



PM GLYNN  
INSTITUTE

Policy  
considerations  
for palliative and  
end-of-life care

Hope when  
health fails



ACU

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# Public policy for the sick and dying

The legalisation of euthanasia or assisted suicide ('voluntary assisted dying' or VAD) in a number of Australian states has highlighted the urgent need for better ways of caring for people as they approach the end of their lives, or as they struggle with a chronic illness.

To provide a better option for the sick and dying than VAD, much more needs to be done to ensure high-quality palliative care and end-of-life care are available to everyone who needs them.

It is not unusual for people to confuse palliative care and end-of-life care.

## PALLIATIVE CARE

Palliative care is defined by the World Health Organisation as an approach that improves the quality of life of patients and their families facing the problems related to a life-limiting illness. It includes the prevention and relief of suffering by means of early identification and exemplary assessment and treatment of pain. It integrates the psychological and spiritual aspects of patient care, and offers a support system to help patients live as actively as possible with their condition.

## END-OF-LIFE CARE

End-of-life care is an integral part of palliative care for people who are dying. Its focus is to assist people to live as well as possible during this time and to die with dignity. It encompasses a person's treatment and support, including the care for their psychosocial, pastoral or spiritual needs, and those of their families and friends.

Palliative care is one constituent of end-of-life care, but it is also helps people with chronic conditions who are not dying or near death. End-of-life care and palliative care do not involve hastening death, as euthanasia does.

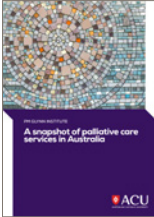
## A HUMAN RIGHT

Arguments in favour of VAD often assert that it is right people should have. Less well known is that palliative care is a well-established and internationally recognised human right, as part of the right to health in the International Covenant for Economic, Social and Cultural Rights.

The reports and papers summarised here underscore the importance of making this right a reality for everyone who is sick or dying.

# Hope when health fails

The PM Glynn Institute has developed a number of resources that address issues relating to palliative care, end-of-life care and attitudes to dying.



## A SNAPSHOT OF PALLIATIVE CARE SERVICES IN AUSTRALIA

In 2018-20, Cris Abbu undertook a study of the provision of palliative care services in Australia.

*A snapshot of palliative care services in Australia* provides an explanation of the findings and makes nine recommendations for improving provision of these services.



## SPEAKING OF SUFFERING

In 2020, Michael Casey led a study of qualitative research on attitudes to death and dying.

*Speaking of suffering* provides a survey of findings about forms of suffering commonly experienced at the end of life, the effects of this suffering, and how it can be addressed through end-of-life care.



## THE RE-FRAMING OF HOPE IN PALLIATIVE CARE

In 2021, Cris Abbu wrote a discussion paper about the need to adopt a more holistic approach to palliative care provision – one that recognises the significance of nurturing hope in patients with life-limiting illnesses.

*The re-framing of hope in palliative care* calls for the adoption of hope-engendering initiatives for palliative care patients in Australia.



## FINISHING UP BUSINESS

In 2021, Kerry Pinkstone investigated attitudes to death and dying in several Aboriginal and Torres Strait Islander communities.

*Finishing up business* offers some suggestions about the relevance of these Indigenous approaches for discussions about how we care for the dying.

Copies of these publications are available at [pmglynn.acu.edu.au](http://pmglynn.acu.edu.au). Printed copies are also available by emailing [pmg@acu.edu.au](mailto:pmg@acu.edu.au).

# A snapshot of palliative care services in Australia

The report provides an overview of palliative care services in Australia, looking at it through the lens of the two principles – access and equity. As such, this report:

- investigates patterns in palliative care service provision, and in some cases, analyses and compares changes over time
- identifies gaps in palliative care provision
- given the gaps, identifies areas for policy action.

## KEY FINDINGS

Particularly important among the report's ten key findings are:

### INCREASING DEMAND

Palliative care hospitalisations have been increasing over time, at an average rate of 5 per cent annually since 2003. This trend is likely to continue as Australia's population continues to age.

### BURDEN ON PUBLIC HOSPITALS

Australia's public hospitals carry the heavier burden in the provision of palliative care, with only 14 per cent of hospitalisations in private hospitals.

### CHILDREN AND PALLIATIVE CARE

Palliative care hospitalisations among children and young adults have increased over time, with double digit rates of annual increase since 2011.

### SHORTAGE OF DOCTORS

Specialist palliative medicine physicians are essential to the effective functioning of any palliative care service. There is currently a significant shortfall of specialists, and a low uptake of palliative care among medical trainees.



### SHORTAGE OF NURSES

Only 1.1 per cent of nurses are palliative care nurses. Although the overall number of employed nurses increased between 2013 and 2017, the percentage of palliative care nurses remained the same.

### SOME POLICY RECOMMENDATIONS

The report's nine recommendations include:

- develop innovative and integrated models of palliative care
- develop a national policy framework or strategy for paediatric palliative care
- actively encourage increased uptake of palliative care training.

# Speaking of suffering

This paper surveys some of the academic research on end-of-life experiences to encourage a conversation about dying and suffering.

## LACK OF DISCUSSION

The anxiety that surrounds the prospect of death often leads us to avoid the topic of illness and dying altogether. The discussions we do have are often marked by fears of suffering and the loss of dignity and autonomy caused by a chronic or end-of-life illness. A public discussion about death and dying would be beneficial in many ways.

