

# WA Cancer & Palliative Care Network

## Rural Palliative Care Model in Western Australia

October 2008

Superseded by the WA End-of-Life and Palliative Care Strategy 2018 – 2028: for reference use only



Government of Western Australia  
Department of Health



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# Table of Contents

EXECUTIVE SUMMARY .....	5
1. INTRODUCTION .....	7
2. METHODOLOGY – THE DEVELOPMENT OF A RURAL PALLIATIVE CARE MODEL .....	
3. THE CURRENT STATE OF PLAY .....	8
3.1 Definition of Palliative Care .....	8
3.2 Burden of Disease .....	8
3.3 Current Rural Palliative Care Service Provision .....	9
3.3.1 Background .....	9
3.3.2 Smaller Towns .....	9
3.3.3 Regional Centres .....	9
3.3.4 Medical Care .....	10
3.4 Quality of Care .....	13
4. MODEL OF CARE .....	18
4.1 The Model .....	18
4.2 Regional Palliative Care Framework .....	19
4.2.1 Regional Governance .....	21
4.2.3 Regional Palliative Care Coordination .....	21
4.2.4 Local Care Coordination .....	21
4.2.5 “PRN Model” .....	22
4.2.6 Medical Care .....	22
4.2.7 Regional Palliative Care Interest Groups .....	22
4.3 Statewide Rural Palliative Care Specialist Interest Group .....	23
4.4 Links with Specialist Palliative Care .....	23
4.5 Indigenous Palliative Care Partnerships .....	24
4.5 The Patient’s Journey .....	26
4.5.1 Scenario 1 .....	26
4.5.2 Scenario 2 .....	27
5. KEY RECOMMENDATIONS .....	28
6. IMPLEMENTATION OF RECOMMENDATIONS .....	28
REFERENCES .....	29
APPENDICES .....	31
Appendix 1: Palliative Care in Western Australia. Final Report December 2005 .....	31
Appendix 2: Palliative Care Australia .....	33
Appendix 3: Capability and Resource Matrix .....	35
Appendix 4: Clinical Services Framework .....	36

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# Index of Tables

<b>Table 1.</b> Current Regional Centre Service Models.....	<b>13</b>
<b>Table 2.</b> Rural Survey Qualitative Responses.....	<b>15</b>
<b>Table 3.</b> Results of the WA Rural Palliative Care Survey.....	<b>16</b>

# Index of Figures

<b>Figure 1.</b> Regional Palliative Care Framework .....	<b>20</b>
<b>Figure 2.</b> Local Care Coordination.....	<b>22</b>
<b>Figure 3.</b> Statewide Rural Palliative Care Specialist Interest Group .....	<b>23</b>
<b>Figure 4.</b> Specialist Palliative Care Tertiary, Secondary, Primary Links .....	<b>24</b>
<b>Figure 5.</b> The Patient's Journey. Scenario 1.....	<b>26</b>
<b>Figure 6.</b> The Patients Journey. Scenario .....	<b>27</b>

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## EXECUTIVE SUMMARY

This Rural Palliative Care Model in Western Australia has the purpose of addressing the specific palliative care needs in rural and remote Western Australia and supplements the Palliative Care Model of Care.

Palliative care in rural Western Australia developed in an ad hoc manner leading to diverse models of palliative care which included a strong volunteer focus and community fund raising. Established regional palliative care services are nurse led models with a palliative care nurse coordinator appointed to set up and lead the service. The ad hoc nature of service development has led to inconsistencies in the work roles of the palliative care coordinators and variable levels of integration and coordination of palliative care across rural health regions. Little attention has been given to a governance structures and little focus on developing service models to meet the palliative care Palliative Care Australia Standards. The quality of palliative care medical input varies according to the interest, skills and good will of local medical practitioners. Short term Medical Specialist Outreach Assistance Program (MSOAP) funding is currently providing medical specialist visits to all rural regions. While this builds capacity in local communities it does not provide sustainable medical specialist services.

A Rural Audit conducted in 2007 found that many rural services care for small number of palliative care patients, have staff with little palliative care education and most education received is of an informal nature. There is a lack of knowledge about implementing palliative care standards but there is agreement that there is a need for systems to improve care, for example clinical pathways.

The Palliative Care Network has worked with rural clinicians, gleaned information from the Rural Audit, visiting medical specialists and rural regions to develop a Rural Palliative Care Model. This Model would provide a quality improvement framework approach to:

- develop sustainable regional palliative care services that will meet the criteria for, at minimum, Palliative Care Australia specialist palliative care Level 1 service capability and resources to provide palliative care according to the needs of patients and families in their local community.

To achieve this goal it will be important to:

- establish regional palliative care governance to provide support to service providers and be accountable for service sustainability and quality of care.
- develop a competent workforce that can access appropriate training, support, and expertise when patient and families needs exceed their knowledge and skill level.
- provide a framework of formalised palliative care links within regions, across WACHS, and with the metropolitan services.

The Rural Model proposes a framework for each of the seven WACHS regions. The key components of this framework are:

- regional governance
- a regional coordination role for each WACHS region
- local care coordination



- a 'PRN' approach to be able to care for patients with one-off needs
- access to medical care
- regional multidisciplinary palliative care special interest groups
- a statewide rural palliative care specialist interest group
- formal links with metropolitan specialist palliative care
- Indigenous palliative care partnerships

The following key recommendations are made:

1. The Rural Palliative Care Model in Western Australia is endorsed.
2. A plan for model implementation is developed by WACHS in conjunction with the Palliative Care Network and local service providers.
3. A state-wide palliative care education plan and implementation strategy is developed to provide access to a health professional workforce with palliative care knowledge and skills.
4. There is a coordinated approach, with the Palliative Care Network linking stakeholders, to the development and implementation of pathways and protocols to guide rural primary care providers in appropriate timely management of palliative care patients.
5. Strategies to provide culturally appropriate Indigenous palliative care are developed in partnership with Aboriginal Health Services and other appropriate stakeholders.

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## 1. INTRODUCTION

“The Palliative Care in Western Australia, Final Report December 2005” (PC Report)<sup>1</sup>, a population based review of palliative care needs, made recommendations for a vision to provide equitable access to an integrated model for palliative care statewide. Recommendations 17-23 (Appendix 1) of the PC Report relate to specific issues for rural and remote communities.

There is considerable evidence that people with advanced cancer wish to be cared for at home, particular at the end of life<sup>2,3</sup>. This is particularly important for people from rural and remote communities who experience considerable distress when cared for at end of life in metropolitan centres<sup>4</sup>. Research has identified the needs and barriers to the delivery of palliative care in rural regions but there is limited evidence of sustainable models of palliative care for rural and remote Australia<sup>3,4,5</sup>.

This Rural Palliative Care Model in Western Australia has the purpose of addressing the specific palliative care needs in rural and remote Western Australia and supplements the Palliative Care Model of Care<sup>6</sup>.

