
Position Paper

End of Life Care

OUR POSITION

- Patients should be provided with the means to make informed choices regarding their treatment, and where appropriate, plan for the end of their life.
- Patients and their carers should be assisted to develop realistic expectations of surgery, its objectives and potential outcomes in an end-of-life care context.
- Patients should be encouraged to develop Advance Care Directives (ACD) in Australia or Advance Directives (AD) in Aotearoa New Zealand.
- Surgeons and other healthcare professionals should honour the wishes of the patient as expressed in an ACD or AD in a culturally safe manner.

CONTEXT

The steady increase in life expectancy alongside the prevalence of chronic conditions has led to an increased need for end-of-life care as many patients are living longer with complex medical problems¹. Experiences for individuals reaching the end of their life differ considerably depending on several factors, including the pathway to death. For some patients, palliative surgery is on that pathway.

People are 'approaching the end of life' when they are likely to die within the next 12 months². End of life care is commonly associated with experiences of chronic and progressive decline in health and function associated with older age, rather than sudden death. End of life care includes the physical, spiritual and psychosocial assessment, care and treatment delivered by healthcare professionals, including the support of families and carers, and care of the patient's body after their death³.

END OF LIFE CARE STANDARDS

In Aotearoa New Zealand and Australia several standards outline principles and actions to support end-of-life care.

Te Ara Whakapiri: Principles and guidance for the last days of life re-released by Manatū Hauora - Ministry of Health in February 2023 outlines the requirements to ensure consistent and quality care for Aotearoa New Zealand adults at the end of life⁴. *Te Ara Whakapiri* offers a holistic approach to end of life care that respectfully involves patients, carers, whānau, and medical practitioners in the end-of-life care planning process. The accompanying *Te Ara Whakapiri: Toolkit* is a set of checklists, flowcharts, tools and patient resources to be used for individual patients at the end of life.

In July 2023, Te Whatu Ora – Health New Zealand began development of a National Palliative Care Work Programme⁵ which seeks to deliver a nationally consistent approach to palliative care across Aotearoa New Zealand. In August 2024 Te Kau Pairuri o Aotearoa – Hospice New Zealand released *the Aotearoa Specialist Adult Palliative Care Guidelines*

The Australian Commission on Safety and Quality in Health Care (ACSQHC) released a *National Consensus Statement: essential elements for safe and high-quality end-of-life care (2023)*⁷. The statement incorporates ten essential elements and nine guiding principles critical to the delivery of safe and high-quality end-of-life care. The guiding principles define safe and high-quality end-of-life care while the essential elements - split between 'care processes' and 'organisational processes' outline the key actions that should be applied by healthcare services.

Palliative Care Australia has established the National Palliative Care Standards for All Health Professionals and Aged Care Services⁸ to complement the National Palliative Care Standards (for specialist palliative care services) (2018)⁹. These standards aim to support better experiences and outcomes for people receiving palliative care, including their family, carers, and substitute decision-makers in non-specialist palliative care settings.

END-OF-LIFE CARE AND THE ROLE OF THE SURGEON

Palliative Care

Palliative care is a multidisciplinary specialty and approach to treatment which aims to relieve suffering and support quality of life for patients and their families facing a life-limiting illness. RACS supports the rights of patients facing life-limiting illness to receive palliative care.

The role of the surgeon regularly intersects with those of intensive care and palliative care physicians and others. Surgeons have a responsibility to ensure patients are provided with appropriate, timely and high-quality palliation, to relieve suffering where possible. This may include palliative surgery, which are interventions by surgeons for the relief of problems associated with all incurable illness. In some cases, surgical intervention will be appropriate for critically ill and high-risk patients to improve a patient's medical condition.

The provision of appropriate pain relief to alleviate symptoms and reduce suffering in patients facing life-limiting illnesses is consistent with a principled approach to end of life care. RACS recognises that the provision of palliative care for the primary purpose of pain relief or to alleviate symptoms may occasionally hasten the death of a patient. In accordance with the position under the law, RACS does not recognise any circumstances where palliative care may be used for the primary purpose of bringing about or accelerating the death of a patient.

Low efficacy surgical intervention

The decision to pursue a surgical intervention often requires multidisciplinary team input and careful evaluation of risks and expected outcomes. Surgeons exercise professional judgement on a case-by-case basis to determine whether an intervention will improve a patient's medical condition or be of little benefit. In some cases, surgical intervention is futile or will not improve the quantity or quality of life of the patient. A decision to withhold a surgical intervention can be difficult for all involved and compounded by differing views regarding the benefits of an intervention.

Where surgeons determine procedures will be futile or of a low efficacy to a patient, patients should be provided with information about alternative treatment options. Patients, families and carers should be equipped with necessary information to make informed choices as to whether to proceed with a surgical intervention or treatment.

Advance directives (Aotearoa New Zealand) / Advance Care Directives (Australia)

RACS encourages patients to develop an undertake advance care planning, including establishing an Advance Directive (AD) or Advance Care Directive (ACD).

In Aotearoa New Zealand, an AD is defined by Te Toihau Hauora, Hauātanga - the Health and Disability Commissioner as:

'...a statement signed by a person setting out in advance the treatment wanted or not wanted in the event of becoming unwell in the future. An advance directive can be a good way to gain more control over the treatment and care you are given if you experience an episode of mental illness that leaves you unable to decide or communicate your preferences at the time'¹⁰.

