



**Government of Western Australia
South Metropolitan Health Service**

Ref A820222:
Enquiries :

Mr Chris Tallentire MLA
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Joint Select Committee on Palliative Care in Western Australia
Parliament House
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Dear Mr Tallentire

**RE: Submission to the Joint Select Committee on Palliative Care in Western Australia,
Inquiry into Palliative Care**

Thank you for the invitation to make a written submission to the Joint Select Committee on Palliative Care in Western Australia, Inquiry into Palliative Care.

Please find attached a written submission from the South Metropolitan Health Service (SMHS) that addresses the

- Progress in relation to the implementation of the recommendations of the Joint Select Committee into End of Life Choices.
- Delivery of services associated with palliative care funding announcements 2019/20
- Progress on ensuring greater equity of access to palliative care services between metropolitan and regional areas.

The submission addresses SMHS resource and funding requirements to meet the findings and recommendations of the Joint Select Committee into End of Life Choices, to deliver appropriate and timely access to palliative care services for all patients. To support our submission the SMHS Implementation Plan for the "WA End-of Life and Palliative Care Strategy 2018-2020 is attached.

Please do not hesitate to contact should you require additional information.

Yours sincerely

Kate Gatti
**A/CHIEF EXECUTIVE
SOUTH METROPOLITAN HEALTH SERVICE**
10 July 2020

Attach:

1. SMHS Submission to the Joint Select Committee on Palliative Care in Western Australia, Inquiry into Palliative Care
2. SMHS Implementation Plan for the "WA End-of Life and Palliative Care Strategy 2018-2020.

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South Metropolitan Health Service submission to the Joint Select Committee on Palliative Care in Western Australia: Inquiry into Palliative Care in Western Australia.

About South Metropolitan Health Service.

South Metropolitan Health Service (SMHS) delivers hospital and community-based services to more than 659,000 people, nearly a quarter of WA's population within nine local government areas. In addition, SMHS provides services to WA Country Health Service (WACHS) patients from Great Southern, South West, Southern Wheatbelt and Goldfields.

SMHS provides public hospital services at:

Hospital	Level of care	Bed numbers	Palliative care service CSF level*
St John of God Murdoch Hospice (SMHS contract)	Hospice – inpatient specialist palliative care	20 beds public/private of which 10 beds are public	Level 5 Inpatient specialist palliative care
Fiona Stanley Hospital (FSH)	Tertiary level care & Emergency Department	783 beds	Level 6 Consultancy palliative care service
Fremantle Hospital (FH)	Specialist care	300 beds	Nurse led service
Rockingham General Hospital (RGH) & Murray District Hospital (MDH)	General hospital & Emergency Department	242 beds	Level 4 Consultancy palliative care service
Peel Health Campus (PHC) SMHS managed under contract with Ramsay Health)	General hospital & Emergency Department	193 beds (public/private) of which 140 beds are public beds	Level 3 GP led palliative care and clinical nurse consultant

* Clinical Service Framework

SMHS Implementation of the recommendations of the My Life My Choice: The Report of the Joint Select Committee on End of Life Choices.

In response to the Department of Health, WA End of Life and Palliative Care Strategy 2018-2028, SMHS has developed the SMHS Implementation Plan for the WA End of Life and Palliative Care Strategy 2018-2028 (attached). The Plan sets out the current state of palliative care service provision and identified gaps which can be summarised as:

- Appropriate access to timely referral to palliative care services do to resource limitations, and
- Education and training for staff.

Finding 4 and Finding 15 with respect to concerns about the use of Goals of Patient Care (GoPC) is acknowledged. SMHS hospitals have actively promoted and implemented the GoPC as a tool to initiate the difficult conversation about end-of-life/palliative care for patients in the Emergency Departments and inpatient setting. In the case of FSH, the GoPC can be automatically uploaded to the patients My Health Record (MyHR) and an auto-

populate function has been added to the medical record. This means that the patient and health professionals eg General Practitioners can review.

Staff are encouraged to discuss Advanced Care Planning and Advanced Care Directives with patients, however as stated in the findings of the Select Committee, this is an areas that staff have identified as requiring additional training.

SMHS has also implemented the Supportive and Palliative Care Indicators Tool (SPICT) which is used to help identify people whose health is deteriorating, to assess them for unmet supportive and palliative care needs.

SMHS has developed and implemented the Patient Centred Cultural Care Guidelines: Aboriginal Health Strategy which includes guidance for staff on end of life care for Aboriginal people. These guidelines have been widely implemented across SMHS. There are further opportunities to build on the cultural care guidelines in palliative and end of life care to provide a sector-wide resource for health professionals.

Palliative Care funding 2019/20.

SMHS acknowledges and welcomes the additional funding made available by the State Government in 2019/20 to improve access and build the capacity of Silver Chain, establish inpatient specialist palliative care services in the northern suburbs and increase funding for palliative and end of life care in regional areas. This funding, however, does not address the identified significant gaps that exist in the current service provision at all SMHS hospital sites to provide equity of access to patients requiring palliative care. Further funding and investment is required.

SMHS key areas for investment to improve palliative and end of life care services.

SMHS hospital sites have undertaken detailed reviews of the current service provision. We have identified key areas where additional resources and funding are required to address the gaps in palliative and end of life care services to meet the demands and needs of patients.

1. Build the capacity to provide appropriate and timely access to palliative and end of life care services to all patients who would benefit at Fiona Stanley and Fremantle hospitals.
2. Build the capacity to provide appropriate and timely access to palliative and end of life care services to all patients who would benefit at Rockingham and Murray Districts hospitals.
3. Advocate for the establishment of an inpatient specialist palliative care hospice in the southern corridor of SMHS catchment to overcome the barriers to access for the residents of Rockingham and Mandurah.
4. Advocate and support the expansion of community-based palliative care service providers to deliver contemporary evidence-based models of care. This includes care coordination and integration across the continuum of care between community, hospital and hospice settings to meet the growing complexity and needs of all patients requiring care.
5. Support and facilitate access to training and education in palliative and end of life care for all SMHS staff in collaboration with the Department of Health, WA Cancer and Palliative Care Network.
6. Build on the SMHS Patient Centred Cultural Care Guidelines to develop the Aboriginal end of life and palliative care cultural care guidelines for implementation across for all Health Service Providers.

SMHS recognise and acknowledge that all staff are committed to providing the best possible care including sensitive and person-centred end of life care for all patients. However, better outcomes can be achieved with access to palliative care specialists across all hospital and community services.

The Report clearly articulates the limited access to palliative care for those people who have life-limiting conditions other than Cancer. Finding 12 states that access to specialist palliative care in the early stages of diagnosis might improve remaining quality of life. Finding 13 states promotion of the understanding of palliative care in the community and with health professionals to ensure that more non-cancer patients who could benefit, receive care. Finding 16 states that access to hands on specialist palliative care is limited for metropolitan and non-metropolitan patients.

SMHS would concur with these findings as an accurate reflection of SMHS hospitals service provision due to resource limitations resulting in inequity of access to palliative care services.

SMHS acknowledges Recommendation 10, to implement a process to determine unmet need for palliative care, measure delivery with an aim of making those services available to more Western Australians. This cannot be achieved without additional funding and resources to meet the workforce benchmarks and overcome the inequity of access across the SMHS catchment and the southern most corridor where the disparity in access mirrors that of regional WA.

The following section describes the current service provision and identified gaps that require additional resources for SMHS to deliver an appropriate and timely palliative care and end of life care service to meet the demands and needs for all patients.

1. Build the capacity to provide appropriate and timely access to palliative and end of life care services at Fiona Stanley Hospital and Fremantle Hospital.

Fiona Stanley Hospital has an inpatient Palliative Care Consultancy Service. The service is made up of medical, clinical nurse consultant and social work staff. The current PCS receives on average 950 referrals per year. While all referrals are for patients with life limiting illness, many are for end of life care, which demonstrates that care is not being offered early in a patient's journey of diagnosis. The majority of care is provided to cancer patients.

Those patients with chronic disease and often with co-morbidities such as COPD, heart failure, end stage renal failure and neurological conditions such as Motor Neuron Disease are not routinely referred despite the life limiting and often debilitating nature of these conditions.

Best practice palliative care assessment and management particularly for those with complex needs and/or co-morbidities recommends the PCS are involved in multi-disciplinary team and case management meetings to assist in care planning and decision making. FSH PCS has very limited capacity to attend MDT meetings for Cancer patients only. This is well below the benchmark and recommendations for optimal palliative care.

