



ST VINCENT'S  
HEALTH AUSTRALIA

UNDER THE STEWARDSHIP OF MARY AIKENHEAD MINISTRIES

# Palliative and end of life care

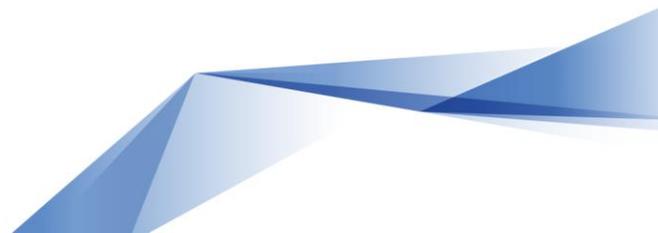
Position statement

**Date**

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# 1. Palliative care

All Australians should be able to access high quality palliative<sup>1</sup> and end of life care<sup>2</sup>.

This needs:

- Evidence-based service delivery models – in hospitals and the community.
- Adequate funding to ensure equity of access across Australia, and in all settings, to support people's choices.
- Appropriately trained health professionals.
- Increased funding for palliative care research.

## 1.1 Evidence-based service delivery models

St Vincent's Health Australia supports:

### 1. Early introduction of palliative care for all people diagnosed with a life-threatening illness

A paradigm shift is required so that palliative care is not seen as just for the end of life (terminal phase). There is strong evidence on the benefits of palliative care in relieving symptoms and pain, and improving quality of life, mood, satisfaction with care for patients<sup>3</sup> (and their carers<sup>4</sup>) and, in some cases, even survival for patients.<sup>5</sup> Palliative care is also associated with cost savings with reduced hospitalisations and ED presentations<sup>6</sup>, and greater likelihood of death at home.<sup>7</sup>

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<sup>1</sup> 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 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.

<sup>2</sup> People are 'approaching the end of life' when they are likely to die within 12 months. This includes people whose death is imminent (expected within a few hours or days) & those with: advanced, progressive, incurable conditions; general frailty and co-existing conditions; at risk of dying from a sudden acute crisis in their condition; life-threatening acute conditions caused by sudden catastrophic events (Australian Commission on Safety and Quality in Health Care. National Consensus Statement: Essential elements for safe high quality end of life care: 2015).

<sup>3</sup> Parikh RB, Kirch RA, Smith TJ, Temel JS. Early specialty palliative care — translating data in oncology into practice. *N Engl J Med* 2013; 369: 2347-51.

<sup>4</sup> Christakis NA, Iwashyna TJ. The health impact of health care on families: a matched cohort study of hospice use by decedents and mortality outcomes in surviving, widowed spouses. *Soc Sci Med* 2003; 57: 465-475.

<sup>5</sup> J Temel, et al (2010), Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer, *New England Journal of Medicine*; 363:733-742.

<sup>6</sup> Parikh et al.

<sup>7</sup> Hui D, Kim SH, Roquemore J, et al. Impact of timing and setting of palliative care referral on quality of end-of-life care in cancer patients. *Cancer* 2014; 120: 1743-1749.

Despite this evidence, referrals to palliative care are generally made when a person is very close to the end of life or death is imminent. This means that patients are missing out on the benefits that palliative care can deliver *throughout* their treatment – including in the curative treatment phase.

Early integration of palliative care:

- Assists with symptom management, alongside active treatment.
- Supports Advance Care Planning.
- Improves patient choice about their treatment regime which can reduce burdensome and futile treatments.
- Enhances support for carers.
- Can potentially reduce health care costs.

Anyone diagnosed with an advanced, life-threatening illness should routinely be introduced to the concept of palliative care in the curative treatment phase.

A lack of understanding about the role of palliative care in both the community and in health services is a key driver of late referrals and better education is required.

## **2. Palliative care embedded in key departments / specialties within hospitals**

Within hospitals, specialist palliative care clinicians should be embedded in Departments with large patient groups affected by terminal illnesses including cancer care, cardiology, neurology, respiratory and nephrology. This could involve a physical co-location of clinicians, or structured collaboration between specialty teams.