## 2. METHODOLOGY – The Development of a Rural Palliative Care Model

The WA Palliative Care Network has the brief of implementing the recommendations of the PC Report. A Palliative Care Network Rural Working Group, inclusive of representation from WA Country Health Services and a core group of rural palliative care clinicians, was established in December 2006 to address the specific rural and remote recommendations and rural issues. This group has met periodically face to face and via teleconference and video conference.

In July–August 2007 an independent Rural Audit was conducted by the University of Western Australia Population Health Unit using a telephone survey of 139 services with 100% response. This Rural Audit provided valuable information about the palliative care needs in rural regions which has supported the development of this rural model for palliative care,

Feedback from MSOAP visiting palliative care medical specialists who commenced rural visits in July 2007 and regional planning meetings held in Albany and Kalgoorlie have also contributed to the model development. Feedback from an extensive consultation process has also informed the final document.



### 3. THE CURRENT STATE OF PLAY

#### 3.1 Definition of Palliative Care

The World Health Organisation definition of palliative care is used for this rural model of care. The World Health Organisation (2006)<sup>7</sup> 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 in rural and remote Western Australia has implications for the provision of palliative care. Australians living in regional and remote areas generally experience poorer health than people living in major cities. In 2002-4 death rates in regional and remote areas were between 10-70% higher than in major cities<sup>8</sup>. Mortality rates in rural WA are significantly higher than the state average<sup>9</sup>. The incidence of cancer was significantly higher in 2001-3 in all Australian regional areas than in major cities. There is also a higher prevalence of Chronic Heart Failure in patients in rural Australia than urban areas<sup>10</sup>.

The poorer health status in country WA is related to the higher proportion of Indigenous people, with poor health outcomes living in remote areas. The overall mortality rates for Indigenous people are almost three times those for non-Indigenous people<sup>11</sup>. Deaths of Indigenous people involve higher rates of co-morbidity than deaths of non-Indigenous people. Twenty seven percent of deaths amongst Indigenous males and 29% of deaths amongst Indigenous females recorded five or more causes of death compared with 15% for non Indigenous male and female deaths<sup>11</sup>.





### 3.3 Current Rural Palliative Care Service Provision

#### 3.3.1 Background

Palliative care in rural Western Australia developed in an ad hoc manner leading to diverse models of palliative care including charity run hospices<sup>12</sup>. Palliative care in larger Regional Centres, for example Bunbury, Albany, Geraldton, Kalgoorlie and Busselton all originated from a community base, with a strong volunteer focus and community fund raising. Historically all Regional Centres have had an identified palliative care service at some point but not all services have been sustained. For example in the Pilbara and the Goldfields, short term Australian Government Commonwealth project funding was used for service provision but when the project expired both services were left unsustainable. This raised community expectations that a comprehensive palliative care service would be ongoing and community wrath when the services disintegrated. Funding committed to palliative care service provision is not consistent from region to region.

#### 3.3.2 Smaller Towns

Later government capital funding allowed even the smallest rural hospitals to establish designated palliative care rooms and local communities fund raised to provide additional equipment and environmental enhancement, for example special garden areas with outdoor furniture and shaded pergolas. Palliative care in smaller hospitals and towns is mainly provided by primary care clinicians with generalist skills. Knowledge, skills and standards of palliative care are variable with some health services dependent on a single nurse with a personal interest in palliative care or who has been allocated a small amount of time for a palliative care coordination portfolio. There is also evidence in rural regions of a lack of formal access to specialist palliative care expertise. Any turnover of the staff allocated to coordinate palliative care can impact significantly on the standard of care provided locally.

#### 3.3.3 Regional Centres

In the Regional Centres where palliative care services are established the model of care has been nurse led with a palliative care nurse coordinator appointed to set up and lead the service. Although palliative care has developed internationally using a formal interdisciplinary team approach, in rural regions there is only limited access to other health disciplines to function as part of a palliative care team. As the patients' clinical care needs have taken precedence, the nurse coordinator has had little time or resources allocated to develop the service. A study of palliative care nursing in rural Western Australia found that the nurses "lived palliative care." They took their work home, the role encroached 7 days a week on their lives. They also had to maintain a public profile and were often approached about patients in the local shopping centre. The role was also multifaceted "wearing many hats" for example, volunteer coordinator, educator, bereavement support as well as being the expert sometimes with not a lot of experience or professional support due to little understanding from others of the stresses inherent in palliative care work<sup>12</sup>.

The ad hoc nature of service development has led to inconsistencies in the allocation of palliative care coordinators' work hours, job descriptions and level of classification throughout the state. The level of integration and coordination of palliative care across health regions is variable. The Kimberley and the Midwest are the only regions that have substantive palliative care nurse coordinator positions that include regional coordination as a component of the role. Little attention has



been given to a governance structure to advise, monitor and support the nurse in the role and to ensure the sustainability of the service. There has been little focus on developing service models to meet the palliative care Palliative Care Australia Standards<sup>13</sup> (Appendix 2) and to date no Regional Centre has attempted to achieve accreditation as a palliative care service. The Rural Working Group has clearly identified a lack of consistency in policies and practices across the state and the lack of clinical support and regional governance relating to palliative care.

### 3.3.4 Medical Care

Until July 2007, medical care for rural palliative care patients was provided exclusively by local general practitioners with limited back up from the Palliative Care Medical Outreach Service 1300 Advisory number. The quality of medical care varied according to the interest, skills and good will of local medical practitioners. Training programs including the Program of Experience in the Palliative Approach (PEPA) and the Medical Specialist Outreach Assistance Program (MSOAP) funded Training Days delivered in rural regions have been important in raising skill levels and awareness of palliative care needs. In one Regional Centre a local GP with a special interest in palliative care is paid on a sessional basis to provide local backup and support for palliative care patients.

It has been demonstrated in the Eastern States of Australia that palliative care medical specialists visits to rural regions can improve patient care and in particular symptom control<sup>14</sup>. From July 2007 a twelve month pilot program funded through MSOAP has made possible palliative care medical specialist visits to all rural regions on a regular basis.

The MSOAP palliative care program aims to:

- Foster professional relationships with local health teams, general practitioners and nurses.
- Support local health professionals by case consultation, education, clinical procedures, and multidisciplinary team input.
- Advise on symptom control for patients with life limiting illness in each region.
- Provide palliative care consultation and expertise as appropriate for patients and their families.

Overall the MSOAP program achieved the expressed aims in the 12 month period, but highlighted the unmet needs in the rural regions. The success of the visits has been dependent on local coordination and this was an identified gap in several regions where prior to implementation of the MSOAP program there was little communication between health services in different towns. Where there is an established regional coordination role the expertise of the visiting medical specialist is used effectively to meet the aims of the program. In other regions where there is no palliative care coordinator role this process is adhoc and is reliant on the goodwill of other health professionals who do not have a designated palliative care role. For example in some regions the regional Cancer Nurse Coordinators are working beyond the scope of their role to fill the palliative care gaps as there is no provision for regional palliative care coordination. The visiting palliative care medical specialists report anecdotally that they have received appropriate referrals to see patients, some with complex problems. They also highlight the lack of local skills to recognise and manage patients with these problems.