Fremantle Hospital does not have access to PCS and the current service is limited to two (2) days per week with a clinical nurse providing a nurse led palliative care service. There is no dedicated medical or social work staff. Given FH has a high proportion of patients who are older and receiving rehabilitation or care awaiting nursing home placement, this service is grossly inadequate given the needs of the patients for palliative and end of life care.

Outpatient clinics delivered by a multi-disciplinary team provide a suitable environment to assess and deliver ongoing palliative and end of life planning, management and care outside of the busy acute care setting. The outpatient clinic also allows for the inclusion of family/carers to participate. FSH currently has one dedicated outpatient clinic which is under-resourced and often over-booked, resulting in less than optimal care. There is no outpatient service at FH.

Additional activity and funding for dedicated palliative outpatient clinics at FSH and FH would improve care planning and patient outcomes as well as provide an efficient model of care. They also provide an opportunity to improve care coordination with the inclusion

of community care providers in attendance for clinical handover and integration between hospital and community services.

Workforce

The Palliative Care Australia benchmark set in 2018 recommends 2 FTE specialist palliative medicine physicians per 100,000 population. Although no Health Service Providers in WA meet the national benchmarking, FSH in comparison with 1.2 FTE specialist physician, is significantly under resourced, taking into account the patient cohort at the FSH quaternary hospital.

In addition to the 1.2 FTE specialist physician, the FSH PCS has 1 FTE social worker, a 0.4 FTE pharmacist, 2.5 FTE Clinical Nurse Consultant/Clinical Nurse and 1.0 Registrar and 0.5 FTE Registered Medical Officer. This team cannot meet the demand for palliative care services.

To overcome the identified gaps in equity of access and ensure the provision of a comprehensive palliative care service at FSH and FH to meet the needs of all patients and their families, additional investment in medical, nursing and allied health staff is required.

2. Build the capacity to provide appropriate and timely access to palliative and end of life care services at Rockingham Hospital and Murray Districts Hospital.

Rockingham Hospital (RGH) provides an inpatient palliative care consultancy service. The service is made up of one medical consultant and one FTE clinical nurse consultant/nurse. There is no social work staff. The current PCS receives on average 515 referrals per year. While all referrals are for patients with life limiting illness, many are for end of life care, which demonstrates that care is not being offered early in a patient's journey of diagnosis. The majority of care is provided to cancer patients.

As stated above, best practice palliative care assessment and management particularly for those with complex needs and/or co-morbidities recommends the PCS are involved in multi-disciplinary team and case management meetings to assist in care planning and decision making. The RGH PCS has no capacity to attend MDT meetings. This is well below the benchmark and recommendations for optimal palliative care. The service at RGH extends to the Murray Districts Hospital. Given the limited staff the current service does not have the capacity to provide a consultancy service to this hospital.

Outpatient clinics delivered by a multi-disciplinary team, provide a suitable environment to assess and deliver ongoing palliative and end of life planning, management and care outside of the busy acute care setting. The outpatient clinic also allows for the inclusion of family/carers to participate.

RGH has one dedicated palliative outpatient clinic per week for patients from across the Rockingham and Mandurah catchment. The clinic is a medical led clinic with no MDT, has a waiting time of up to 6 weeks and is often over-booked resulting in less than optimal care.

Additional activity and funding for dedicated palliative outpatient clinics at RGH would improve care planning and patient outcomes as well as provide an efficient model of care. It would also provide an opportunity to improve care coordination with the inclusion of community care providers in attendance for clinical handover and integration between hospital and community services.

The Peel Health Campus provides a GP led palliative care and clinical nurse consultant inpatient palliative care service. They do have inpatient palliative care services. An expansion of the RGH outpatient palliative care service would include the Mandurah catchment.

Workforce

The Palliative Care Australia benchmark set in 2018 recommends 2 FTE specialist palliative medicine physicians per 100,000 population. Although no Health Service Providers in WA meet the national benchmarking, RGH in comparison with 1.0 FTE specialist physician, is significantly under resourced, taking into account the population and inpatient services provided at RGH.

The RGH PCS team is made up of 1.0 FTE specialist physician and 1.0 FTE Clinical Nurse. There is no allied health staff. RGH has previously had a Registrar position but more recently this position has not been recruited to as there is not the capacity to provide a clinical service and the teaching role.

To overcome the identified gaps in equity of access and ensure the provision of a comprehensive palliative care service at RGH and MDH to meet the needs of all patients and their families, additional medical, nursing and allied health staff is required.

3. Access to specialist inpatient palliative care.

Finding 9 states that access to inpatient specialist palliative care in Perth is limited and further evidence of this is stated in Finding 17, that WA has the lowest number of inpatient palliative care beds per head of population. In addition, Finding 10 of the Report states that apart from a small number of private beds at Glengarry Hospital, there is no inpatient specialist palliative care in the northern suburbs with Recommendation 7 requesting the Minister for Health should facilitate the establishment of an inpatient specialist palliative care hospice providing publicly funded beds in the northern suburbs of Perth. SMHS concurs with these findings.

SMHS has a contract with SJOG Murdoch Hospice for the equivalent of 10 public beds for the provision of inpatient specialist palliative care (SPC). The distance is a barrier for residents from Rockingham and Mandurah to access SPC at Murdoch which can result in less than optimal care in the community or care being delivered in an acute setting.

While funds have been allocated to the northern metropolitan catchment to increase the number of SPC beds, no funding has been allocated in the southern corridor despite similar population profile and distance from existing services.

It is therefore requested that SMHS is funded to establish a SPC service in the southern corridor of its catchment to meet the needs and demands of residents of Rockingham and Mandurah area.

4. Expansion of community based palliative care service providers to deliver contemporary evidence based models of care.

SMHS welcomes the additional funding for home based services by the State Government, and recognises that additional investment is required to improve appropriate and timely access to home-based palliative care. As stated in the Report, SMHS acknowledges the service provided by Silver Chain and supports Recommendation 8, that the Minister for Health should ensure that community palliative care providers, such as Silver Chain, are adequately funded to provide for growing demand.

SMHS staff are keen to participate in any opportunities to work with the Department of Health and other stakeholders eg Palliative Care WA to explore and develop contemporary evidence-based community palliative and end of life models of care. This would include care coordination and integration across the continuum of care between community, hospital and hospice settings to meet the growing complexity and needs of all patients requiring care.

It is more difficult to quantify the level of community-based palliative care service provided to SMHS residents as the service is provided by Silver Chain, an external organisation. Our experience is that the current community-based palliative care service providers can

only accept those referred whose health is in decline or require end of life care as they do not have the resources to provide ongoing care. Therefore, to meet the findings and recommendations of the Report requires significant additional funding to ensure equity of access across the metropolitan area.

5. Support and facilitate access to training and education in palliative and end of life care for all SMHS.

SMHS fully supports the Report recommendations relating to the education and training of staff across all health settings and disciplines. SMHS encourages and supports inclusion and participation of consumer and carer led organisations in education and training of staff.

The SMHS Implementation Plan for the WA End of Life and Palliative Care Strategy 2018-2028 has, as a priority, identified a range of education and training requirements to improve the knowledge and skill of staff including “commencing the hard conversation”, Advanced Care Planning, Goals of Patient Care, end of life care conversations, recognising diversity of culture and care pathways and access to care.

SMHS will promote and support staff to participate in education and training to enhance skills and knowledge in partnership with training and education providers.

SMHS also recognises and acknowledges that PCS staff have an important and critical role in improving the clinical skill and knowledge of SMHS staff at point of care providing clinical advice and participation in multi-disciplinary team meetings as well as through providing mentoring, tutoring and supervision of registrars and students across all disciplines. This role must be funded to build the capacity and capability of the current and future workforce of SMHS to improve patient care and patient and family outcomes.

6. Develop the Aboriginal end of life and palliative care cultural care guidelines for implementation across for all Health Service Providers.

The Report considers the submissions from Aboriginal Legal Service WA and Aboriginal Health Council of WA, with agreement that the community controlled health services offer a holistic model of care delivered by Aboriginal health services for Aboriginal people in communities. SMHS fully supports this approach and recognises the ongoing collaboration with the Aboriginal community controlled health sector. SMHS also recognises that many Aboriginal people are admitted to hospitals and have their ongoing management and care in outpatient and day hospital settings.

