



Short title: End-of-life care

1. Purpose

To assist doctors involved in caring for patients at the end of life for whom surgery or an interventional procedure is being considered.

2. Scope

This guideline is intended to apply to anaesthetists, surgeons and other medical practitioners, involved in caring for patients at the end of life who are being considered for emergency or elective surgery or interventional procedures.

3. Background

The pathways to death in countries like Australia and New Zealand are changing. People are living longer despite suffering multiple medical co-morbidities and the incidence of dementia is increasing. Consequently, people are dying at increasingly older ages over one to two years, with more significant medical decision points at the end of life. The public often has expectations of curative capacity that exceed reality on the one hand, and exhibit widespread concern about bad dying on the other. Clinicians still struggle with treatment limitation decisions and issues related to causation and responsibility for death.

It is therefore, not surprising that people who are considered for surgery and interventional procedures in Australia and New Zealand tend to be older and sicker. This trend is likely to escalate as these demographic transitions evolve. Life-prolonging surgery may confer a favourable outcome, although surgical outcome review committees and coronial reports in both countries demonstrates higher morbidity and mortality in this older population. Importantly, surgery has a pivotal role in good palliative care, for example, for hip fractures, intestinal obstruction or wound debridement.

Doctors often express uncertainty when caring for patients at the end of life who are considered for surgery. This may range from moral distress at subjecting patients to invasive procedures when they are dying, to frustration that a potentially beneficial procedure is being denied. Concerns include futile treatment, high morbidity and mortality and uncertainty regarding advance care directives and limitations on medical treatment in the perioperative period.

4. Principles of care

- Identify patients at the end of life: 'diagnosing' dying.
- Consider the intention of the proposed surgery or procedure.
- Promote a shared-care decision making process exploring patient-centred outcomes.
- Promote cultural safety
- Mitigate the potential for clinical momentum¹ if surgery proceeds
- Manage limitations on medical treatment² (LOMT) in the perioperative period (including medico-legal implications).

¹ The automatic offer of a cascade of increasingly invasive interventions without critical evaluation of the benefit of interventions or the consideration of alternative actions

² Non-escalation decisions regarding health care or interventions.

Surgery should not be considered for patients at the end of life who have entered the terminal phase but may be beneficial for those in the palliative phase where anticipated survival can be months or even years.

Clinical Directive Forms, encompassing a “Goals of Care” framework, outline aims of and limitations on medical treatment based on curative, palliative and terminal phases of an illness trajectory. These replace older, binary ‘Not for Resuscitation’ orders. Legal documents i.e., Advance Care Directives, may form the basis of such documents with consequent medicolegal implications that vary by jurisdiction.

4.1 Key ethical and legal concepts

- 4.1.1 It is important to sensitively, directly and clearly, raise death and dying, risk and prognostic issues, with patients, families, and substitute decision-makers. Communication skills training and experience are key.
- 4.1.2 Patients with decision-making capacity have the right to refuse any medical treatment, including resuscitative measures or surgery.
- 4.1.3 Doctors have a duty of care to patients that complies with legal, professional and organisational regulations.
- 4.1.4 Clinicians are not compelled to treat dying people as if they are curable, nor to institute management that they consider too risky or unlikely to confer benefit for the patient (futile treatment).
- 4.1.5 Advance Care Directives must always be taken into consideration and instructions, where legally binding, must be followed.
- 4.1.6 Patients or substitute decision-makers should be consulted if limitations on medical treatment (LOMT) are implemented. This includes if modifications or suspensions are made to LOMT for the perioperative period.
- 4.1.7 In an emergency, consent does not need to be obtained for treatment that will save a person’s life or prevent significant harm or distress to the patient (therapeutic privilege).
 - 4.1.7.1 This applies when patients lack decision-making capacity and their substitute decision-maker is unavailable in a reasonable time frame to provide consent.
 - 4.1.7.2 Advance care directives, where known, can be used to guide treatment.
- 4.1.8 Medicolegal obligations vary by country, state or territory. Doctors must be aware of relevant legal and institutional requirements and procedures for the jurisdiction and organisation in which they work.

