



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



# Palliative Care – Meeting people's needs and expectations of care over the last 1000 days

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# Changing trajectories of patient needs, choices and care over the last 1000 days

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# The Origin of Palliative Care

- From the very first days of medicine, caregivers have understood the primary importance of reducing their patients' suffering
- In 1948, Dame Cicely Saunders, a British nurse, social worker and physician, founded the first formal hospice, specifically to care for patients with terminal illness

## Gaining momentum...

- Through her work and research, others began to recognise the value in respecting people's wishes and needs at the end of life. They began to understand that the approach could apply to people who were not imminently dying as well.
- In 1987, Palliative Care was established as a new specialty in Australia, New Zealand and the UK.
- In 1990, Palliative Care was recognised by the World Health Organization (WHO) as a distinct specialty.

“Palliative care is a philosophy based not on physical facilities but on attitudes”

*Saunders C. The evolution of palliative care. J R Soc Med. 2001;94:430–432*

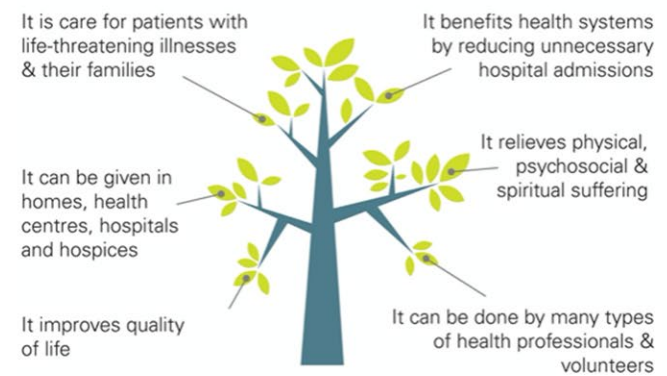


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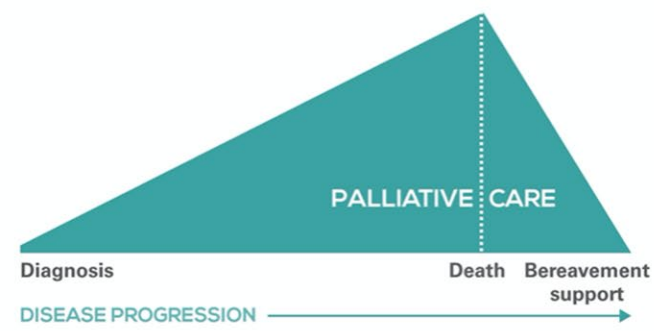


# IMPROVING ACCESS TO PALLIATIVE CARE





## WHAT IS PALLIATIVE CARE ?



## WHEN IS PALLIATIVE CARE NEEDED ?



## WHAT ARE THE BARRIERS ?

-  Poor public awareness of how palliative care can help
-  Cultural & social barriers, such as beliefs about pain and dying
-  Insufficient skills and capacities of health workers
-  Overly restrictive regulations for opioid pain relief

# The changing landscape of palliative care...

## **Patients**

- Increased numbers due to population growth and higher proportion of older people
- Fewer acute deaths
- Increased multimorbidity
- Increased disease complexity
- Increasing understanding of and expectations of palliative care

## **Advances in medicine**

- Changing disease trajectories
- Advances in imaging and treatment
- Advances in symptom control

## **Societal changes**

- Increasingly death-defying society
- Palliative care as a human right
- Compassionate communities
- Culturally appropriate palliative care
- Palliative care for minority groups

## **Political context**

- Prioritisation of palliative care
- Voluntary assisted dying

# The changing landscape of palliative care...

## **Models of care**

- Standards and regulation
- Early intervention
- Moving from 'prognostic paralysis' to active total care from diagnosis
- All diagnoses
- Increasing focus on planning ahead and patient choice
- Patient/family engagement in service development, planning and delivery
- End of life health

## **Data driven**

- Increasing evidence base for interventions and models of service delivery
- Patient reported outcome measures
- Palliative Care Outcomes Collaboration
- Funding models

