



Submission to the
Joint Select Committee on Palliative Care in
Western Australia

10 July 2020

Table of Contents

Introduction	1
Bethesda Health Care	1
Progress of Palliative Care in WA	2
More Deaths.....	2
More Older People	2
More People with Complex Health Needs	3
Inpatient Palliative Care Services in Perth	4
Community Palliative Care Services in Perth	4
Interdisciplinary Palliative Care.....	5
Variations in Care.....	5
Psycho-Social and Spiritual Care	6
<i>My Life, My Choice</i> Recommendations Implementations	7
Recommendation 1	7
Recommendation 11.....	8
Recommendation 15.....	9
Recommendation 17	9
2019-20 Funding Announcement Implementations	10
Improving Equity of Access to Palliative Care	11
Overall.....	11
People with Non-Cancer Conditions.....	11
Early Palliative Care	11
People in Custody	12
Indigenous Western Australians	12
Under-Served Populations.....	12
Concluding Remarks.....	12
More Information	12

Introduction

The Parliament of Western Australia appointed a Joint Select Committee on Palliative Care in Western Australia on 28 May 2020. The Committee's Chair is Mr Chris Tallentire, MLA.

The inquiry will examine:

- progress in relation to palliative care, in particular the implementation of recommendations made by the Joint Select Committee into End of Life Choices in August 2018
- the delivery of services associated with palliative care funding announcements in 2019-20
- the delivery of palliative care into regional and remote areas
- the progress of ensuring greater equity of access to palliative care services between metropolitan and regional areas.

Bethesda Health Care

Bethesda Health Care is a Christian organisation established to actively contribute and to make a difference in our community and the world in which we live. Our mission is 'to deliver the highest quality healthcare experience for our patients', and our values are:

- teamwork – creating an environment of unity and togetherness
- respect – recognising and acknowledging the uniqueness and value of every individual
- integrity – demonstrating honesty and trustworthiness
- compassion – expressing God's love through a caring, kindness, tolerance and tenderness
- excellence – excelling in all that we do so that we can promote our mission
- professionalism – taking pride in our work.

Bethesda operates a medium-sized licensed hospital at Claremont which offers privately-funded medium-acuity surgical services and inpatient care, and publicly- and privately-funded inpatient care palliative care.

We are also contracted by the Western Australia Department of Health to manage the Metropolitan Palliative Care Consultancy Service (MPaCCS), which provides consultancy support, education and ongoing clinical support to residential care facilities, (aged care, mental health, disability and correctional) throughout Perth.

Progress of Palliative Care in WA

Palliative care in Western Australia has steadily progressed in the last decade.

While policy and planning improvements are evident, funding for Western Australian specialist palliative care services has been sub-optimal for many years. Some palliative care services are awarded indexation increases, but base funding has not grown across the system at a rate to match demographic and epidemiological changes over time.

The state's expanding and ageing population, which has higher levels of chronic illness, has increased demand for specialist palliative care services. The nature of care and treatment provided by these services has changed substantially, becoming more intensive and medicalised, and thus more expensive.

