the National Palliative Care Strategy • Goal 2: Quality and effectiveness • Goal 3: Partnerships in care *Access to quality palliative care* • End of Life Pathway Policy endorsement • Referral/Admission/Discharge Policy • WA Health Work Life Balance Policy	State Government DoHWA	
Organisational Level	End of Life Care • Referral pathway • Ongoing holistic palliative care needs assessment • Care planning • Clinical protocols & pathways • Symptom management • Bereavement Risk Assessment Psychosocial support • Counseling support • Spiritual support • End of Life Pathway on "diagnosis" of dying (E.g. LCP) • Access to inpatient beds or hospice beds • Culturally appropriate support • Discharge/transfer planning • Specialist equipment e.g. Syringe pumps	All Health Care Providers • Specialist Palliative Care Teams • Primary Health Care Providers	Home Hospital – general wards & specialist units, e.g. ICU, Palliative Care Units/Hospice Aged Care Facilities Mental Health Facilities Corrective Services Disability services
Individual level	• Care according to End of Life Pathway • Appropriate timely communication and information for both patient and family • Choice of place of death – for example at home or in inpatient facility.	All health professionals & volunteers	

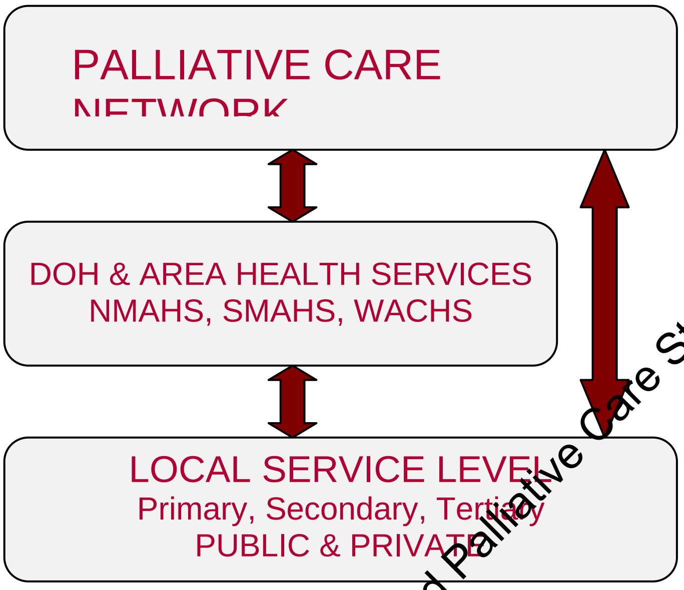
	• Facilitation of transfer to home or inpatient facility if required. • Family support		

4. Bereavement			
	What should be provided?	**Who should provide it?**	**Where should it be provided?**
Policy Level	"Standards for providing quality palliative care for all Australians" (4th edn., PCA 2005) Bereavement Support Policy	PCA Health Services	
Organisational Level	• Policy implementation • Information Package for family members • Training and support for staff and volunteers involved in bereavement support • Bereavement risk assessment • Directory of professional counseling resources and referral process.	All Health Care Providers/ Services • Palliative Care services • Primary Health Care Providers	Home Hospital – general wards & specialist units, e.g. ICU, Palliative Care Units/Hospice Aged Care Facilities Mental Health Facilities
Individual Level	Information on grief and loss provided to family members Support offered according to need and Bereavement Policy. E.g. Follow up phone contact. Encourage support from local community	Health professionals Family and friends	Local Community Via phone

5. APPLICATION OF THE PALLIATIVE CARE MODEL IN WESTERN AUSTRALIA

The Palliative Care Network will work strategically with Area Health Services: North, South and Country, to develop and implement a coordinated approach to the integration of palliative care across the state. The PC Report (2005) has made specific recommendations relating to the development and coordination of specialist palliative care services in metropolitan Perth and in rural and remote WA. By coordinating the functions of normally separate services including alignment of practices, processes, protocols and systems, it is anticipated that this will result in improved outcomes and efficiencies for the patient and family as well as the services involved.

Figure 7. Model Implementation Relationships



Policy Development
- Best practice - Standards
- Service planning
- Pathways & Protocols
- Coordination

Strategic Planning
- Service Infrastructure
- Governance
- Workforce Issues
- Resources - equipment

Model Implementation
- Area Health Teams
- Pathways & protocols
- Workforce e.g. mentoring/training

5.1 South and North Metropolitan Area Health

Figures 8 and 9 illustrate the tertiary, secondary and primary service locations, based on a population based approach, and Clinical Service Framework levels of palliative care services in both the South Metropolitan Area Health Service (SMAHS) and the NMAHS. Figures 8 & 9 also highlights that the tertiary hospital services operate interdependently with highly specialised inpatient and community services to ensure timely discharge from the acute care sector, ongoing care and follow-up.

Tertiary palliative care services are required to offer high levels of expertise and from a medical perspective must meet the criteria set by the Royal Australasian College of Physicians Combined Specialist Advisory Committee (CSAC) in Palliative Medicine (Appendix 5) for accreditation as a service and also meet the PCA Standards[20] at Specialist Level 3. These services must also have the capacity and resources to provide leadership, outreach advice, episodic care and consultancy to secondary and primary care services in both metropolitan and rural locations.

