



LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT

Ms Bec Cody MLA (Chair), Mrs Vicki Dunne MLA (Deputy Chair), Ms Tara Cheyne MLA,
Mrs Elizabeth Kikkert MLA, Ms Caroline Le Couteur MLA.

Submission Cover Sheet

End of Life Choices in the ACT

Submission Number: 483

Date Authorised for Publication: 19/4/18

ACT Office

Telephone +61 2 6285 4023

Email: college.act@surgeons.org

29 March 2018

ACT Legislative Assembly
Select Committee on End of Life Choices
GPO Box 1020
Canberra ACT 2601

Email: LACommitteeEOLC@parliament.act.gov.au

Dear Ms Cody and Members,

End of life choices in the ACT

Thank you for the invitation to provide a submission to this inquiry. Included with this cover letter is the Royal Australasian College of Surgeons position on end of life care.

Patients are often admitted to the acute hospital setting with significant and life threatening injuries and diseases that may result in a death in hospital. End of life choices in this setting is often complicated by the lack of an advanced care directive, goals of therapy and the inability of the patient to make these choices due to their illness.

Death in this situation is often traumatic both for the patient and their family. Some of these patients will receive treatment that is futile. An acute care hospital may not always provide a peaceful and a dignified death. With an ageing population we will be increasingly faced with such situations.

The ACT should invest in the provision of appropriate palliative care services, easy access to hospice and also home-based palliative care services for those that wish to die at home.

Patients dying in acute care hospitals should be able to access private rooms or single rooms away from the acute setting where death is imminent. This will allow a peaceful and dignified death.

Patients approaching end of life seen in emergency departments should be able to be managed by the palliative care service or hospice without being admitted to the acute care wards.

We have often received patients from peripheral hospitals with injuries and disease processes that are unsalvageable. These patients often die in an acute care setting away from their homes and loved ones. Deciding whether to transfer these patients is difficult, and the retrieval team and ambulance service should coordinate this following a discussion about the goals of therapy prior to transport where possible.

Advance care directives (ACD)

ACDs are an important way for patients to let people know their wishes about healthcare and treatment before they become seriously ill or injured. They can help identify goals of therapy. ACDs should be linked to hospital and patient records so that they are available when required. Linking ACDs to the hospital system will enable easy access when required and will help avoid futile and unnecessary treatment.

Greater promotion of and education about ACDs among general practitioners and specialists is also needed. Having trained personnel that can help treating doctors when required to discuss end of life decisions and ACDs in

the hospital and community setting would help facilitate the decision making process. Not all doctors are comfortable or trained to have these discussions. As they are often busy and overworked, they are not always the best person to have deep and meaningful discussions with patients about end of life care, so support is needed.

Victoria is implementing binding Advance Care Plans which will mean patients can make binding decisions about future treatment (include “do not resuscitate”). This is part of [The Medical Treatment Planning and Decision Act 2016](#). As part of this a series of forms and guidelines are currently being developed.

Data

We have little or no data to determine how well (or not) we are dealing with end of life choices. We need information to understand our current practice and where we can improve.

Significant resource allocation is needed to measure outcome data and implement improvements. The ACT is uniquely placed to do this as it is a small jurisdiction.

While RACS does not have a position on euthanasia as an organisation, members are required to act in accordance with the law. Part of Victoria’s Voluntary Assisted Dying legislation requires the establishment of a [Review Board](#). The purpose of this board will be to review every request for VAD but they will also be required to collect and report on data (the number of applications, the number approved, the number “completed”, and the number not followed through on).

Sincerely,



A/Professor Sivakumar Gananadha
RACS ACT Committee Member

Cc Dr Ailene Fitzgerald, RACS ACT Chair



End of Life Care

INTRODUCTION

The Royal Australasian College of Surgeons (RACS) is committed to excellence in all areas of clinical practice and encourages medical practitioners, health services and governments to actively consider policy and practice in the delivery of services towards the end of a patient's life.

Over the past 50 years the progress of modern medicine has seen Australia's and New Zealand's average life expectancy increase markedly. During these additional years, vitality and well-being are not always guaranteed and many individuals experience impaired function, diminished mental capacity, pain and discomfort towards the end of their lives. It is therefore important that patients are provided with the means to make informed choices regarding their treatment, and where appropriate, plan for the end of their life.

Patient autonomy, dignity and respect are principles central to the effective operation of modern healthcare. These principles are reflected in RACS's core values of service, integrity, respect, compassion and collaboration. As life sustaining treatments and palliative care advance, it is essential that these principles continue to inform the provision of health services to patients.

