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

WA End-of-Life and Palliative Care Strategy 2018–2028

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Contents

Foreword

I am pleased to introduce the *WA End-of-Life and Palliative Care Strategy 2018-2028* – the first strategy of its kind in Western Australia.

This Strategy is a testament to how important it is for the WA health system to have clear and defined priorities for end-of-life and palliative care.

Approximately 70 per cent of all deaths are expected and most of us will die with a chronic condition.

More people are living longer with chronic life-limiting conditions, and an estimated 30 per cent of Australians aged 65 years and over live with three or more chronic conditions.

While the inevitability of death and dying is something we all share, the impact of symptoms, the effects of treatments and the value we place on quality of life are different for each of us.

This Strategy places people and their family/carer at the centre of care and ensures people are treated within a culture of compassion and quality.

It also aligns with national and state strategies, policies and frameworks; and draws from national and international best practice.

It is vital that the WA health system commits to the six priorities outlined in this Strategy, and embraces the recommended contemporary approach to statewide leadership, direction-setting and local implementation.

I urge you all to work collaboratively to find new ways of delivering quality care, while at the same time ensuring that end-of-life and palliative care is centred on the individual needs of the person and their family/ carers.

Dr D J Russell-Weisz
Director General
WA Department of Health

Executive summary

End-of-life and palliative care aim to improve the quality of life of people and their family/carer facing life-limiting illness through the prevention and relief of suffering. An increasing demand for services combined with an ageing population with complex needs means that the WA health system needs to continue to strengthen the way it delivers end-of-life and palliative care.

Care at end-of-life is everyone's business, whether it is provided by specialist palliative care or non-specialist healthcare providers. It occurs in all settings, from primary to tertiary health care, as well as community and residential aged care. Policy makers, executives, clinicians, researchers and the wider community all have a role to play to ensure that people of all ages, and their family/carer, have access to high-quality care, systems and services at a time when many feel vulnerable, during advancing illness and at end-of-life.

The WA Cancer and Palliative Care Network (WACPCN), WA Department of Health, led and coordinated the development of the Strategy. Consultation events provided healthcare providers, the community and consumers with the opportunity to identify gaps, innovations and improvements, and to contribute to a shared vision for end-of-life and palliative care. A working group contributed to the Strategy using the outcomes of the consultations as the foundation. The Strategy has been distributed for consultation to ensure the views of the broader health, community and aged care systems are accurately represented.

The aim of the *WA End-of-Life and Palliative Care Strategy 2018-2028* (the Strategy) is to provide strategic statewide policy direction and outline the vision, values and priorities for end-of-life and palliative care in Western Australia to 2028. It provides a 10-year vision for improving the lives of all Western Australians through quality end-of-life and palliative care. This Strategy affirms that palliative care is a human right and is fundamental to improving the quality of life, wellbeing and dignity of all individuals.[1] It outlines the care values and supporting factors that are at the foundation of end-of-life and palliative care. Care values are defined as care centred on the patient and family; sustainability; culture of continuous quality improvement; and seamless, continuous and integrated care. Supporting factors include clinical support and workforce capacity; research evidence and evaluation; evidence-informed care, appropriate education and technology.

The Strategy will be reviewed after five years, or if a major change is required.

Priority areas aim to guide and inspire public, private, community and non-government health sectors to partner for the provision of best-practice end-of-life and palliative care for the next ten years. This includes the delivery of specialist and non-specialist teams providing end-of-life and palliative care. The identified priority areas from 2018-2028 are:

1. Care is accessible to everyone, everywhere.
2. Care is person-centred.
3. Care is coordinated.
4. Families and carers are supported.
5. All staff are prepared to care.
6. The community is aware and able to care.

Achieving the outcomes of the identified priority areas will enable people of all ages and their families to receive comprehensive care within a more integrated, coordinated and collaborative health system. Individuals, teams and services providing this care will be supported through a system-wide approach.

Many systems, services and programs already contribute to these priority areas. The Strategy affirms that implementation and evaluation need to occur on a local and statewide level. We specifically require Health Service Providers (HSPs) and local systems and services to implement a process for achieving these priorities.

The WACPCN in the WA Department of Health will lead and oversee the statewide implementation of the Strategy in its role as System Manager and will monitor performance via system-wide trends and data collection.

The Vision is to improve the lives of all Western Australians through quality end-of-life and palliative care.

Introduction

The purpose of the *WA End-of-Life and Palliative Care Strategy 2018-2028* (the Strategy) is to provide strategic statewide direction and to outline the values and priorities for end-of-life and palliative care in WA over the next 10years. The Strategy places people and their family/carer at the centre of care and aims to provide this care within a culture of compassion and excellence. It describes how end-of-life and palliative care systems and services can work collaboratively to provide integrated high-quality care at end-of-life.

The Strategy informs public, private, community and non-government health sectors of the priority areas within end-of-life and palliative care over the next 10 years. The Strategy acknowledges existing systems, services and programs that already contribute to these priority areas.

The Strategy is applicable to all services in WA that support and care for people with life-limiting illness, and their families, from paediatric services to aged care services, including:

- public, private, community, aged care services and non-government organisations, including primary healthcare teams
- administrators in public, private, community, aged care services and non-government organisations (including training, research and educational institutions).

This includes specialist and non-specialist teams providing end-of-life care and specialist palliative care teams with recognised qualifications or accredited training in palliative care. It is also relevant to people, their family/carer and the wider community.

The Strategy recognises that end-of-life and palliative care is focused on improving a person’s quality of life and that palliative care is more than terminal care. This includes raising public awareness and normalising death as part of life.

Our priorities

The Strategy presents six overarching priorities, providing a broad direction enabling local and statewide implementation and evaluation. Each priority describes what is already known and the building blocks required realising it. The priority areas are:

1. Care is accessible to everyone, everywhere.
2. Care is person-centred.
3. Care is coordinated.
4. Families and carers are supported.
5. All staff are prepared to care.
6. The community is aware and able to care.

Achieving the outcomes of the identified priority areas will enable people of all ages and their families to receive comprehensive care within an integrated, responsive, coordinated and collaborative health system. Individuals, teams and services providing this care will be supported through a system-wide approach.