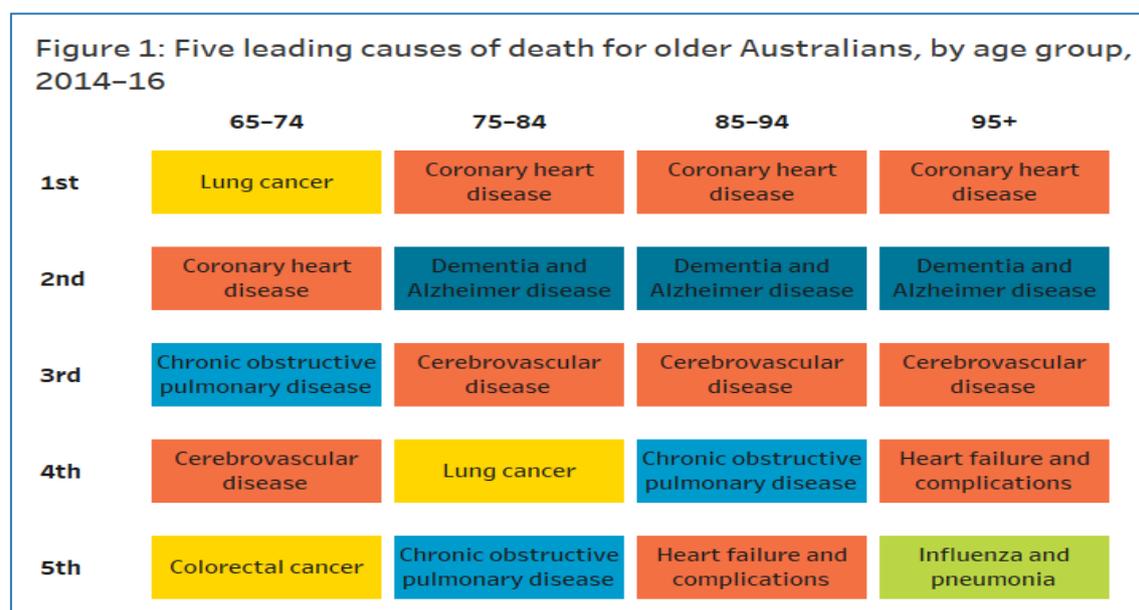
More Deaths

As the Western Australian has grown, deaths have increased by 9.35% in 7 years:¹

Year	Estimated Population	Number of Deaths	% Increase
2012	2,425,507	13,399	0.00%
2013	2,486,944	13,414	0.11%
2014	2,517,608	13,787	2.78%
2015	2,540,627	14,448	4.79%
2016	2,555,978	14,839	2.71%
2017	2,575,452	14,494	-2.32%
2018	2,595,877	14,652	1.09%

More Older People

The state's population is also ageing.² The likelihood of dying from a health condition which is amenable to palliative care³ increases with age:⁴



¹ Australian Bureau of Statistics, Australian Government (2019) 3302.0 – Deaths, Australia, 2018 – 'Table 3: Deaths, Summary, Statistical Area Level 4 – 2012 to 2018' @ www.abs.gov.au/AUSSTATS/abs@nsf/DetailsPage/3302.02018?OpenDocument accessed 06 Jul 20

² Australian Bureau of Statistics, Australian Government (2017) 2071.0 – Census of Population and Housing: Reflecting Australia – Stories from the Census, 2016 @ www.abs.gov.au/ausstats/abs@nsf/Lookup/by%20Subject/2071.0~2016~Main%20Features~Ageing%20Population~14 accessed 06 Jul 20

³ Murtagh et al (2014) 'How many people need palliative care? A study developing and comparing methods for population-based estimates' – *Palliative Medicine* – 28(1)

⁴ Australian Institute of Health and Welfare, Australian Government (2018) *Older Australia at a Glance: Causes of Death* @ www.aihw.gov.au/reports/older-people/older-australia-at-a-glance/contents/health-functioning/causes-of-death accessed 06 Jul 20

More People with Complex Health Needs

Growing populations of people with complex health needs add to the demands on palliative care services.⁵

Multimorbidity

*By definition, older adults with multimorbidity are heterogeneous in terms of severity of illness, functional status, prognosis, and risk of adverse events even when diagnosed with the same pattern of conditions. Priorities for outcomes and health care also vary.*⁶

Older people have, on average, more health conditions,^{7,8} and experience a range of symptoms and issues as they approach the end-of-life, with a low quality of life.^{9,10} As Harrison and Siriwardena note, 'the care of patients with multimorbidity can be complex and overwhelming' for patients and healthcare providers alike.¹¹

Making decisions and delivering end-of-life care for individuals with multimorbidities is especially challenging due to the need to tailor management to address problems caused by several conditions at different stages, the interactions of treatments for discrete conditions, and the lack of good evidence to guide clinicians.^{12,13}

Frailty

*Symptom relief and optimising quality of life remain the backbone of palliation because symptom burden is often high in the presence of significant frailty.*¹⁴

Frailty is 'a medical syndrome with multiple causes and contributors that is characterised by diminished strength, endurance, and reduced physiologic function that increases the individual's vulnerability for developing increased dependency and/or death.'¹⁵ Individuals become more susceptible to frailty as they age,¹⁶ with about a quarter of Australian women aged 80 years or more exhibiting the phenotype.¹⁷ Substantial increases in the prevalence of this condition have been forecast.¹⁸

People with frailty experience a wide range of troubling physical and psychological symptoms in the last weeks of life (but simple drug treatments may not be safe or effective), and prognostication is extremely difficult.¹⁹ A 'traditional palliative care paradigm', with a focus on responding to single-system illnesses, and a preference for predictable trajectories, fails to meet the needs of the frail population.¹⁴

⁵ Mitchell (2017) 'Rapidly increasing end-of-life care needs: A timely warning' – *BMC Medicine* – doi 10.1186/s12916-017-0897-2

⁶ American Geriatrics Society Expert Panel on the Care of Older Adults with Multimorbidity (2012) 'Guiding principles for the care of older adults with multimorbidity: An approach for clinicians' – *Journal American Geriatrics Society* - 11

⁷ Tinetti et al (2012) 'Designing health care for the most common chronic condition – multimorbidity' – *Journal American Medical Association* - 307

⁸ Salive (2013) 'Multimorbidity in older adults' – *Epidemiologic Reviews* – 35(1)

⁹ Nicholson et al (2018) 'What are the main palliative care symptoms and concerns of older people with multimorbidity?' – *Annals Palliative Medicine* – 7(Supp 3)