SMHS Aboriginal Health Strategy has worked in collaboration with the local Nyoongar community to develop the SMHS Patient Centred Cultural Care Guidelines. These guidelines support SMHS staff in the delivery of safe, clinical and culturally responsive care for Aboriginal patients across the continuum of care and in all settings. The guidelines have been widely adopted by SMHS staff and in particular the SMHS Aboriginal Health Champions who are Wadjela staff nominated as champions and trained to support Aboriginal patients. The guidelines have also received wide acceptance across other Health Service Providers.

There is an opportunity to build on the expertise and knowledge within the SMHS Aboriginal Health Strategy Team to develop End of Life and Palliative care cultural care guidelines for implementation across for all Health Service Providers. This would be undertaken in consultation with community providers and community members.

SMHS would require one-off seeding funding to undertake the development of this resource.

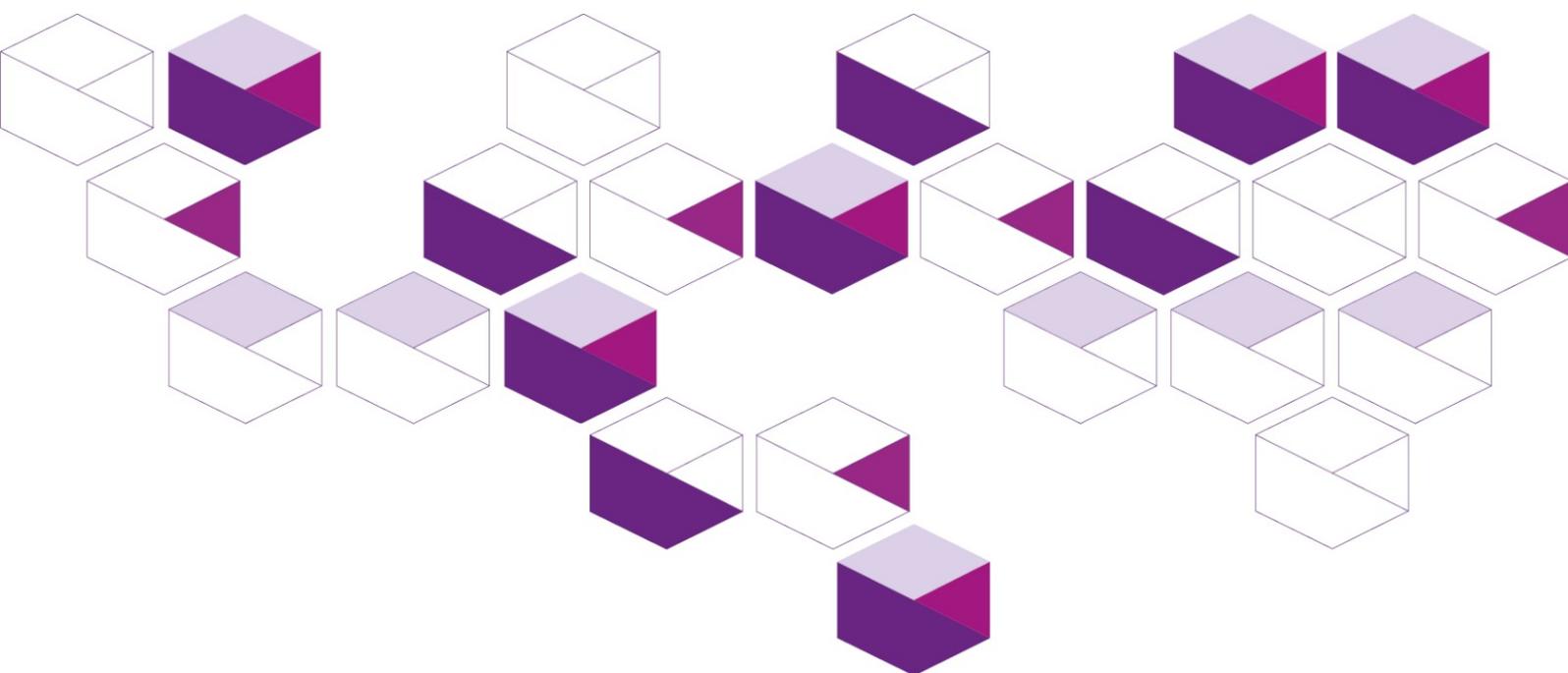


Government of **Western Australia**
South Metropolitan Health Service

Implementation Plan for the “WA End-of-Life and Palliative Care Strategy 2018-2028”

South Metropolitan Health Service

May 2019



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Acknowledgement

South Metropolitan Health Service (SMHS) would like to thank all of the stakeholders and clinicians involved in the development of this Implementation Plan (the Plan); from providing clinical expertise in the consultation process to reviewing draft iterations of the Plan which has resulted in a clear vision for the direction of end-of-life and palliative care going forward.

An Aboriginal Health Impact Statement and Declaration has been completed for this Plan.

This plan was endorsed by the SMHS Area Executive Group (AEG) on 31 May 2019.

1.0 Introduction

End-of-Life and palliative care services are current trending topics, with many recommendations being made regarding the provision and delivery of these services.

In 2018 the Western Australian Cancer and Palliative Care Network (WACPCN) launched the WA End-of-Life and Palliative Care Strategy 2018-2028 (the “Strategy”). This Strategy aligns with national and state policies and frameworks, and draws from national and international best practice.

The Strategy presents six overarching priorities providing a broad direction for implementation of integrated, responsive, coordinated and collaborative palliative care services. These six priorities underpin this Plan (see Appendix One):

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.

The Report of the Joint Select Committee on End of Life Choices (“My Life, My Choice”) was also released in 2018. This is significant to this Plan as the State Government supports all of the recommendations in My Life, My Choice, including several related to palliative care. The State Budget, released on 9 May 2019, provides a \$41 million boost to palliative care services, acknowledging that high quality palliative care is vital prior to assisted dying being legalised to avoid people ending their lives without having had access to high quality palliative care.

The Sustainable Health Review (SHR): Final Report to the Western Australian Government (April 2019) found that individuals want more say over their medical treatment. The SHR has made specific recommendations regarding end-of-life and palliative care which have been incorporated into this Plan..

This Plan aligns with the National Safety and Quality Health Service (NSQHS) standards and principles (second edition, 2017), specifically Standard 2: Partnering with Consumers Standard and Standard 5: Comprehensive Care Standard, which further support patient inclusion in decision making.

Work is already underway within SMHS on initiatives aimed at empowering patients and giving them back ownership of the decisions involved in their end-of-life and palliative care. Examples of this work include Goals of Patient Care and the Choosing Wisely Campaign.

Extensive consultation with internal and external stakeholders has occurred to develop this Plan. This Plan takes into account the current service provision for SMHS residents, identified gaps in service provision and proposed solutions, as well as the education and training requirements of SMHS staff. See Appendix Two for full details regarding the methodology used in the development of this Plan.

This Plan places the person at the centre of decision making and will ensure SMHS clinicians discuss what is important to their patient and their patients' preferences and hopes for their future care (including end-of-life and palliative care). This Plan also ensures SMHS is providing end-of-life and palliative care services which align with the direction and recommendations mentioned in all of the above reports and pieces of work.

1.1 Definition of End-of-Life and Palliative Care

Historically, palliative care has predominantly been provided at end-of-life for patients with cancer. However, increasingly palliative care is recognised as being required for those at end-of-life due to non-cancer diagnoses or chronic conditions.

End-of-life is defined as “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”¹. Those approaching end-of-life are considered likely to die within the next 12 months¹.

Palliative care is defined as “an approach to care that improves the quality of life of patients and their carers/families facing problems associated with life-limiting illness, through the prevention and relief of suffering”¹. It serves to maximise the quality of life and considers the physical, social, financial, emotional and spiritual distress. It is an approach / philosophy aimed at making a disease or its symptoms less severe, without removing the cause². A palliative care approach can be provided by any treating clinician or health care team, with or without support from a Specialist Palliative Care (SPC) team, depending on the individual requirements and circumstances.

SPC is undertaken by a professional palliative care team or service with recognised qualifications or accredited training in palliative care. The role of SPC 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.