Policy context

The Strategy builds on four previously developed and implemented models for palliative care in WA:

- *Palliative Care Model of Care* – April 2008.[2]
- *Rural Palliative Care Model in Western Australia* – October 2008.[3]
- *Paediatric and Adolescent Palliative Care Model of Care* – September 2009.[4]
- *Perinatal Palliative Care Model of Care* – August 2015.[5]

The Strategy supports The End-of-life Framework,[6] with both aligned with national and state strategies, policies and frameworks and drawing from national and international best practice. See **Appendix One** for more information.

Scope of end-of-life and palliative care

To palliate means to 'make (a disease or its symptoms) less severe without removing the cause'.[7]

There are differing terms for palliative care across the world. Some terms are used interchangeably which can lead to confusion. It is important to differentiate between the terms palliative care and end-of-life care, in the Western Australian context.

The term palliative care is referred to in this document as the concept, not as the multidisciplinary specialty. Where referring to the specialty, the term 'specialist palliative care' is used.

End-of-life

End-of-life is the timeframe during which a person lives with, and is impaired by, a life-limiting/fatal condition, even if the prognosis is ambiguous or unknown.[8] Those approaching end-of-life will be considered likely to die during the next 12 months.[8]

End-of-life care

End-of-life care is care needed for people who are likely to die in the next 12 months due to progressive, advanced or incurable illness, frailty or old age.[9] During this period, people may experience rapid changes and fluctuations in their condition and require support from a range of people, including health services,[9] as well as family and carers.

Palliative care is an approach that improves the quality of life of individuals, including their family/carer, facing problems associated with life-threatening illness/condition, through the prevention and relief of suffering.[10] Palliative care recognises the person and the importance and uniqueness of their family/carer. It serves to maximise the quality of life and considers physical, social, financial, emotional, and spiritual distress. Such distress not only influences the experience of having a life-limiting illness but also influences treatment outcomes.[11]

Specialist palliative care is undertaken by a professional palliative care team or service with recognised qualifications or accredited training in palliative care. The role of specialist palliative care services includes providing consultation services to support, advise, educate and mentor specialist and non-specialist teams to provide end-of-life and palliative care and/or to provide direct care to people with complex palliative care needs.[8] See **Appendix Two** for more detailed information on the classification of specialist palliative care services.

Recognising that a person is entering the last months or year of life can be difficult to determine.[9] Being able to recognise that a person may be dying can also be difficult, but is an essential requirement for clinicians.[9] Recognising that a person is entering the last months or year of life enables purposeful conversations with people and their families/carers to discuss their preferences and what matters to them.

Why the Strategy is needed

End-of-life care is care that affects us all and is not a response to a particular illness or condition. Everyone will die; therefore, the Strategy is relevant and important to all of us. Death is unavoidable; however, we can change the way we talk about/manage end-of-life, death and bereavement and the way we plan, care and support those who are dying, including those who are close to them, such as their families/carer.

The Strategy aims to support people and their family/carer at end-of-life by developing and encouraging an integrated system that is better able to:

- increase timely end-of-life discussions
- achieve people's preferences at end-of-life and improve quality of life[12-15]
- provide care in a person's place of choice and reduce unnecessary hospitalisations[12]
- support family and carers and provide seamless and integrated care from diagnosis to death/bereavement
- provide impeccable symptom management.

Delivering equitable end-of-life and palliative care across WA is challenging. This contributes to the need for a strategic, integrated, coordinated and collaborative approach.

Particular challenges include:

- inequitable access to end-of-life and palliative care based on need, e.g. geographical isolation and population groups
- increasing complexity, e.g. ageing and growing population
- ad hoc integration of specialist palliative care into care for people with chronic conditions
- delivering health care that is high-quality, effective, efficient and sustainable.
- advances in medicine have resulted in people living longer but often with greater morbidity, increasing care needs, and placing additional pressure on individuals, families and the health system. This strengthens the need for a coordinated, sustainable system that is better able to care for people living with life-limiting illness.

The impact of chronic conditions is also an important factor in why this Strategy is needed.

Approximately 70 per cent of deaths are expected.[16] Not all deaths are the same for example, cancer, organ failure, frailty and dementia exhibit different illness trajectories.[16] Approximately 29 per cent of Australians aged 65 years and over have three or more chronic conditions.[17]

Delivery of end-of-life and palliative care in Western Australia

End-of-life and palliative care is delivered by all health services caring for people with a life-limiting illness. This includes, but is not limited to, services and settings such as[18]:

- acute care settings (adult and paediatric)
- specialist services, including but not limited to oncology, renal, cardiac and respiratory
- primary care, including general practice
- aged care facilities, including aged care and disability
- not-for-profit agencies, organisations and facilities
- community services
- mental health services and facilities
- correctional facilities.

Specialist palliative care service delivery in WA is overall well-coordinated, collaborative and staffed by dedicated professionals and strengthened by statewide initiatives to provide comprehensive, high-quality and consistent care for people of all ages. Service providers are supported by a strong government priority for end-of-life and palliative care. As with many areas of health, specialist palliative care services in WA are challenged to meet growing demand and complexity within an environment of constrained resources. Implementation of the Strategy will assist in meeting this challenge.

Every Western Australian with a life-limiting illness has a right to high-quality integrated end-of-life and palliative care, but not everyone will require specialist palliative care services. See **Appendix Three** for more detailed information on the range and location of specialist palliative care services in WA.

Implementation of the Strategy

Through the WA Cancer and Palliative Care Network (WACPCN), the Department of Health will lead and oversee the implementation of the Strategy. The WACPCN will provide statewide leadership and stewardship and monitor performance to provide assurance that the priorities in the Strategy are implemented.

The Strategy is being provided to HSPs and other relevant stakeholders so that these priorities can be brought to reality. These stakeholders are well placed to lead, convene, and coordinate local initiatives to implement the Strategy, making these priorities, their priorities.

Overview of priorities

1

Care is accessible to everyone, everywhere.

I have access to good quality end-of-life and palliative care, regardless of who and where I am, or how I live my life.

2

Care is person-centred.

I am seen as an individual, and I have the opportunity to be involved in honest discussions with those important to me about my care. My values, culture and spirituality are respected and taken into account when care is given.

