



Short title: End-of-life care BP

1. Purpose

The accompanying guideline was developed with the intention of assisting doctors involved in caring for patients at the end-of-life for whom surgery or an interventional procedure is being considered

It is in the context that acknowledges the often-multidisciplinary involvement of care in these patients.

2. Scope

Given the multidisciplinary involvement it was decided that PG67(G) should be developed as a co-badged document comprising membership of the document development group derived from relevant stakeholders. Consequently, the document is intended to apply to all registered medical specialists, specialist international medical graduates, and specialist trainees involved in end-of-life care.

The issue of futile surgery is a separate matter that was considered out of scope, as was the issue of voluntary assisted dying.

3. Discussion

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, with the process often extending over several years. There are often multiple decision points during this period of decline and the end of life (the period when death is anticipated due to disease progression, frailty and general deterioration in physical and/or cognitive function^[1, 2]). 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.^[2]

It is therefore, not surprising that people who are considered for surgery and interventional procedures in Australia and New Zealand tend to be older, more medically complex with multiple co-morbidities, and have a greater rate of geriatric syndromes such as frailty, cognitive impairment and functional decline^[3]. 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 increased in-hospital, 30-day, 90-day and 1 year mortality following surgery as well as lower quality of life, increased length of hospital stay and lower rates of discharge home^[4-7]. However, while the perioperative period involves increased risks for this patient cohort, there are also well documented benefits related to symptom relief, improvement of quality of life and even increased life expectancy^[8], particularly in patients suffering an acute crisis that would dramatically shorten their prognosis. Importantly, surgery has an established and 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^[3, 9, 10], clinical momentum^[11], high morbidity and mortality^[3-7] and uncertainty regarding implications of advance care directives and limitations on medical treatment in the perioperative period^[12, 13].

There are two key aspects in the decision-making process when considering surgery in patients at the end of life

- 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

Balancing the risk-benefit ratio of surgery requires an ability to identify persons at the end of life, an understanding of the intended benefits and anticipated complications of surgery and exploring important patient centred outcomes to assess values-based benefit. Combining these with expertise in shared-care decision making enables clinicians to tailor decision making to individual patients and mitigate the delivery of non-beneficial treatment in the perioperative period should surgery proceed^[14].

3.1 Key Concepts

3.1.1 Decision-making capacity and consent

A person has decision-making capacity when they can understand, retain and weigh up information and then communicate their decision^[15]. An adult with decision making capacity is deemed legally 'competent' and can consent to and/or refuse treatment offered to them as part of their healthcare^[16]. Importantly, consent can only be given for medical treatment that is offered after medical assessment and advice, and there is no right to either compel a clinician to treat a dying person as if they are curable^[17], or institute treatment they believe to be non-beneficial or overly risky^[18]. When a person lacks decision making capacity (either temporarily or permanently), legislation, which varies by jurisdiction, determines how consent is gained for medical treatment. In an emergency, therapeutic privilege exists whereby medical treatment necessary to save a person's life or prevent distress or harm to that person, can proceed if the patient lacks decision-making capacity and their substitute decision maker (SDM) is not available within a reasonable time-frame to provide consent^[10]. It is incumbent upon clinicians to understand the consent process and the medicolegal implications of legal documents (i.e., advance care directives) in the jurisdiction that they are employed.

Further information regarding consent and decision-making capacity can be found here for:

Australian States and Territories

<https://end-of-life.qut.edu.au/capacity#statetercap>

New Zealand

<https://www.mcnz.org.nz/assets/standards/79e1482703/Statement-on-informed-consent.pdf>

3.1.2 Advance Care Planning, Advance Care Plans (ACP) and Advance Care Directives (ACD)

For patients at the end of life, advance care planning forms a crucial role in guiding medical treatment, including decisions regarding surgery, resuscitation and critical care management. Advance care planning is a process whereby a 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^[19]. Advance care planning is a discussion which can occur between patient and clinician or within a patient's care circle. It may be formal or informal, a single discussion or a series of discussions. If documentation occurs during or following an advance care planning discussion, this documentation is

known as an advance care plan. Advance care plans (ACP) document the person's stated values and wishes that are established during the advance care planning discussion^[19]. ACPs are used to guide health care when patients lose decision-making capacity. Refusal of certain interventions and hence limitations on medical treatment (non-escalation decisions regarding health care and interventions) may result out of an advance care planning discussion and are subsequently documented on an ACP, however, they may be written in language that is difficult to interpret in a specific medical situation.