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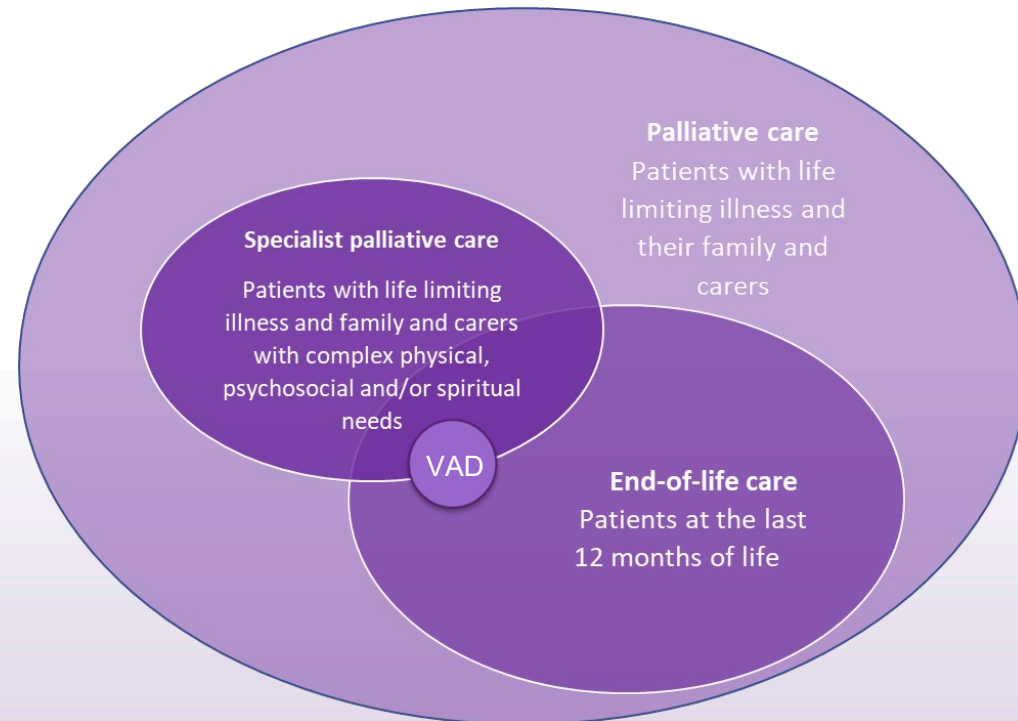


# Busting some myths...

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# Palliative care is everybody's business

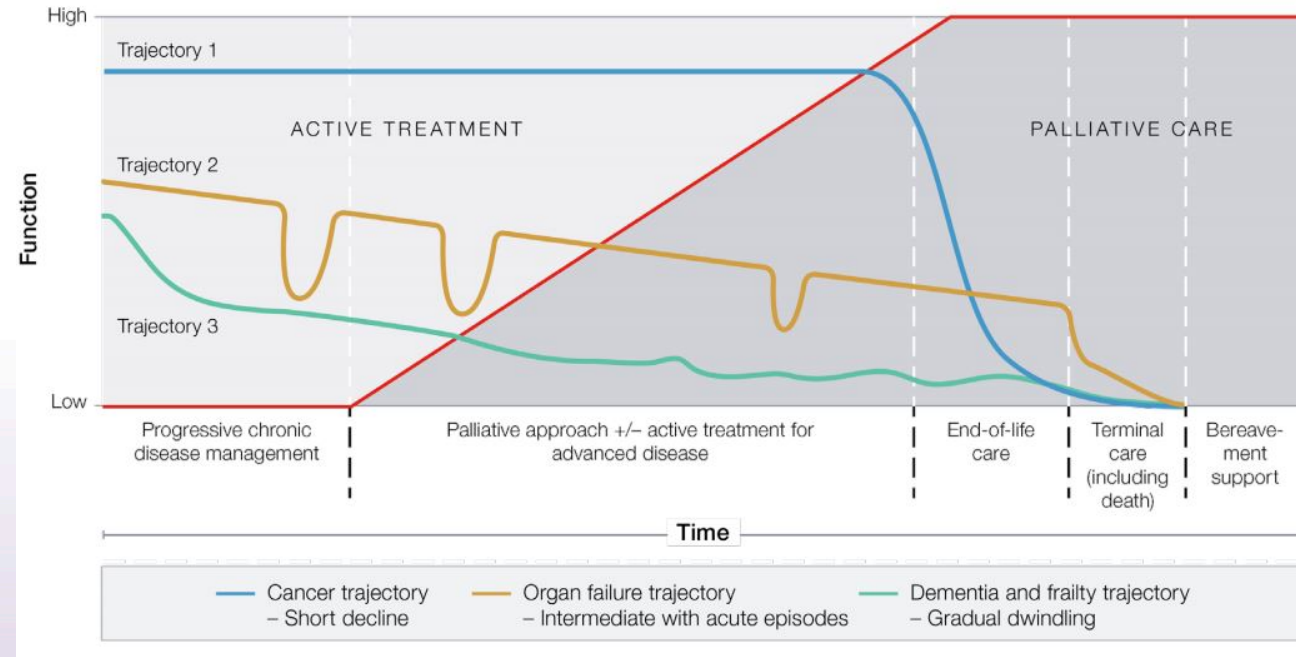
- Access to care
- Person centred care
- Connected care
- Family and carer support
- Workforce capacity
- Public awareness
- Compassionate communities