In Australia, the Department of Health and Aged Care define an ACD as a formalised version of a patient's advance care plan which outlines a patient's preferences for your future care along with their beliefs, values and goals¹¹. Advance care directives differ between Australian states and territories, and it is important that surgeons are aware of obligations that are specific to their jurisdiction.

Advance care planning including an AD or ACD are an important way for patients to communicate their wishes in situations where they may be unable to give informed consent. Patients can express their expectations about future medical treatment should certain situations arise. In practice, not all eventualities can be predicted or discussed with a patient prior to the development of an illness or situation which may require surgery. Surgical intervention may also necessitate a period of increased risk and expected transient or permanent deterioration in patient function.

On occasion, an ACD or AD may conflict with the care required for a successful outcome of surgery, such as when a patient has chosen not to undergo intubation and ventilation. Faced with the reality of surgery, some patients may change their mind as to the level of care they reject or are willing to receive. It is important that discussions with the patient are ongoing and that an ACD or AD is modified to best reflect a patient's wishes at that point in time.

In many cases surgery is undertaken with the understanding that patients will accept an increased level of circulatory or respiratory support where this would not normally be the case. The multidisciplinary team should keep this in mind when discussing advance care planning in the perioperative context and when determining what the patient's wishes would be in the setting of unexpected but potentially salvageable deterioration in the immediate postoperative period.

Voluntary Assisted Dying (VAD) and Mate Whakaahuru - Assisted Dying

In Australia, voluntary assisted dying (VAD) is the assistance provided by a health practitioner to a person with a terminal illness, disease or medical condition to end their life and includes:

- **self-administration**, where the person takes the VAD medication themselves, and
- **practitioner administration**, where the person is given the medication by a health practitioner.

'Voluntary' means it is the person's voluntary choice. The person must have decision-making capacity to decide to access VAD¹². VAD is legal in all Australia states subject to meeting eligibility criteria¹³. In the Australian Capital Territory (ACT), VAD will commence on 3 November 2025¹⁴ and while it remains illegal in the Northern Territory (NT) the introduction of the Restoring Territory Rights Act 2022 (Cth) in December 2022 means the NT can now consider legalising voluntary assisted dying (VAD)¹⁵.

In Aotearoa New Zealand, te reo Māori translation for assisted dying is mate whakaahuru – to die in a warm and comforting manner¹⁶. Mate Whakaahuru is regulated under the End of Life Choice Act (2019),

which is under review in 2024¹⁷. Access is subject to strict eligibility and a person must meet all of the criteria to be eligible to access the assisted dying service¹⁸.

RACS recognises that the topic of assisted dying is emotive and raises complex ethical issues, and that there is a broad spectrum of opinion in Australian and Aotearoa New Zealand. Surgeons are not compelled to consider assisted dying. A patient may approach their surgeon independent of a general practitioner, for advice, counselling and access to assisted dying. Surgeons should be familiar with the legislation and assessment process and be ready to discuss processes as defined in the relevant Act and alternative treatment options.

End-of-Life Care and Paediatric Patients

With medical and technology advances, children and young people with life limiting medical conditions are living longer. Medical and technological advances have allowed children and young people with life limiting chronic conditions to live longer than before. However, the prognosis and expected course of illness is frequently more difficult to determine in paediatric complex chronic illnesses than it is in diseases more commonly seen in adults. This uncertainty is such that decisions on surgical options are often very difficult for patients and their families to navigate.

The Australian Paediatric Palliative Care National Action Plan¹⁹ provides guidance and direction on key priorities and actions to improve outcomes for children, young people and their families living with a life-limiting condition. It is a roadmap for a national approach to prioritise and work towards common goals and objectives for paediatric palliative care.

In Aotearoa New Zealand, Te Whatu Ora provides Guidance for Integrated Paediatric Care Services²⁰, with a number of regional services available including a palliative care team is based at the Starship Hospital in Auckland²¹ and Rei Kōtuku provides specialised paediatric palliative and bereavement care to pēpi, tamariki, rangatahi²².

The surgeon has an important role in helping a family weigh up the risks and benefits of potential surgical procedures and ensure interventions align with family goals. The approach to the care of a dying child by medical, palliative care and surgical teams greatly influences the ability of the parents and siblings to cope with the child's death.

Culturally Competent and Culturally Safe Care

Culturally competent and culturally safe care for all patients and their families or whānau is essential to delivering end-of-life care. The impact of on-going health disparities and socioeconomic inequities in some communities is also an important consideration for surgeons and others. In Australia²³ and Aotearoa New Zealand, the impact of health disparities for indigenous people can be particularly severe.²⁴

In Aotearoa New Zealand, Te Kahu Pairuri o Aotearoa - Hospice New Zealand provides *Mauri Mate*²⁵, a Māori palliative care framework as a guide for the hospices in Aotearoa. Surgeons should also be familiar with *Te Whare Tapa Whā* which represents a Māori holistic model of health. The model outlines four cornerstones that apply to the total wellbeing of any person – te taha tinana (physical health), te taha whānau (extended family/whānau), te taha hinengaro (mental and emotional wellbeing) and te taha wairua²⁶.

In Australia, providing culturally safe end-of-life care for Aboriginal and Torres Strait Islander people includes adhering to principles of equity of access; empowerment and autonomy, trust²⁷. Resources to assist in supporting Aboriginal and Torres Strait Islander people include²⁸, while most Australian States and Territories publish guidelines including 'Sad News, Sorry Business: Guidelines for caring for Aboriginal and Torres Strait Islander people through death and dying'.²⁹

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