3

Care is coordinated.

I receive the right care at the right time, in the right place, from the right people. My care occurs within a coordinated/collaborative approach, enabling care to be delivered seamlessly.

4

Families and carers are supported.

Those close to me and/or caring for me are supported and involved in my care. The contributions made by my family/carer are recognised and valued by those providing my care, including their need to be supported during and after my death.

5

All staff are prepared to care.

Wherever and whenever I am cared for, all staff involved in my care have expertise, empathy and compassion. All staff provide confident, sensitive and skilful care, before, during and after my death.

6

The community is aware and able to care.

I feel supported and empowered to make decisions. My individual preferences are expressed through Advance Care Planning (ACP) and reflected in my end-of-life and palliative care. My community is aware and able to support me and those close to me.

Priority One

Care is accessible to everyone, everywhere.

I have access to good quality end-of-life and palliative care, regardless of who and where I am, or how I live my life.

What is already known:

- Better outcomes are achieved when people and their family/carer access the right care, at the right time, in the right place, delivered by the right provider or team.
- A statewide, consistent and collaborative approach to end-of-life and palliative care will assist in meeting this need.
- Gaps exist in access to care for identified populations, people with specific needs related to their condition, and marginalised groups.[19]

Building blocks to realise Priority One	
Improve equity of access	Every person living in WA with life-limiting illness has access to timely end-of-life and palliative care if required, and regardless of age, illness, location or ethnicity. People have access to integrated care in their preferred setting or location: home, aged care home, hospital, metropolitan, rural or remote. People and their family/carer receive seamless care through improved partnerships and collaborations across and between services. The specialist palliative care workforce meets service demand. The Rural Palliative Care Program continues to build workforce capacity and improve access to specialist palliative care. Health, community and aged care providers demonstrate greater capability, understanding and application of end-of-life care practices.
Improve access to care for Aboriginal people	Culturally respectful and appropriate care is provided to Aboriginal people and their families in their place of choice. Health, community and aged care providers: ▪ work collaboratively with Aboriginal Health Workers ▪ have a greater understanding of beliefs and values at end-of-life ▪ have access to culturally appropriate information in relevant formats and languages.

Building blocks to realise Priority One	
Improve access to care for Culturally and Linguistically Diverse communities	Culturally respectful and appropriate care is provided to culturally and linguistically diverse people and their family/carer in their place of choice. Health, community and aged care providers have access to: ▪ culturally appropriate information in relevant formats and languages to enable appropriate assessment and care for people and their family/carer ▪ interpreter services.
Strengthen care for children with a life-limiting illness	Health, community and disability providers are guided by WA specific strategy in their care for children with a life-limiting illness and their families.
Improve access to care for condition-specific groups, e.g. people with dementia or those experiencing mental health issues	Appropriate and respectful care is provided to people with condition-specific needs and their family/carer. Health, community and aged care providers have access to education and resources to enable appropriate assessment and care for people and their family/carer.
Improve access to care for marginalised groups, e.g. homeless people and refugees and lesbian, gay, bisexual, transgender, intersex and queer (LGBTIQ) communities.	Appropriate and respectful care is provided to people and their family/carer, irrespective of their culture, beliefs, values, social circumstances or personal characteristics. Health, community and aged care providers have access to education and resources to enable appropriate assessment and care for people and their family/carer.

Priority Two

Care is person-centred.

I am seen as an individual, and I have the opportunity to be involved in honest discussions with those important to me about my care. My values, culture and spirituality are respected and taken into account when care is given.

What is already known:

Outcomes are improved when people and their family/carer:

- receive the right care, at the right time, in the right place, delivered by the right team
- receive seamless and integrated care, across all services from referral to bereavement[20]
- are involved in decision-making[21] and have their values respected.[22]

Building blocks to realise Priority Two	
People and their family/carer co-designing care with health teams, to include: - **culturally respectful and comprehensive care** - **opportunities to talk about and plan for death, including ACP**	People and their family/carer: - have the confidence to be actively involved in the decision-making related to their care, including the importance of ACP - have sufficient information and are supported to make informed decisions - are able to identify their goals of care with the support of their treating team, including their GP. Clinical decision-making is a collaborative process, involving patients, families/carers, health, community and aged care providers involved in a person's care. People are identified for timely care through innovative approaches to assessment, e.g. use of clinical indicators. Health, community and aged care providers have the confidence to initiate ACP discussions and document goals of care with people and their family/carer. The ACP resources, Goals of Patient Care summary and Care Plan for the Dying Person are widely used across WA. Health, community and aged care providers have the knowledge and confidence to initiate open conversations about ACP. Increased uptake of ACP reduces the number of inappropriate hospital admissions.

Building blocks to realise Priority Two	
Care is centred on people and their family/carer	Health, community and aged care providers have the capacity and ability to anticipate and respond to the changing needs and preferences of people and their family/carer; across advancing disease, increasing decline, last days of life, and in death and bereavement.[6] Communication and coordination with people and their family/carer and between providers, including primary care, is improved. People transition seamlessly through and between services across all settings, allowing optimal use of resources and potentially reducing unnecessary/unwanted hospital admissions. Multiple services work together beyond organisational, clinical and disciplinary boundaries to support care in the person's preferred location. Access to patient information across and between services is enhanced through safe, efficient and effective systems.

Priority Three

Care is coordinated.

I receive the right care at the right time, in the right place, from the right people. My care occurs within a coordinated/collaborative approach, enabling care to be delivered seamlessly.

What is already known:

Quality of life for people and their family/carer is improved through:

- an inter-disciplinary approach to care[19, 23]
- the smooth transition of care, across and between services
- improved communication and collaboration between health, community and aged care providers
- timely and appropriate referrals to specialist palliative care.

Building blocks to realise Priority Three	
Strengthened referral pathways between end-of-life and specialist palliative care teams	Specialist palliative care teams receive timely and appropriate referrals from treating teams. There is: - increased recognition of the value of allied health professionals in the provision of end-of-life and palliative care - an increase in the number of allied health professionals providing quality, comprehensive, specialist palliative care, enabling people to maximise the quality of life and receive care in their place of choice.
Adequate resources to support health, community and aged care providers delivering end-of-life and palliative care	Patient transfer across and between services is facilitated by stronger networks between health, community and aged care providers and specialist palliative care teams. The use of innovative technology connects people and their family/carer to all teams providing their care.