2.0 Objectives

To inform this Plan, the following objectives were established:

- Define access to end-of-life and palliative care services for people residing in the SMHS catchment, including services delivered by SMHS, private and community providers across all sectors.
- Obtain a clear understanding of actual palliative care activity in hospital settings. This snapshot will include what activity / services are provided now, and identify potential gaps in service provision.
- Articulate the pathways across the continuum of care and the interface between primary, community and acute care sectors.

¹ World Health Organisation. WHO Definition of Palliative Care (online): World Health Organisation; 2016 (cited available from <http://www.who.int/cancer/palliative/definition/en>)

² WA End-of-Life and Palliative Care Strategy 2018-2028

- Define education and training requirements for staff, consumers, private providers, GPs and the general community.
- Identify dedicated palliative care resource requirements.

3.0 Current State

The WA Health Clinical Services Framework (CSF) 2014-2024 sets out the role delineation and level of palliative care services provided in the hospital setting.

The following table provides a summary of level and type of services provided by SMHS:

Service Type	
Inpatient Specialist Palliative Care (provide direct care to patients in a palliative care unit via an on-site team in an inpatient setting)	<ul style="list-style-type: none"> • SJOG Murdoch (Hospice) – 10 public beds (CSF Level 5) and 10 private beds.
Hospital Consultancy Service (provide advice and build capacity of treating teams or facilities)	<ul style="list-style-type: none"> • Fiona Stanley Hospital (FSH) (CSF Level 6) • Rockingham Kwinana Peel Group (CSF Level 4)
Palliative Care (generalist)	<ul style="list-style-type: none"> • Fremantle Hospital (nil – see below; “other”) • Peel Health Campus (CSF Level 3)
Community Services (Department of Health contract Silver Chain)	<ul style="list-style-type: none"> • Community Palliative Care Service (Silver Chain) <ul style="list-style-type: none"> - Delivers care to patients in their home - Service operates 24/7 - Cares for people of all ages - interdisciplinary • Other services which support people with advanced life limiting illness (without complex symptoms) including <ul style="list-style-type: none"> - Clinical Nursing Service - Respiratory Service - Home Hospital Service • Palliative Nurse Consultancy Service <ul style="list-style-type: none"> - Support to Aged Care Facilities who do not have 24 hour Registered Nurses on duty. The patient’s GP maintains clinical governance. • Bereavement support
Other	<ul style="list-style-type: none"> • Fremantle Hospital: CNS in-reach from FSH, which provides bereavement support for patients, the provision of education to generalist / non-specialist staff, and information collection (EPaICIS) • Advance care planning: This is an ongoing process of planning for one’s future treatment decisions. It is a collaborative process involving family/carers and health professionals. Advance care planning includes: <ul style="list-style-type: none"> - An Advance Care Plan (ACP) - An Advance Health Directive (AHD) - Appointing an Enduring Power of Guardian (EPG) - A Goals of Patient Care form (see below) • Goals of Patient Care <ul style="list-style-type: none"> - WA-wide form used in hospitals to document Goals of Patient Care discussions

	<ul style="list-style-type: none"> - Documents the most medically appropriate agreed goal of care that will apply in the event of clinical deterioration - Includes rationale for decisions, details of discussions and patient preferences - Note it is not legally binding <ul style="list-style-type: none"> • Pastoral Care (available at Fiona Stanley Hospital, Fremantle Hospital, Peel Health Campus and Rockingham General Hospitals. Also available at Murray District Hospital upon request.) • Metropolitan Palliative Care Consultancy Service (MPaCCS); a multi-disciplinary palliative ambulatory consultancy team, providing advice based on the unique needs of the patients, carer and family when facing a life-limiting prognosis • Patient Centred Cultural Care Guidelines³ – specifically regarding End-of-Life care guidelines • Paediatric palliative care: statewide service at Perth Children’s Hospital (PCH). There is work currently underway to translate the Goals of Patient Care form (mentioned above) for paediatric use.
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For further detail on the CSF see Appendix Three.

3.1 Current Demand

There is an increasing demand for end-of-life / palliative care services. The proportion of older people in the Australian population is increasing faster than population growth due to increased average life expectancy at birth and the ageing baby boomer generation⁴. In addition to this, the number of people living with a chronic condition is steadily increasing.

Chronic diseases are the leading cause of illness, disability and death in Australia, accounting for 90% of all deaths in 2011⁵. Often more than one disease is associated with a death; three diseases is the average⁶. More than 11 million Australians (50%) reported having at least one chronic disease in 2014-15⁶.

It is notable that chronic diseases occur more often in Indigenous Australians, and at a much younger age. 80% of the mortality gap for Indigenous Australians aged 35-74 years is due to chronic disease, measured in terms of potential years of life lost. The major contributors are heart diseases, diabetes, liver diseases, chronic lower respiratory disease, cerebrovascular diseases and cancer⁶.

People with a mental illness have a higher incidence of chronic disease than the general population. The Duty to Care Report⁷ found that death rates from all main causes are higher in people with a mental illness. The overall death rate of people with a mental illness was 2.5 times higher than the general population of WA. The greatest number of excess deaths in people with a mental illness was due to heart disease, at 16% excess deaths.

³ Patient Centred Cultural Care Guidelines, Aboriginal Health Strategy (South Metropolitan Health Service, 2018)

⁴ Swerissen H, Duckett S. Dying well: Grattan Institute Report No. 2014-10

⁵ Chronic disease – Australia’s biggest health challenge, Australian Institute of Health and Welfare, 2014

⁶ Contribution of chronic disease to the gap in mortality between Aboriginal and Torres Strait Islander people and other Australians, Australian Institute of Health and Welfare, 2011

⁷ Coghlan, Lawrence, Holman, Jablensky (2001): Duty to Care: Physical Illness in People with Mental Illness

(n.b. the expected number of deaths in people with a mental illness from any given cause is calculated by applying the general population death rate to the population of people with a mental illness. Deaths above this number are called excess deaths).

Of the top ten causes of death for SMHS residents from 2011-2015⁸, seven of those are conditions which end-of-life / palliative care would have likely been appropriate. Likewise, in the 2017/18 there were 498 patients who died in a SMHS hospital under specialties that indicate palliative care would likely have been appropriate.

Of those deaths the top three causes were under the specialties of respiratory medicine (n=165), cardiology (n=91), and neurology (n=81). This mirrors the Australian statistics of chronic disease being the leading cause of death.

Generally, chronic disease is associated with an “expected death”⁴, indicating that health service providers have an opportunity to provide planned, end-of-life care, and planned palliative care as most people will have contact with a GP or hospital service.

3.2 What SMHS does well

- Staff believe that high quality end-of-life / palliative care is provided. There is evidence of positive relationships between SMHS hospitals, SJOG Specialist Inpatient Palliative Care and Silver Chain Community Palliative Care service resulting in continuity of care for patients.
- SMHS has adopted the Choosing Wisely Campaign which aims to support patients with better decision making, in turn decreasing unwarranted interventions across a range of specialities and situations. Of particular note is Goals of Patient Care (GoPC), a tool to initiate the difficult conversation about end-of-life / palliative care for patients in the ED and inpatient setting. See Appendix Four. Training and education for staff in the use of GoPC is being implemented across SMHS.
- Specialist Palliative Care Service; both at FSH and RGH, which provides a consultative service for patients with advanced disease and limited prognosis. The focus of care is on pain and symptom management, psychosocial care, end-of-life care and discharge planning.
- SJOG Murdoch provision of Specialist Inpatient Palliative Care (via contract with SMHS). SJOG was one of only 6 services out of 120 across Australia to achieve “outstanding results” against Australian benchmarks in the Palliative Care Outcomes Collaboration (PCOC).⁹

3.3 Identified gaps

Education and training as well as appropriate and timely referral to end-of-life / palliative care services were recurring themes raised by SMHS staff and external palliative care service providers. Specifically, clinicians advised that they need more training regarding how to initiate and conduct the end-of-life conversation with patients and their families, often referred to as the “difficult conversation”.

⁸ Top ten causes of death for SMHS residents. Epidemiology Branch, Public Health Division, Dept of Health WA in collaboration with the Cooperative Research Centre for Spatial Information. Accessed 4 Dec 2018

⁹ <https://www.sjog.org.au/our-locations/st-john-of-god-murdoch-hospital/news/news/2017/03/10/08/20/benchmarking-tool-puts-hospice-at-top>

In addition to the timeliness of referrals, another theme raised was the number of referrals to hospitals for which the hospital would not be able to offer different / better care. These referrals often occur as a result of the needs of patients not being met by Residential Aged Care Facilities (RACF). It is recognised that hospitals need to work closely with RACFs to provide support to staff to make care decisions which have the best possible outcome for their residents.