¹⁰ Reinke et al (2019) 'Symptom burden and palliative care needs among high-risk veterans with multimorbidity' – *Journal Pain Symptom Management* – 57(5)

¹¹ Harrison & Siriwardena (2018) 'Multimorbidity' – *Australian Journal General Practice* – doi: 10.31128/AJGP-11-17-4404

¹² Expert Panel on the Care of Older Adults with Multimorbidity, American Geriatrics Society (2012) 'Guiding principles for the care of older adults with multimorbidity: An approach for clinicians' – *Journal American Geriatrics Society* - 11

¹³ Roland & Paddison (2013) 'Better management of patients with multimorbidity' – *British Medical Journal* - 346

¹⁴ Moorhouse et al (2015) 'End of life care in frailty' – in Rockwood (ed) *Frailty in Ageing: Biological, Clinical & Social Implications*

¹⁵ Morley et al (2013) 'Frailty consensus: A call to action' – *Journal American Medical Directors Association* - 14

¹⁶ Fried et al (2001) 'Frailty in older adults: Evidence for a phenotype' – *Journals Gerontology* – 56(3)

¹⁷ Thompson et al (2018) 'Frailty prevalence in Australia: Findings from four pooled Australian cohort studies' – *Australasian Journal Ageing* - doi: 10.1111/ajag.12483

¹⁸ Taylor et al (2019) 'Geospatial modelling of the prevalence and changing distribution of frailty in Australia: 2011 to 2027' – *Experimental Gerontology* - 123

¹⁹ Harwood & Enguella (2019) 'End-of-life care for frail older people' – *BMJ Supportive Palliative Care* – doi: 10.1136/bmjspcare-2019-001953

Inpatient Palliative Care Services in Perth

A proportion of people will always need specialist inpatient care at the end-of-life. Low levels of function and refractory symptoms require 24-hour specialist care, particularly as people approach death.²⁰

Hospitals – where about half of all Australian deaths occur²¹ – do not necessarily provide evidence-based palliative care.^{22,23,24,25} Care at home is not always possible for a range of reasons including the individual's preferences, the availability and capacity of family carers, access to specialist palliative care services for support, etc.²⁶

The geographical distribution of inpatient palliative care units in Perth is not optimal.

As noted in Bethesda's response to *My Life, My Choice*,²⁷ population-level analysis reveals the South Metropolitan Health Service is also under-served in terms of inpatient palliative care, and investment in this region is required.

We calculated South Metropolitan Health Service (SMHS) has about 2.6 publicly-funded palliative care beds per 100,000 population (NMHS has about 4.84 beds/100,000 population). In addition, the SMHS beds are located towards the northern end of the catchment, resulting in long journeys for patients and their families from suburbs south of, say, Armadale Road.²⁸

Inpatient palliative care services need a minimum number of beds (perhaps as many as 15) in order to ensure long-term viability, and to recruit and retain a skilled workforce.

Bethesda's internal analysis shows admissions can vary considerable month-to-month, and units need a basic level of assured funding to cover fixed costs during periods of low activity.

Furthermore, palliative care units need access to a range of medical specialists (eg psychiatry, rehabilitation health, respiratory and sleep medicine, cardiology etc) as the clinical complexity of the patient group increases. Units managed by non-government providers (eg Bethesda and Murdoch) do not have sufficient funds to routinely pay for these medical services (nor can they simply draw upon specialists from elsewhere in the hospital at no cost, as in the public system).

Community Palliative Care Services in Perth

Accessible, safe, comprehensive, and sustainable community palliative care services are a fundamental element of any palliative and end-of-life care system.

The funding available for community palliative care service provision in Perth has not grown at a sufficient rate to meet increasing demand, affecting service quality and outcomes. A substantial injection of additional funding is urgently required.

Specifically, inadequate funding has led Silver Chain to limit the duration of care they can provide to patients. The service cannot accept many early referrals and appears to be constrained to providing care to people approaching or in the terminal phase.

²⁰ Gaetner et al (2012) 'Palliative care consultation service and palliative care unit: Why do we need both?' – *Oncologist* – doi: 10.1634/theoncologist.2011-0326

²¹ Australian Institute of Health and Welfare (2017) *Deaths in Australian Hospitals 2014-15*

²² Virdun et al (2015) 'Dying in the hospital setting: A systematic review of quantitative studies identifying the elements of end-of-life care that patients and their families rank as being most important' – *Palliative Medicine* – doi: 10.1177/0269216315583032

²³ Dwyer et al (2014) 'A systematic review of outcomes following emergency transfer to hospital for residents of aged care facilities' – *Age Ageing* – 43(6)

²⁴ Productivity Commission, Australian Government (2018) 'End-of-life care in Australia' – *Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services*

²⁵ Cardona-Morell et al (2016) 'Non-beneficial treatments in hospital at the end of life: A systematic review on extent of the problem' – *International Journal Quality Health Care* – doi: 10.1093/intqhc/mzw060

²⁶ Wahid et al (2017) 'Barriers and facilitators influencing death at home: A meta-ethnography' – *Palliative Medicine* – doi: 10.1177/0269216317713427

²⁷ Bethesda Health Care (2018) *Response to My Life, My Choice* (available to the Joint Select Committee on request)

²⁸ The local government areas with the largest populations south of the Swan River are Gosnells, Rockingham, Melville and Cockburn.