The proposed spread of secondary specialist palliative care services across each region permits patients to receive access to public funded domiciliary and inpatient care close to

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[20] Palliative Care Australia. (2005). *Standards for Providing Quality Palliative Care for all Australians.*

their homes. Secondary palliative care services also provide a support role to primary care providers.

Silver Chain Hospice Care and Peel Community Palliative Care services give patients and families throughout Perth and the Peel region the choice of high level specialist palliative care at home. It is widely acknowledged that people wish to spend most time at home, but the need to have 24 hour 7 day access to inpatient beds is emphasised.

The PCA Framework and Standards

The PCA (2005) framework, for accessing palliative care based on level of need, recognises the role of primary care providers and defines specialist palliative care services by the level of resources available to them and by their expected capabilities. The PCA Standards (Appendix 4) are applied according to the service level. *Table 5: PC Services Framework* demonstrates the relationship between the Palliative Care Australia and the WA Clinical Services Framework. Further explanation of service capabilities and resource requirements are detailed in Appendices 2 & 3.

Table 5: PC Services Framework

WA Clinical Services Framework[21] Level	Palliative Care Australia Level
1-2	Primary Care
3	Specialist Palliative Care Level 1
4	Specialist Palliative Care Level 2
5-6	Specialist Palliative Care Level 3

5.2 Area Health Palliative Teams

The PC Report (2005) recommendation 6 advocates for Area Health Palliative Teams to be implemented in both the NMAHS and SMAHS regions. The governance of the Area Health Palliative Team has not been fully explored but it is essential that the Palliative Care Network remains as the central link with stakeholders to promote quality and equitable service provision statewide. It is proposed that an Area Health Palliative Team would:

- function at operational level to provide seamless care systems for patient transition between palliative care units, consultative services, and domiciliary care and supporting community based services and rural care.
- link all services under the clinical oversight of a single team of clinicians for the purposes of:
  - staff rotation: for example RMO and Registrar rotations
  - staff exchange between services to provide opportunities for career development and the promotion of seamless care
  - integrated on call systems
  - providing Graduate Nurse program access into palliative care
  - having a common staff development program
  - staff support
  - enhancing quality improvement opportunities
  - research
  - common data collections
  - shared pool of volunteers

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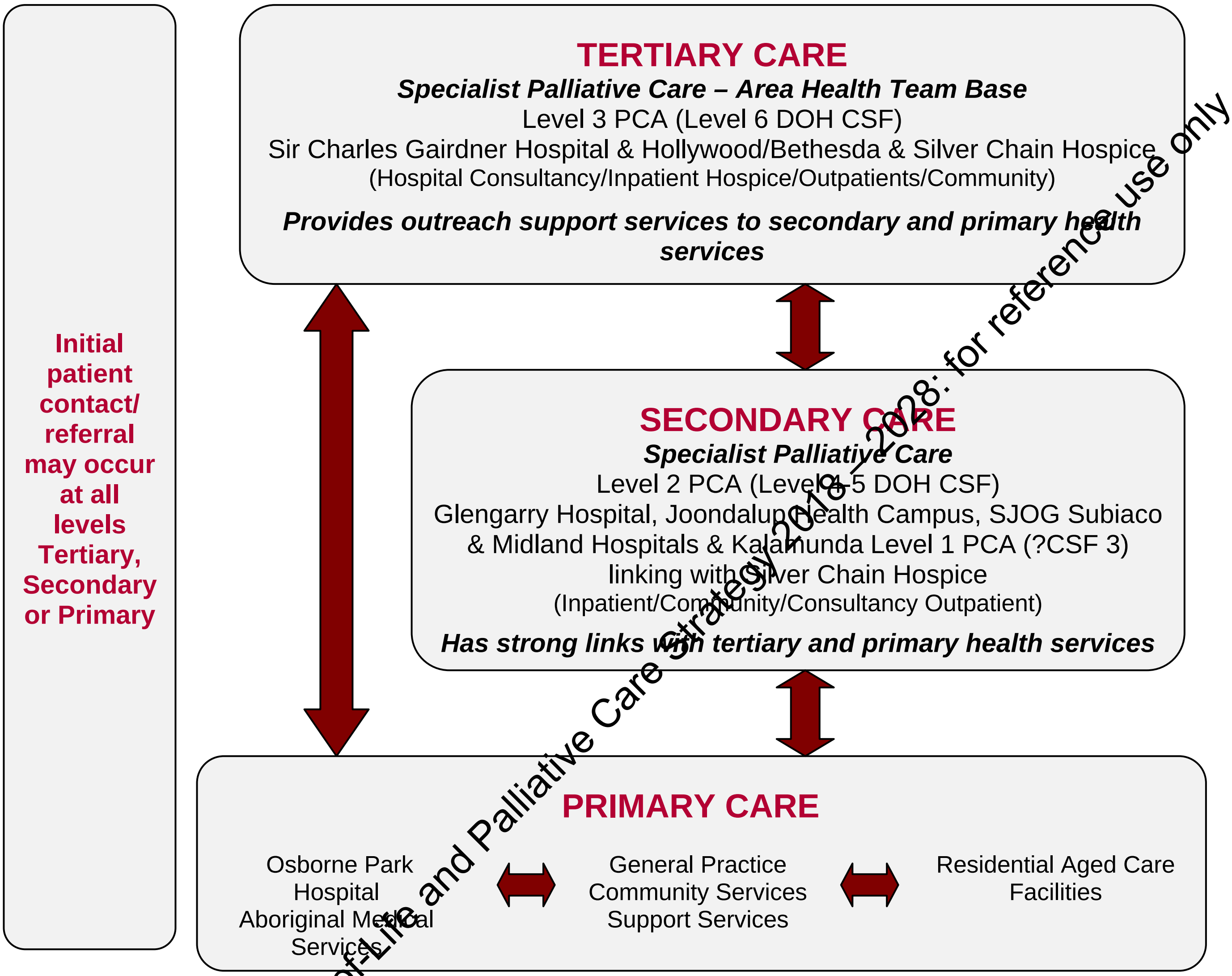
[21] Department of Health (2005), Clinical Services Framework 2005-2015, Perth, Western Australia, Department of Health WA.