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# Palliative care is not just for cancer patients

- Most people will die of non-malignant disease with uncertain disease course
- Palliative care should be based on **need** not prognosis or age, including any chronic or malignant disease, even if the trajectory is ambiguous or unknown



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# Palliative care is not just for the dying

Growing evidence for the benefit of early integration of palliative care

- Small number of studies report benefit of early palliative care in terms of quality of life and symptom intensity
- Effect sizes are small, but clinical significance may be substantial
- Strong support for an approach of “general palliative care for all plus specialist palliative care as needed”

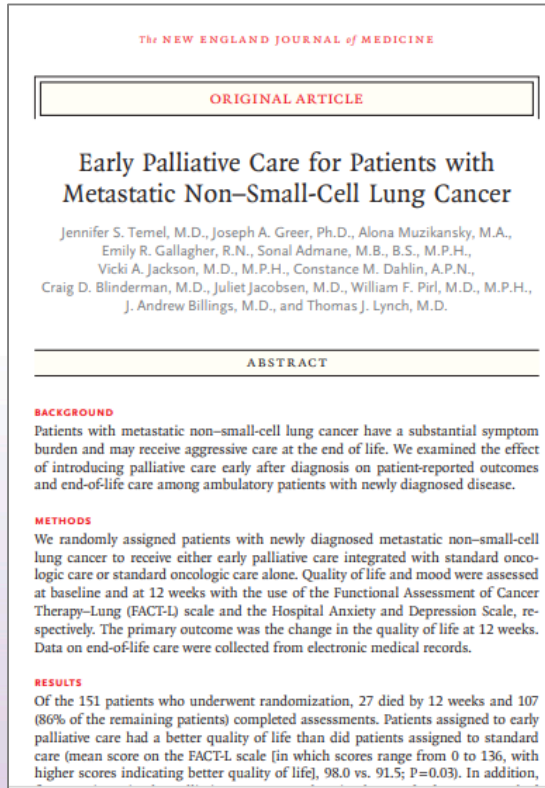
## ***2017 Systematic Review – Hospital, Hospice and Community Settings***

Gaertner J, Siemans W, Meerpohl J et al. Effect of specialist palliative care services on quality of life in adults with advanced incurable illness in hospital, hospice, or community settings: systematic review and meta-analysis. *BMJ* 2017; 357 :j2925

## ***2017 Cochrane Review - Advanced Cancer Patients***

Haun M, Estel S, Rucker G, et al. Early palliative care for adults with advanced cancer. *Cochrane Database of Systematic Reviews* 2017, Issue 6.

# Palliative care does not shorten life. It may prolong it.



151 patients with metastatic non-small cell lung cancer  
Randomized within 8 weeks of diagnosis to either monthly visits to an outpatient palliative care clinic plus usual oncology care or usual oncology care alone.