Interdisciplinary Palliative Care

Interdisciplinary palliative and end-of-life care is widely recognised as best practice, facilitating holistic person-centred care, improving patient and family carer safety, and minimising in-hospital deaths.^{29,30} A true interdisciplinary team:

*shares information and works interdependently. Leadership is task-dependent, with tasks defined by the individual patient's situation.*³¹

The core of the interdisciplinary team is typically comprised of nurses, doctors and social workers with specialist skills in palliative care, while the extended team should include allied health providers such as occupational therapists, physiotherapists, rehabilitation specialists, speech pathologists, dieticians, psychologists, pharmacists, welfare officers etc.³² As Palliative Care Australia states:

*Allied health professionals play an essential role in meeting the palliative care needs of people living with a life-limiting illness, their families and carers.*³³

The WA Health Clinical Services Framework 2014-24 capability framework for the delivery of end-of-life care indicates 'specialist palliative care' (levels 4, 5 and 6) services should have allied health resources. WA does not have structured evidence-based training programs for allied health professionals working in palliative and end-of-life care.

Non-government inpatient palliative care services in Western Australia can struggle to provide true interdisciplinary care because they are not funded to employ allied healthcare providers.

The activity-based funding structure at the Metropolitan Palliative Care Consultancy Service (MPaCCS) undermines interdisciplinary care. Our internal data show two team members (eg a nurse and a social worker) are required – due to clinical complexity – to attend the patient together at least 15% of the time. But Bethesda can only bill the Department of Health for the attendance of one clinician per patient per day.

Variations in Care

Bethesda is aware of substantial variation in specialist palliative care practice across Perth. For example:

- Bethesda Palliative Care Unit, SJOG Murdoch Community Hospice and Kalamunda Hospice all seem to be differently resourced (Kalamunda can offer allied health interventions which Bethesda and Murdoch cannot afford) so people across the city do not have equitable access to best-practice care
- the palliative care teams at Royal Perth, Sir Charles Gairdner, Joondalup and Fiona Stanley hospitals all operate differently depending on the priorities of their hospitals (for example, now some oncology services have returned to RPH, the team is unable to systematically support parts of the hospital where patients have non-malignant conditions).

²⁹ LeClerc et al (2014) 'The effectiveness of interdisciplinary teams in end-of-life palliative care: A systematic review of comparative studies' – *Journal Palliative Care* – doi: 10.1177/082585971403000107

³⁰ Fernando and Hughes (2019) 'Team approaches in palliative care: A review of the literature' – *International Journal Palliative Nursing* – doi: 10.12968/ijpn.2019.25.9.444

³¹ Crawford & Price (2003) 'Team working: Palliative care as a model of interdisciplinary practice' – *Medical Journal Australia* – doi: 10.5694/j.1326-5377.2003.tb05575.x

³² Haugen et al (2010) 'The core team and the extended team' – Hanks et al (eds) *The Oxford Textbook of Palliative Medicine: 4th Edition*

³³ Palliative Care Australia (2018) *Background Report to the Palliative Care Service Development Guidelines*

Psycho-Social and Spiritual Care

In general, dying people want to:^{34,35}

- be free from pain and other physical symptoms
- maintain their function for as long as possible
- avoid a prolonged dying experience
- have their cultural or customary preferences acknowledged and respected
- be involved in their own care and treatment decisions
- feel connected with those about them
- be able to prepare themselves for death
- live with meaning and hope.

Structured psycho-social interventions improve quality of life and reduce existential and emotional distress for people receiving palliative care.^{36,37}

Spiritual distress occurs when a person is unable to find sources of meaning, hope, love, peace, comfort, strength, or connection in life. Evidence suggests strong positive relationships between spiritual wellbeing and quality of life.³⁸ Spiritual care interventions display 'promising effects on the global quality of life and spiritual well-being among patients with terminal illness.'³⁹

Critical gaps in the ability of services to provide comprehensive evidence-based psycho-social-spiritual support to patients and their family carers affects outcomes at different levels (individual, family, community and health system). Palliative care providers need more funding to provide comprehensive psycho-social-spiritual care for their patients and family carers.

The bereavement supports in Perth – and across the state – are particularly patchy. Most people will have uncomplicated bereavements, and cope with the support of family, friends, and their personal resources. A small percentage (10%) have a prolonged grief reaction, characterised by long-term psychological disability. This is only evident 18-24 months after their bereavement, when they are no longer attached to a palliative care provider, or other supports. Resources to routinely identify and support people with prolonged grief disorder are required within WA's end-of-life care system.