  - student placements
- share common criteria for all referrals
- develop the role of Palliative Care Nurse Practitioner
- develop specialist allied health roles
- aim for patient held records to aid seamless care and negate the need for re-referral between services
- provide consultation into Residential Aged Care Facilities
- have direct integration with university based education and research facilities
- have palliative care consultancy teams in the tertiary hospitals, Sir Charles Gairdner Hospital (NMAHS) & Fiona Stanley (SMAHS) to maximise access to palliative care services, throughout the hospital, for all patients regardless of diagnosis and to minimise the time spent in tertiary care
- allow for patient follow-up in the community setting to reduce the unnecessary patient/family burden, of returning, as an outpatient, to the tertiary setting
- have access to video conferencing facilities.

5.3 North Metropolitan Area Health Region

Figure 8: Draft North Metro Area Health Service Palliative Care Services



Initial patient contact/ referral may occur at all levels Tertiary, Secondary or Primary

TERTIARY CARE

Specialist Palliative Care – Area Health Team Base

Level 3 PCA (Level 6 DOH CSF)

Sir Charles Gairdner Hospital & Hollywood/Bethesda & Silver Chain Hospice

(Hospital Consultancy/Inpatient Hospice/Outpatients/Community)

Provides outreach support services to secondary and primary health services

SECONDARY CARE

Specialist Palliative Care

Level 2 PCA (Level 4-5 DOH CSF)

Glengarry Hospital, Joondalup Health Campus, SJOG Subiaco & Midland Hospitals & Kalamunda Level 1 PCA (?CSF 3) linking with Silver Chain Hospice

(Inpatient/Community/Consultancy Outpatient)