Further MSOAP funding has been accessed to continue the medical specialist visits across the state for 2008-9 financial year but MSOAP has the focus of "building



capacity” in local communities rather than providing a sustainable medical specialist service. It is noted that MSOAP funding is not available for centres that have an ARIA code rated Highly Accessible. This applies to Bunbury, Busselton and Northam.

Regions will have to build contingency plans for future long term access to medical specialist palliative care. According to the Australian Medical Workforce Advisory Committee (ANWAC) 2004.4 Report<sup>15</sup> rural centres and urban centres with population catchments of between 50,000 and 80,000 are large enough to support infrastructure requirements for the provision of specialist palliative medicine. Factors that increase the catchment size for palliative medicine include communities with well established networks, short travel distances and commitment to the delivery of palliative care. For example the Southwest catchment region of Bunbury and Busselton would fit the category guidelines to warrant the development of a viable specialist palliative medicine service.

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**Table 1. Current Regional Centre Service Models.**

(Please note that palliative care is provided outside of the main centres by primary care clinicians.)

Region	Regional Centre Service Models
South West	<p><u>Bunbury</u>: SJOG Health Service is contracted by DoH to provide palliative care for public patient beds in a 4 bed wing in the hospital and community care for the Bunbury region. The community service boundaries are restricted by post codes.</p> <p><u>Busselton Hospice</u>: Inpatient care provided in Busselton Hospice by volunteers and community care provided by Silver Chain. The Palliative Care Nurse Coordinator (funded 1/3 by Silver Chain &amp; 2/3 by community and raising.) coordinates the service. The Hospice Committee provides governance to the service. Service boundaries restricted by postcodes.</p>
Kimberley	Regional palliative care service, housed in Broome was established in 2003. The service has a substantive regional palliative care nurse coordinator 1.0 FTE position and has a regional governance structure. The PC Coordinator position has remained vacant since May 2007.
Mid West	Mid West palliative care service. Nurse Coordinator 1.0 FTE. Coordinates care of patients in the community, the regional hospital, SJOG Hospital Geraldton, aged care facilities and support to the region.
Wheat Belt	A service based at the Avon Hospice in Northam provides inpatient care and community palliative care to Northam, York and Moodyay regions with post code boundaries.
Pilbara	No formalized palliative care service in the Pilbara
Goldfields	Kalgoorlie Regional Hospital has a 0.5FTE palliative care nursing position and community palliative care is provided by Silver Chain.
Great Southern	Albany Palliative Care Service – Palliative Care Nurse Coordinator 1.0 FTE. Coordinates service Albany Regional Hospital, Albany Hospice, Silver Chain & aged care facilities and support to the region. A GP provides medical support to the service.

### 3.4 Quality of Care

To gain a better understanding of the current palliative care service provision in rural and remote locations in Western Australia, the WA Cancer and Palliative Care Network commissioned the University of Western Australia, School of Population Health to perform a Telephone Survey<sup>16</sup>, in July-August 2007, all rural government health services, Silver Chain services and Nursing Homes. There were 139 respondents – a 100% response rate.



The survey addressed four key areas:

- Provision of services/patient care outcome.
- Delivering palliative care.
- Assessment and care planning.
- Links/Support to deliver services.

The survey results are summarised in Table 2. Qualitative responses to questions contribute to the story of the difficulties experienced in rural communities in their endeavour to provide palliative care in their local region.

The findings of the survey reflect that many rural services care for small number of palliative care patients and it is likely that staff have little palliative care education and most education received is of an informal nature, for example attendance at in-service or study days. There is generally a lack of knowledge about implementing palliative care standards but agreement that there is a need for systems to improve care, for example, referrals systems and clinical pathways. The difficulties of working in isolation were highlighted. The need for better communication and coordination within regions was identified and there was strong support for a regional nurse coordination role. There is evidence that many rural people are unaware of the option of linking with specialist palliative care services for support with patient care. Issues were raised in some regions about the lack of access to skilled medical care and the impact this could have, for example on prescribing and accessibility of appropriate medications or on certification of death. Difficulties accessing and transporting equipment was an issue that arose many times. There was also little reporting of paediatric palliative care.

Despite the higher mortality rates of rural Indigenous people, 70% of services have not provided palliative care to Indigenous patients in the past year. Anecdotal comments suggest that palliative care for Indigenous people occurs sporadically especially in the Kimberley and Pilbara regions. Australian Government funding has been accessed in the Kimberley to address specific Indigenous needs for example the Kimberley Aboriginal Medical Service has a Renal Palliative Care Project to provide a palliative approach to care for Indigenous people.

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**Table 2. Rural Survey Qualitative Responses**

<p><b>Medical Issues</b></p> <ul style="list-style-type: none"><li>■ “The GP’s are not trained in palliative care support and management; it is very frustrating as they don’t know what to do in organizing medication and pain control...”</li><li>■ “...GP’s knowledge ....need to give appropriate dosing and prescribe the right medications.”</li><li>■ “Limited access to a doctor.....we only have a doctor here two days a week”</li><li>■ “We had a patient who died with vomiting and it could have been resolved quickly if we had the specialists and medication but we don’t so the person had to keep vomiting until he died, things like that can be resolved...”</li><li>■ We only have one doctor from a different cultural background overseas. He has trouble with issues relating to death and tends to refer to a tertiary hospital even after specialist advice of no further treatment</li><li>■ Certification Problems- No doctor to certify death; one GP said bring the body to the surgery and I’ll see it in the car park</li></ul>
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<p><b>Isolation, Lack of Communication, Coordination and Support</b></p> <ul style="list-style-type: none"><li>■ “...to come under one organization instead of being split up into three different towns...it makes networking hard.”</li><li>■ “...better communication between the delivering services...to have meetings with people in our region.”</li><li>■ “We need to have palliative care for the whole region. It needs a coordinator. I can’t go over my boundary by one yard.”</li><li>■ Our main thing is isolation – because of this we do not have good networking and communication. I mean we do liaise but it would be helpful if there were a network for palliative care to fall under one umbrella.</li><li>■ We are very far from support services and help. Once a gentleman died. We called for help on a Thursday and over the weekend he died. We only heard from the hospital on Tuesday.</li><li>■ Because of isolation it is difficult to care for people in their homes.</li><li>■ “...people want to be able to be looked after at home...more use of technology...webcams and computers.”</li><li>■ Lack of resources because of isolation. The patients don’t get proper access to allied health professionals because we just don’t have them here.</li><li>■ Because of the distance by the time we get equipment to the client they have died. It takes too long to get equipment to and from places.</li></ul>
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## Rural Issues

### Story from a Rural Nurse

The patient lives approximately two hours from Perth. He is reaching the terminal phase of his illness. The town where he lives does not have a palliative care service. The doctor is leaving town. There is a community nurse who works two days a week. She is willing to visit, but has little palliative care experience. There is a palliative care service in the region, but the nurses in this service are not permitted to see patients beyond geographical boundaries determined by post codes. The family want to care for the patient in their local community. This is what we teach in palliative care – that people should die in their place of choice. The Perth hospital doctor has given the patient a follow up appointment even though they are aware of the poor prognosis. The only way to the appointment is by ambulance.