Priority Four

Families and carers are supported.

Those close to me and/or caring for me are supported and involved in my care. The contributions made by my family/carer are recognised and valued by those providing my care, including their need to be supported during and after my death.

What is already known:

- Families/carers:
  - play a critical role as part of the treating team in supporting people with life-limiting illness[24, 25]
  - require specific and considerable assistance to perform their caring role[22, 26]
  - have improved health and bereavement outcomes if their caring experience is positive.[19]
- Family support is vital if people wish to be cared for at home.
- Planning is needed to address the complexity of care, anticipate care needs and invest in strategies to reduce potentially avoidable hospital admissions.
- Funding models that recognise family values and needs are essential.
- Bereavement support requires additional resourcing, appropriate costing and greater coordination across services.[27]

Building blocks to realise Priority Four	
Improved practical advice and support for families	Health, community and aged care providers: • understand the importance of informing, educating and supporting family and carer(s) • understand the financial burden to families who are caring for a person at end-of-life • have the skills and resources to identify family needs early in the referral process • have access to standardised, evidence-based carer assessment tools. Families have equitable access to respite and support, are able to advocate for the enactment of their loved one's preferences through ACP and advocate for access to specialist palliative care, if required.

Building blocks to realise Priority Four	
Improved awareness by health, community and aged care providers regarding family access to bereavement support	Health, community and aged care providers understand: ▪ the importance of informing, educating and supporting family and carer(s) ▪ the potential for complicated family grief in bereavement, and the importance of timely identification of such. Health, community and aged care providers have access to: ▪ standardised, evidence-based bereavement assessment tools. ▪ referral systems to local, community and non-specialist palliative care organisations, if needed. Families have access to timely and appropriate bereavement support.

Priority Five

All staff are prepared to care.

Wherever and whenever I am cared for, all staff involved in my care have expertise, empathy and compassion. All staff provide confident, sensitive and skilful care, before, during and after my death.

What is already known:

- End-of-life care is everyone's business, and quality end-of-life care can be delivered when health, community and aged care providers have the required skills and supports.
- The population is ageing and expectations of care are high, and the transition of skills and knowledge is required to meet this need.
- Gaps exist in coordination and continuity of care for people and their family/carer at end-of-life.
- Health, community and aged care providers need to know when to refer to specialist palliative care.[2, 6]
- Quality care at end-of-life supports appropriate use of health resources.

Building blocks to realise Priority Five	
Improved health, community and aged care provider understanding of end-of-life care, and appropriate referrals to specialist palliative care	Health, community and aged care providers have the confidence and capability to support people to discuss and document ACP and Goals of Patient Care, provide quality end-of-life care, and know when to refer to specialist palliative care. Funding models and strategies are established to address identified gaps and challenges.
The generalist healthcare workforce supported and mentored to increase capacity, knowledge and skills **Improved succession planning for an ageing workforce** **Workforce better equipped to support an ageing population**	The person's treating team is well supported to provide integrated end-of-life and palliative care through established partnerships between primary, secondary, tertiary and specialist palliative care services. The specialist palliative care workforce grows to meet demand and improve equity of access. Specialist palliative care teams have ongoing access to education and training opportunities.

Priority Six

The community is aware and able to care.

I feel supported and empowered to make decisions. My individual preferences are expressed through Advance Care Planning (ACP) and reflected in my end-of-life and palliative care. My community is aware and able to support me and those close to me.

What is already known:

- Awareness raising is required to increase community knowledge of end-of-life and palliative care and to view death as part of life.
- Increased knowledge assists and empowers people and their family/carer to make informed decisions.
- Better outcomes are achieved when people and their family/carer identify and advocate for their goals of care early in their illness trajectory.[2]
- A confident workforce is able to support people to make informed decisions about end-of-life and palliative care.

Building blocks to realise Priority Six	
Increased awareness and uptake of ACP	The general public has a better understanding of the value of ACP, including how to: • have conversations about preferences for care • access and complete relevant forms • make ACP available to health, community and aged care providers • advocate for appropriate care.
Improved public understanding of end-of-life and palliative care	People and their family/carer are able to: • clearly identify and document their goals of care with support of health, community and aged care providers • identify and request care that is consistent with their goals of care • the wider community has a better understanding of the benefits of timely end-of-life and palliative care.

Implementation and evaluation

The Strategy is a non-mandatory supporting document to the mandated *Clinical Services Planning and Programs Policy Framework* (Policy Framework). The Strategy supports and informs the implementation of this Policy Framework and provides a blueprint to achieve areas of focus and key elements of delivery.

Statewide

WA Cancer and Palliative Care Network

Through the WACPCN, the Department of Health, in its role as System Manager, will lead and oversee the implementation of the Strategy. The WACPCN's role is to provide clinical and health system leadership and advice to support health reform across the priority areas. The WACPCN will support stakeholders to connect and collaborate to enable the provision of an integrated, coordinated and strategic approach to influence policy, purchasing, workforce and planning.

The WACPCN will monitor performance via system-wide trends and data to provide assurance that the health system is delivering high-quality end-of-life and palliative care to Western Australians. See **Appendix Four** for more information on the importance of this data.

The WACPCN will facilitate statewide actions with HSPs and other stakeholders to implement and evaluate the Strategy at a statewide level. The Strategy also provides direction for future funding initiatives.

Local

Health Service Providers

At the individual HSP level, it is expected that these six priorities will be realised and enacted through local action and evaluation plans (including planning and reporting mechanisms) in consultation with the WACPCN on behalf of the Department of Health. HSPs are responsible for establishing local policy for their services, consistent with the *Clinical Services Planning and Programs Policy Framework* (see **Appendix One**).

Review

A review of the Strategy will be undertaken in 2023, or if a major change is required. The aim of the review will be to understand how the Strategy and associated implementation is being applied statewide, to consider factors that determine their effectiveness, and to make recommendations for improvements.