5. Recommendations

There are two aspects to providing care for patients at the end of life who are being considered for surgery or interventional procedures.

- Evaluating benefits of surgery with respect to the patient’s illness trajectory, values and preferred outcomes.
- Mitigating non-beneficial treatment and interventions if surgery proceeds

5.1 Evaluate benefits of surgery with respect to the patient’s illness trajectory, values and preferred outcomes.

- 5.1.1 Re-evaluate requirement for surgery and anaesthesia in the context of the end-of-life³.
 - Identify the end-of-life (palliative) phase and predicted illness trajectory.
 - Carefully consider the intention of surgery/procedure.
 - Common aims are prognostication, life prolongation or symptom control/prevention (or a combination of these)

³ National Safety and Quality Health Service (NSQHS) Comprehensive Care. Element 2 of Standard 5.

- 5.1.2 Assess patient decision-making capacity^{1,4}.
- Patients with decision-making capacity have the right to consent to or refuse any medical treatment (including surgery or resuscitative measures).
 - For patients without decision-making capacity, decisions regarding surgery and perioperative management of complications can be guided by advance care directives, advance care plans or substitute decision-makers.
- 5.1.3 Promote shared-care decision-making discussions^{5,6}.
- Explore patient-centred outcomes and values.
 - Meaningful patient-centred outcomes following surgery include survival, satisfaction, functional status, well-being, health-related quality of life and preparation for a good death.
 - Given the multidisciplinary nature of end-of-life care all practitioners involved in the care of such patients should work collaboratively to guide informed decision-making through provision of a unified consensus.
 - Assess the implications of Advance Care Directives or Plans during surgery and anaesthesia.
 - Discuss “best-case/worst-case scenarios” emphasising potential patient outcomes instead of procedural risk.
 - Be clear with patients and/or substitute decision-makers about the intention of surgery and alignment with patient centred outcomes following surgery.
- 5.1.4 Promote cultural⁷ safety.
- Be sensitive to culture, language and ethnicity in culturally and linguistically diverse (CALD) populations.
 - Consider the needs of New Zealand Māori⁸, Australian Aboriginal and Torres Strait Islander peoples.
 - Explore assistance from liaison health care workers and seek guidance if uncertain.

5.2 Mitigate non-beneficial treatments and interventions if surgery proceeds.

- 5.2.1 Mitigate the potential for clinical momentum.
- Discuss
 - Range of outcomes with and without resuscitation
 - Responses to iatrogenic complications
 - Intended and possible locations for postoperative care
 - Form mutual understanding and agreement around acceptable patient centred outcomes following surgery, and realistic potential to meet these outcomes.
 - Pro-actively implement goals of care and limitations on medical treatment (LOMT) to provide guidance on post-operative care.
 - This includes direction on resuscitative measures or intensive care unit admission.
- 5.2.2 Manage pre-existing limitations on medical treatment (LOMT)

⁴ National consensus statement: essential elements for safe and high-quality end of life care. Element 1, Part A.

⁵ NSQHS Comprehensive Care. Element 2 of Standard 5, Action 5.15 and 5.20.

⁶ National consensus statement: essential elements for safe and high-quality end of life care. Element 1 Part A.

⁷ ANZCA PS62(G) *Statement on cultural competence*. <https://www.anzca.edu.au/getattachment/294afc96-4beb-4119-8151-b280642bd872/PS62-Statement-on-cultural-competence#page=>

⁸ Mauri Mate - A Māori Palliative Care Framework for Hospices. Available from: <https://www.hospice.org.nz/wp-content/uploads/2019/04/Mauri-Mate-full-framework-for-hospices-FINAL-2020pdf.pdf>

- This may be documented on a clinical directive form (e.g., goals of care form, resuscitation plan) or a legal document (i.e., Advance Care Directive)
- Discuss:
 - implication of LOMT
 - likelihood of requiring resuscitation
 - potential interventions and consequences
- Decide to suspend, modify (techniques-based or values-based) or continue LOMT in the perioperative period
- Establish agreement
 - prospectively decide when pre-existing LOMT should be reinstated (if suspended or modified)
- Document decision making process and staff involved.

