

Interim Report: Feedback

Following the Sustainable Health Review Interim Report feedback was sought. Open feedback provided by the organisation or individual is detailed below.

Your Personal Details	
1. Title	Mr <input type="checkbox"/> Miss <input type="checkbox"/> Mrs <input type="checkbox"/> Ms <input type="checkbox"/> Dr <input type="checkbox"/> Other <input type="checkbox"/>
2. First Name(s)	
3. Surname	
4. Contact Details	
5. Organisation	Palliative Care WA
6. Location	<input type="checkbox"/> Metropolitan <input type="checkbox"/> Regional WA <input type="checkbox"/> Outside WA
7. Are you providing a response on behalf of your group/organisation or as an individual? (Required)	<input checked="" type="checkbox"/> Group/organisation <input type="checkbox"/> Individual <input type="checkbox"/> Other, please specify _____
Q8. Do you consent to your feedback being published, in summaries or in the Final Report? (Required)	
<input checked="" type="checkbox"/> I consent to my feedback being published <input type="checkbox"/> I consent to my feedback being published anonymously <input type="checkbox"/> I do not consent to my feedback being published	

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18 May 2018

Dear Ms Kruk

RE: PALLIATIVE CARE WA'S RESPONSE TO SUSTAINABLE HEALTH REVIEW (INTERIM REPORT)

Thank you for the opportunity to provide a response to the Interim Report of the Sustainable Health Review ('the Report'). Palliative Care WA ('PCWA') is the peak body for palliative care in Western Australia (WA). Its members include individuals and organisations who support our mission of awareness of and access to quality palliative care for all Western Australians.

For context, the World Health Organization (WHO) defines palliative care as: "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."

The Sustainable Health Review ('SHR') was announced by the State Government in June 2017 to develop a more sustainable health system for Western Australia (WA). PCWA consider it imperative that there is more emphasis on the value of palliative care in supporting a system of care for all Western Australians.

The only mention of palliative care (although not using the term "palliative care") is on page 20 of the Report, viz:

"Honest and open conversations. It is clear that the WA health system must facilitate, encourage and support the challenging and difficult conversations required about 'what's needed', 'what the community expects', and 'how to make best use of resources' for a sustainable health system. This will require strengthening existing measures and new approaches to local engagement which include the wider community in the planning of health services. At an individual level, a critical component of this is good communication between patients and staff. International experience demonstrates that doctors choose less aggressive procedures for themselves than they provide for their patients (16 – 18). Similarly patients tend to choose less treatment when they are given greater detail of the impact, potential benefits and harms of a proposed intervention (16 – 18). Consumers and staff agree that it is time to have open and honest conversations about goals of care and end-of-life decisions. In Australia it is estimated that while 70 per cent of Australians wish to die at home, only around 14 per cent do so (19). WA is leading work in this area. We also spend more money in the last 1,000 days of peoples' lives and sometimes the quality of that life or death is no better (20)."

However, there is nothing substantially relevant in the 12 “Directions” set in the Report. Moreover, lacking is the input from participants at the Q & A sessions in March 2018, of which PCWA were attendees, relating to the vision of promoting community awareness about advance care planning (ACP) and the importance of establishing and supporting ‘compassionate communities’ to reduce the burden and cost of individuals spending the last days of their life in a hospital setting.

PCWA’s Position on the Importance of Palliative Care as Part of the SHR

PCWA firmly believe that palliative care should be available to individuals with life-limiting disease (malignant cancers and chronic disease) whose quality of life is being impacted by their symptoms. Palliative care focuses on the holistic needs of patients through careful assessment, management of pain and other symptoms, and the provision of physical, psychological, social and spiritual care. Importantly, palliative care recognises the needs of caregivers as well as patients. The increasing demand for palliative care is directly related to the increasing number of deaths in WA/ growing population.

Increasing Number of Deaths and Growing Population

After a declining death rate for several decades (as a result of public health initiatives and medical advances), the total number of deaths in Australia is now expected to grow at increasing rates year-on-year as a result of growing and ageing populations and the impact of chronic disease:¹

Initially deaths are expected to increase at rates of around 1.3% to 1.8% per year. Between 2022 and the early 2040s, deaths are projected to increase more rapidly (up to 2.7% per year)...