Glossary

The Strategy uses definitions and terms which encompass a range of services and disciplines. The following is an explanation of these terms.

Bereavement

A broad term that encompasses the entire experience of family members and friends in the anticipation, death and subsequent adjustment to living following the death of a loved one.[28]

Carer

Those who provide ongoing unpaid care and support to a family member or friend who has a disability, chronic condition, mental illness, terminal illness or general frailty. This includes parents and guardians caring for children.[29]

Care values

Care centred on the patient and family; sustainability; culture of continuous quality improvement; and seamless, continuous and integrated care.

Community care

Care provided by health professionals in the community setting (i.e. person's home) rather than in hospital.

End-of-life

End-of-life is the timeframe during which a person lives with, and is impaired by, a life-limiting/fatal condition, even if the prognosis is ambiguous or unknown.[8] Those approaching end-of-life will be considered likely to die during the next 12 months.[8]

End-of-life care

Care that improves the quality of life of people and their family/carer facing problems associated with life-limiting illness.[10] End-of-life care, supportive care, anticipatory care, comfort care, symptom management and palliative approach are sometimes used interchangeably.

End-of-life care encompasses a palliative approach to care and recognises that it is the responsibility of public, private, community and non-government health sectors to provide quality end-of-life care for their patients.[22, 30] It also recognises that support of people and their family/carer is most effective with a team approach[10] through a network of healthcare professionals.

End-of-life care includes connecting the person's primary treating team with specialist palliative care and enabling access to clear information and referral pathways if the person's complexity is beyond the scope of the professional or team.

Family

Those who are closest to the person in knowledge, care and affection. This may include the biological family, the family of acquisition (related by marriage or contract), and the family and friends of choice.[31]

Interdisciplinary team

A team of healthcare providers who work together to develop and implement a plan of care. Membership depends on the services required to identify and address the expectations and needs of the person and their family/carer. An interdisciplinary team might typically include one or more doctors, nurses, social workers, spiritual advisers, occupational therapists, pharmacists and personal care workers. Other disciplines such as speech therapists and physiotherapists may be part of the team depending on the needs of the person and the resources available. Hospital volunteers, people and their family/carer may also be considered as part of the interdisciplinary team.[8]

Life-limiting illness

An illness or condition that can be reasonably expected to cause the death of a person within the foreseeable future. This definition is inclusive of both malignant and non-malignant illness.

Model of Care

The principles, best practice care and provision of health services per specialty/population area to support people to access the right care, at the right time, by the right team and in the right place.

Palliative care

An approach that improves the quality of life of people and their family/carer facing the problems associated with life-limiting illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems – physical, psychosocial and spiritual.

Palliative care provides relief from pain and other distressing symptoms and:

- 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 people live as actively as possible until death
- offers a support system to help the family cope during the person's illness and in their own bereavement
- uses a team approach to address the needs of people and their family/carer, including bereavement counselling if indicated
- will enhance the 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.[10]

Specialist palliative care

Specialist palliative care is undertaken by a professional palliative care team or service with recognised qualifications or accredited training in palliative care. They provide direct care to people, and their family/carer with complex palliative care needs and/or provide consultation services to support, advise and educate specialist and non-specialist teams providing end-of-life care.[8]

While every Western Australian with life-limiting illness has a right to a quality palliative approach through end-of-life care, not everyone requires specialist palliative care.

Supporting factors

Includes the following factors: clinical support and workforce capacity; research evidence and evaluation; evidence-informed care, appropriate education and technology.

Terminal care

Care of the dying in the last days or hours of life.

Treating team (also known as primary care provider)

The person's primary treating team, inclusive of general practitioners, community nurses, and staff from aged care homes, multi-purpose centres, mental health services, prisons and correctional facilities. Includes other specialist services and staff, e.g. oncologists, renal, cardiac or respiratory physicians, and acute care hospital staff.

WA health system

The public health system in WA:

- Department of Health
- Health Service Providers
- Contracted health entities only to the extent they treat public patients.[32]

Care levels:

Primary care

The care the person receives at first contact with the healthcare system, usually involving coordination and continuity of care over time.

Secondary care

Care provided by a specialist or facility upon referral by a primary care physician.

Tertiary care

Care provided by a facility that includes highly-trained specialists and often advanced technology.

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Appendix One

Alignment with policy and quality strategies

The Strategy aligns with national and state strategies, policies and frameworks and draws from national and international best practice, including:

National

Document	How the Strategy aligns
Supporting Australians to live well at the end of life: *National Palliative Care Strategy 2010*[18] (currently under review)	The Strategy aligns with the four national goals of: ▪ Awareness and understanding. ▪ Appropriateness and effectiveness. ▪ Leadership and governance. ▪ Capacity and capability.
National Palliative Care Standards[33]	The Strategy aligns and supports the 9 standards, core values of the national Palliative Care Standards and the capability and resource matrix used to define the specialist palliative care service levels. It supports the criteria identified for specialist palliative care services.
National consensus statement: Essential elements for safe and high-quality end-of-life care[8]	This statement describes suggested practice for the provision of end-of-life care in settings where acute care is provided. It aligns with the National Safety and Quality Health Service Standards and provides recommended, rather than mandatory, practice. The Consensus Statement aligns with the guiding principles and essential elements of the *National Consensus Statement: Essential elements for recognising and responding to clinical deterioration*.[34]
National Strategic Framework for Chronic Conditions[35]	The Strategy supports the *National Strategic Framework for Chronic Conditions* as a nationally agreed agenda to encourage a coordinated response to the growing impact of chronic conditions on the health of Australians and the healthcare system and aligns with its Holistic approach to the quality care of a person with chronic condition/s.