**Table 3. Results of the WA Rural Palliative Care Survey**

Regions and Numbers of Organisations Surveyed	
<ul style="list-style-type: none"> <li>■ Goldfields 16</li> <li>■ Great Southern 12</li> <li>■ Kimberley 7</li> <li>■ Midwest 26</li> </ul>	<ul style="list-style-type: none"> <li>■ Pilbara 11</li> <li>■ South West 31</li> <li>■ Wheatbelt 36</li> </ul>
1. Provision Of Services & Patient Care Outcomes	
<p>In the previous 12 months the organisations surveyed reported that:</p> <ul style="list-style-type: none"> <li>■ 56% cared for 5 or less palliative care pts</li> <li>■ 16% cared for 6 to 10 patients</li> <li>■ 10% cared for over 30 patients</li> <li>■ 70% had not care for an Indigenous patient</li> <li>■ 12% cared for 1 Indigenous patient</li> <li>■ 90% had not care for babies, children or adolescents</li> <li>■ 20% had no deaths</li> <li>■ 37% had 1 to 4 deaths</li> <li>■ 28% had 10 or more deaths</li> </ul> <p>Organisations reported that:</p> <ul style="list-style-type: none"> <li>■ 50% provided hospital service</li> <li>■ 58% provided long term care</li> <li>■ 64% provided community care</li> <li>■ 57% provided inpatient palliative care.</li> <li>■ 14% had problems with certification of death</li> <li>■ 52% have a formal process for allocating people to palliative care</li> </ul>	

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## 2. Delivering Palliative Care

Of the organisations surveyed:

- 71% have a person responsible for coordinating palliative care. Only 36% of these organisations said that it was the person's sole responsibility
- 44% had a multi-disciplinary team that meets to discuss palliative care for patients.
- 36% had no staff with palliative care training. Most education was of an informal nature eg. In-service attendance or study days.
- 72% provided after hours palliative care support. 11% did not pay staff to deliver this service
- 88% agreed that there was a need for a clinical nurse consultant to coordinate palliative care across the region.
- 54% were aware of the 2005 "Standards for providing quality care for all Australians." But only 34% had implemented them.
- 47% had a planned bereavement program.

## 3. Assessment & care planning

- 81% of respondents agreed that standardised palliative care referral systems, protocols, care plans and clinical pathways would improve care.
- 48% collect specific information about palliative care

## 4. Links and supports to deliver services

- 74% do not have formal links with metropolitan palliative care services
- 88% had staff support services
- 71% had links with palliative care providers in their local health region.
- 43% had heard of the 1300 Palliative Care Outreach Medical Advisory number. Only 20% had used it in the past 12 months.
- 50% had heard of the Silver Chain Hospice rural telephone nurse advisory service. Only 13% had used it in the last 12 months.

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## 4. MODEL OF CARE

This Rural Palliative Care Model supplements the Palliative Care Model of Care to provide a framework for patients and their families to have access to palliative care in rural and remote Western Australia that meets the Palliative Care Australia Standards. The key elements and principles of the Palliative Care Model of Care remain the foundations for the rural model:

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

Principles of particular relevance to rural and remote regions:

- Palliative care is multidisciplinary and is an integral part of the health care system.
- People with life limiting illness will have access to quality care to meet their needs 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 care that is coordinated across all settings with other medical, health or community care providers.
- Palliative care is culturally appropriate.

### 4.1 The Model

The rural model builds on the Recommendations 17 and 18 of the PC Report (Appendix 1) to integrate palliative care across each rural region. The Rural Model will provide a quality improvement framework approach to:

**develop sustainable regional palliative care services that will meet the criteria for, at minimum, Palliative Care Australia specialist palliative care Level 1 service capability and resources ( Appendix 3 & 4) to provide palliative care according to the needs of patients and families in their local community.**

To achieve this goal it will be important to:

- establish regional palliative care governance to provide support to service providers and be accountable for service sustainability and quality of care.
- develop a competent workforce that can access appropriate training, support, and expertise when patient and families needs exceed their knowledge and skill level.
- provide a framework of formalised palliative care links within regions, across WACHS, and with the metropolitan services.



## 4.2 Regional Palliative Care Framework

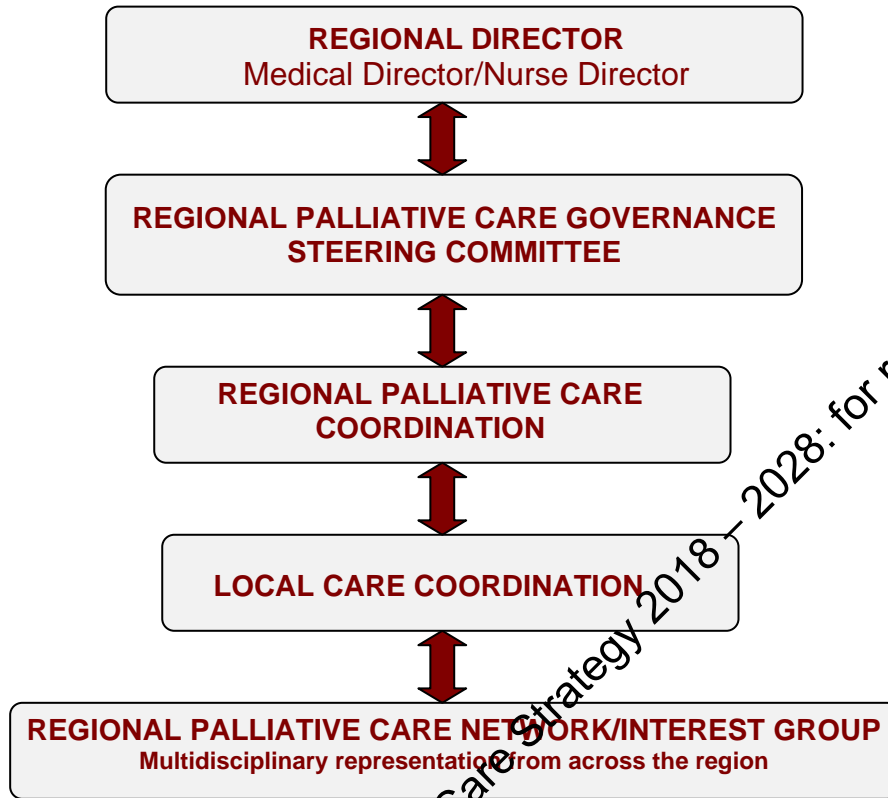
The rural model proposes a framework for each of the seven WACHS rural regions with a palliative care special interest group to link all regions. The key components of this framework:

- Governance of palliative care service at WA Country Health Service (WACHS) regional level
- a palliative care coordination role for each WACHS region
- local care coordination
- a 'PRN' approach for local communities to be able to care, even at short notice for patients with complex or special needs. For example paediatric palliative care patients.
- access to medical care
- the creation of regional multidisciplinary palliative care network/specialist interest groups
- representation from each rural region on a rural palliative care specialist interest group to report to WACHS
- formal links with metropolitan specialist palliative care.
- Indigenous palliative care partnerships

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Figure 1. Regional Palliative Care Framework



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#### 4.2.1 Regional Governance

It is proposed that each region has a regional Steering Committee with representation of key stakeholders across the region. The membership of this committee would be determined within each region and could include representation from residential aged care, Aboriginal Medical Services, private health services, public hospitals, community services, general practice, visiting palliative care medical specialist, Regional Coordinator, HACC, mental health services, allied health. The aim of this committee would be to ensure there is a consistent approach to palliative care, shared aspiration to improve quality of care and “ownership” across the region. The committee would provide advice, monitor and support the regional coordinator and clinical team and be accountable for the sustainability of the service.

#### 4.2.3 Regional Palliative Care Coordination

It is proposed that there is a regional coordinator position in each rural region. A generic JDF is proposed, but the model of coordination may vary according to population numbers and geographical distribution/distance within each region. The role would have responsibility for the standard of clinical care and the alignment of processes, protocols and systems across the region.

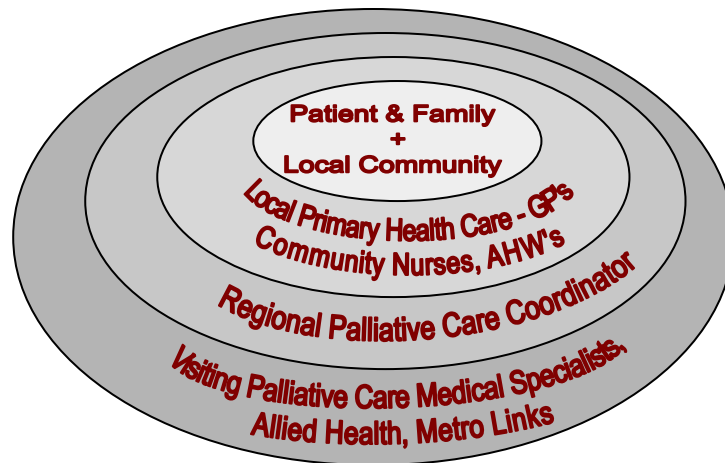
A service coordination approach would ensure agencies across the region operate as independent services but work collaboratively as a team in a cohesive and coordinated way to allow patients to experience seamless care. The coordinator would not case manage patients but build capacity in staff throughout the region by providing support, clinical consultation and education. The use of technologies: phone, email, webcam and video conferencing would be essential to the success of this role. It is proposed that this is a nursing role with palliative care clinical expertise in order to provide consultation and advice across the region and to access appropriate specialist support especially for complex patient care. This role would require administration support. As this is a regional role, this position would be line managed by the Regional Nurse Director.

#### 4.2.4 Local Care Coordination

Every patient will have their care coordinated. Co-ordination will depend on local circumstances but a single point of coordination should be identified for every patient to ensure they have an initial assessment of needs and a care plan developed to assist the patient and family to access the right services when required. All patients should be tracked on one information system within the region, therefore assisting in regional service coordination.

Each local community team should identify the other teams/services with which they interact most frequently and should develop plans to promote co-ordinated care. This may include participating in multidisciplinary meetings that include people from different services at remote locations.

**Figure 2. Local Care Coordination**



#### 4.2.5 “PRN Model”

*(Plan of response according to need)*

In some circumstance there will be a need to respond to “one-off” patient’s needs. For example in areas where palliative care patients are cared for infrequently, or when a referral is received to care for patients with special or extremely complex needs. The response plan may include accessing training from specialist services targeted to address specific care issues, for example the management of conditions, symptom control, or special equipment and involve ongoing communication with the regional coordinator or specialist metropolitan services. It is envisaged that the recently launched Paediatric Palliative Care Program will work with this approach to tailor care individually.

#### 4.2.6 Medical Care

Each patient will be required to have an identified general practitioner or medical officer locally. Each region will also require a sustainable plan of access to best practice palliative care medical support. This may include an identified local general practitioner or medical officer, visiting palliative care medical specialist, and guidelines for after hours support including access to the WA Palliative Care Outreach service advisory phone line.

#### 4.2.7 Regional Palliative Care Interest Groups

At regional level a Palliative Care Interest Group would be multidisciplinary and be comprised of the key service providers and stakeholders. The aims of this group would be to ensure:

- ongoing communication and coordination across the region
- clinical review of complex patients/families
- workforce issues are addressed eg. staff relief
- professional support and development - ongoing education
- consistent policies and protocols professional support
- community awareness/ Health Promotion



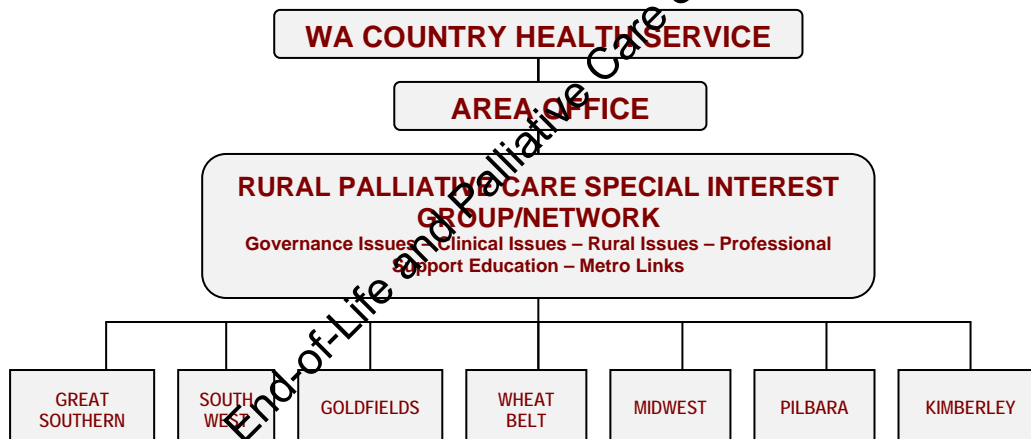
- volunteer support
- the needs of special groups are met – children, aged care, Indigenous care
- effective use of resources eg. Equipment
- service evaluation

Effective functioning of this group would improve regional coordination and integration of palliative care into health care practice and increase the level of expertise across the region. It is proposed that the group meet on a regular basis via video conference/ teleconference and face to face at least 6 monthly with an annual palliative care regional education program.