References

National Safety and Quality Health Service (NSQHS) Standards. Comprehensive Care Standard. Available at: <https://www.safetyandquality.gov.au/standards/nsqhs-standards/comprehensive-care-standard> Accessed 8/11/2021.

Australian Commission on Safety and Quality in Health Care. National Consensus Statement: essential elements for safe and high-quality end-of-life care. Available at: <https://www.safetyandquality.gov.au/publications-and-resources/resource-library/national-consensus-statement-essential-elements-safe-and-high-quality-end-life-care> Sydney: ACSQHC, 2015.

This document is accompanied by a background paper (PG67(G)BP) which provides more detailed information regarding the rationale and interpretation of the Guideline.

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Promulgated: 2021
Current document: July 2022

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Appendix 1

End of life (EOL)^[1]

The period when death is anticipated due to disease progression, frailty and general deterioration in physical and/or cognitive function. This period may be years before eventual death or it may be a shorter period of time (weeks to months). It is distinct from the terminal phase.

Palliative Phase^[2]

When disease or condition is considered to be incurable and progressive

Terminal Phase^[2, 3]

Imminent death expected within hours or days

Futile Treatment^[4, 5]

A treatment or intervention that is unlikely (*relative futility*), or definitely will not (*absolute futility*), achieve its objective(s). Futility and futile treatment are clinical concepts, not legal or bioethical ones. In clinical practice, non-beneficial treatment is the preferred terminology.

Advance Care Planning^[6]

A process of planning for future health and personal care, whereby the person's values and preferences are made known so that they can guide decision-making at a future time when the person cannot make or communicate their decisions.

Goals of Care (GOC) Framework^[2]

An illness phase categorisation system to guide escalation or non-escalation (limitation on medical treatment), and communicate this within a health system. It is based on whether a person is in a curative/restorative, palliative or terminal phase. It is the basis of a medical order or clinical directive. It is distinct from an advance care directive.

Limitation on Medical Treatment (LOMT)^[2]

A non-escalation decision regarding health care and interventions, usually reached proactively. It may be expressed in an advance care plan (ACP), advance care directive (ACD), or on a clinical directive form (e.g., Goals of Care Form).

Advance Care Plan (ACP)^[6]

A document that sets out a person's preferences about health and personal care, and preferred outcomes. Results from an advance care planning discussion.

Advance Care Directive (ACD)^[6]

An advance care plan that is legally recognised by either common law (common law ACD) or specific legislation (statutory ACD) that is completed and signed by an adult with decision making capacity.

Clinical Directive Form^[2]

A local health system or hospital document that records directions regarding medical treatment in order to guide clinicians (e.g., Goals of Care form, Resuscitation Plan etc.) Previously, known as 'Not-for-Resuscitation' or "Do not attempt resuscitation" forms, these simple, binary orders have been superseded by forms based on a Goals of Care Framework.

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4. Ashby, M.A., *The Futility of Futility: Death Causation is the 'Elephant in the Room' in Discussions about Limitation of Medical Treatment*. *Journal of Bioethical Inquiry*, 2011. **8**(2): p. 151-154.
5. Lewis, M.C. and N.S. Yeldo, *The Ethics of Surgery at End of Life*. *Anesthesiol Clin*, 2019. **37**(3): p. 561-571.
6. Australian Commission on Safety and Quality in Health Care., *National Consensus Statement: essential elements for safe and high-quality end-of-life care.*, ACSQHC, Editor. 2015: Sydney.