State

Document	How the Strategy aligns
Carers Recognition Act 2004[29]	The Strategy recognises the role of carers in the community, and provide a mechanism for the involvement of carers in the provision of services that impact on carers and the role of carers.[29]

WA Department of Health

Document	How the Strategy aligns
WA Health Strategic Intent 2015-2020[36]	The Strategy aligns with the priorities of 'health services' and 'prevention and community care services' in the *WA Health Strategic Intent 2015-2020*.
WA Health Clinical Services Framework 2014-2024[37]	The *WA Health Clinical Services Framework 2014-2024* (CSF) guides the provision and delivery of safe, high-quality, public healthcare in Western Australia. The CSF provides direction for where and at what level palliative care services are delivered in health facilities across WA. The Strategy refers to the CSF to direct the level of palliative care service delivery in health facilities across WA. The CSF was a component used to map specialist palliative care service delivery across Western Australia.
Clinical Services Planning and Programs Policy Framework[38]	The *Clinical Services Planning and Programs Policy Framework* contains mandatory policies, minimum standards, and supporting documents. It is issued by the Director General of WA Department of Health and is binding for the WA board governed HSPs. HSPs are responsible for the establishment of local policy for their services, consistent with the Policy Framework. The Policy Framework was developed within the context of the *WA Health Clinical Services Framework 2014-2024*.[37] The Strategy sits within the overarching Policy Framework as a supporting document.
The End-of-life Framework[6]	The *End-of-life Framework* is a statewide model for the provision of comprehensive, coordinated care at end-of-life in Western Australia. It provides direction for best-practice care across a patient's end-of-life trajectory, commencing when they are diagnosed with a life-limiting illness or their death is expected. It focuses specifically on end-of-life care in acute healthcare settings. It affirms that whilst some patients may have complex care needs and require access to specialist palliative care; most patients can be cared for by their primary care provider or primary specialist team through end-of-life care, also known as the palliative approach. The Strategy supports the stages of end-of-life care including: advancing disease, increasing decline, last days of life, death and bereavement support for families. The Strategy sits alongside this supporting document within the *Clinical Services Planning and Programs Policy Framework*.[38]

Document	How the Strategy aligns
Palliative Care Model of Care[2] *Rural Palliative Care Model in Western Australia*[3] *Paediatric and Adolescent Palliative Care Model of Care*[4] *Perinatal Palliative Care Model of Care*[5]	Models of Care outline principles, best-practice care and the provision of health services per speciality/population area to support people accessing the right care, at the right time, by the right team and in the right place. Over time, the implementation of the Strategy will replace all or some of the WA Palliative Care Models of Care.[2-5]
Western Australia Cancer Plan 2012-2017[39] (currently under review)	*The Western Australia Cancer Plan 2012–2017* provides a framework for a cohesive, integrated, statewide approach to cancer control that is founded on the best available evidence, reflects national and state directions and utilises international benchmarks of effectiveness. The scope of end-of-life and palliative care is across all life-limiting illnesses, including cancer care. The Strategy sits alongside this supporting document within the *Clinical Services Planning and Programs Policy Framework*.[38]
Advance Care Planning Policy (currently in development)	The Advance Care Planning Policy provides strategic direction and service delivery models for Advance Care Planning and Advance Health Directives in WA. The Strategy is in alignment with this supporting document within the *Clinical Governance, Safety and Quality Policy Framework*.[40]

Appendix Two

Classification levels within the Clinical Service Framework (CSF)

The Diagram below depicts the palliative care service classification levels in the *WA Health Clinical Services Framework 2014-2024*[37] (CSF). In WA, a service is classified as a specialist palliative care service providing specialist care if it meets the criteria for Palliative Care Level 4 and above. A service in Levels 4-6 would also be delivering end-of-life care, with specialist palliative care.

Delivery of end-of-life care (Levels 1–6)

End-of-life care (Levels 1–3) | **Specialist palliative care** (Levels 4–6)

	Level 1	Level 2	Level 3	Level 4	Level 5	Level 6
Medical Services						
Palliative Care	▪ Assessment referral and management by GPs. ▪ Emergency assessment and referral. ▪ Links with the palliative care network. ▪ Visiting primary healthcare providers. ▪ Access to Telehealth services or support.	As for level 1 plus: ▪ Inpatient care by GP in consultation with specialist services. ▪ Access to some allied health services. ▪ 24/7 cover by RN. ▪ Referral coordination and link with specialist community and inpatient programs.	As for level 2 plus: ▪ 24/7 cover by clinical nurse with training and/or experience in palliative care services.	As for level 3 plus: ▪ Palliative care patients managed by GP and medical practitioner specialising in palliative care. ▪ Access to specialist SRN. ▪ Access to designated allied health services. ▪ Some allied health undergraduate education.	As for level 4 plus: ▪ Inpatient care by on-site palliative care physician. ▪ Registrar/RMO. ▪ Regional referral role. ▪ Undergraduate teaching and some research role. ▪ Integrated community consultative service under direction of palliative care physician. ▪ Links with oncology radiotherapy, anaesthetics, psychiatry, pain clinic and rehabilitation. ▪ Access to specialised allied health services.	As for level 5 plus: ▪ Full range of palliative care services with palliative care specialist providing consultancy to other units referral hospitals. ▪ Emergency services available. ▪ Statewide referral role. ▪ Undergraduate and postgraduate teaching role. ▪ 24/7 on-call specialist.

Appendix Three

Available specialist palliative care services in Western Australia

Access to specialist palliative care services is broad, which reflects the breadth of the state of WA. The distribution of specialist palliative care also reflects the distribution of the population, with the majority of Western Australians, living in the metropolitan area. The maps below inform the location, range and services offered by specialist palliative care services across WA.

Services providing end-of-life and palliative care are not shown on the maps as end-of-life, and palliative care is provided by all health, community and aged care services caring for people with life-limiting illness/conditions.