### 4.3 Statewide Rural Palliative Care Specialist Interest Group

It is proposed that each WACHS rural region has representation on a group that operates under the umbrella of WACHS. The group will take on the role of providing feedback on governance, clinical and rural issues to ensure that palliative care across rural regions is of a consistent standard and remains an important focus of WACHS. This group will also provide a mechanism for providing professional support, the implementation of statewide palliative care protocols and policies and foster rural, metro links.

Figure 3. Statewide Rural Palliative Care Specialist Interest Group



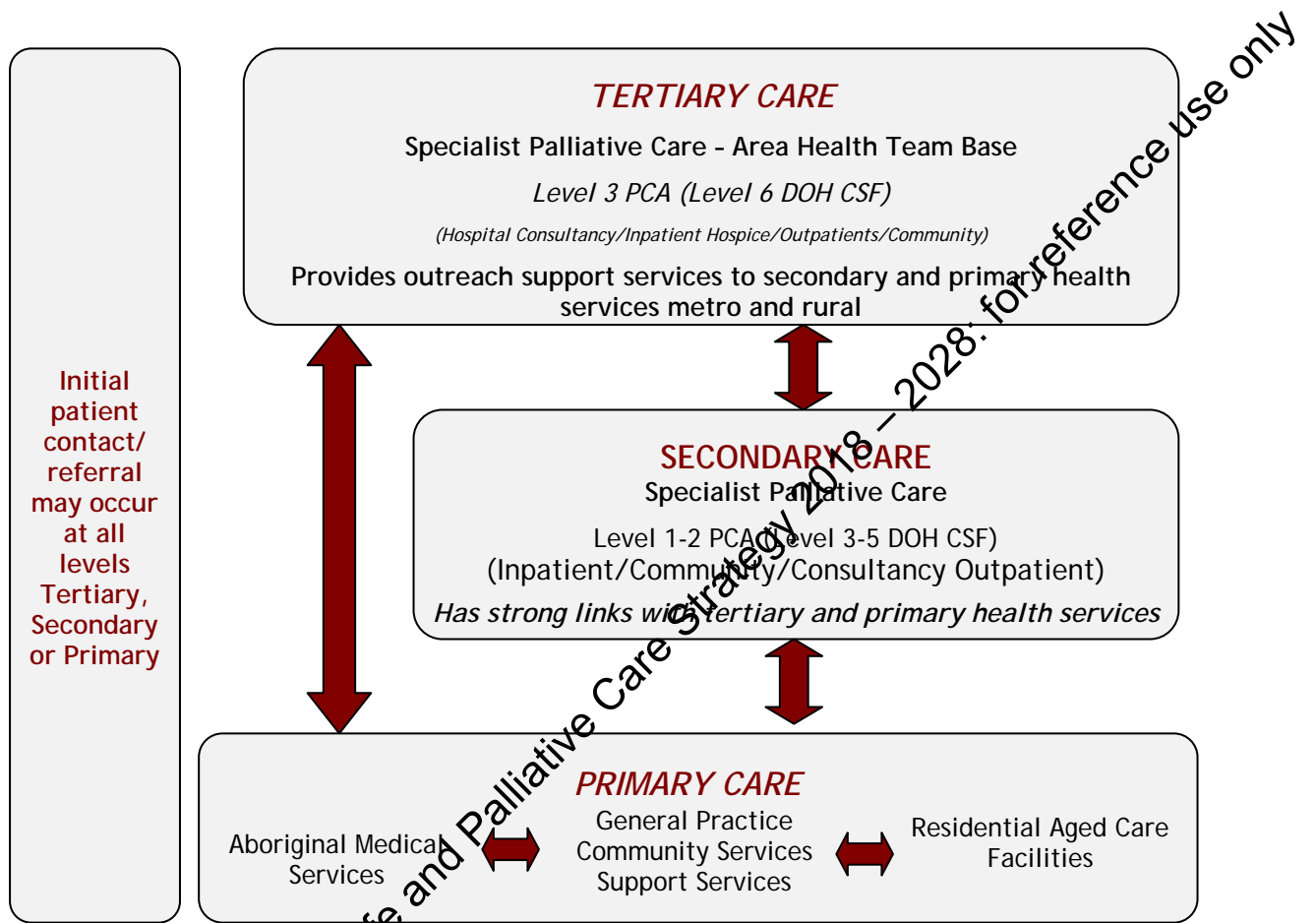
### 4.4 Links with Specialist Palliative Care

PCA (2005)<sup>17</sup> 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, it is recognised that the primary care providers in all health care settings will assume a role in caring for people with life limiting illness. The care providers will be able to partner with specialist palliative care teams/services in order to provide the best possible care according to 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. Tertiary services based in Perth will play an important role in outreaching to secondary and primary services in rural regions. The MSOAP visits to rural regions are one way of providing expertise but



the use of technology, for example Telehealth, will be important to provide access to ongoing consultation and also to other members of the multidisciplinary team. The implementation of the Palliative Care Model of Care will address the need to formalise links with rural and remote regions.

**Figure 4. Specialist Palliative Care Tertiary, Secondary, Primary Links**



#### 4.5 Indigenous Palliative Care Partnerships

It is proposed that partnerships are formed at regional level with Aboriginal Health Services and communities to develop strategies to promote holistic and culturally appropriate palliative care for Indigenous people. The clinical care and support of Indigenous people including: the aboriginal view of life-death-life as a continuum, spirituality, the importance of dying in country, ceremonies and practices surrounding death will be included as a core component of education for health professionals.