The population of Perth has grown rapidly, will continue to grow. The Australian Bureau of Statistics (ABS) publication 3218.0 – Regional Population Growth, Australia, 2016² summarises recent growth in the Perth metropolitan area:

Western Australia's population grew fastest (that is it had the strongest growth rate) in the ten years to 2016 (mainly due to strong growth between 2006 and 2011), increasing by 25%.

From June 2006 to June 2016, the ten statistical areas level 2 (SA2s) with the largest population increases in Western Australia were all within Greater Perth.

In late 2013 the ABS published population growth projections covering the period 2012 to 2061.¹ The Bureau anticipated the net growth rate will slow gradually during the next fifteen years, but will remain healthy. Perth will be the fastest growing state capital city in Australia. They plotted three likely scenarios:

- Series A– reflects higher growth
- Series B– consistent with current trends in fertility, life expectancy and migration
- Series C– shows lower growth

The following table shows Series B growth forecasts for WA at three milestones over the next 15 years:

milestone	2020	2025	2030
population ³	2,461,784	2,819,746	3,185,217
# increase (over preceding 5 years)	441,784	357,962	365,471
% increase (over preceding 5 years)	21.87%	14.54%	12.96%

Table 1: ABS projections – WA population growth to 2030

¹ Australian Bureau of Statistics (2013) 3222.0 Population Projections, Australia, 2012 (Base) to 2101

² Australian Bureau of Statistics (2017) 3218.0 – Regional Population Growth, Australia, 2016

³ The baseline is 2,020,000 as at June 2014

The WA Planning Commission (WAPC) has released population growth forecasts for the years 2014 to 2026.⁴ Like the ABS, the WAPC plotted different growth rate scenarios (high, medium and low). The median projections for the combined SA4 areas of Perth North West, Perth South West, Perth South East, Perth North East and Mandurah are:

milestone	2016	2021	2026
population	2,110,380	2,371,580	2,637,130
# increase (over preceding 5 years)		261,200	265,550
% increase (over preceding 5 years)		12.38%	11.2%

Table 2: WAPC projections – Perth population growth to 2026

Ageing Population

The Productivity Commission states simply that ‘Australia’s population will... age dramatically over the coming years.’⁵ The reasons include lower mortality rates (especially since 1970) and longer lives, while birth rates have also fallen. Their report gives a ‘striking illustration’ of the nature of the changes:

Growth rates of the oldest segments of the population will accelerate over the coming years... In 2012, there was roughly one person aged 100 years old or more to every 100 babies. By 2060... there will be around 25 centenarians for every 100 babies, and... by 2100, there will be more people aged 100 or more years than babies born in that year.

Even if there are no further improvements in mortality rates after 2012, the percentage of people aged 85 years or over will increase from 1.9% to 2.7% by 2030 and 5.9% by 2060. These projections are the ‘base case’ scenario used in the study; the percentage of oldest old people in the community increases if overseas immigration and fertility rates are low and mortality rates continue to improve.

As people age they are more likely to live in residential aged care, and over one third of Australians live in permanent residential aged care during their last year of life.⁶ The number of operational residential aged care places in Perth is approximately 13,500,⁷ about 14% more than in 2014.

Increasing Burden of Chronic Illness

The Australian Institute of Health and Welfare (AIHW) describes the features of chronic disease:⁸

- complex causality
- multiple risk factors
- long latency periods
- a prolonged course of illness
- functional impairment or disability

Further:⁹

Most chronic diseases do not resolve spontaneously, and are generally not cured completely. Some can be immediately life-threatening, such as heart attack and stroke. Others can persist over time and can be intensive in terms of management (e.g. diabetes). Most chronic diseases persist in an individual through life, but are not always the cause of death (e.g. arthritis).