³⁴ Steinhauser & Tulsky (2010) 'Defining a "good death"' – *Oxford Textbook of Palliative Medicine: 4th Edition*

³⁵ Singer et al (1999) 'Quality end-of-life care: Patients' perspectives' – *Journal American Medical Association* – 281(2)

³⁶ Warth et al (2019) 'Brief psychological interventions improve quality of life of patients receiving palliative care: A systematic review and meta-analysis' – *Palliative Medicine* – doi: 10.1177/0269216318818011

³⁷ Teo et al (2018) 'Psychosocial interventions for advanced cancer patients: A systematic review' – *Psycho-Oncology* – doi: 10.1002/pon.5103

³⁸ Steinhauser et al (2017) 'State of the science of spirituality and palliative care research: Part 1 – definitions, measurement and outcomes' – *Journal Pain Symptom Management* – 54(3)

³⁹ Chen et al (2018) 'The effects of spiritual care on quality of life and spiritual well-being among patients with terminal illness: A systematic review' – *Palliative Medicine* – doi: 10.1177/0269216318772267

***My Life, My Choice* Recommendations Implementations**

Bethesda is aware that the Western Australia Department of Health has several workstreams addressing different *My Life, My Choice*⁴⁰ recommendations. Bethesda staff are involved in steering committees for projects in these workstreams.

In our view, implementation is still in the early stages – much remains to be done. Only when the independent review process outlined at Recommendation 14 of *My Life, My Choice* is up and running will we know the ultimate outcome of the changes and funding programs currently underway. Bethesda's observations about some of the report's recommendations follow.

Recommendation 1

The Attorney-General, in consultation with the Minister for Health, appoint an expert panel to review the relevant law and health policy and practice, and provide recommendations in relation to the following matters:

- a) *the establishment of a purpose-built central electronic register for advance care directives that is accessible by health professionals 24-hours per day and a mechanism for reporting to Parliament annually the number of advance care directives in Western Australia*
- b) *a requirement that health professionals must search the register for a patients' advance health directives, except in cases of emergency where it is not practicable to do so*
- c) *amendments to the current Western Australian template for advance health directives in or order to match, as a minimum, the leading example across Australia, taking into account Finding 7*
- d) *consider how the increasing numbers of people diagnosed with dementia can have their health care wishes, end of life planning decisions and advance care directives acknowledged and implemented once they have lost capacity.*

Recommendation 1a

Bethesda is aware that the Government is pressing ahead with a registry, but we can give only cautious support for the idea because documents in such a repository may be out of date, or may have been revoked by the maker subsequent to registration, and yet will be relied upon by healthcare providers in emergency situations. Government must manage these risks.

Recommendation 1b

Healthcare providers must always make a faithful attempt to discover the wishes and preferences of their patients before the provision of care and treatment. This attempt should not end – if an individual does not have capacity to make a care and treatment decision in the moment – with the search of a register for an advance health directive; all reasonable avenues must be explored.

Recommendation 1c

Bethesda supports this recommendation, agrees that existing WA advance health directives need improvements, and notes the recommendations of the Ministerial Expert Panel on Advance Health Directives.⁴¹

Recommendation 1d

Bethesda supports this recommendation. Bethesda – particularly through the Metropolitan Palliative Care Consultancy Service – continues work to improve advance care planning for people with dementia and other neurodegenerative conditions.

We have adopted a multi-faceted approach, seeking to address and improve:

- care, treatment, communications and decision-making policies and processes
- information and educational resources for both consumers and healthcare providers
- documentation templates
- ongoing training for Bethesda and external staff.

Bethesda's materials are available upon request.

⁴⁰ Joint Select Committee on End of Life Choices, 40th Parliament of WA (2018) *My Life, My Choice: The Report of the Joint Select Committee on End of Life Choices*

⁴¹ Government of Western Australia (2019) *Ministerial Expert Panel on Advance Health Directives: Final Report*

Recommendation 11

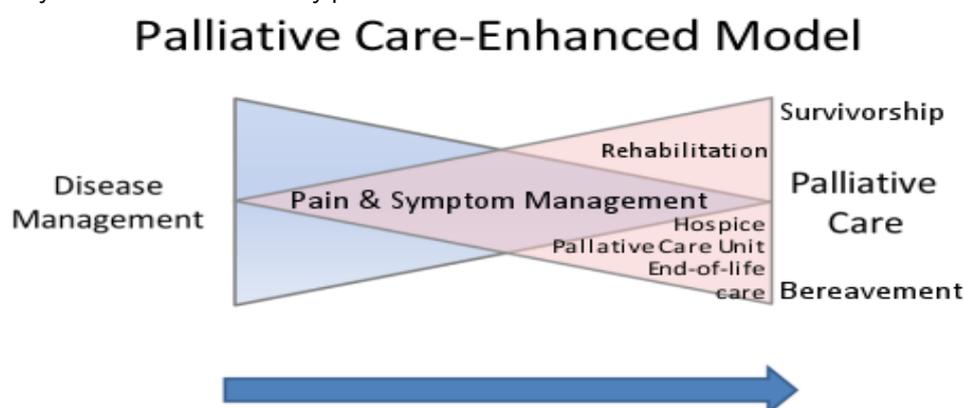
To improve understanding of palliative care in Western Australia, WA Health should:

- establish a consistent definition of palliative care to be adopted by all health professionals
- provide comprehensive, accessible and practical information and education services about palliative care to health professionals and the community
- encourage knowledge sharing by palliative care specialists with their generalist colleagues
- establish a palliative care information and community hotline.

Recommendation 11a

Bethesda subscribes to the World Health Organisation's definition of palliative care, and sees no reason why this should not be the definition adopted across Western Australia.

Pippa Hawley's 'Bow Tie Model' may reassure patients and families that 'palliative care' is not a pathway in which the only possible outcome is death, and perhaps expose more people in our community to the benefits of early palliative care:⁴²



MPaCCS has adopted the definitions of 'end-of-life' and 'end-of-life care' used by the Australian Commission on Safety and Quality in Health Care⁴³ (also adopted by the Western Australian Department of Health⁶⁵), and promotes them in our educational interventions. Clinical terminology used by the Palliative Care Outcomes Collaboration has potential for wider uptake.

Recommendation 11b

High quality palliative care education for healthcare providers is already available from Palliative and Supportive Care Education (PaSCE) at Cancer Council WA.

The experience of MPaCCS is that medium- to long-term mentoring by palliative care clinicians builds the capacity of GPs and aged care providers most effectively. This model should be expanded to other settings and palliative care services should be funded to provide it.

Recommendation 11c

The development and maintenance of relationships which maximise the effect of knowledge sharing takes time. Specialist providers need to be resourced to undertake this work in a more intentional and strategic manner.

Recommendation 11d

Bethesda was pleased to learn the Department of Health worked with Palliative Care WA to reallocate funds originally committed to community advance care planning workshops (no longer possible during the recent coronavirus outbreak) so that the Palliative Care Information and Support Line could be established in April 2020.

⁴² Hawley (2015) 'The "Bow Tie Model" of 21st century palliative care' – *Canadian Virtual Hospice* @ www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/For+Professionals/For+Professionals/The+Exchange/Current/The+Bow+Tie+Model+of+21st+Century+Palliative+Care.aspx accessed 10 Jul 20

⁴³ Australian Commission on Safety and Quality in Health Care (2015) *National Consensus Statement: Essential Elements for Safe and High Quality End-of-Life Care*

Recommendation 15

WA Health should provide ongoing professional development for all health professionals – beyond undergraduate training – about the right of a patient to refuse medical treatment. WA Health should also specifically amend the Consent to Treatment Policy to provide comprehensive information in relation to a competent patient's absolute right to refuse medical treatment.

Bethesda agrees with Australia's outgoing Chief Medical Officer, Dr Brendan Murphy, who argues health professionals also need education on their right to refuse to provide futile care and treatment.⁴⁴ This is in addition to the obligation of health professionals to fully disclose the likely harms and benefits of any proposed course of care and treatment to patients and their family carers – an obligation not always discharged at the end-of-life.

Recommendation 17

WA Health should provide ongoing professional development – beyond undergraduate training – for all health professionals about the transition from curative to non-curative end-of-life care and effective discussions with patients and families about futile treatments.

WA Health should consider how it might effectively educate the community about end-of-life decision-making, and implement appropriate health promotion in this area.

In the past year, Bethesda's Metropolitan Palliative Care Consultancy Service has actively sought to address the long-standing issue of identifying the transition from curative to non-curative care and treatment, developing an evidence-based *Deteriorating Phase Nursing Assessment* (available on request), and providing additional education and training for facility staff in how to identify and respond to 'increasing decline'.⁴⁵

⁴⁴ Murphy (2008) 'What has happened to clinical leadership in futile care discussions' – *Medical Journal Australia* – 188(7)

⁴⁵ Department of Health, Government of Western Australia (2016) *The End-of-Life Framework: A Statewide Model for the Provision of Comprehensive, Coordinated Care at the End-of-Life in Western Australia*

2019-20 Funding Announcement Implementations

The value of ongoing investment in palliative care is highlighted by KPMG in their recent report *Investing to Save: The Economics of Increased Investment in Palliative Care in Australia*.⁴⁶ The benefits of investment identified in the report include reduced health service utilisation, improved coordination across the healthcare system, improved wellbeing and productivity for family carers, and lower bereavement costs.⁴⁷

Government of Western Australia initiatives and funding allocations in the last 2 years have the potential to improve palliative care across the state. The final objectives of these investments must be consistent with the priorities described in the *WA End-of-Life and Palliative Care Strategy 2018-2028*.