Lastly, a disconnect was identified between primary and secondary / tertiary care in the provision of end-of-life / palliative care services. All parts of the health sector need to work together including GPs to promote an increase in the use of ACP and AHDs as a “conversation starter” for all people living with a chronic condition. There is a requirement for SMHS staff and GPs to work collaboratively and not only share care, but also conversations about the end-of-life and palliative care wishes of patients.

3.3.1 Education and Training

Clinicians identified a number of reasons for not having the difficult conversation with patients when appropriate:

- Clinician focus on intervention and new treatment modalities and what else can be done, rather than person-centred care that is inclusive of the patient in the decision-making process.
- Time limitations to spend with patients and families to discuss all the options.
- It is simply an uncomfortable conversation.

Mental health clinicians identified specific issues for patients with a mental illness who require end-of-life / palliative care. These include assessing whether or not the person has the mental capacity to participate in a conversation regarding treatment options, ensuring physical health care as well as mental health care needs are met, where end-of-life / palliative care services can be provided and need for shared care and partnership with mental health clinicians.

We are unable to determine whether appropriate end-of-life/palliative care services were provided to people with mental illness however, anecdotally, commencing discussions with patients with a mental illness is not done well and there is an opportunity to improve mental health patient care through the provision of training to mental health clinicians.

The following education and training has been identified as required for SMHS staff:

- Having the difficult conversation with everyone who has a life limiting condition.
- Communication skills and training in use of tools to support earlier assessment and enabling active end-of-life / palliative care planning and decision making.
 - Goals of Patient Care Form
 - Advance Care Planning
 - Advance Health Directives

The above will include completion of the forms as well as actioning and recording in the patient’s medical record.

- Communicating with people with mental illness about end-of-life and palliative care.
- Communicating with Aboriginal people to ensure delivery of culturally secure end-of-life and palliative care.

While not the responsibility of SMHS staff there are opportunities to influence, support and facilitate education for the general community about planning for end-of-life and palliative care. Education for the community is as important as education for health professionals, to ensure patients are making considered, informed and educated decisions. Initiating the

difficult conversation as early as possible with patients will assist to improve their awareness and understanding of options, rights, and the ramifications of same, early on.

3.3.2 Appropriate and timely referral to palliative care services

There are opportunities to improve access to end-of-life / palliative care through increased knowledge and implementation of referral pathways.

This is supported by SJOG and Silver Chain Community Palliative Care Service (SCCPCS) who have identified the need for earlier referral to their services. This is also demonstrated by the SCCPCS Palliative Care Outcomes Collaboration (PCOC) data from January to June 2018 showing 111 patients died within three days of their referral to SCCPCS.

In order to improve appropriate and timely referral to palliative care services, increasing clinician awareness of and use of referral pathways is required including:

- Considerations during discharge planning
- Referral processes, guidelines for when to refer, inclusion and exclusion criteria and handover requirements for SPC, SCCPCS and other palliative care services
- Guidelines regarding when the provision of a palliative care approach is required. This includes having a discussion around the use of clinical indicators; tools used to identify when a patient is deteriorating in clinical care, such as the Supportive and Palliative Care Indicators Tool (SPICT) (see Appendix Five).

There are opportunities for SMHS to improve communication with GPs, through sharing information such as the Goals of Patient Care form and discharge summaries that include palliative care services. This information can be uploaded to patients' My Health Records.

The interface between primary and secondary / tertiary care as set out in the End-of-Life and Palliative Care: Services Matrix (see page 11) identifies where two-way communication would be optimal for information sharing to ensure patients receive the best care possible across the entire continuum of their journey.

The following case study is an example of a palliative care patient which highlights some of the gaps in care:

Meg was a female in her mid-60's, admitted to FSH following a stroke complicated by various comorbidities. Behaviourally, Meg presented as quite agitated, and demanding of nursing staff. On the second day of her admission, Meg's family requested a referral to Pastoral Care. Pastoral Care observed that it seemed apparent Meg was dying, and noted this in the Digital Medical Record.

The medical team spent the first two weeks of Meg's admission discussing options such as rehabilitation, how to return Meg to her baseline level of function, and discharge planning.

Two weeks into the admission, and a week and a half prior to death, the focus of treatment changed. At the request of Meg's family, a family meeting was held, and the family was advised that the medical team felt that Meg was dying.

Pastoral Care provided a referral for Meg to Palliative Care; however there was a delay in access and the Specialist Palliative Care team only saw Meg during the last few days of her life.

Issue identified:

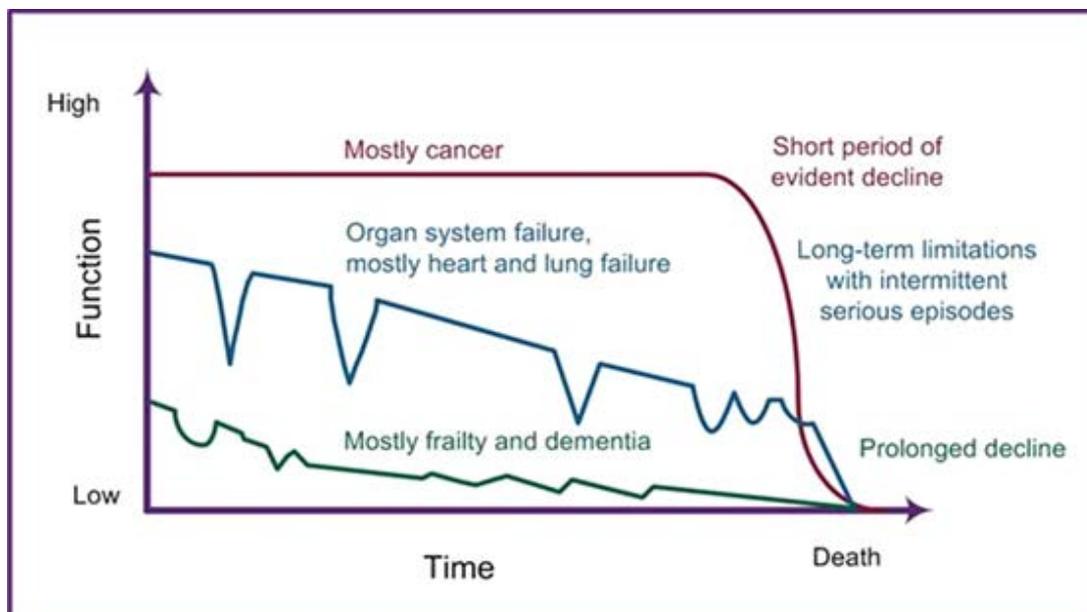
- *Timely access to Specialist Palliative Care.*

Consideration point:

- *How could the care have been different? What would be your approach to ensure Meg's last few days were managed optimally?*

4.0 End-of-Life and Palliative Care: Services Matrix

The figure below¹⁰ provides a representation of the variable disease trajectories that people with life limiting illness may experience, suggesting the need for palliative care services to be adaptable to a range of care needs over time:



With the increasing incidence of chronic disease and multiple comorbidities, our patients will likely be faced with multiple trajectories. The reality is becoming increasingly more complex than the above diagram.

The End-of-Life and Palliative Care Matrix (over page) details types of services / activities which should be undertaken during a palliative approach to care. The services / activities detailed are what SMHS needs to actively provide to all patients requiring end-of-life / palliative care, in order to achieve the six priorities identified in the Strategy, which SMHS is fully supportive of.

First and foremost, the difficult conversation needs to commence at diagnosis and continue through to last days of life. The matrix suggests opportune moments along the disease trajectory for certain interventions, however, all actions are interchangeable along phases of illness based on patient needs. It is also acknowledged that there will be differences in the provision of end-of-life / palliative care provided to all patients, due to variations such as diagnosis, cultural considerations and patient wishes.

There are three service providers in the matrix, the roles of which can be described as:

1. Primary Care / GP
2. Community Service Organisations
3. Hospital (ED, ward, outpatients)

Please note, many of the primary care services described below are also provided in the outpatient hospital setting.

The matrix has been colour-coded to align with the six priorities in the Strategy, however it is recognised that actions will often contribute to achieving multiple priorities.