There are several models for integration. However the Supportive Renal Care model in NSW is now well-researched and has delivered excellent results.<sup>8</sup>

### **Case study: Renal Supportive Care at St George Hospital NSW**

St George nephrology department introduced a new model of care for their (mostly elderly) patients with end stage kidney disease. The model aimed to avoid dialysis for patients where it would not provide a benefit or may do harm, while improving symptom management and quality of life, and planning for a 'good death'. It provides an active treatment program for patients on a non-dialysis pathway.

This model established a supportive care clinic within the renal department. It embedded a palliative care specialist as part of the department, with support from a social worker and dietician to provide holistic care. Patients on dialysis and non-dialysis pathways referred to the supportive care clinic routinely.

For patients who choose not to start or continue with dialysis, patient care continues under their usual nephrologist in line with the principle of 'non-abandonment'.

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<sup>8</sup> A list of recent publications on the Supportive Renal Care Model – along with contact information for the St George Renal Department – can be found at: <https://stgrenal.org.au/renal-supportive-care>.

### 3. Integrated hospital and community palliative care, including with aged care

The separation of providers for hospital-based (inpatient or outpatient) specialist palliative care and community palliative care is unhelpful. It limits clients' choice about where they receive care and doesn't support continuity of care when people move in and out of hospital according to their needs.

Funding models also inhibit integration:

- Provision of palliative care by GPs is low due to a lack of funding incentives for home visits, and a lack of expertise.
- Servicing people in residential aged care is particularly challenging due to different funders. There is significant opportunity to develop new models of palliative care in partnership with residential aged care providers.

#### Case study: integrated palliative care at Sacred Heart

Sacred Heart in Darlinghurst provides an example of integrated palliative care. Sacred Heart delivers both inpatient and community palliative care (as part of a community collaborative) which allows the same medical specialist to oversee care for patients across public and private hospitals and their patients' home (including residential aged care), ensuring integration and seamless care.

### 4. Enhanced psychosocial support, including for family.

Palliative care is a holistic model aimed at addressing physical, psychosocial and spiritual needs. However, access to psychosocial and bereavement support – particularly for families – can be limited.

Palliative care services should routinely assess unmet family carer needs and identify those at risk of distress by palliative care services. Primary family carers should be formally identified and offered support and training in the carer role and receive bereavement support where needed.

### 5. New palliative care models in the private hospital sector to provide multi-disciplinary and community care.

Funding models in the private hospital sector traditionally have not supported good palliative care practice. Palliative care is by definition interdisciplinary, but private sector funding is fee-for-service and highly doctor driven, which does not support multidisciplinary team working.

Further, private health insurers have historically been reluctant to offer policy-holders coverage for community-based, end-of-life care. Most private health funds only fund the inpatient part of this process, effectively limiting a private patient's choice in terms of where they would like to receive palliative care and die.

#### Case study: Palliative care partnership – St Vincent's Private Hospital Brisbane and Bupa

St Vincent's Health Australia and Bupa recently announced a two-year pilot program to provide private patients with the choice to receive intensive, specialist palliative care services at home.

Managed by the Specialist Palliative Care Team at St Vincent's Private Hospital Brisbane (which operates Queensland's largest palliative care inpatient unit), the program is available for Bupa members in Brisbane

who have complex symptoms or are in the last few days of their life and want to receive palliative care at home.

Following assessment, patients will be able to access:

- specialist palliative care multidisciplinary assessment and Advance Care Planning
- at-home specialist palliative care as required from physicians, palliative care nurses, and allied health professionals such as occupational therapists, physiotherapists, and counsellors
- intensive specialist palliative care which may include physician and nurse visits as well as additional at-home nursing support
- 24/7 telephone support access for patients, carers and family
- direct access to the hospital's Palliative Care inpatient unit if required, avoiding any need to present at the Emergency Department.

St Vincent's Health Australia and Bupa will evaluate the pilot against a range of outcomes including the patient's experience receiving palliative care at home compared to in hospital, the number of patients who received palliative care at their preferred location, and health care costs.

## 6. Standards to assure quality

St Vincent's supports standards of care that clearly discern criteria for referral to specialist palliative care (hospital-based and in the community) and the expectations of generalist health care providers. Health services should be formally and regularly assessed on the quality of palliative care provided.