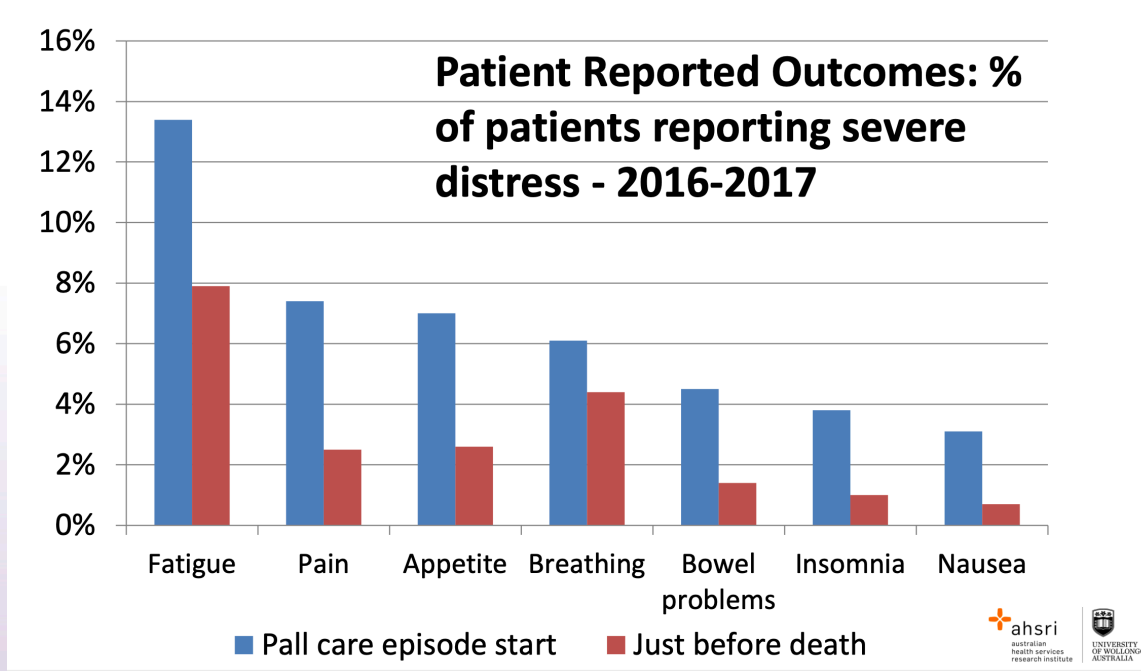
After 3 months, the palliative care group had:

- Better quality of life
- Better symptom control
- Less major depressive disorder (4% vs 17%)
- Fewer hospitalisations and ED visits
- Greater recording of resuscitation preferences (53% vs 28%)
- Median survival was 11.6 months from enrollment vs. 8.9 months in the usual care group

N Engl J Med 2010;363:733-42

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# Pain is not the most prevalent symptom at the end of life



Palliative Care Outcomes Collaboration 2017, Common symptoms at End Of Life

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# Palliative care at home is not the same as palliative care in hospital



OPEN ACCESS

## Palliative care is effective: but hospital symptom outcomes superior

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### ABSTRACT

**Objectives** To explore differences in severe symptom outcomes for palliative care patients receiving hospital care compared with those receiving care at home.

**Methods** Change in symptom distress from the start of an episode of palliative care to just prior to death was measured for 25679 patients who died under the care of a hospital or home-based palliative care team between January 2015 and December 2016. Logistic regression models controlled for differences between hospital and home and enabled a comparison of the number of severe symptoms just prior to death.

**Results** All symptoms improved and over 85% of all patients had no severe symptoms prior to death. Pain control illustrates this with 7.4% of

of care. In 2016, the PCOC data collection represented 12.4% of all deaths in Australia (including unpredictable deaths) and more than 80% of all patients seen annually by specialist palliative care services. An important role of PCOC is to report on this repository of prospectively collected information. Previously, PCOC researchers have found that palliative care services achieve statistically significant improvements in pain and other symptoms<sup>2</sup> and have described symptom prevalence at the time dying is diagnosed.<sup>3</sup> In those previous studies, the palliative care phase<sup>2,3</sup> was the unit of counting with the outcome being the change from the beginning to the end of each phase.

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# Good palliative care isn't expensive, it can actually save money

- By promoting advance care planning
- By avoiding unnecessary and unwanted interventions
- By getting control of symptoms and distress faster
- By helping with planning to get people with complex needs home and
- By preventing unnecessary readmissions to hospital, particularly if home is where the person wants to die



## Meeting needs, improving choice

- Early and effective ACP, and better systems to acknowledge and respond to wishes
- Earlier and more timely access to palliative care
- Staff knowledge and training levels
- Care coordination
- Seamless transitions between care settings
- Rapid access to care packages
- Better access to psychological support
- Out of hours care and support
- Access to and delivery of pain relief/medication
- Improving support for families and carers

Palliative care, if we do it well, lives on in the memories of the people who are left behind.

Likewise, if we do it badly, it also lives on in the memories of people who are left behind.

“You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to help you live until you die.”

*Dame Cicely Saunders*