⁴ WA Planning Commission (2012) *Western Australia Tomorrow: Population Report # 10, 2014-2026 and Sub-regions 2016-2026*

⁵ Productivity Commission (2013) *An Ageing Australia: Preparing for the Future*

⁶ Australian Institute of Health and Welfare (2012) *Patterns in Use of Aged Care 2002-03 to 2010-11 – Data Linkage Series 18*

⁷ Australian Government Department of Health (2017) *Stocktake of Australian Government Subsidised Aged Care Places and Ratios as at 30 June 2017*

⁸ Australian Institute of Health & Welfare (2017) www.aihw.gov.au/reports-statistics/health-conditions-disability-deaths/chronic-disease/about - accessed 13 Apr 18

⁹ Australian Institute of Health & Welfare (2015) www.aihw.gov.au/chronic-diseases/ - accessed 29 April 2015

The incidence of chronic illness is high,^{10,11} many people have multiple chronic conditions,¹² and these diseases are significantly associated with death.¹³

Currently, 9 in 10 deaths have chronic disease as an underlying cause. Cardiovascular diseases (coronary heart disease and stroke), dementia and Alzheimer's disease, lung cancer and chronic lower respiratory disease including COPD are the most common underlying causes, together being responsible for 40% of all deaths.

Recent decades have seen the rise of chronic conditions as the leading contributors to death in developed countries. Age is a major risk factor for developing chronic illness.¹⁴ This becomes an urgent problem in Australia, where (as shown above) the population is ageing.

Access to Palliative Care

In addition to supporting those with a clearly terminal illness, we must find ways to better assist those for whom a serious chronic illness or multiple chronic problems present an ongoing threat of sudden exacerbation and death. End-of-life care must also serve those who become increasingly frail, even without a life-threatening illness.¹⁵

Not all people with a life-limiting illness need specialist palliative care.¹⁶

People with Malignant Conditions

Cancer still causes the most deaths in Australia.¹⁷ Recent information from the ABS¹⁸ shows there were 4,188 cancer deaths in 2016 in WA. The AIHW reports:¹⁹

Between 2014 and 2025 the death rate from all cancers combined is projected to continue an overall downward trend from an estimated 208 to 180 deaths per 100,000 males, and from 133 to 120 deaths per 100,000 females.

People with advanced cancer mostly have high levels of function early in their final year of life, but are substantially more disabled 3 months prior to death.¹⁵ Murray et al²⁰ describe a typical cancer trajectory:

- a short period of evident decline – mostly over weeks or months
- most weight loss, reduction in performance status and disability occurs in the last few months
- with early intervention, there is generally time to anticipate needs and plan for the end of life
- fits well with services which aim at providing comprehensive care for a short period

Rosenwax et al²¹ determined that 68.8% of 7,411 people who died of cancer in WA in 2009-10 accessed a specialist palliative care service in their last year of life.

¹⁰ Harrison et al (2013) 'Incidence of chronic conditions in Australia' – *PLOS one* – 8(7)

¹¹ Harrison et al (2017) 'The prevalence of diagnosed chronic conditions and multimorbidity in Australia: A method for estimating population prevalence from general practice encounter data' – *PLOS ONE* – 12(3)

¹² Harrison et al (2016) 'The prevalence of complex multimorbidity in Australia' – *Australian New Zealand Journal Public Health* – 40(3)

¹³ Australian Institute of Health and Welfare (2016) *Australia's Health 2016*

¹⁴ Divo et al (2014) 'Ageing and the epidemiology of multimorbidity' – *European Respiratory Journal* – 44(4)

¹⁵ Lunney, Lynn & Foley (2003) 'Patterns of functional decline at the end of life' – *Journal American Medical Association* – 289(18)

¹⁶ Palliative Care Australia (2005) *A Guide to Palliative Care Service Development: A Population Based Approach*

¹⁷ Australian Institute of Health and Welfare (2016) *Australia's Health 2016*

¹⁸ Australian Bureau of Statistics (2017) *3303.0 Causes of Death, Western Australia, 2016* – 'Table 6.1 Underlying cause of death, All causes, Western Australia, 2016'

¹⁹ Australian Institute of Health and Welfare (2015) *Cancer Mortality Trends and Projections: 2014 to 2025* -

www.aihw.gov.au/reports/cancer/cancer-mortality-trends-and-projections-2014-to-2025/contents/all-cancers-combined accessed 12 Apr 18

²⁰ Murray et al (2005) 'Illness trajectories and palliative care' – *British Medical Journal* – 330(7,498)

²¹ Rosenwax et al (2016) 'A retrospective population-based cohort study of access to specialist palliative care in the last year of life: Who is still missing out a decade on?' – *BMC Palliative Care* – 15(46)

People with Non-Malignant Conditions

People who die from a chronic non-malignant condition experience a fluctuating pattern of decline, with poorer function in the last 3 months of life.¹⁵ The end-of-life trajectory for this population has been described as 'long term limitations with intermittent serious episodes'.²⁰ Its distinctive characteristics include:

- patients are usually ill for many months or years
- gradual deterioration in function is punctuated by occasional acute, often severe, exacerbations
- each or any exacerbation may result in death, but the timing of death is typically uncertain

People on this trajectory in their study were more likely to die in hospital and be unmarried or widowed,^{22,23} and less likely to die in the place they prefer,²⁴ than those whose cause of death is cancer.