Has strong links with tertiary and primary health services

PRIMARY CARE

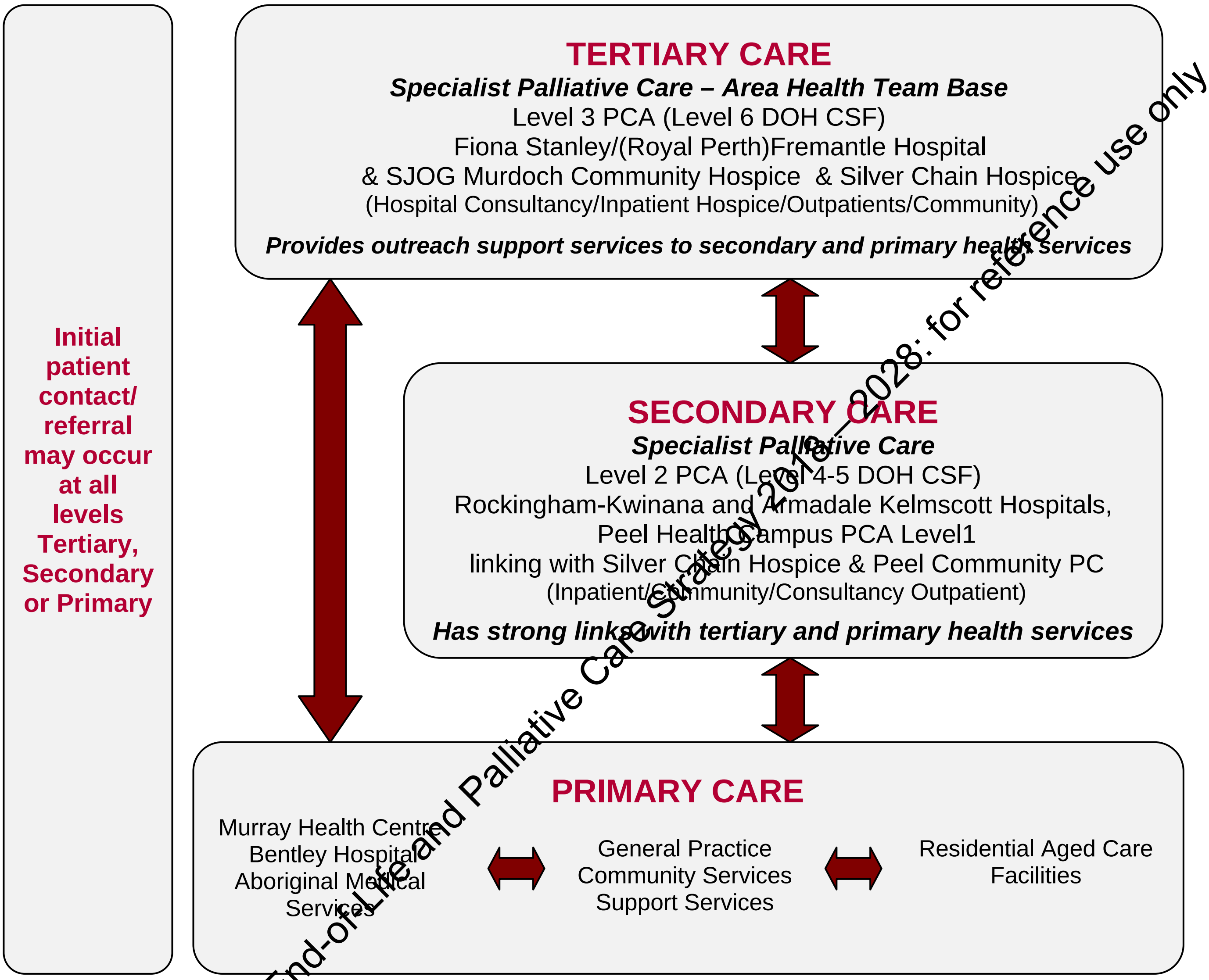
Osborne Park Hospital
Aboriginal Medical Services

General Practice
Community Services
Support Services

Residential Aged Care Facilities

5.4 South Metropolitan Area Health Region

Figure 9: Draft South Metro Area Health Service Palliative Care Services



Initial patient contact/ referral may occur at all levels Tertiary, Secondary or Primary

TERTIARY CARE

Specialist Palliative Care – Area Health Team Base

Level 3 PCA (Level 6 DOH CSF)
Fiona Stanley/(Royal Perth)Fremantle Hospital
& SJOG Murdoch Community Hospice & Silver Chain Hospice
(Hospital Consultancy/Inpatient Hospice/Outpatients/Community)

Provides outreach support services to secondary and primary health services

SECONDARY CARE

Specialist Palliative Care

Level 2 PCA (Level 4-5 DOH CSF)
Rockingham-Kwinana and Armadale Kelmscott Hospitals,
Peel Health Campus PCA Level1
linking with Silver Chain Hospice & Peel Community PC
(Inpatient/Community/Consultancy Outpatient)

Has strong links with tertiary and primary health services

PRIMARY CARE

Murray Health Centre
Bentley Hospital
Aboriginal Medical Services

General Practice
Community Services
Support Services

Residential Aged Care Facilities

5.5 Rural Palliative Care

Recommendations 17-23, of the PC Report, relate to issues for Rural and Remote Communities. The Palliative Care Network has been addressing these issues by further consultation at regional level, by the formation of a Rural Working Group and by conducting a Rural Audit in July/August 2007. The report of the Rural Audit highlights that rural people are passionate about the need for palliative care, but care at local community level is variable and often dependent on the interests of individuals. There is not the opportunity to work in a coordinated, structured environment that provides access to expertise and peer support.

To complement this model of care document a Rural Model of Palliative Care to address the specific needs of rural and remote communities is currently being developed and will under go further consultation. A key component of the Rural Model will be the establishment of links with metropolitan palliative care specialist expertise. Medical Specialist Outreach Assistance Program (MSOAP) funding has been accessed for the current 2007-8 financial year. This funding is being used to pilot regular palliative care medical specialist visits to each of the seven rural regions. The evaluation of the MSOAP program will help to inform the future needs of each region and the Rural Model of Palliative Care for consideration by WA Country Health Service (WACHS).

Other key initiatives proposed for rural regions are:

- a country health Area Palliative Care Team/Network
- regional governance of palliative care
- regional coordination
- the use of technologies including Telehealth to maintain rural metro and regional links.

Metro-Rural Links – Partnerships - Ongoing Complex Needs:

Bob, diagnosed with metastatic colorectal cancer, lived with his wife in the Wheatbelt. He developed intractable pain which caused him to be bedridden for six weeks. He was referred by his Medical Oncologist to a Perth Hospital Palliative Care Consultancy Service. Bob was trialled on various analgesia regimens unsuccessfully before an intrathecal port-a-cath was inserted to administer continuous intrathecal analgesia. He quickly stabilised and was rehabilitated ready to return home to the country.