### 1.2 Equity of access

Although Australia has some very high quality palliative care services, many Australians miss out. Further, the overwhelming majority of people with a terminal illness want to be cared for in their own homes for as long as possible. Inadequate resourcing often means this does not happen, with only about 15 percent of Australians supported to die at home.

Inequitable access – including to support people's choice about where they would like to die – is a result of:

- *Geography* – across Australia different states have different levels of service; within states different area health services fund and deliver palliative care services differently depending on their priorities; access is very low in regional, rural and remote communities.
- *Type of illness* – palliative care is more readily offered and available to patients with cancer whereas patients with non-malignant but life-threatening diseases such as COPD have very low access. Increasing access for non-cancer patients would significantly increase demand on the system.
- *Treating clinician* – some doctors have a better understanding and are more supportive of palliative care than others. Palliative care is not yet embedded as part of routine care.

St Vincent's supports equitable access to specialist palliative care for all Australians, no matter where they live or what type of illness they have. Service gaps vary by state and location and it is difficult to identify where the key gaps are due to lack of data on access. However there are some consistent access issues nationally.

St Vincent's Health Australia supports:

**7. Investment from governments in key areas of need to support people's choice:**

- a. Outpatient clinics and community services to provide urgent/imminently dying care in-home including:
  - i. Support to move home from hospital when death is imminent.
  - ii. Palliative care assistants (trained carer, non-clinical) to provide practical support for families when their loved one is dying at home.
- b. A telephone advice service for generalist health professionals and family carers providing care in the home to access palliative care specialists.
- c. Improved access to outpatient allied health services such as occupational therapy and physiotherapy.
- d. Resources to support 24 hour specialist palliative care in the acute setting.
- e. Enhanced access to bereavement and psychosocial support for families.

**8. Development of service delivery models based on need rather than diagnosis and that incorporate evidence-based pathways to identify all patients requiring palliative care.**

**9. Reporting on palliative care access for patients who died of chronic illness by all area health services nationally.**

**10. Hospital performance and quality processes including mortality and morbidity meetings should assess access to, and quality of, palliative / end of life care.**

### 1.3 Education and training

All health professionals – in acute, primary and community care – will need to care for patients with life-threatening illnesses including patients who are dying. As such, all should be appropriately qualified to provide the fundamentals of palliative care and to know when to engage specialist palliative care services. Health professionals should also know how to start discussions about Advance Care Planning and how to initiate discussions about the appropriateness of various forms of resuscitation in an in-patient setting. This is not the reality in the health sector today.

Talking about the implications of advanced disease including death and dying also requires advanced communication skills, which many clinicians – including at senior levels – do not have. This can result in a lack of clarity about the goals of care and treatment options.

Education and training of health professionals is critical to improving access to, and quality of, palliative care.

St Vincent's Health Australia supports:

- 11. Strategies and resources to ensure all generalist health care providers receive training in the essential aspects of palliative care provision (symptom management, psychosocial support, communication skills, family carer support, and bereavement care).**
- 12. A systematic approach to building communication skills regarding palliative care for all health professionals and building competencies into health care professional training skill sets.**

A strategy should also be in place to ensure there are sufficient numbers of multidisciplinary palliative care specialists for patients with complex needs and that all clinicians provide consistent standards of care.

Family carers also need preparation for their challenging role. This is also likely to increase the proportion of people who can be cared for at home.

St Vincent's Health Australia supports:

- 13. Developing a national competency framework for all health professions involved in the delivery of specialist palliative care, with providers assessed on a regular basis.**
- 14. Ensuring sufficient training positions to meet current and future needs of the specialist palliative care workforce.**
- 15. Funding to develop training programs and scholarships in palliative care for specialists and generalists.**
- 16. Resourcing and implementation of family carer education and training programs.**

## 1.4 Research and evidence

Investment in palliative care research is inadequate. Approximately one in three people will die of cancer within 5 years yet the Centre for Palliative Care estimates that palliative care research receives only around 1 per cent of the cancer research dollar.