¹⁰ Department of Health WA, Palliative Care Model of Care, Cancer & Palliative Care Network; 2008

End-of-Life and Palliative Care: Services Matrix					
	Diagnosis	Advancing Disease	Increasing Decline	Last Days of Life	Death / Bereavement
	<p>Note: actions are interchangeable along phases of the illness trajectory*, based on patient needs, and the “difficult conversation” needs to commence at diagnosis and continue through to last days of life. Advocacy for patient choice also occurs along all phases of the illness trajectory</p>				
<p>Priority 1: Care is accessible to everyone, everywhere</p> <p>Priority 2: Care is person-centred</p> <p>Priority 3: Care is coordinated</p> <p>Priority 4: Families and carers are supported</p> <p>Priority 5: All staff are prepared to care</p> <p>Priority 6: The community is aware and able to care</p>	Primary Care / GP	<p>Assessment; history, physical exam, social structures / supports, decision making capacity</p> <p>Starting the difficult conversation;</p> <ul style="list-style-type: none"> Psychological and emotional response to the illness Spirituality / religious beliefs Expectations regarding care and outcomes <p>Clarification of communication, any further information required</p>	<p>Patient and family / carers</p> <ul style="list-style-type: none"> Information and education on diagnosis and prognosis Clarification of understanding / further information required Self management advice Referral to appropriate services <p>Share information with appropriate stakeholders; patient, family / carer, nursing home, agencies referred to</p>	<p>Consider referral to Silver Chain Home Hospice, MPaCCS etc</p> <p>Bereavement risk assessment</p> <p>Symptom management</p> <p>Referral to hospital for symptoms which cannot be managed at home by the patient and GP, or by a visiting treatment team</p>	<p>Full assessment (ongoing assessment) and referral to appropriate services</p> <p>Psychosocial and spiritual support</p> <p>Follow-up phone contact (review of family will be ongoing)</p>
	Community Service Organisations	<p>Community education regarding scope and services involved in a palliative approach to care</p>	<p>Communication: at the heart of the palliative approach</p> <ul style="list-style-type: none"> Information and support Clarification / check for further information required <p>Examples of services available:</p> <ul style="list-style-type: none"> Silver Chain Home Hospice MPaCCS ** St John of God Murdoch (SJOG) WACPCN *** Carers WA (M-F 8-5 counselling) 	<p>Silver Chain: holistic palliative care needs assessment > Care Plan</p> <p>Access to respite</p> <p>Access to counselling</p>	<p>Silver Chain: facilitation of transfer to home or inpatient facility as required. Specialist equipment as required.</p> <p>Family meeting</p> <p>Psychosocial and spiritual support</p> <p>Information of grief and loss provided to family/carers (SJOG, Carers WA, Cancer Council)</p>
	Hospital (ED, ward, outpt)	<p>Start the difficult conversation about Goals of Care and Advance Care Planning</p> <p>Early referral to Aboriginal Health Liaison Officer (AHLO) for culturally appropriate contribution to a palliative approach to care</p>	<p>Assessment, including Goals of Patient Care form, and Advance Care Planning; upon referral (<i>i.e. early</i>)</p> <p>Continue the difficult conversation (throughout to last days of life) →</p> <p>Communication with GP, nursing home / other relevant parties (letters, D/C summaries)</p> <p>Use of Patient Journey Boards to ensure true MDT approach</p>	<p>MDT approach; palliative care model with access to Specialist Palliative Care for consultation / advice</p> <p>Referral to Specialist Palliative Care team: Care Plan review, communication with GP</p> <p>Family meeting</p> <p>Symptom management</p>	<p>Discharge / transfer planning (eg to SJOG hospice)</p> <p>Palliative care model, provided by any specialty (eg cardiac, renal, respiratory, neurology, oncology)</p> <p>Family meeting</p> <p>Psychosocial and spiritual support</p> <p>Information package for family members</p> <p>Support offered according to need and Bereavement Policy</p>

Ongoing training and education (information and education for patients, their families/carers, the general community, primary care (GPs), secondary care services, tertiary care services, community & aged care services):
When to provide a palliative approach, when and how to have the difficult conversation, training and support for staff and volunteers involved in bereavement support

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

* MPaCCS: Metropolitan Palliative Care Consultancy Service

** WACPCN: WA Cancer and Palliative Care Network

5.0 Implementation Plan

Improvement in end-of-life and palliative care provided to patients is a priority for SMHS staff. The Sustainable Health Review (SHR)¹¹ provides a staged approach to implementing it's recommendations pertaining to a dignified end of life:

Stage 1 (2019):

- Directions of the “My Life My Choice” report explored to identify implementation priorities

Stage 2 (July 2021):

- More people complete Advance Care Directives and are aware of end of life choices
- Coverage of evidence-based palliative care models expanded
- Training for staff to support realistic end of life conversations started

Stage 3 (July 2024):

- Adoption of new integrated models of care for older people increasing
- People experience a dignified end of life in a setting they choose
- Whole-of-government implementation plans are progressing

Stage 4 (July 2029):

- Older people with complex chronic conditions cared for in the community or in more appropriate settings

The End-of-life and Palliative Care: Services Matrix (previous) is not an exhaustive list of interventions which should be provided to patients throughout their end-of-life journey, and clinicians will be required to tailor interventions on a case-by-case basis. However the matrix (and this Plan) is a significant step towards reaching the above milestones.

In order to achieve above and strengthen the implementation of all parts of the matrix, key indicators are necessary.

5.1 Key indicators for successful end-of-life and palliative care

“Successful” end-of-life and palliative care will involve the application of the above matrix in a consistent, systematic approach. Application of the matrix can be measured via:

- Record of advance care planning;
 - o Advance Health Directive (legally binding)
 - o Advance Care Plan (ongoing conversation)
- Record of Goals of Patient Care form
- Record about any discussions had between treating medical team and the patient in medical records, including in discharge letters to GPs / referring specialists.

As aforementioned, this Plan aligns with NSQHS, specifically standards 2 and 5. The intention of standard 2 is:

- Consumers as partners in planning, design, delivery, measurement and evaluation of systems and services
- Patients as partners in their own care, to the extent they choose

¹¹ Sustainable Health Review (2019). Sustainable Health Review: Final Report to the Western Australian Government. Department of Health, Western Australia.

The intention of standard 5 is that patients care is aligned with the patient's expressed goals of care and healthcare needs, considers the effect of the patient's health issues on their life and wellbeing, and is clinically appropriate.

Completion and recording of advance care planning, Goals of Patient Care and all discussion regarding end-of-life wishes will contribute towards ensuring the provision of end-of-life and palliative care by SMHS is successful for all stakeholders. It will also provide evidence for the achievement of NSQHS standards 2 and 5.

All patients identified as having a chronic condition or estimated to be in the last 1000 days of life will have:

- Evidence of advance care planning
- Completed Goals of Patient Care form
- Record of treatment options and end-of-life care conversations in medical records and written correspondence to the patients GP or referring specialist.

5.2 Accountability and governance of end-of-life and palliative care

End-of-Life and palliative care of SMHS patients is everyone's business. As illustrated in the previous matrix, it is the role of the patient, their GP / primary care provider, community service organisations, and the hospital (whether that be in the emergency department, an inpatient ward, or in an outpatient appointment).

Within SMHS, end-of-life and palliative care can be difficult to measure. The Department of Health (via the WA Cancer and Palliative Care Network) is currently developing their own key measures for monitoring the provision of end-of-life and palliative care services, however SMHS has an opportunity now to determine which measures are most meaningful for SMHS and optimal patient care.

Evidence of advance care planning, completed Goals of Patient Care forms, and recording of treatment options/end-of-life conversations (including via written correspondence to GPs) are three tools we can use to measure how we are performing now. This information is currently available via HIMS.

The Clinical Service Planning and Population Health team will provide a report to SMHS Area Executive Group (AEG) annually, to inform AEG how SMHS is performing in terms of end-of-life and palliative care provision, in line with the WA End-of-Life and Palliative Care Strategy 2018-2028. Initially, evidence of the above three tools will be used as a reference point for accountability, however these will be revised once the Department of Health releases its own key measure recommendations.

5.3 Workforce capability and capacity

End-of-life and palliative care of SMHS patients is everyone's business. There is a small amount of Palliative Care Specialist FTE at FSH and RGH, who should be consulted with for complex or difficult cases.