## 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.

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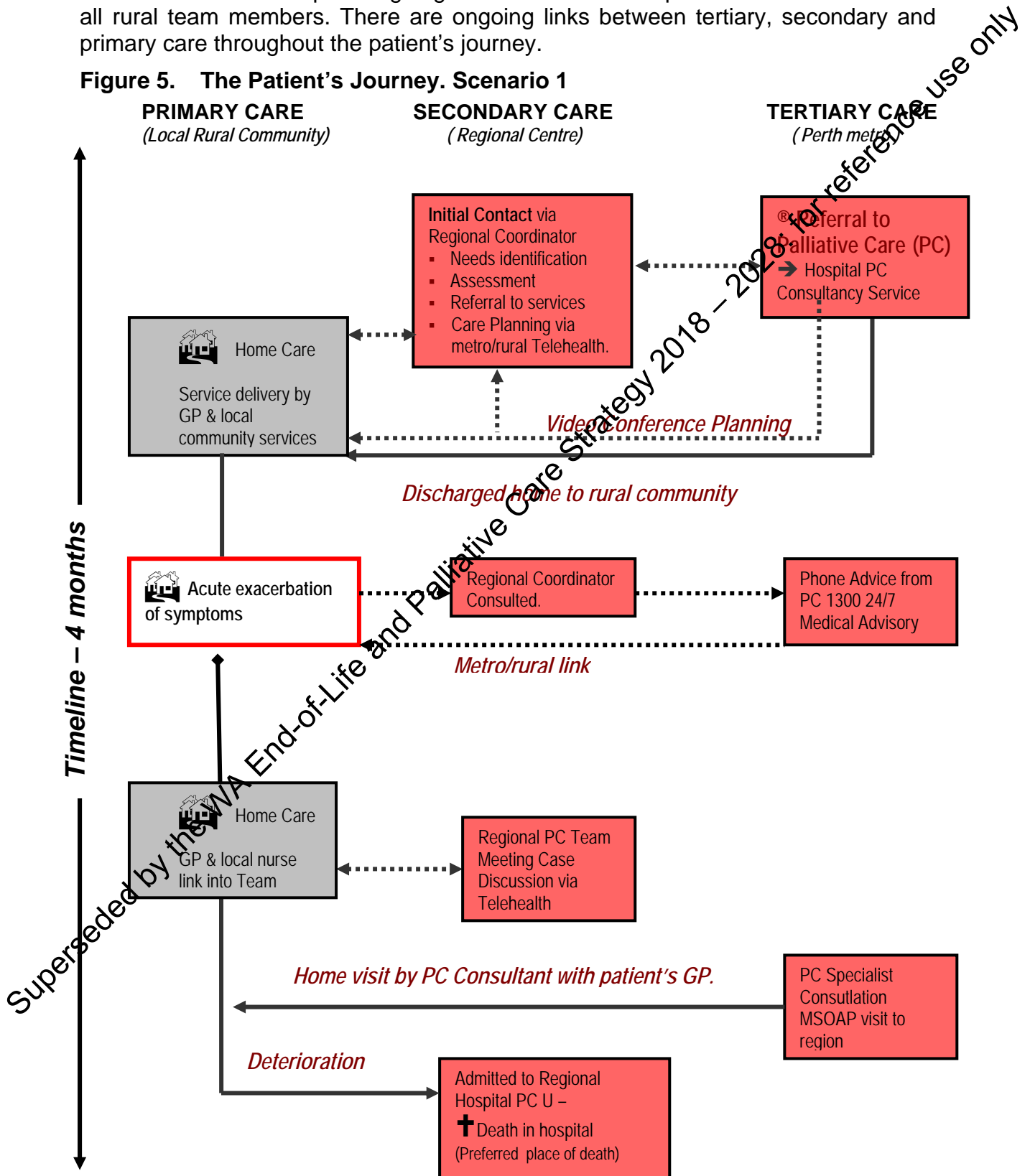


## 4.5 The Patient's Journey

### 4.5.1 Scenario 1

The initial palliative care referral for this rural patient with ongoing complex needs is received by a tertiary hospital palliative care consultancy team. The initial rural contact is made via the Regional Coordinator who commences service coordination. A video conference to plan ongoing care links the metro palliative care service with all rural team members. There are ongoing links between tertiary, secondary and primary care throughout the patient's journey.

**Figure 5. The Patient's Journey. Scenario 1**

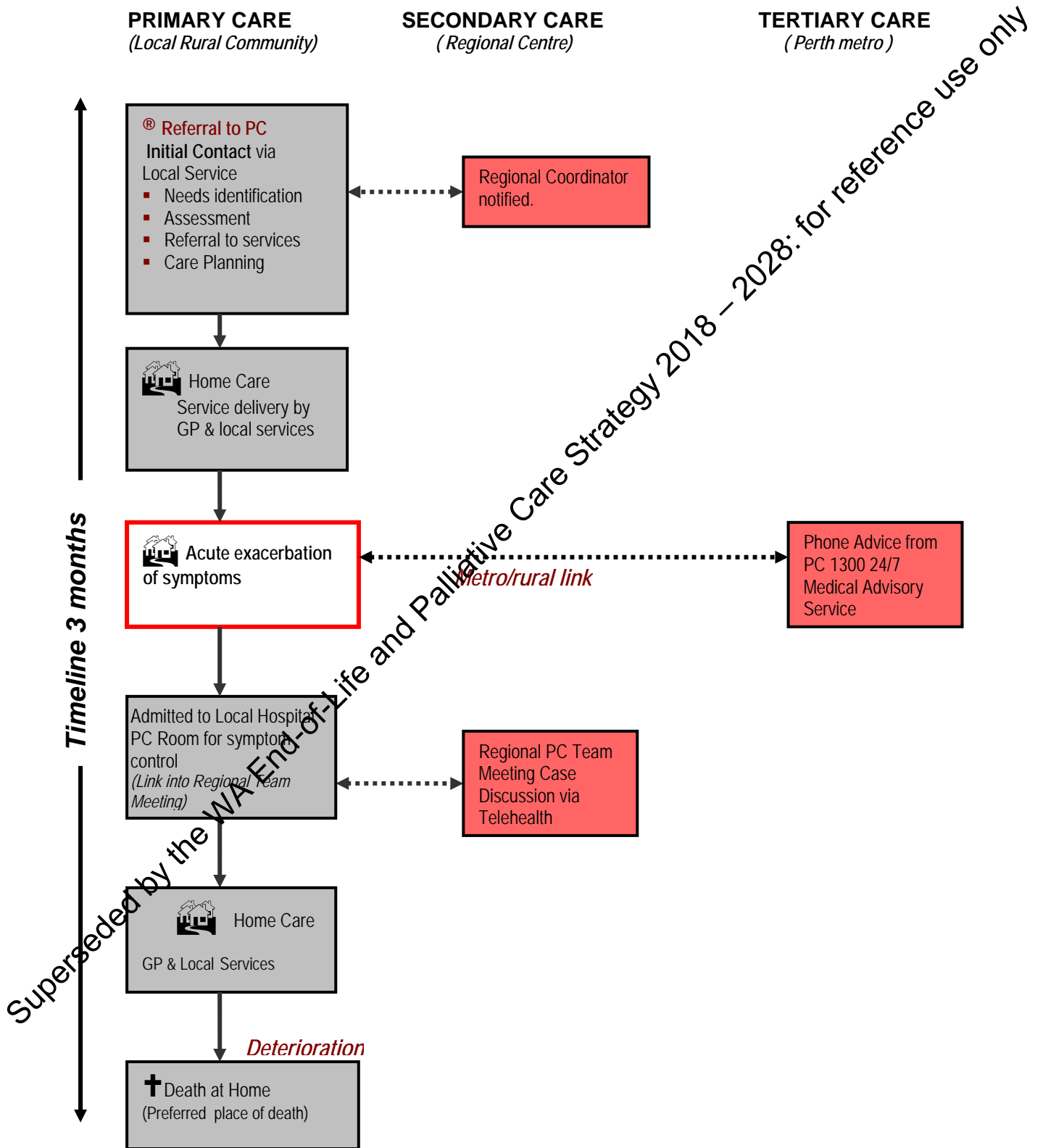




### 4.5.2 Scenario 2

This rural patient with non complex needs is cared for throughout their illness in the local community. Initial contact is by local health care service who coordinate services for the patient. Regional links are maintained. The only tertiary link is for telephone advice.