In the area of End of Life Care, RACS affirms that:

- Patients and their carers should be assisted to develop realistic expectations of surgery, its objectives and potential outcomes.
- Members of the community should be better informed about Advance Care Directives (ACD), and encouraged and assisted to put one in place before the need arises.
- Surgeons and other healthcare professionals should honour the wishes of the patient as expressed in an Advance Care Directive.
- RACS will continue to educate and support surgeons in the multidisciplinary environment in which end of life decisions are made.
- RACS does not have a position on euthanasia as an organisation. RACS requires that its members act in accordance with the law.

PALLIATIVE CARE

Due to the invasive nature of surgical intervention, the role of the surgeon regularly intersects with those of intensive care and palliative care physicians, and others. Surgeons have a responsibility to ensure that patients are provided with appropriate, timely and high quality palliation. The provision of appropriate pain relief to alleviate symptoms and reduce suffering in the terminally ill is consistent with a principled approach to end of life care.

RACS supports the rights of terminally ill patients to receive palliative care. RACS also 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.

Approved by: Professional Development and Standards Board	Version: 1	Approval date: October 2016
Document owner: Manager, Professional Standards	Review date: October 2019	Reference number: FES-PST-057



INFORMED CHOICE AND LOW EFFICACY PROCEDURES

Surgeons, like intensivists and other proceduralists, are often placed in situations where intervention and a period of increased medical support are required to improve a patient's medical condition. In some cases, surgical intervention will be appropriate for critically ill and high risk patients. There will however, be cases where surgical intervention is futile or will not improve the quantity or quality of life of the patient. Surgeons should use professional judgement in these circumstances and be cognisant of the College values of service, integrity, respect, compassion and collaboration.

Judging whether an intervention will be futile or of little benefit to the patient is often uncertain and can be dependent on the condition and expectations of the individual patient. A decision to withhold a surgical intervention can be difficult for both the surgeon and the patient or their family. This difficulty can be compounded where there are differing views regarding the benefits of an intervention, or where there are cultural differences contributing to misunderstanding.

The decision to pursue an interventional course often requires a multidisciplinary team. It is the responsibility of this team, with surgeons usually as leaders, to carefully evaluate and explain the risks and expected outcomes of a surgical intervention. Many surgeons are regularly faced with patients with terminal conditions, and have experience in advising patients and their families about appropriate levels of care.

It is important that surgeons have sufficient insight and awareness to identify procedures which will be futile or of a low efficacy to a patient, and to provide patients with all possible information about alternatives to such interventions or treatments. This process allows patients and (where relevant) their substitute decision makers to make informed choices as to whether to proceed with a surgical intervention or treatment.

ADVANCE CARE PLANNING IN THE SURGICAL CONTEXT

Advance care planning provides a means of ascertaining a patient's wishes in situations where they are otherwise unable to give informed consent. This allows patients to express their expectations as to the nature of 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. Furthermore, surgical intervention may necessitate a period of increased risk and expected transient or permanent deterioration in patient function.

RACS strongly encourages patients to develop ACDs. An ACD provides a patient with a means of communicating their beliefs, values and goals, and can be an invaluable aid to surgeons, patients and carers when deciding how to proceed in any given situation. ACDs can benefit all patients regardless of whether their health is deteriorating or not.

On occasion, an ACD 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. Treating doctors should determine whether there is an ACD in place and take due cognisance of it and its directions as best as can be followed. Faced with the reality of surgery, some patients may change their mind as to the level of care

Approved by: Professional Development and Standards Board	Version: 1	Approval date: October 2016
Document owner: Manager, Professional Standards	Review date: October 2019	Reference number: FES-PST-057



they reject or are willing to receive. It is therefore important that discussions with the patient are ongoing and that ACDs are 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. Surgeons, anaesthetists and intensivists 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.

RESOURCES

Australian and New Zealand Intensive Care Society (ANZICS), *ANZICS Statement on Care and Decision-Making at the End of Life for the Critically Ill*, 2014

Royal Australasian College of Physicians, *Improving Care at the End of Life*, 2016.

Australian Commission on Safety and Quality in Health Care (May 2015). National Consensus Statement: essential elements for safe and high-quality end-of-life care

Australian and New Zealand Society of Palliative Medicine (ANZSPM) Position Statement (February 2014). Quality end of life care. Part 1: Essential elements for quality, safety and appropriate clinical care at the end of life.

Approved by: Professional Development and Standards Board	Version: 1	Approval date: October 2016
Document owner: Manager, Professional Standards	Review date: October 2019	Reference number: FES-PST-057