For all other patients identified as having a chronic disease or in the last 1000 days of life, it is up to all staff to have the difficult conversation; including advance care planning, completing Goals of Patient Care and recording treatment options and end-of-life conversations in medical records (and relaying these conversations to GPs / primary care providers).

Throughout the consultation completed in the development of this Plan, staff were open and communicative about a reluctance to have these difficult conversations, and identification of training required in order to improve confidence and efficacy in having conversations about end-of-life and palliative care.

The following outlines actions identified by staff, as well as available evidence regarding the ongoing training and education required to improve patient outcomes:

Needs identified	Resources available
<p>1. Education program for all staff regarding:</p> <ul style="list-style-type: none"> ▪ The nature, purpose and effect of AHDs and ACPs and enduring powers of guardianship ▪ How to identify a valid AHD ▪ How to identify the lawful substitute treatment decision-maker ▪ Bereavement resources 	<p>Advance Health Directives training and resources (statutory training)</p> <p>https://ww2.health.wa.gov.au/Health-for/Health-professionals/End-of-life (DoH weblink)</p> <p>Goals of Patient Care</p>
<p>2. Education for all staff regarding the transition from curative to non-curative end of life care and effective discussions with patients and families about futile treatment.</p>	<p>Site based existing clinical guidelines. Information regarding what patients look like in the transition towards last days of life.</p> <p>Information regarding what the provision of good care at this stage looks like.</p>
<p>3. Education for all staff regarding the right of a patient to refuse medical treatment, as well as the absolute right of a competent patient to refuse food and water.</p>	<p>Mentoring regarding <i>how</i> to have the difficult conversation.</p>
<p>4. Education for all staff regarding:</p> <ul style="list-style-type: none"> ▪ The importance of recognising diversity of culture in relation to death and dying, specifically for Aboriginal and Culturally and Linguistically Diverse communities. ▪ Palliative care provision for people with a mental illness. 	<p>Program of Experience in the Palliative Approach (PEPA) - Learning Guides for:</p> <ul style="list-style-type: none"> ▪ GPs and rural and remote medical practitioners ▪ Aboriginal and Torres Strait Islander Healthcare Professionals ▪ Nurses and allied health professionals ▪ Cultural Care Guidelines
<p>5. Increasing awareness of SMHS staff regarding community palliative care options available, including referral pathways and criteria. At an operational level, SMHS needs to ensure that all staff, particularly frontline clinical staff, have access to referral pathways and criteria for all end-of-life / palliative care services which are available and appropriate for patients.</p>	<p>https://ww2.health.wa.gov.au/Health-for/Health-professionals/End-of-life</p>

5.4 Communication strategy

Following endorsement of this Plan, the communication strategy below will be formalised and implemented, under the direction of the SMHS site EDs (Fiona Stanley Fremantle Hospitals Group and Rockingham Peel Group):

Target audience	Key message
SMHS staff	<ul style="list-style-type: none"> ▪ End-of-life care planning and palliative care is everyone's business. ▪ <i>Not</i> having the conversation is mismanagement. It is a failure to give patients to opportunity to get out of their life what they want to fit in. ▪ Patients identified as having a chronic disease and / or estimated to be in the last 1000 days of their life to commence advance care planning as soon as possible. ▪ The following is to be recorded in the above patients' medical records: <ul style="list-style-type: none"> - Evidence of advance care planning - Completed Goals of Patient Care form - Record of treatment options and end-of-life care conversations in medical records and written correspondence to the patients GP or referring specialist ▪ Inclusion of patient consent to discuss end-of-life / advance care planning conversations with treating GP / other involved specialists. ▪ Sharing of information with primary care providers involved in each patient's care.
Patients	<ul style="list-style-type: none"> ▪ Advance care planning – resources available, benefits of planning ahead while still well (opportunity to plan for the life you want). ▪ Legal considerations.
GPs / primary care	<ul style="list-style-type: none"> ▪ Alignment with contemporary best practice, and recommendations in End-of-Life and Palliative Care Strategy as well as the SHR: Need to have the difficult conversation early (responsibility of everyone, and to share that information). ▪ <i>Not</i> having the conversation is mismanagement. It is a failure to give patients to opportunity to get out of their life what they want to fit in. ▪ Advance Care Plans / Advance Health Directives are a small part of the patient journey, which needs to be ongoing and continuous with anyone with a chronic disease. It can be positive; it can be about what the patient would like to fit in to their remaining time. ▪ Working towards building a culture of choice in treatment options
General community	Education about end-of-life decision making: <ul style="list-style-type: none"> ▪ AHDs and ACPs and enduring guardians ▪ Bereavement support options

Appendix One

Priority	Principles
<p>1. Care is accessible to everyone, everywhere</p>	<p>A life-limiting illness is an illness that can be reasonably expected to cause the death of a patient within a foreseeable future.</p> <p>People with life-limiting illness will have access to quality care to meet their needs. This care is delivered by trained staff who are supported by specialist palliative care services.</p> <p>SMHS will ensure that choices regarding care are fully understood, and care will only be provided in safe environments.</p> <p>This Plan will aim to ensure SMHS is able to meet the growing demand for palliative care within finite resources across the continuum of care.</p> <p>This Plan will also ensure the service provided by SMHS is culturally respectful and appropriate.</p>
<p>2. Care is person-centred</p>	<p>Quality of life can be enhanced by access to physical, psychological, emotional, social and spiritual support provided in a culturally appropriate manner.</p> <p>Emphasis is placed on providing patients' with the ability to plan their own future treatment, for example with education regarding Choosing Wisely and Advance Care Planning.</p> <p>There is a formal process of assessment, informed consent inclusive of boundaries of care and decision making around Advance Care Plans.</p>
<p>3. Care is coordinated</p>	<p>Patients and families need to experience a seamless service system, with smooth and timely transitions from one service to another.</p> <p>This Plan aims to facilitate integration of care across and between services, as well as communication and collaboration between all services.</p>
<p>4. Families and carers are supported</p>	<p>The patient and family are the unit of care given that: the person's illness affects not only the person who is unwell but also the family. Any difficulties experienced by the family will in turn impact the person who is unwell.</p> <p>People with a life-limiting illness, and their families, will have access to information about options for future care so that they are able to actively participate in decision making about treatment, care and end-of-life issues.</p> <p>This Plan will assist to ensure that end-of-life and palliative care is a collaborative process involving family and carers.</p>

<p>5. All staff are prepared to care</p>	<p>Palliative care is multidisciplinary and is an integral part of the health care system. Every person with a life-limiting illness has a fundamental right to access care that is underpinned by a palliative approach.</p> <p>Education and training strategies will be included in the Plan.</p>
<p>6. The community is aware and able to care</p>	<p>People with life-limiting illness have the right to spend as much time as possible in their own home and community, therefore outpatient 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.</p> <p>Community engagement and education strategies will be addressed in this Plan.</p>

Appendix Two

Plan development methodology:

A review of existing Palliative Care Models of Care was completed;

- Palliative Care Model of Care (April 2008) (WA Cancer and Palliative Care Network)
- Paediatric and Adolescent Palliative Care Model of Care (September 2009) (WA Cancer and Palliative Care Network)
- Perinatal Palliative Care Model of Care (August 2015) (WA Cancer and Palliative Care Network)
- Rural Palliative Care Model of Care (October 2008) (WA Cancer and Palliative Care Network)

Existing work and documents were reviewed and considered to ensure this Plan aligns with contemporary and evidence-based best practice (as well as the Strategy);

- WA End-of-Life and Palliative Care Strategy 2018-2028 (WA Cancer and Palliative Care Network)
- SMHS Strategic Plan 2017-2020
- The End-of-Life Framework (2016) (WA Cancer and Palliative Care Network)
- National Palliative Care Standards (5th edition, 2018), Palliative Care Australia
- WA Clinical Services Framework 2014-2024
- Fiona Stanley Hospital Service Specialty Plan: Palliative Care (V1.0, 2014)
- Advance Care Planning
- Choosing Wisely campaign
- My Life, My Choice: the Report of the Joint Select Committee on End of Life Choices (August 2018) (note: assisted dying legislation is out of scope of this Plan)
- Sad News, Sorry Business: Guidelines for caring for Aboriginal and Torres Strait Islander people through death and dying (version 2) (Queensland Health, 2015)

The current service model / type of service provision was articulated and mapped via process mapping workshops and discussion groups with stakeholders and experts in the field. One workshop was held at Rockingham General Hospital and one at Fiona Stanley Hospital.