Bethesda is aware of two recent palliative care funding announcements:

- 10 October 2019: \$17.8M (for 10 beds in the northern suburbs, and enhanced metro and rural community services)
- 09 May 2019: \$41M (FY20 Budget, for a facility in Carnarvon, and rural service improvements).

Most of these initiatives appear to have been progressed by the Department of Health, regional health services, and the Palliative Care Network.

As mentioned above, Bethesda has not seen evidence that funding for Perth community palliative care services has increased.

Bethesda has been impressed by the progress made by WACHS in recent months in improving rural palliative care service provision in WA.

WACHS has devoted resources to statewide program development, coordination and support, with the aim that all country Western Australians can access the care and treatment they need, where-ever they live. In addition, all regions are well on the way to recruiting additional clinicians of different disciplines, made possible by recent funding announcements.

Bethesda has proposed ways in which palliative care in rural residential aged care facilities can be further supported, using funding provided as part of a National Partnership Agreement between the Government of Western Australia and the Australian Government. We hope to learn whether we have been awarded funds from this initiative in July 2020.

Bethesda notes the Department released a tender for the construction of the new facility in Carnarvon on 15 November 2019.

⁴⁶ KPMG (2020) *Investing to Save: The Economics of Increased Investment in Palliative Care in Australia* @ <https://palliativecare.org.au/kpmg-palliativecare-economic-report> accessed 22 Jun 20

⁴⁷ This same report shows that the Western Australian specialist palliative care system is understaffed relative to other Australian jurisdictions.

Improving Equity of Access to Palliative Care

Overall

Poor access to quality palliative care, when it is needed, is likely to contribute to patients attempting/completing suicide or seeking voluntary assisted dying (VAD) services.⁴⁸ These are only the most visible of a multitude of potential harms to people with life-limiting illnesses, their families and friends, and the broader community, that result from an inadequate palliative and end-of-life care system.

Increasing the amount of resources in the palliative and end-of-life care system within Western Australia will tend to improve consumer access to the level of care and treatment they need at all stages of their end-of-life trajectories. In this context, recent funding announcements are warmly welcomed.

Bethesda agrees with the Joint Select Committee on End of Life Choices, which found it is important to provide ongoing community education, more healthcare provider training, and better systems of care coordination, to improve access to and use of palliative care.⁴⁰

The Joint Select Committee on End of Life Choices was provided with evidence that awareness of palliative care – and the services available – is limited across the Western Australian community.⁴⁰ In addition, in Bethesda's experience, many members of the public and healthcare providers wrongly understand that palliative care only is relevant in the terminal phase. Poor awareness and understanding of contemporary palliative care are barriers to access. Effective implementation of Recommendation 11 of *My Life, My Choice* is an urgent necessity.^{40,49}

People with Non-Cancer Conditions

Western Australian studies^{50,51} have shown that patients with non-cancer primary diagnoses access palliative care services in their last year of life at disproportionately low rates, although they are likely to have problems similar to those experienced by people dying from cancer.⁵²

The advent of MPaCCS has substantially improved this situation: at least 75% of 2,100 patients admitted by the Service in 2019-20 had a non-cancer diagnosis, but only individuals who live in residential care facilities (prisons, mental health, disability, aged care) are seen by MPaCCS.

Early Palliative Care

Robust scientific evidence supports the value of early access to specialist palliative care.^{53,54,55,56,57} Late referral to specialist palliative care remains a serious problem, however.

Recent audits have shown about 1/3 of people admitted to Bethesda's Palliative Care Unit die within 72 hours of arrival: over two thirds of these cases are referred from a hospital, and a high proportion have a non-cancer diagnosis. Outcomes for patients, their families and friends, Unit staff and our service are all compromised.

Ongoing work with hospital-based healthcare providers caring for people with non-cancer chronic conditions approaching the end-of-life to improve referrals to palliative care services is essential, and palliative care services need resources to do this.

⁴⁸ Gallagher et al (2020) 'Hastened death due to disease burden and distress that has not received timely, quality palliative care is a medical error' – *Medical Hypotheses* – doi: 10.1016/j.mehy.2020.109727

⁴⁹ It is surely no accident that improving awareness and understanding of palliative care is priority 1 in the Australian *National Palliative Care Strategy 2018*.