The Rosenwax and McNamara group reported in 2004²⁵ that only 8% of people who died from a palliative-care-amenable non-malignant condition in WA in 2000-02 (2.5 years) had at least one day of specialist services in their last year of life. Their follow-up study²¹ reported that a decade later (2009-10), this had increased to 14% but the biggest gain was in the inpatient setting: in the community the increase was from 3.1% to 4.7% over ten years. Nationally, only 23.5% of all people who receive specialist palliative care from services which participate in the Palliative Care Outcomes Collaboration have a primary diagnosis of a non-cancer condition.²⁶

Spilsbury et al²⁷ analysed WA cost data from 2009-10, and observed that people with non-cancer palliative-care-compatible conditions who accessed community palliative care (Silver Chain) incurred an average of 27% less hospital cost than those who did not.

People with Dementia

Australian cause of death data from the last 20 years tell the stark story of a significant increase in the number of deaths attributable to dementia:

Causes of Death – Rank in 2016 ²⁸	Rank in 2008 ²⁹	Rank in 1998 ³⁰
1. ischaemic heart diseases	1	1
2. dementia (including Alzheimer's disease)	3	7
3. cerebrovascular diseases	2	2
4. malignant neoplasm of the trachea, bronchus and lung	4	3
5. chronic lower respiratory diseases	5	4

Table 3: ABS leading causes of death 1998, 2008 & 2016

Dementia typically follows a trajectory which has been called 'prolonged dwindling':²⁰

- progressively worse disability from an already low baseline of cognitive or physical function

²² Morin et al (2016) 'Estimating the need for palliative care at the population level: A cross-national study in 12 countries' – *Palliative Medicine* – 31(6)

²³ Reeve et al (2017) 'Health care use and costs at the end of life: A comparison of elderly Australian decedents with and without a cancer history' – *BMC Palliative Care* – 17(1)

²⁴ Billingham & Billingham (2013) 'Congruence between preferred and actual place of death according to the presence of malignant or non-malignant disease: A systematic review and meta-analysis' – *BMJ Supportive Palliative Care* – 3

²⁵ McNamara & Rosenwax et al (2004) *Who Receives Specialist Palliative Care in WA – And Who Misses Out?*

²⁶ Palliative Care Outcomes Collaboration (2017) *Patient Outcomes in Palliative Care: National Results for January-June 2017 – Detailed Report*

²⁷ Spilsbury (2017) 'Community-based specialist palliative care is associated with reduced hospital costs for people with non-cancer conditions during the last year of life' – *BMC Palliative Care* – 16(1)

²⁸ Australian Bureau of Statistics (2017) *3303.3 Causes of Death, Australia, 2016*

²⁹ Australian Bureau of Statistics (2015) *3303.3 Causes of Death, Australia, 2014*

³⁰ Australian Bureau of Statistics (2009) *3303.3 Causes of Death, Australia, 2007*

- patients experience weight loss and declines in functional capacity, then may succumb to a minor event
- the trajectory may be cut short by death after an acute event such as an infection or fall-related injury.

Only 6.1% of 608 people whose death was recorded as being caused by Alzheimer's disease in the Rosenwax cohort²¹ accessed any specialist palliative care in 2009-10. (This has jumped since then: in 2016 there were 448 people in WA whose primary cause of death was Alzheimer's,³¹ and MPaCCS admitted 122 people with this primary diagnosis,^{32,33} which amounts to 27.23% of the state total.)

Older People with 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.³⁴

Frailty is 'a medical syndrome with multiple causes and contributors that is characterised by diminished strength, endurance, an reduced physiologic function that increases the individual's vulnerability for developing increased dependency and/or death.'³⁵ Moderate or severe frailty is an independent risk factor for readmission to hospital or death within 30 days of discharge³⁶ (although some have argued that readmission rates for frail people would be minimised if healthcare providers routinely introduced a palliative approach to the care of these individuals³⁷).