## TYPES OF SUFFERING

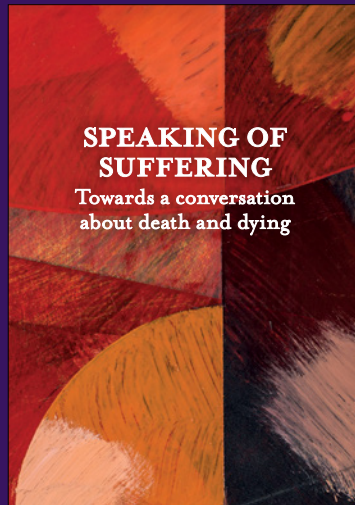
Suffering at the end of life can extend beyond physical pain and affect the whole person. It includes:

- physical suffering
- psychosocial and existential suffering
- loss of autonomy and dignity.

Each of these forms of suffering has many aspects that need to be understood and addressed.

## A CONVERSATION ABOUT DYING

The success of a public conversation in fostering deeper reflection and a sense of reassurance depends upon dealing with the reality of death in an open and sensitive manner. Dying can be very difficult for some people and very distressing for families, and it is essential to be clear about what can and what cannot be achieved through palliative and end-of-life care.



## EFFECTIVE END-OF-LIFE CARE

Highlighting that effective avenues for treatment at end of life exist is a key starting point, including raising awareness about palliative care. Good palliative care and social support makes it possible to provide physical, psychosocial, and spiritual comfort that helps relieve the symptoms of suffering.

## LIFE IS STRONGER

Establishing an integrated approach to treat all aspects of suffering can help to alleviate the fear of dying and of being a burden. In this way, it is possible to replace the loss of dignity and autonomy that is often experienced with a sense that life is stronger than death, even in the midst of sickness and dying.

# The re-framing of hope in palliative care

The paper discusses the role of hope in patient care and suggests that a holistic approach to palliative care is one that incorporates and recognises the significance of sustaining and nurturing hope in patients with life-limiting illness.

## MAINTAINING QUALITY OF LIFE

The effects of hope are well known. Various studies have recognised its importance particularly to those with life-limiting conditions. It is positively correlated with quality of life. Thus, increasing hope and quality of life for patients with life-limiting illness has been the focus of psychosocial, hope-fostering strategies and interventions.

A few of these interventions include:

- the application of self-awareness and reflection activities by nurses and other palliative care health professionals
- positive communication strategies so that the worth and value of patients are affirmed
- adopting a holistic approach to care (eg. helping the patient to focus on everyday life in the present moment, assisting in maintaining interest in their hobbies, helping them participate in creative arts projects)
- giving emotional support (eg. being optimistic, focusing on the positive aspects, having a sense of humour).

## TAKING A HOLISTIC APPROACH

Surprisingly, the role of hope and the importance of maintaining it is not usually considered in palliative care provision. Given that people at end of life have a variety of needs that are linked to all aspects of their personhood, a holistic approach that places significance on the role of hope in the provision of palliative care is crucial.



## IMPORTANCE OF SUSTAINING HOPE

Hope is a central concept in caring for patients at end of life. They need to be nurtured, respected, affirmed and valued. This puts an incredible importance on sustaining hope as a significant aspect of a holistic approach to palliative care.

# Finishing up business

Australia has 65,000 years of traditional Aboriginal and Torres Strait Islander knowledge that remains undervalued when approaching issues in our modern society. One of these issues is our approach to dying and death.

This paper seeks to better inform the debate our nation is continuing to have about end-of-life care, including voluntary assisted dying.

## HEARING INDIGENOUS VOICES

Culturally, Indigenous people are hesitant to talk about dying and death. There is a risk their views are not considered, and that the broader discourse on end-of-life issues continues without understanding what we could learn from Indigenous peoples.

## CULTURALLY UNACCEPTABLE

The period before death is an important time for passing on cultural knowledge through ceremonies, healing relationships, and coming together, and is seen as preparation for the next stage of a person's spiritual journey. Euthanasia is therefore culturally unacceptable given the importance of this time for the individual, their family and community.

## BURDEN OF PREMATURE DEATHS

The burden of disease and premature death weighs heavily on Aboriginal and Torres Strait Islander peoples. When life is taken away prematurely, it becomes more precious.



## MISUNDERSTANDING VALUES

When Indigenous views are considered in debates about legalising euthanasia, they are typically reduced to a problem of misinformation leading to a fear of doctors and making people fearful of accessing care, rather than as a deep cultural opposition that is values-based.

## INDIGENOUS INTERDEPENDENCE

Humans are relational beings whose sense of identity and interests are shaped by our connections to others. Our connectedness as a society means we are called to honour our fellow human being and respect life. Listening to the wisdom of Indigenous peoples on this issue can help all Australians to rediscover this sense of connectedness and respect.

The PM Glynn Institute was established by Australian Catholic University (ACU) in 2016 as a public policy think tank to analyse issues of concern the Catholic Church and the wider Australian community. Its focus is public policy for the common good.

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Cover image: Maery Gabriel, *Cross*; 1997 (detail). Glazed ceramic tiles and stone tiles.  
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