The Regional Palliative Care Service (RPCS) had no experience in the management of intrathecal analgesic devices and did not provide a service in the area in which Bob lived, but agreed to be involved in his care as Bob's local hospital initially declined to care for the intrathecal device. The Perth PC Consultancy Service coordinated a complex action plan to get Bob home. The plan was set up for the RPCS to provide 24hr telephone support to Bob's local hospital and to see Bob in the regional hospital weekly to provide intrathecal care. The education needs of Bob and his wife, the RPCS and the local hospital were also addressed with the assistance of the pharmaceutical company which supplied the pump and port and a visit to the regional hospital by the Perth service's Clinical Nurse Consultant. In addition, the Perth service worked closely with the GP, Medical Oncologist and local health services, providing contingencies and plans for complications and 24 hour telephone support.

Bob's care continued to be shared by the medical oncology and palliative care teams. He required episodic readmission to Perth for support of complex symptoms, such as acute obstruction, fistula formation, throughout the remainder of his life. He enjoyed many weeks/months of good stable symptom control at home where he remained independent in between these admissions. Bob identified that without the benefit of Intrathecal analgesia he would have died much earlier in his disease. He died in the place of his choice, his district hospital, nearly 12 months later.

5.6 Paediatric Palliative Care Model

The specific palliative care needs of children and adolescents will be addressed in a Paediatric Palliative Care Model currently being developed with the Child and Adolescent Health Services.

6. HORIZON SCANNING

The ageing population, combined with predicted population growth, will increase the need for palliative care services and impact on the WA health care system. The challenge will be to minimise this impact by addressing workforce issues, including health professional training, and effective resource use.

- In the event that Legislation relating to End of Life is implemented in WA, there will be a flow on need for information/education.
- Workforce issues will impact across all sectors:
  - Medicine: WA is fortunate to have effective post graduate palliative care medical training systems in place. Unless substantive medical positions are created within the health care system to meet the need for expanded palliative care services, future graduates will be lost to WA.
  - There will be a need to diversify nursing roles including the introduction of Nurse Practitioners.
  - Palliative care will need to be introduced as a core component in nursing and allied health curriculum.
  - Primary care providers will require upskilling to provide a palliative approach in all care settings.
- Morbidity associated with palliative care patients can be reduced by:
  - the implementation across the health care system of clinical protocols to address poor symptom management
  - improved access to appropriate medications in the community
  - implementation of a program of clinical research.
- The use of technologies such as Telehealth and computer related technology will enable improved capacity to care for people in their own homes especially in remote and rural regions.
- As the population ages, and with increased public awareness, there will be an expectation of quality palliative care in all sectors of the WA Health system.

7. KEY RECOMMENDATIONS

Recommendation 1

The Palliative Care Network **Model of Care** is endorsed.

Recommendation 2

A plan for model implementation is developed by the DoH and Area Health Services in conjunction with the Palliative Care Network and local service providers.

Recommendation 3

That palliative care services are integrated state wide with the Palliative Care Network linking stakeholders to promote quality and equitable service provision.

Recommendation 4

A study is conducted to pilot and cost a model of supportive community care for patients with ongoing life limiting illness with intermittent needs. These needs of this population are unmet by current palliative care services.

Recommendation 5

A referral pathway is developed and implemented to ensure appropriate timely referral to specialist palliative care services according to patient needs.

Recommendation 6

An End of Life pathway is endorsed, within a quality improvement framework, for implementation statewide.

Recommendation 7

Evidence based clinical protocols, to guide primary care providers in appropriate timely management of palliative care patients, are introduced to the WA health system statewide.

Recommendation 8

That the Palliative Care Network works collaboratively with Palliative Care WA (Peak Body)to develop a Health Promoting Palliative Care strategy to increase consumer and health provider awareness of palliative care and end of life issues.

Recommendation 9

A Business Case is developed to scope the palliative care data collection needs and feasibility of database development.

8. IMPLEMENTATION OF RECOMMENDATIONS

The Palliative Care Network proposes that the implementation of the recommendations be phased according to resource needs and further planning and development. There is scope within existing Network resources to implement Phase One recommendations in the near future but Phase Two recommendations will require additional planning and will have resource implications.

Phase One

The Palliative Care Network with existing resources can undertake:

- to link stakeholders to promote quality and equitable service provision (Rec 3)
- to develop a Referral Pathway to ensure appropriate timely referral to specialist palliative care services according to patient needs (Rec 5)
- the implementation of an end of life pathway (Rec 6)
- the implementation of evidence based clinical protocols, to guide primary care providers in appropriate timely management of palliative care patients (Rec 7)
- the development of a Health Promoting Palliative Care Strategy to increase consumer and health provider awareness of palliative care and end of life issues (Rec 8)
- a study conducted to pilot and cost a model of supportive community care for patients with ongoing life limiting illness with intermittent needs (Rec 4)

Phase Two

The implementation of the following recommendations will require further planning and will have human and financial resource implications:

- planning for the implementation of the model by Area Health Services in conjunction with the Palliative Care Network and local service providers (Rec 2)
- ongoing training for health professionals, in the use of pathways and protocols, will require the support of Area Health Services
- the development of a Business Case to scope the palliative care data collection needs and feasibility of database development (Rec 9)

GLOSSARY

Model of Care

A model of care is a multifaceted concept, which broadly defines the way health services are delivered (Queensland Health, 2000[22]) A model of care outlines best practice patient care delivery through the application of a set of service principles across identified clinical streams and patient flow continuums(Waikato Health Board, 2004[23]) .