There is a high need for research in symptom management, psychosocial support (including family carers and bereavement), health service evaluation, and legal and ethical aspects of decision-making processes. We need to develop a critical mass of palliative care researchers which will require funding for academic positions including Chairs in relevant disciplines. It is also important to secure funding to develop and evaluate models of palliative care delivery for all the various disease cohorts where palliative care can make a difference

St Vincent's Health Australia supports:

- 17. A comprehensive, sufficiently resourced palliative care research strategy.**

## 2.Reducing unnecessary and futile treatments

Aggressive treatments for people with terminal illnesses can decrease quality of life for the patient and their family, and are in many cases therapeutically ineffective and/or overly-burdensome to the patient (in addition, they may be unnecessarily costly to the health system). In many cases, patients are not aware of the full range of treatment options available and the benefits and harms in order to make an informed choice.

St Vincent's Health Australia supports:

### **18. An awareness and engagement campaign about dying, Advance Care Planning and end of life care choices.**

Australia needs a systematic and sustained public education program to encourage a community conversation about dying, the goals of medicine when the patient's condition is terminal, and preferences for decision making.

Clinicians are reluctant to talk to their patients about the likelihood of dying and most do not have the skills required for these difficult conversations. Patients and families can also have unreasonable expectations of the health system.

The downside is that many patients continue to receive treatments that are reducing quality of life without providing compensatory benefits. A reluctance to talk about dying also prevents palliative care being initiated early.

### **19. Resources to support Advance Care Planning and end of life care planning.**

All Australians should be encouraged to consider and provided the opportunity to specify the type of care they would like in the end of their life. Advance Care Planning offers everyone, and particularly people living with a terminal illness, the opportunity to take control of decisions which affect their care and to exercise their choices.

St Vincent's supports:

- Public education approaches to encourage understanding of Advance Care Planning including but not limited to Advance Care Plans (which in some places are known as Directives).
- Development of resources to support patients and the public who wish to engage in Advance Care Planning and facilitate discussions with their health care providers
- Training for health professionals to provide Advance Care Planning.
- The use of My Health Record and local health information systems to record and store Advance Care Plans so that they are available to all clinicians, palliative care specialists and family members at the appropriate times.

- For patients diagnosed with a life-threatening illness, the early opportunity of Advance Care Planning in the curative treatment phase.

## **20. National standards for Advance Care Planning and greater legislative consistency on Advance Care Plans.**

### **3. Euthanasia (or physician-assisted suicide)**

There is a misconception in the community – including among some health professionals – that death is inherently painful, undignified and traumatic for both patient and family.

The reality is that most patients who receive quality palliative care can be made comfortable and enabled to communicate their wishes and say farewells. Families of patients who have received palliative care have commented on how peaceful the death was and identified the positive aspects associated with their caregiving role, amid the inevitable distress and grief.

We acknowledge that even with well-resourced palliative care some people will still request euthanasia. But such requests are infrequent, even rare, with around 50,000 palliative care patients admitted to Australian hospitals each year, and less than approximately 1% having a sustained desire for euthanasia.<sup>9</sup>

Despite the very low number of requests for euthanasia among patients receiving palliative care, these requests nevertheless require a professional and compassionate response. Such a response requires exquisite skills, judicious timing and the capacity to engage in shared decision-making, particularly when confronting the less tangible 'existential' aspects of suffering.

These skills are neither commonplace nor included in existing health professional curricula. In contrast to palliative care's multi-disciplinary team approach, well-meaning general clinicians may be ill-equipped or poorly supported to address this suffering, leaving them overwhelmed by a sense of helplessness.

We believe the broader community – including healthcare professionals – needs to be reassured of palliative care's significant role in relieving all aspects of suffering. Increased resources and effort must be directed toward training, research, community engagement, and ensuring adequate palliative care. Until everyone in the community has access to first-class palliative care, the legalisation of euthanasia ought not even be considered.

Given the small number of people receiving comprehensive palliative care who actually desire euthanasia, investment in palliative care will have much greater population impact than any investment euthanasia.

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<sup>9</sup> Peter Hudson, Mark Boughey, et al (2015) Physician-assisted suicide and/or euthanasia: Pragmatic Implications for palliative care, *Palliative and Supportive Care*, Oct; 13(5):1399-409.