**Figure 6. The Patients Journey. Scenario 2**





## 5. KEY RECOMMENDATIONS

### Recommendation 1

The Rural Palliative Care Model in Western Australia is endorsed.

### Recommendation 2

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

### Recommendation 3

A statewide palliative care education plan and implementation strategy is developed to provide access to a health professional workforce with palliative care knowledge and skills.

### Recommendation 4

There is a coordinated approach, with the Palliative Care Network linking stakeholders, to the development and implementation of pathways and protocols to guide rural primary care providers in appropriate timely management of palliative care patients.

### Recommendation 5

Strategies to provide culturally appropriate Indigenous palliative care are developed in partnership with Aboriginal Health Services and other appropriate stakeholders.

## 6. 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. The Palliative Care Network is already undertaking work for example on an education plan, referral pathways, end of life pathways as well as medication and other evidence based protocols that will be implemented statewide. There is scope within existing Network resources to support and partner with WACHS to assist regions to develop a coordinated approach to the development of regional services.

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## APPENDICES

### Appendix 1: Palliative Care in Western Australia. Final Report December 2005

#### Rural and Remote Communities

##### Recommendation 17: Linkages and Coordination

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

##### Recommendation 18: Regional Coordination

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

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

##### Recommendation 19: Education & Standards

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

##### Recommendation 20: GP Education

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

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

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

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

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

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

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

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## Appendix 2: Palliative Care Australia

### 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 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 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.

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## Appendix 3: Capability and Resource Matrix

### 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	<ul style="list-style-type: none"> <li>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.</li> <li>Has formal links with a specialist palliative care provider for purposes of referral, consultation and access to specialist care as necessary.</li> </ul>	<p>General medical practitioner, nurse practitioner, registered nurse, generalist community nurse, aboriginal health worker, allied health staff.</p> <p>Specialist health care providers in other disciplines would be included at this level.</p>
SPECIALIST PALLIATIVE CARE LEVEL 1	<ul style="list-style-type: none"> <li>Provides specialist palliative care for patients, caregiver/s and families whose needs exceed the capability of primary care providers.</li> <li>Provides assessment and care consistent with needs and provides consultative support, information and advice to primary care providers.</li> <li>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.</li> <li>Has quality and audit program.</li> </ul>	<p>Multidisciplinary team including medical practitioner with skills and experience in palliative care, clinical nurse specialist/consultant, allied health staff, pastoral care and volunteers. A designated staff member if available coordinates a volunteer service.</p>
SPECIALIST PALLIATIVE CARE LEVEL 2	<ul style="list-style-type: none"> <li>As for level 1</li> <li>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.</li> <li>Has formal links with primary care providers and level 3 specialist palliative care services for patients, caregiver/s and families with complex needs.</li> </ul>	<p>Interdisciplinary team including medical practitioner and clinical nurse specialist/consultant with specialist qualifications. Includes designated allied health and pastoral care staff.</p>
SPECIALIST PALLIATIVE CARE LEVEL 3	<ul style="list-style-type: none"> <li>Provides comprehensive care for the needs of patients, caregiver/s and families with complex needs.</li> <li>Provides local support to primary care providers, regional level 1 and/or 2 services including education and formation of standards.</li> <li>Has comprehensive research and teaching role.</li> <li>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.</li> </ul>	<p>Interdisciplinary team including a medical director and clinical nurse consultant/nurse practitioner and allied health staff with specialist qualifications in palliative care.</p>

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## Appendix 4: Clinical Services Framework.

### CLINICAL SERVICES FRAMEWORK: PALLIATIVE CARE

Clinical Service Level	Service Provision	PC Model Requirements
<p><b>ONE &amp; TWO</b></p> <p><i>(PCA PRIMARY CARE)</i></p>	<p>Generalist health professionals provide a palliative approach to care in:</p> <p>General practice and generalist community services</p> <p>All Residential Aged Care Facilities</p> <p>Primary care providers- medical, oncology and other wards/ units/services in the acute care sector</p>	<p>Meets the PCA Standards at Primary Care Level.</p> <p>Has access to specialist palliative care support and consultation</p> <p>All staff should access and participate in palliative care professional development.</p> <p>Uses palliative care assessment tools, pathways and protocols</p>
<p><b>THREE</b></p> <p><i>(PCA SPECIALIST PALLIATIVE CARE LEVEL 1)</i></p>	<p>Has a multidisciplinary approach</p> <p>Medical and nursing staff have palliative care experience</p> <p>Provides assessment and care consistent with patient/family and caregiver needs</p> <p>Accesses help from tertiary and secondary palliative care services when required</p> <p>Has access to allied health professionals eg. social work, pastoral care, occupational therapy, physiotherapy, pharmacy, dietitian.</p> <p>Access to visiting palliative care specialist</p> <p>Volunteer program</p> <p>Provides bereavement support</p>	<p>Meets the PCA Standards at Specialist Level 1</p> <p>Has formal access to tertiary and secondary specialist palliative care support and consultation</p> <p>Uses palliative care assessment tools, pathways and protocols</p> <p>Collects palliative care data</p>
<p><b>FOUR</b></p> <p><i>(PCA SPECIALIST PALLIATIVE CARE LEVEL 2)</i></p>	<p>As for level 3 plus:</p> <p>Medical practitioner with palliative care qualifications</p> <p>Access to Medical Registrar</p> <p>Access to CNC/ specialist experienced (and qualified) in palliative care</p> <p>Provides consultation to other services</p> <p>24 hour on call service</p> <p>Access to anaesthetic &amp; radiology services</p> <p>Access to general medicine services</p> <p>Access to respite care</p> <p>Participates in research</p> <p>Participates in palliative care Quality Improvement</p> <p>Health Promotion Activities</p>	<p>Meets the PCA Standards at Specialist Level 2</p> <p>Meets Criteria for GP Trainee supervision</p> <p>Has formal access to tertiary specialist palliative care support and consultation and supports primary care</p> <p>Uses palliative care assessment tools, pathways and protocols</p> <p>Collects palliative care data</p>

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<p style="text-align: center;"><b>FIVE –SIX</b></p> <p style="text-align: center;"><i>(PCA SPECIALIST PALLIATIVE CARE LEVEL 3)</i></p>	<p>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 &amp; Allied Health) Palliative care specialist team provides consultancy to other units Develops &amp; 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</p>	<p>Meets the PCA Standards at Specialist Level.3</p> <p>Meets requirements for Royal College of Physicians accreditation:</p> <ul style="list-style-type: none"> <li>▪ 1 FTE Palliative Care Physician</li> <li>▪ CNC position</li> <li>▪ Oncall service</li> <li>▪ Access to medical oncology</li> <li>▪ Access to radiation oncology</li> <li>▪ Access to haematology</li> <li>▪ Access to pain or anaesthetic service</li> </ul> <p>(Meets future accreditation requirements for other health disciplines.) Is resourced to provide outreach to secondary and primary care services Collects palliative care data</p>
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Delivering a Healthy WA

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