Life Limiting Illness

This term is used to describe illnesses that can be reasonably expected to cause the death of the patient within a foreseeable future. This definition is inclusive of both a malignant and non-malignant illness.

Primary Care Provider

The use of the term is taken to include all those health services and staff that have a primary or "first contact" relationship with the patient with a life limiting illness. This is inclusive of general practitioners, community nurses, staff of residential aged care facilities and multipurpose centres. It also includes other specialist services and staff, for example oncologists, renal, cardiac or respiratory physicians, and staff of acute care hospitals. These staff, while specialists in their own areas, may undertake an ongoing role in the support of patients with a life limiting illness. In this context they are seen as the primary care service with a specialist palliative care service involved on an 'as required' basis only. In general the substantive work of the primary care provider is not in palliative care (PCA, 2005).

Specialist Palliative Care Service

This term is used to denote a multi-disciplinary health care service whose substantive work is with patients who have a life limiting illness.

Specialist palliative care professionals would be expected to have recognised qualifications or accreditation in palliative care.

Specialist palliative care services provide consultative and ongoing care for patients with a life limiting illness and provide support for their primary carer and family during and after the patient's illness.

In general, specialist palliative care services would not be directly involved in the care of people who do not have complicated needs associated with a life limiting illness (Palliative Care Australia 2005).

Palliative Approach

A palliative approach is care on the basic principles of palliative care.

A palliative approach aims to improve the quality of life for individuals with a life-limiting illness or who are dying due to the ageing process, and their families, by reducing their suffering through early identification, assessment and holistic treatment of pain, physical, psychological, social, cultural, and spiritual needs. A palliative approach is not delayed until the end stages of an illness or the ageing process. 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 residents and their families understanding that

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[22] Queensland Health (2000) Changing Models of Care Framework, Queensland, Queensland Health.

[23] Waikato Health Board (2004) Child & Adolescent Clinical Stream: Proposed Model of Care, New Zealand, Health Waikato Division.

they are being actively supported through this process. Underlying the philosophy of a palliative approach is a positive and open attitude towards death and dying.

Family

This term includes those closest to the patient in knowledge care and affection. The family may include biological family, the family of acquisition (related by marriage/contract) and the family of choice and friends (including pets) (PCA, 2005).

The patient's family or carers may well provide the majority of care, with education and support provided by health care staff.

Interdisciplinary Team

Interdisciplinary function is generally the aim of specialist palliative care teams, with members contributing from their particular expertise. The team shares information and works interdependently.[24]

Multidisciplinary Team

Professional identities are clearly defined and team membership is secondary. Professionals may contribute expertise in isolation from one another.[25]

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[24] Crawford, G. & Price, S. (2003) Team working: palliative care as a model of interdisciplinary practice. *Medical Journal of Australia.* 179: S32-S34.

[25] Crawford, G. & Price, S. (2003) Team working: palliative care as a model of interdisciplinary practice. *Medical Journal of Australia.* 179: S32-S34.

APPENDICES

Appendix 1

Domains of Palliative Care:

* Other common symptoms include, but are not limited to:

Cardio-respiratory: breathlessness, cough, oedema, hiccups, apnoea

Gastrointestinal: anorexia, nausea, vomiting, constipation, bowel obstruction, diarrhoea, bloating, dysphagia, dyspepsia

Oral conditions: dry mouth, mucositis, candidiasis

Skin conditions: dry skin, nodules, pruritus, rashes, fungating wounds, fistulas, pressure areas

General: fatigue, weakness, cachexia, drowsiness, effusions (pleural, peritoneal), fever/chills, metabolic imbalance including hypercalcaemia, insomnia, incontinence, lymphoedema, myoclonus, odour, sweats, syncope vertigo, coagulopathy, cord compression, terminal agitation/restlessness/delirium.