St Vincent's Health Australia believes:

- 21. Priority must be given to the policies and resources necessary to ensure all Australians have access to palliative care. Until that priority is met, consideration should not be given to legalising euthanasia and assisted suicide.**
- 22. Any change to the laws in relation to euthanasia and/or physician assisted suicide must never compromise the provision and resourcing of end of life care and palliative care services.**

### Ethical concerns

The Catholic tradition of healthcare provides strong support for palliative care and Advance Care Planning but cannot ever support legislation which seeks to enact euthanasia.

Our *Code of Ethical Standards for Health and Aged Care Services* affirms the following in relation to End of Life:

*A patient who knows that his or her life is nearing its end, and in particular that an illness is likely to lead to death, may need an increased level of support both from family, carers and healthcare practitioners. Those caring for the person should therefore seek to establish a relationship of trust, compassion and confidence with all those in their care, and should thereby place their humanity, knowledge, experience and skill at the service of the dying person.*

We believe that euthanasia and the option for euthanasia erodes this relationship of trust.<sup>10</sup>

Our further ethical concerns include but are not limited to the following:

- St Vincent's commitment to those who are vulnerable leads us to consider that people are usually no more vulnerable than when they are reaching the end of life. St Vincent's regards people such as those from non-English speaking backgrounds, those living in poverty, people who have addictions or mental health issues and the elderly would be most vulnerable if euthanasia were legalised.

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<sup>10</sup> By 'euthanasia' we mean the adopting and carrying out of a proposal that, as part of the medical care being given to someone, his or her life be terminated on the ground that it would be better for him or her if that were done. Euthanasia can be voluntary (at the request of the person), non-voluntary (where the person is not capable of either making or refusing to make such a request) or involuntary (where the person is capable of making such a request but has not done so).

This definition of euthanasia distinguishes in a straightforward way, on the one hand, choosing to bring about someone's death with drugs to relieve the person of pain and suffering and, on the other, choosing to relieve someone of their pain and suffering by giving drugs, in a dosage determined by the drugs' capacity for relief of pain and suffering, foreseeing that the drugs in that dosage may cause death. The former is euthanasia, the latter is not.

By 'assisted suicide' we mean providing the patient with the means for terminating his or her own life.

- The fundamental principle underpinning our healthcare service is acknowledgement of the dignity of the person. Each human being, by virtue of the mere fact of being human, has an intrinsic value we call 'dignity'. Respect for the dignity of the person is the fundamental principle of interpersonal morality. Both euthanasia and assistance in suicide violate the dignity of the person.

### Clinical concerns

Euthanasia and assistance to commit suicide are sometimes described as 'public health care interventions'. Australia's National Health and Medical Research Council have clear guidelines on the steps required to develop and implement a new intervention, including sufficient evidence to underpin it, pilot testing and exploring the implementation and health resource costs. The evidence base underpinning euthanasia does not meet any benchmark for the introduction of a major new health intervention.

The range of practical and clinical risks and complexities includes:

- Which health professionals would provide euthanasia and how would it be resourced?
- What training would health professionals who administer euthanasia require?
- What are the resources needed to implement and monitor euthanasia?
- What community education would occur?
- What ongoing research and evaluation would occur?
- What are the implications for palliative care provision?
- What assessment criteria would be needed to establish the 'unbearableness' of a person's suffering?
- What would be the time point in the disease trajectory when euthanasia would be available, noting that prognostication in terminal disease is typically inaccurate?
- How will those who are marginalised or vulnerable, such as Aboriginal Australians, people from non-English speaking backgrounds, the elderly and people living in poverty, be protected in any euthanasia proposal?

Further, evidence from jurisdictions that have legalised euthanasia shows that:

- The number of instances of euthanasia and assisted suicide is growing rapidly in all major jurisdictions where it is legal, despite being introduced to assist a very small minority of people for whom it was claimed that their pain could not be effectively managed. This indicates significant scope creep.
- Safeguards have proven difficult to enforce – for example, many cases are unreported resulting in a lack of transparency and effective regulatory oversight, doctors experience difficulty in determining whether a condition is terminal, people with mental illness and people vulnerable to coercion are not adequately protected.