1:1 consultation / meetings were also held with key identified stakeholders, such as the Medical and Service Directors of Service 1 (Cancer and Specialist Services) of Fiona Stanley Fremantle Hospitals Group, and the Service Director of Service 5 (Mental Health Services); in relation to the interface between palliative care and other services. In addition to the workshops held internally within SMHS, consultation also occurred with St John of God (SJOG) Hospice in Murdoch and Silver Chain.

This Plan, in draft form, was distributed to key stakeholders to obtain feedback prior to finalisation.

Appendix Three

WA Health Clinical Service Framework, Palliative Care:

Delivery of end-of-life care	End-of-life care	↑	Level 1	<ul style="list-style-type: none"> • Assessment, referral and management by local GPs • Emergency assessment and referral • Links with the palliative care network • Visiting primary healthcare providers • Access to Telehealth services or support 	
		↑	Level 2	<p>As for Level 1 plus:</p> <ul style="list-style-type: none"> • 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 inpatient programs 	
		↑	Level 3	<p>As for Level 2 plus:</p> <ul style="list-style-type: none"> • 24/7 cover by clinical nurse with training and/or experience in palliative care services 	
	Specialist palliative care	↓	↓	Level 4	<p>As for Level 3 plus:</p> <ul style="list-style-type: none"> • 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
			↓	Level 5	<p>As for Level 4 plus:</p> <ul style="list-style-type: none"> • Inpatient care by on-site palliative care physician • Registrar / RMO • Regional referral 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
			↓	Level 6	<p>As for Level 5 plus:</p> <ul style="list-style-type: none"> • 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 Four



Hospital:	Family Name	UMRN	
GOALS OF PATIENT CARE	First Name	DOB	Gender
	Ward:	Address	
Dr / Consultant:			Postcode

SECTION 1 BASELINE INFORMATION

Primary illness: _____

Significant co-morbidities: _____

In the event that the patient is unable to speak for themselves, who would they wish to speak for them? This is known as the **'Person responsible'**

Name: _____ Relationship: _____

Does the patient have?:

- * Advance Health Directive (AHD) Yes No
- * Advance Care Plan (ACP) Yes No
- * Enduring Power of Guardianship (EPG) Yes No

EPG contact name: _____ Phone: _____

- * Does the patient have a registered organ donation decision? Yes No
- * Are the family aware of the patient's donation decision? Yes No

Clinician's Name (please print): _____ Designation: _____

Date: ____/____/____ Time: _____ Signature: _____

SECTION 2 GOAL OF CARE

Please tick one only and complete section 3 over the page to be valid. In discussion with the clinician, patient, person responsible and/or family/carer(s), please select the most medically appropriate agreed goal of patient care that will apply in the event of clinical deterioration.

All life sustaining treatment

- * For Rapid Response (MER/MET Calls)
- * For CPR
- * For ICU

Life extending intensive treatment – with treatment ceiling

- * Not for CPR
- * For Rapid Response Yes No
- * For ventilatory support, including intubation Yes No
- * Specify maximum level of support
- * For ICU/HDU admission Yes No
- * Additional comments (e.g. use of inotropes, NIV, dialysis)

Active ward based treatment – with symptom and comfort care

- * Not for CPR
- * Not for ICU
- * Not for intubation
- * For Rapid Response Yes No
- * For ventilatory support (intent is symptom control) Yes No
- * Specify maximum level of support
- * Additional comments (e.g. use of antibiotics, IV fluids)

Optimal comfort treatment – including care of the dying person

- * Not for Rapid Response
- * Not for CPR
- * Not for intubation
- * Not for ICU
- * For ongoing review to identify transition to the terminal phase
- * Ensure timely commencement of the *Care Plan for the Dying Person*

All patients can have Rapid Response based on 'Worried Criteria' or to 'Summon Clinical Review'.

DO NOT WRITE IN MARGIN

ESCALATION PLAN

HCCZZFMR00H1

MR00H.1
07/17

MR00H.1 GOALS OF PATIENT CARE SUMMARY TRIAL

GOALS OF PATIENT CARE	Family Name	UMRN	
	First Name	DOB	Gender
	Address		Postcode

Hospital:

Ward:

Dr / Consultant:

SECTION 3 SUMMARY OF DISCUSSION(S)

Goals of Patient Care has been discussed with: _____ Date: ___/___/___ Time: _____

Patient: Yes No Person Responsible: Yes No Family/carer(s): Yes No

Name(s) of those present at this discussion: _____

Is the patient able to fully participate in this discussion? Yes No

Comments: _____

What is the patient's likely response to CPR and critical intervention? _____

Patient preferences (needs, values and wishes): _____

Decision rationale for agreed **Goals of Patient Care** (please tick one only):

Medically-driven decision Patient wishes Shared decision-making

Other information: _____

Doctor's name (please print): _____ Designation: _____

Signature: _____ Date: ___/___/___ Time: _____

Consultant review completed: Name (please print): _____

Signature: _____ Date: ___/___/___ Time: _____

SECTION 4 EXTENDED USE

Consultant endorsement for extended use beyond this admission for 12 months or until ___/___/___

This includes patient transportation to another facility or home following the current admission.

Consultant's comments: _____

Consultant's name (please print): _____ Signature: _____

Specialty: _____ Date: ___/___/___ Time: _____

ENDORSEMENT BY A CONSULTANT

DO NOT WRITE IN MARGIN

Appendix Five



Supportive and Palliative Care Indicators Tool (SPICT™)

The SPICT™ is used to help identify people whose health is deteriorating. Assess them for unmet supportive and palliative care needs. Plan care.

Look for any general indicators of poor or deteriorating health.

- Unplanned hospital admission(s).
- Performance status is poor or deteriorating, with limited reversibility. (eg. The person stays in bed or in a chair for more than half the day.)
- Depends on others for care due to increasing physical and/or mental health problems.
- The person's carer needs more help and support.
- The person has had significant weight loss over the last few months, or remains underweight.
- Persistent symptoms despite optimal treatment of underlying condition(s).
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

Look for clinical indicators of one or multiple life-limiting conditions.

Cancer

Functional ability deteriorating due to progressive cancer.

Too frail for cancer treatment or treatment is for symptom control.

Dementia/ frailty

Unable to dress, walk or eat without help.

Eating and drinking less; difficulty with swallowing.

Urinary and faecal incontinence.

Not able to communicate by speaking; little social interaction.

Frequent falls; fractured femur.

Recurrent febrile episodes or infections; aspiration pneumonia.

Neurological disease

Progressive deterioration in physical and/or cognitive function despite optimal therapy.

Speech problems with increasing difficulty communicating and/or progressive difficulty with swallowing.

Recurrent aspiration pneumonia; breathless or respiratory failure.

Persistent paralysis after stroke with significant loss of function and ongoing disability.

Heart/ vascular disease

Heart failure or extensive, untreatable coronary artery disease; with breathlessness or chest pain at rest or on minimal effort.

Severe, inoperable peripheral vascular disease.

Respiratory disease

Severe, chronic lung disease; with breathlessness at rest or on minimal effort between exacerbations.

Persistent hypoxia needing long term oxygen therapy.

Has needed ventilation for respiratory failure or ventilation is contraindicated.

Other conditions

Deteriorating and at risk of dying with other conditions or complications that are not reversible; any treatment available will have a poor outcome.

Kidney disease

Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.

Kidney failure complicating other life limiting conditions or treatments.

Stopping or not starting dialysis.

Liver disease

Cirrhosis with one or more complications in the past year:

- diuretic resistant ascites
- hepatic encephalopathy
- hepatorenal syndrome
- bacterial peritonitis
- recurrent variceal bleeds

Liver transplant is not possible.

Review current care and care planning.

- Review current treatment and medication to ensure the person receives optimal care; minimise polypharmacy.
- Consider referral for specialist assessment if symptoms or problems are complex and difficult to manage.
- Agree a current and future care plan with the person and their family. Support family carers.
- Plan ahead early if loss of decision-making capacity is likely.
- Record, communicate and coordinate the care plan.

Please register on the SPICT website (www.spict.org.uk) for information and updates

SPICT™, April 2017

This document can be made available in alternative formats on request.

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