Appendix 2: Clinical Services Framework - Palliative Care

Clinical Service Level	Service Provision	PC Model Requirements
ONE & TWO *(PCA PRIMARY CARE)*	Generalist health professionals provide a palliative approach to care in: General practice and generalist community services All Residential Aged Care Facilities Primary care providers- medical, oncology and other wards/ units/services in the acute care sector	Meets the PCA Standards at Primary Care Level. Has access to specialist palliative care support and consultation All staff should access and participate in palliative care professional development. Uses palliative care assessment tools, pathways and protocols
THREE *(PCA SPECIALIST PALLIATIVE CARE LEVEL 1)*	Has a multidisciplinary approach Medical and nursing staff have palliative care experience Provides assessment and care consistent with patient/family and caregiver needs Accesses help from tertiary and secondary palliative care services when required Has access to allied health professionals eg. social work, pastoral care, occupational therapy, physiotherapy, pharmacy, dietician. Access to visiting palliative care specialist Volunteer program Provides bereavement support	Meets the PCA Standards at Specialist Level.1. Has formal access to tertiary and secondary specialist palliative care support and consultation Uses palliative care assessment tools, pathways and protocols Collects palliative care data
FOUR *(PCA SPECIALIST PALLIATIVE CARE LEVEL 2)*	As for level 3 plus: Medical practitioner with palliative care qualifications Access to Medical Registrar Access to CNC/ specialist experienced (and qualified) in palliative care Provides consultation to other services 24 hour on call service Access to anaesthetic & radiology services Access to general medicine services Access to respite care Participates in research Participates in palliative care Quality Improvement Health Promotion Activities	Meets the PCA Standards at Specialist Level.2 Meets Criteria for GP Trainee supervision Has formal access to tertiary specialist palliative care support and consultation and supports primary care Uses palliative care assessment tools, pathways and protocols Collects palliative care data
FIVE –SIX *(PCA SPECIALIST PALLIATIVE CARE LEVEL 3)*	As for level 4 plus: Provides complex care including complex parenteral medication regimes. Inpatient care by resident palliative care Physician Registrar/RMO roles Full range of interdisciplinary team members trained in palliative care (eg. Nursing & Allied Health) Palliative care specialist team provides consultancy to other units Develops & uses evidence based protocols Undergraduate and postgraduate teaching role Leads research and quality activities. Links with oncology, radiotherapy, anaesthetics, psychiatry, surgery, general medicine, pain clinic and rehabilitation. Provides ambulatory care services Statewide referral role Has staff with conjoint appointments with universities Has health promotion responsibility	Meets the PCA Standards at Specialist Level.3 Meets requirements for Royal College of Physicians accreditation: ▪ 1 FTE Palliative Care Physician ▪ CNC position ▪ Oncall service ▪ Access to medical oncology ▪ Access to radiation oncology ▪ Access to haematology ▪ Access to pain or anaesthetic service (Meets future accreditation requirements for other health disciplines.) Is resourced to provide outreach to secondary and primary care services Collects palliative care data

Appendix 3: Palliative Care Australia - Capability and Resource Matrix

The level and complexity of a patient's needs, as well as strengths and limitations of the patient, their caregiver/ and family will determine the level of care required. Palliative Care Australia has developed a framework which describes the interwoven roles of primary health care and specialist palliative care services defined by the level of resources available to them and by their expected capabilities.

Level	Capability	Typical resource profile
PRIMARY CARE	▪ 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. ▪ Has formal links with a specialist palliative care provider for purposes of referral, consultation and access to specialist care as necessary.	General medical practitioner, nurse practitioner, registered nurse, generalist community nurse, aboriginal health worker, allied health staff. Specialist health care providers in other disciplines would be included at this level.
SPECIALIST PALLIATIVE CARE LEVEL 1	▪ Provides specialist palliative care for patients, caregiver/s and families whose needs exceed the capability of primary care providers. ▪ Provides assessment and care consistent with needs and provides consultative support, information and advice to primary care providers. ▪ Has formal links to primary care providers and level 2 and/or 3 specialist palliative care providers to meet the needs of patients and family/carers with complex problems. ▪ Has quality and audit program.	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.
SPECIALIST PALLIATIVE CARE LEVEL 2	▪ As for level 1 ▪ Able to support higher resource level due to population base (eg regional area). Provides formal education programs to primary care and level 1 providers and the community. ▪ Has formal links with primary care providers and level 3 specialist palliative care services for patients, caregiver/s and families with complex needs.	Interdisciplinary team including medical practitioner and clinical nurse specialist/consultant with specialist qualifications. Includes designated allied health and pastoral care staff.
SPECIALIST PALLIATIVE CARE LEVEL 3	▪ Provides comprehensive care for the needs of patients, caregiver/s and families with complex needs. ▪ Provides local support to primary care providers, regional level 1 and/or 2 services including education and formation of standards. ▪ Has comprehensive research and teaching role. ▪ Has formal links with local primary care providers and with specialist palliative care providers level 1 and 2, and relevant academic units including professorial chairs where available.	Interdisciplinary team including a medical director and clinical nurse consultant/nurse practitioner and allied health staff with specialist qualifications in palliative care.

Appendix 4: Palliative Care Australia - Standards for providing Quality Palliative Care for all Australians

The Standards have been developed for use in a number of ways to support and enhance quality care for patients with a life limiting illness. Services and providers will be encouraged to adopt the Standards on a voluntary basis, and accreditation services will be asked to incorporate these Standards as part of their assessment of palliative care. Each of the 13 Standards has criteria for primary care services and three levels of criteria for specialist palliative care services.

Standard One

Care is based on a respect for the uniqueness of the patient, their caregiver/s and family. The patient, caregiver and family needs and wishes are acknowledged and guide decision-making and care planning.