A systematic review estimated a frailty prevalence rate of 10.7% amongst community-dwelling people ≥ 65 years.³⁸ A study to establish the prevalence of frailty in Australia is planned (the investigators characterise the 10.7% prevalence rate estimate as 'conservative').³⁹

Reeve et al⁴⁰ found that amongst DVA clients in NSW the older cohort – those most likely to exhibit frailty – were less likely to use hospitals during the final six months of life (bearing out the findings of Goldsworthy et al⁴¹) – probably because many live in residential care facilities.

Frail older people and their carers viewed specialist palliative care as an acceptable "additional layer of support" with a range of benefits.⁴²

A 'traditional palliative care paradigm', with a focus on responding to single-system illnesses, and a preference for predictable trajectories, will fail to meet the needs of this population.³⁴

³¹ Australian Bureau of Statistics (2017) *3303.0 Causes of Death, Western Australia, 2016* – 'Table 6.1 Underlying cause of death, All causes, Western Australia, 2016'

³² Palliative Care Outcomes Collaboration (2016) *Metropolitan Palliative Care Consultancy Service Patient Outcomes in Palliative Care: January – June 2016*

³³ Palliative Care Outcomes Collaboration (2017) *Metropolitan Palliative Care Consultancy Service Patient Outcomes in Palliative Care: July – December 2016*

³⁴ Moorhouse et al (2015) 'End of life care in frailty' – in Rockwood (ed) *Frailty in Ageing: Biological, Clinical & Social Implications*

³⁵ Morley et al (2013) 'Frailty consensus: A call to action' – *Journal American Medical Directors Association* - 14

³⁶ Kahlon et al (2015) 'Association between frailty and 30-day outcomes after discharge from hospital' – *Canadian Medical Association Journal* – 187(11)

³⁷ Maida & Devlin (2015) 'Frailty, thy name is palliative!' – *Canadian Medical Association Journal* – 187(17)

³⁸ Collard et al (2012) 'Prevalence of frailty in community-dwelling older adults: A systematic review' – *Journal American Geriatrics Society* – 60(8)

³⁹ Ambagtsheer et al (2017) 'Feasibility, acceptability and diagnostic test accuracy of frailty screening instruments in community-dwelling older people within the Australian general practice setting: A study protocol for a cross-sectional study' – *British Open* – 7(e016663)

⁴⁰ Reeve et al (2017) 'Health care use and costs at the end of life: A comparison of elderly Australian decedents with and without a cancer history' – *BMC Palliative Care* – 17(1)

⁴¹ Goldsworthy et al (2015) 'Acute hospital-based services used by adults during the last year of life in NSW: A population-based retrospective cohort study' – *BMC Health Services Research* – 15

⁴² Bone et al (2016) 'Developing a model of short-term integrated palliative and supportive care for frail older people in community settings: Perspectives of older people, carers and other key stakeholders' – *Age Ageing* – 45

People with Progressive Incurable Neurological Conditions

Number of Western Australians die from progressive incurable neurological conditions: 31

- Cerebral Palsy (CP): 21
- Huntington's Disease (HD): 2
- Motor Neuron Disease (MND): 55
- Multiple Sclerosis (MS): 14
- Parkinson's Disease (PD): 139.

People with these conditions typically have substantial daily support needs, heavy symptom burdens, long and unpredictable end-of-life trajectories, and multiple co-morbidities. They require ongoing care planning and care coordination, even early in their journeys, and are at high risk of hospitalisation at the end-of-life. As the WAMND model of care⁴³ states, 'the main factor prolonging tertiary hospital length of stay is lack of an exit strategy' for these patients.

A dedicated specialist service could offer – in conjunction with a range of partners – early intervention, continuity of care throughout the person's end-of-life journey, and direct inpatient care as an 'exit strategy' from tertiary hospitals, or when care in the community becomes unsustainable. Additional resources, and co-location with a public hospital, would be required.

Early Palliative Care – Individual and System Outcomes

Based on randomised trials, it does appear that for the full benefits of palliative care to be realised, continuity by a multidisciplinary team is needed for at least 3-4 months.⁴⁴

PCWA supports advocacy efforts to secure more resources which would permit more early palliative care across the Western Australia health system.