The maps are intended to be used for:

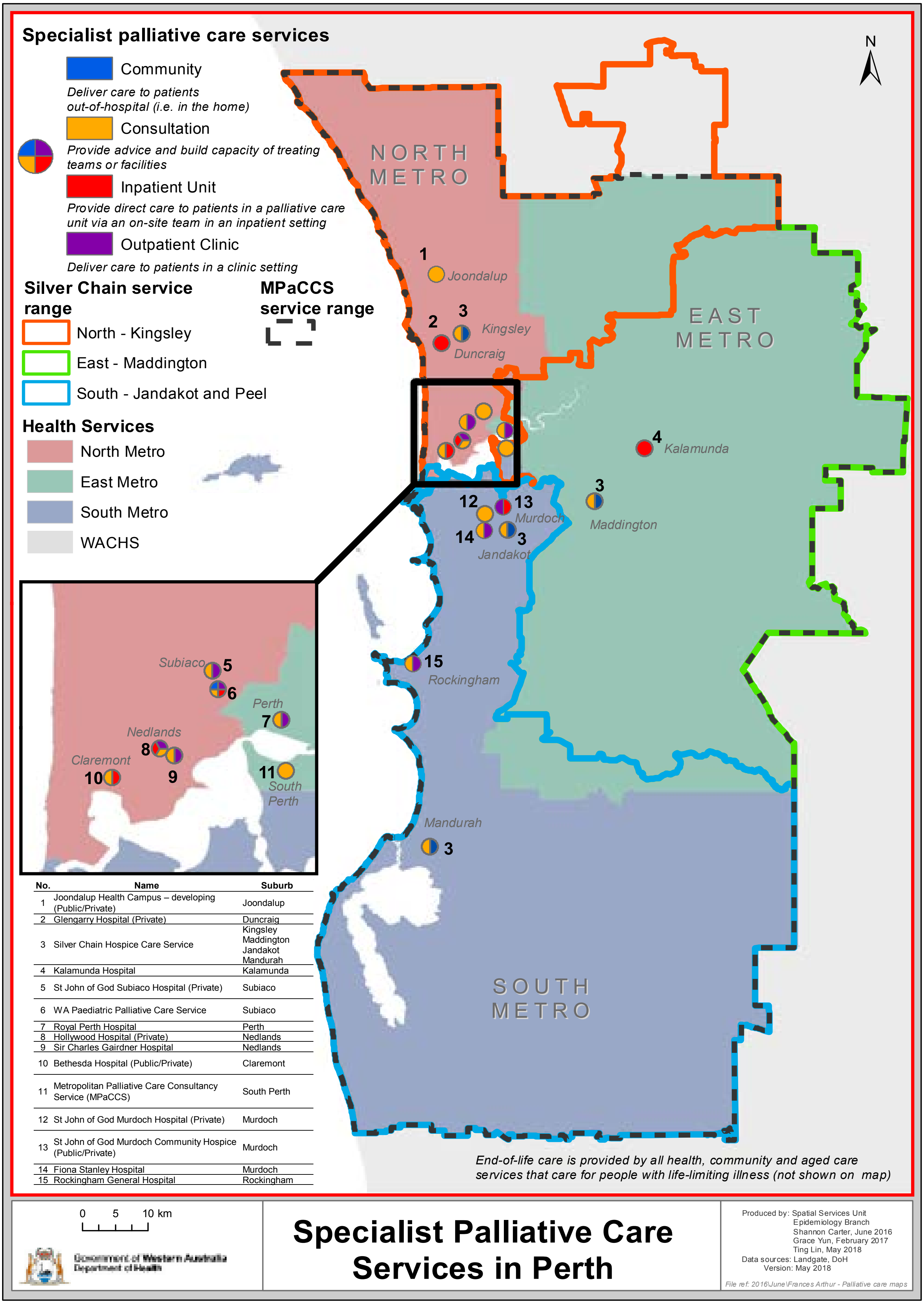
- Health professionals to make appropriate referrals.
- Health planners for policy and health planning development.
- People and their family/carer to understand the services available to them in their locality.

The following criteria were used to determine the inclusion of palliative care services in the maps:

1. Services listed as Palliative Care Level 4 and above in the *WA Health Clinical Services Framework 2014-2024*.[37]
2. Definitions listed in the *Admission, Readmission, Discharge and Transfer Policy for WA Health Services 2017*[41] http://www.health.wa.gov.au/circularsnew/pdfs/13365.pdf
3. Guide to Specialist Palliative Care Services.[42]
4. Other evidence of specialist palliative care service provision.

A WA Country Health Service map showing regions and sites with the ‘hub and spoke’ model for health services is available at: http://www.wacountry.health.wa.gov.au/index.php?id=833.

Specialist Palliative Care Services in Perth



No.	Name	Suburb
1	Joondalup Health Campus – developing (Public/Private)	Joondalup
2	Glengarry Hospital (Private)	Duncraig
3	Silver Chain Hospice Care Service	Kingsley Maddington Jandakot Mandurah
4	Kalamunda Hospital	Kalamunda
5	St John of God Subiaco Hospital (Private)	Subiaco
6	WA Paediatric Palliative Care Service	Subiaco
7	Royal Perth Hospital	Perth
8	Hollywood Hospital (Private)	Nedlands
9	Sir Charles Gairdner Hospital	Nedlands
10	Bethesda Hospital (Public/Private)	Claremont
11	Metropolitan Palliative Care Consultancy Service (MPaCCS)	South Perth
12	St John of God Murdoch Hospital (Private)	Murdoch
13	St John of God Murdoch Community Hospice (Public/Private)	Murdoch
14	Fiona Stanley Hospital	Murdoch
15	Rockingham General Hospital	Rockingham

End-of-life care is provided by all health, community and aged care services that care for people with life-limiting illness (not shown on map)