Standard Two

The holistic needs of the patient, their caregiver/s and family, are acknowledged in the assessment and care planning processes, and strategies are developed to meet those needs, in line with their wishes.

Standard Three

Ongoing and comprehensive assessment and care planning are undertaken to meet the needs and wishes of the patient, their caregiver/s and family.

Standard Four

Care is coordinated to minimise burden on patient, their caregiver/s and family.

Standard Five

The primary caregiver/s is provided with information, support and guidance in their role according to their needs and wishes.

Standard Six

The unique needs of dying patients are considered, their comfort maximised and their dignity preserved.

Standard Seven

The service has an appropriate philosophy, values, culture, structure and environment for the provision of competent and compassionate palliative care.

Standard Eight

Formal mechanisms are in place to ensure that the patient, their caregiver/s and family have access to bereavement counseling, information and support services.

Standard Nine

Community capacity to respond to the needs of people who have a life limiting illness, their caregiver and family is built through effective collaboration and partnerships.

Standard Ten

Access to palliative care is available for all people based on clinical need and is independent of diagnosis, age, cultural background or geography.

Standard Eleven

The service is committed to quality improvement and research in clinical and management practices.

Standard Twelve

Health professionals and volunteers are appropriately qualified for the level of service offered and demonstrate ongoing participation in continuing professional development.

Standard Thirteen

Staff and volunteers reflect on practice and initiate and maintain effective self-care strategies.

Appendix 5: The Royal Australasian College of Physicians Combined Specialist Advisory Committee (CSAC) in Palliative Medicine

Accreditation of Advanced Training Positions

CRITERION A

The trainee shall be provided with appropriate supervision for advanced training.

A.1 The Training Position shall be provided with a minimum of two Palliative Medicine Consultants as staff members who are able to supervise the trainee locally. *The purpose of having two individuals is to ensure that at least one consultant is always available to provide supervision and advice. It is recognised that much of the supervision can be provided by telephone, but the trainee must be able to call upon the consultant to provide supervision in person.*

A.2 The Training Site must have at least 1.0 Full Time Equivalent (FTE) Palliative Medicine Specialists as staff members.

A.3 A Palliative Medicine Consultant, holds the FRACP (or FAChPM in the case of Chapter Trainees) who is also a member of the Australian and New Zealand Society of Palliative Medicine.

A.4 The two Palliative Medicine Consultants shall provide complete back-up cover for trainees involved in after-hours and on-call work.

A.5 Supervisors should be trained in the supervision of advanced trainees in palliative medicine. Supervisors must have attended College Supervisor Workshops at least once every 5 years.

CRITERION B

The trainee shall be provided with a sufficient workload of clinical material to support each advanced trainee. A Palliative Medicine Consultant shall ensure that the trainee is involved in all aspects of the work of the Service. This includes regular sufficient numbers of new patients, consultations, review consultations, outpatient consultation clinics, inpatients and appropriate procedures including paracenteses.

B.1 An inpatient (hospice) unit should have a minimum of 200 admissions per training position.

B.1.2 The inpatient (hospice) unit should have an interdisciplinary team to manage patients.

B.2 A Community Palliative Care Unit should be seeing a minimum of 200 referrals a year per training position.

B.3 A Hospital Palliative Care Consult service should be seeing a minimum of 250 new referrals a year per training position.

B.3.1 The Hospital Palliative Care Consult service should have at least 1.0 FTE Clinical Nurse (preferable at Nurse Specialist level for the purposes of education) on the service.

B.4 The trainee must participate in an oncall service (where available) for Palliative Care, in conjunction with a Palliative Medicine Specialist.

CRITERION C

The trainee shall be provided with a suitable infrastructure for advanced training.

C.1 The Training Position shall include provision for the trainee to attend regularly scheduled interdisciplinary palliative care clinical meetings (at least one per week), peer-review meetings and correlative imaging meetings or other methods that can be documented.

C.2 The Training Position shall include provision of an appropriate academic environment for advanced training, through direct teaching, journal clubs, or other methods that can be documented.

C.3 The trainee shall be provided with access to a medical library with current books, relevant journals and computer facilities.

C.4 The trainee shall be provided with on-line internet access to clinical literature.

CRITERION D

The trainee should be provided with encouragement to undertake research (which can include clinical trials, audits, and QA activities) and/or continuing professional development during advanced training.

D.1 The Training Site shall provide opportunities for research in clinical or laboratory aspects of palliative care for each trainee.

D.2 The trainee shall be encouraged to be involved in one project annually. Supervision to be provided by the staff in the Department or other competent person.

D.3 Trainees shall be encouraged to attend scientific meetings of local, national and international societies, and to submit abstracts to such meetings.

CRITERION E

The trainee should be provided with access to other services such as oncology, haematology, radiation oncology and other specialist services.

E.1 The Palliative Care Training Site will have access to medical oncology.
E.2 The Palliative Care Training Site will have access to haematology.
E.3 The Palliative Care Training Site will have access to radiation oncology.
E.4 The Palliative Care Training Site will have access to pain or anaesthetic service.

Delivering a **Healthy WA**

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