A recent review⁴⁵ acknowledged early (or 'concurrent') palliative care is associated with numerous benefits, including improved quality of life, less aggressive care, cost savings, increased longevity, improved symptoms, less depression and distress, and better satisfaction with care and communications (although evidence on the impact of early palliative care on factors 'in the last days of life' agreed as important to patients/carers is still lacking).

A 2015 systematic review reached similar conclusions,⁴⁴ while a 2017 Cochrane Collaboration review on the effect of early palliative care for adults with advanced cancer⁴⁶ concluded 'interventions may have more beneficial effects on quality of life and symptom intensity among patients with advanced cancer than... usual/ standard cancer care alone.'

In Australia, the Palliative Care Trial at Southern Adelaide Palliative Service (SAPS)⁴⁷ showed that patients receiving earlier palliative care (at least 2 months before death), and a palliative care case conference, could experience a 10% improvement in performance status, which in many cases would be 'sufficient to... reduce reliance on caregivers, community health services and inpatient units.' The investigators concluded 'participants who lived longest derived the most benefits.'

⁴³ Government of Western Australia, Department of Health (2008) *Motor Neuron Disease Services for Western Australia – Neurosciences & the Senses Health Network*

⁴⁴ 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)

⁴⁵ Zambrano et al (2016) 'The impact of early palliative care on the quality of care during the last days of life: What does the evidence say?' – *Current Opinion Supportive Palliative Care* – 10(4)

⁴⁶ Haun et al (2017) 'Early palliative care for adults with advanced cancer' – *Cochrane Database Systematic Reviews* – 12(6)

⁴⁷ Abernethy et al (2013) 'Delivery strategies to optimise resource utilisation and performance status for patients with advanced life-limiting illness: Results from the "palliative care trial"' – *Journal Pain Symptom Management* – 45(3)

West Australian research proved that early palliative care reduces the use of emergency departments in the 90 days before death.⁴⁸

Carers can also benefit from early intervention, as demonstrated in a large US study.⁴⁹ Carers who received three early one-on-one telephone sessions to discuss a carer guidebook with a palliative care nurse had lower depression and stress scores than carers who received the intervention late. These findings have been borne out in a more recent Canadian study,⁵⁰ which showed carers and patients randomised to early palliative care had higher levels of satisfaction with care.

In addition to benefiting patients and those close to them, early palliative care is likely to help primary care providers. GPs and community nurses surveyed about their experiences working with an 'enhanced palliative care team' in Canada⁵¹ particularly appreciated improved access to specialist support, education, coordination of services, communications and working relationships.

Early introduction of palliative care permits routine advance care planning (ACP). Research has shown both do-not-resuscitate (DNR) and do-not-hospitalise (DNH) orders reduce unwanted treatments and tend to improve access to palliative care, while advance directives (ADs) are associated with more palliative care in the community, whereas so-called 'complex ACP interventions' have all these benefits, plus increased compliance with the patient's wishes and satisfaction with care.⁵² Green et al⁵³ concluded advance care planning does not adversely affect hope or increase anxiety among patients with advanced cancer.

A review⁵⁴ examined the cost benefits of facilitated ACP, finding seven eligible studies of varying quality, designs, settings and participants. Analysis showed ACP programs with clear content and style of communication, comprehensive facilitator training, and effective implementation are likely to 'reduce net health expenditures – despite the costs of implementation and maintenance'. These findings were borne out in a separate review,⁵⁵ which also states 'there is no evidence to suggest ACP is likely to be more costly.'

Gaertner et al⁵⁶ argue, based on reports of the implementation of hospital consultation teams, that the cost of 'universally available early palliative care... would be surprisingly low.' An economic analysis of a service in the UK⁵⁷ found 'total costs in the last year of life were substantially lower' due to early referral. Early palliative care is a cost-effective intervention because proactively seeks to educate and train family carers and other health care providers to provide care at the end of life with the objective of reducing reliance on services.