⁵⁰ Rosenwax et al (2016) 'A retrospective population-based cohort study of access to specialist palliative in the last year of life: Who is still missing out a decade on?' – *BMC Palliative Care* – 15(46)

⁵¹ Rosenwax & McNamara (2006) 'Who receives specialist palliative care in Western Australia – and who misses out?' – *Palliative Medicine* – 20(4)

⁵² Moens et al (2014) 'Are there differences in the prevalence of palliative care-related problems in people living with advanced cancer and eight non-cancer conditions? A systematic review' – *Journal Pain Symptom Management* – doi: 10.1016/j.jpainsymman.2013.11.009

⁵³ Wright et al (2018) 'Earlier initiation of community-based palliative care is associated with fewer unplanned hospitalisations and emergency department presentations in the final months of life: A population-based study among cancer decedents' – *Journal Pain Symptom Management* – 55(3) – **this is a WA study**

⁵⁴ Davis et al (2015) 'A review of the trials which examine early integration of outpatient and home palliative care for patients with serious illness' – *Annals Palliative Medicine* – 4(3)

⁵⁵ Greer et al (2013) 'Early integration of palliative care services with standard oncology care for patients with advanced cancer' – *CA Cancer Journal for Clinicians* – 63(5)

⁵⁶ Vanbutssele et al (2020) 'The effect of early and systematic integration of palliative care in oncology on quality of life and health care use near the end of life: A randomised controlled trial' – *European Journal Cancer* – doi: 10.1016/j.ejca.2019.11.009

⁵⁷ Haun et al (2017) 'Early palliative care for adults with advanced cancer' – *Cochrane Database of Systematic Reviews* - 6:CD011129

People in Custody

The WA prison population is ageing.⁵⁸ Prisoners are more likely to exhibit debilitating chronic illnesses, multimorbidity and premature ageing.⁵⁹ Government must make plans to meet an increase in the palliative care needs of this population⁶⁰ if prisoners are to be 'provided [with] a standard of health care equal to services available in the community.'⁶¹

In the 42-month period between January 2016 and June 2019, MPaCCS delivered 40 episodes of care to 24 patients in correctional facilities. The average age was 62.6 years (20 years less than the MPaCCS average), the vast majority were male, and 12.2% of patients identified as indigenous.

While MPaCCS has undoubtedly improved access to palliative care for people in custody, the work is resource-intensive and should be funded at a higher level. More training in providing palliative and end-of-life care within prison is required, especially as the new infirmary is opened at Casuarina Prison.

Indigenous Western Australians

Data indicate Aboriginal and Torres Strait Islander West Australians access specialist palliative care at low rates. These people comprise 3.9% of the state's population,⁶² but only 1.7% of all patients seen by WA palliative care services that participate in the Palliative Care Outcomes Collaboration.⁶³

Under-Served Populations

Bethesda notes recent work commissioned by the Commonwealth on key barriers and promising approaches for improving access to palliative care for nine traditionally under-served population groups.⁶⁴

Concluding Remarks

Bethesda Health Care is committed to working in the field of end-of-life and palliative care. We see ourselves as partners with the WA Department of Health, and other stakeholders, in a long-term effort to improve outcomes for all Western Australians living with, and dying from, life-limiting illnesses, their families, friends and communities.

Government of Western Australia initiatives and funding allocations in the last 2 years have the potential to improve palliative care across the state. The final objectives of these investments must be consistent with the priorities described in the *WA End-of-Life and Palliative Care Strategy 2018-2028*,⁶⁵ as well as the recommendations in *My Life, My Choice*.

Bethesda Health Care staff would be pleased to provide more detailed information relating to the Joint Select Committee's enquiry if it is required.

More Information

Please contact, for more information:

Dr Neale Fong, Chief Executive Officer
Bethesda Health Care
PO Box 45, CLAREMONT WA 6910
Phone: 08 9340 6300
Email: info@bethesda.org.au
Internet: www.bethesda.org.au.

⁵⁸ Ginnivan et al, ARC Center of Excellence in Population Ageing Research (2018) *Working Paper 2018/6: Australia's Ageing Prisoner Population: The Demographic Shift and Implications for the Economic and Social Costs of Care*

⁵⁹ Turner et al (2017) 'Palliative care in UK prisons: Practical and emotional challenges for staff and fellow prisoners' - *Journal Correctional Health Care* - 23(1)

⁶⁰ Palliative Care Australia (2016) 'Frail elderly put new pressure on prisons to provide palliative care' - *Palliative Care Matters*

⁶¹ Corrective Services Administrators Council (2018) *Guiding Principles for Corrections in Australia*

⁶² Australian Bureau of Statistics (2018) 3238.0.55.001 - *Estimates of Aboriginal and Torres Strait Islander Australians, June 2016*

⁶³ Palliative Care Outcomes Collaboration (2020) *Patient Outcomes in Palliative Care: Western Australia, January to June 2019*

⁶⁴ AHA Consulting, Department of Health, Australian Government (2020) *Exploratory Analysis of Barriers to Palliative Care @ www.health.gov.au/resources/collections/exploratory-analysis-of-barriers-to-palliative-care* accessed 07 Jul 20

⁶⁵ Department of Health, Government of Western Australia (2018) *WA End-of-Life and Palliative Care Strategy 2018-2028*