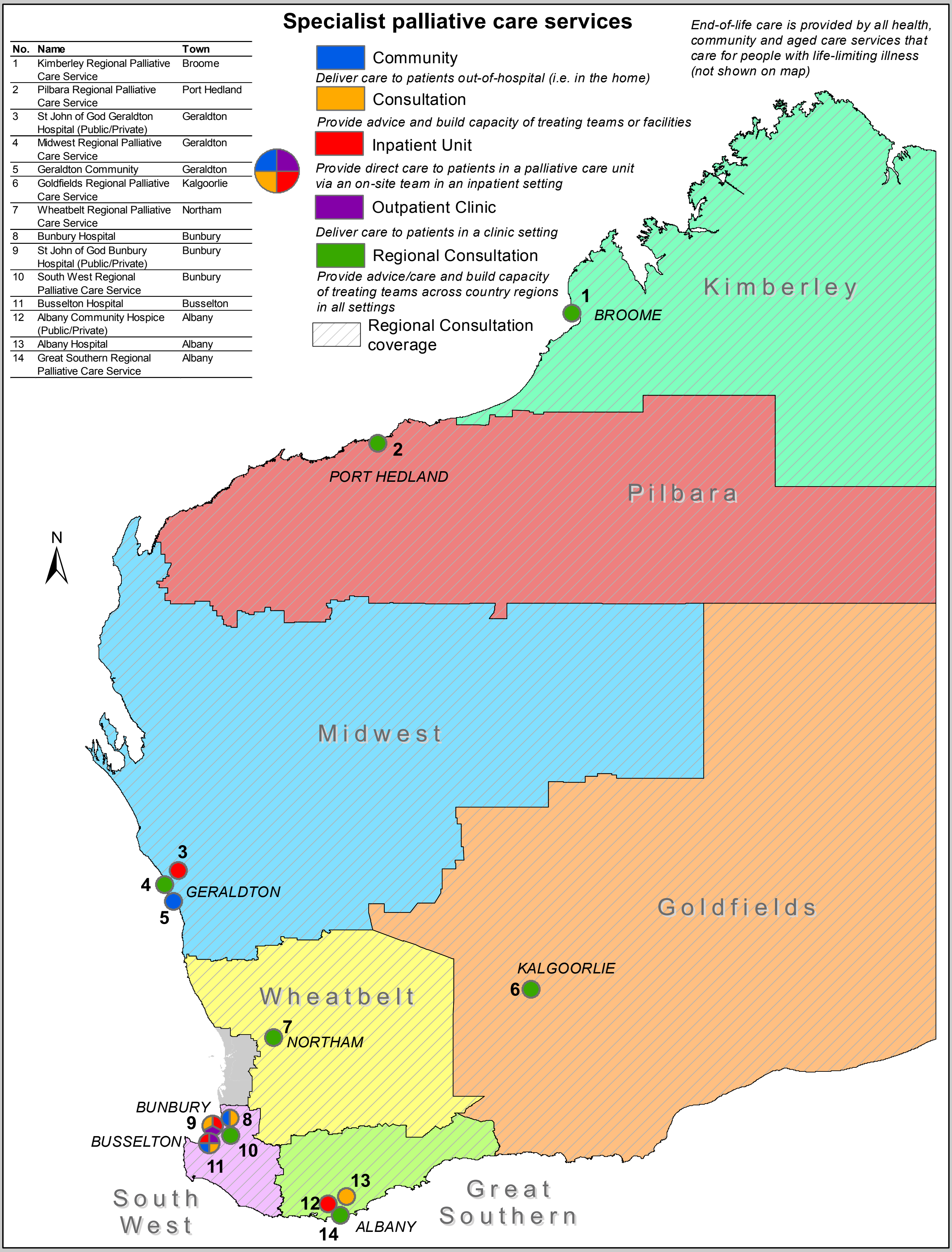
Government of Western Australia
Department of Health

Specialist Palliative Care Services in Perth

Produced by: Spatial Services Unit
Epidemiology Branch
Shannon Carter, June 2016
Grace Yun, February 2017
Ting Lin, May 2018
Data sources: Landgate, DoH
Version: May 2018

File ref: 2016\June\Frances Arthur - Palliative care maps

Specialist Palliative Care Services in WA



Specialist palliative care services

No.	Name	Town
1	Kimberley Regional Palliative Care Service	Broome
2	Pilbara Regional Palliative Care Service	Port Hedland
3	St John of God Geraldton Hospital (Public/Private)	Geraldton
4	Midwest Regional Palliative Care Service	Geraldton
5	Geraldton Community	Geraldton
6	Goldfields Regional Palliative Care Service	Kalgoorlie
7	Wheatbelt Regional Palliative Care Service	Northam
8	Bunbury Hospital	Bunbury
9	St John of God Bunbury Hospital (Public/Private)	Bunbury
10	South West Regional Palliative Care Service	Bunbury
11	Busselton Hospital	Busselton
12	Albany Community Hospice (Public/Private)	Albany
13	Albany Hospital	Albany
14	Great Southern Regional Palliative Care Service	Albany

🟦 Community
Deliver care to patients out-of-hospital (i.e. in the home)

🟧 Consultation
Provide advice and build capacity of treating teams or facilities

🟥 Inpatient Unit
Provide direct care to patients in a palliative care unit via an on-site team in an inpatient setting

🟪 Outpatient Clinic
Deliver care to patients in a clinic setting

🟩 Regional Consultation
Provide advice/care and build capacity of treating teams across country regions in all settings

▨ Regional Consultation coverage

End-of-life care is provided by all health, community and aged care services that care for people with life-limiting illness (not shown on map)

Specialist Palliative Care Services in WA

Government of Western Australia
Department of Health

Produced by: Spatial Services Unit
Epidemiology Branch
Shannon Carter, June 2016
Grace Yun, February 2017
Data sources: Landgate, DoH
Version: May 2018
File ref: 2016\June\Frances Arthur - Palliative care maps

Appendix Four

The importance of data

The collection of high-quality, accurate and timely data is essential to the efficient operation of the health system, including the implementation and evaluation of the Strategy. Data influences funding, purchasing and resource allocation.[43] In turn, this contributes to improved patient experiences and outcomes at an individual and population level.[44]

End-of-life data is collected by service providers, but there is no coordinated or consistent national approach, making it difficult to determine usage patterns, costs or outcomes.[45] At a minimum, data should enable governments to understand the care needs and preferences of people approaching the end of life, and fund services that best align with those needs and preferences.[45]

Relevant data systems in WA include the electronic palliative care information system, ePalCIS, the hospital morbidity data system and web patient administrative system. Services can also participate in the national Palliative Care Outcomes Collaboration, utilising standardised clinical assessment tools to measure and benchmark patient outcomes. Separate national systems are in place for paediatric data. Private services also use their own systems, with cross collaboration via the Western Australian Data Linkage program. At a local level, ePalCIS has been implemented across numerous public specialist palliative care services to collect Activity Based Funding, clinical management and service activity data as part of a standardised data system.

The collection and analysis of data is essential to planning, evaluation and ongoing quality improvement in end-of-life and palliative care. The collection of data can facilitate research and develop an evidence base to support, enhance or redefine the six priorities within the Strategy. Translating this knowledge into policy and procedure ensures our practice is evidence based.[46]

This document can be made available in alternative formats on request for a person with disability.

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