Early intervention can be difficult because there is confusion in the health system about who should initiate a referral to a service with an early engagement capability (like CPCN): GPs in one recent study

⁴⁸ McNamara et al (2013) 'Early admission to community-based palliative care reduces use of emergency departments in the ninety days before death' – *Journal Palliative Medicine* – 16(7)

⁴⁹ Dionne-Odom et al (2015) 'Benefits of early versus delayed palliative care to informal family caregivers of patients with advanced cancer: Outcomes from the ENABLE III randomised controlled trial' – *Journal Clinical Oncology* – 33(13)

⁵⁰ McDonald et al (2017) 'Impact of early palliative care on caregivers of patients with advanced cancer: Cluster randomised trial' – *Annals Oncology* – 28(1)

⁵¹ Marshall et al (2008) 'Enhancing family physician capacity to deliver quality palliative home care: An end-of-life, shared care model' – *Canadian Family Physician* – 54

⁵² Brinkman-Stoppelenburg (2014) 'The effects of advance care planning on end of life care: A systematic review' – *Palliative Medicine* – 28(8)

⁵³ Green et al (2015) 'Advance care planning does not adversely affect hope or anxiety among patients with advanced cancer' – *Journal Pain Symptom Management* – 49

⁵⁴ Klingler et al (2016) 'Does facilitated advance care planning reduce the costs of care near the end of life? Systematic review and ethical considerations' – *Palliative Medicine* – 30(5)

⁵⁵ Dixon et al (2014) 'The economic evidence for advance care planning: Systematic review of the evidence' – *Palliative Medicine* – 29(10)

⁵⁶ Gaertner et al (2015) 'Resource allocation issues concerning early palliative care' – *Annals Palliative Medicine* – 4(3)

⁵⁷ Noble et al (2015) 'Can comprehensive specialised end-of-life care be provided at home? Lessons from a study of an innovative consultant-led community service in the UK' – *European Journal Cancer Care* – 24(2)

tended to think this was the role of ‘the specialist’, ‘even if they did not think that specialists were good at doing this.’⁵⁸

Billings and Bernacki⁵⁹ highlight the importance of timing, noting that advance care planning can be undertaken too early (the patient’s preferences change or are not relevant to the situation), too late or never (plans are rushed and inadequately represent the patient’s values, goals and preferences, or do not exist at all), or just right (the patient understands their condition and prognosis, and the clinical options, people have time to deliberate, decisions are appropriately documented, choices are revisited). They recommend the use of triggers that prompt healthcare providers to identify people who may benefit from palliative care

In Summary

Approximately 16,000 Western Australians died last year. Conservative estimates are that 50-70% of those death are anticipated, and therefore may benefit from palliative care. More than 70% of Australians wish to die at home but the majority do not. The WA Cancer and Palliative Care Network (‘WACPCN’) advise that 59% of WA hospital expenditure occurs in people in their final three years of life. WA averages 7.8 hospitalisations in the last year of life and >\$2 billion per annum is spent on older people who die in hospital. Nine percent of hospital costs are spent on older people in their last year of life. Better awareness of, and access to, palliative care would assist more Western Australians to die in their home or aged care facility, and reduce avoidable hospitalisations in the final year of life.

PCWA believe that any discussion about the sustainability of WA’s health system must include the importance of palliative care and advance care planning in improving the end of life care, as recognised by the recent Productivity Commission report on Reforms to End-of-Life death.⁶⁰ Moving resources from hospitals to the community for people in their last years of life, “would better meet users’ needs and could cost less than its hospital equivalent.” A 2017 study of three tertiary hospitals in Queensland showed a “substantial [impact] in terms of both the bed days and cost incurred” of futile treatment given in the last year of life death.⁶¹

Yours sincerely,



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Palliative Care WA

⁵⁸ Coulton & Boekel (2017) *Research Into The Awareness, Attitudes And Provision Of Best Practice Advance Care Planning, Palliative Care And End Of Life Care Within General Practice* – Australian Government Department of Health

⁵⁹ Billings & Bernacki (2014) ‘Strategic targeting of advance care planning interventions: The Goldilocks Phenomenon’ – *JAMA Internal Medicine*- 174(4)

⁶⁰ Productivity Commission 2017, *Introducing Competition and Informed User Choice into Human Services Reforms to Human Services*, Report No. 85, Canberra.

⁶¹ Carter HE, Winch S, Barnett AG, et al. ‘Incidence, duration and cost of futile treatment in end-of-life hospital admissions to three Australian public- sector tertiary hospitals: a retrospective multicentre cohort study’. *BMJ Open* 2017;7:e017661. doi: 10.1136/bmjopen-2017-017661