Advance care directives (ACD) may also result from an advance care planning discussion. An advance care directive is the legally recognised form of an advance care plan^[19]. There are two types of advance care directives – common law and statutory^[20]. Common Law ACDs are recognised by the common law i.e., decision made by judges. Common Law ACDs do not follow a particular format and there are no formal requirements other than being made voluntarily by a person with decision making capacity. ACPs created by a person with decision-making capacity can be interpreted as a common law ACD. Although common law ACDs are considered legally binding, this has only been tested under the common law in New South Wales (NSW). In 2009, the NSW Supreme Court ruled that common law directives are valid ways for people to indicate their objection to particular treatments^[21]. Statutory ACDs are ACDs created under state-based legislation. Statutory ACDs follow a particular format and criteria (e.g., witnesses, wording etc.) set out by legislation, and are also titled differently depending on the jurisdiction (e.g., Advance Care Directive, Advance Health Directive, Advance Personal Plan, Health Direction). Legislation determines which instructions in a statutory ACD are legally binding particularly regarding consent for or refusal of particular interventions. For both common law and statutory ACDs, a person must have decision making capacity when they create the ACD and the ACD only becomes valid and legally binding once the person loses decision-making capacity. Legal recognition of common law and statutory ACDs differ by jurisdiction. Australian states and territories may recognise one or both types of ACDs^[22]. Common Law ACDs are recognised in all states and territories except for Queensland. In Victoria, common law ACDs are only legally binding if they refuse treatment. Statutory ACDs are recognised in all states and territories except for New South Wales and Tasmania.^[20] In New Zealand, ACDs are known as Advance Directives and are a common law ACD. An Advance Directive is considered legally binding if it is valid^[23, 24].

3.1.3 Goals of Care (GOC) Framework, Limitations on Medical Treatment (LOMT), and Clinical Directive Forms

Limitations on medical treatment (LOMT) are non-escalation decisions regarding health care or interventions^[25,26]. They are usually reached pro-actively and may be recorded on advance care plans or directives (see above) or by a Goals of Care (GOC) Framework. A GOC Framework is an illness phase categorisation system to guide escalation or non-escalation of medical treatment and communicates this within a health system^[27]. GOC are based on whether a person is in a curative/restorative, palliative or terminal phase. Patients in the curative/restorative phase have a probably indefinite (normal) life expectancy and care is directed towards cure, prolonged disease remission or restoration to pre-episode health status. Patients in the palliative phase are living with disease that is deemed incurable and progressive and death is anticipated, although the time frame may be years, or shorter (weeks to months). Care is directed towards symptom control/prevention and quality of life with life prolongation being a secondary objective. Patients in the terminal phase are actively dying with imminent death expected within hours to days. Care is directed towards comfort, dignity and preparation for a good death.

Establishing goals of care (GOC) relies on high-quality clinical assessment to identify patients at the end of life and to differentiate patients in the terminal phase (see below).

Good communication skills are vital to sensitively, directly and clearly raise dying, prognosis and outcome with patients, their families and substitute decision-makers. GOC provides the basis of medical orders or clinical directives regarding medical treatment or interventions. The purpose is to ensure that patients who are unlikely to benefit from specific medical treatment are not subjected to burdensome or non-beneficial interventions, particularly if it is contrary to their wishes.

Clinical Directive Forms document the establishment of GOC during hospital admission and escalation or non-escalation (limitations) of medical treatment. These are local health system or hospital documents that are primarily a clinical tool to aide clinicians in difficult decisions for patients they may not know e.g., by resuscitation teams or in the after-hours period. Names vary depending on local policy and include Goals of Care forms, Resuscitation Plans etc. Previously, “Not for Resuscitation (NFR)” forms were the predominant type of clinical directive form, however this simple, binary order style has been superseded by clinical directive forms based on GOC frameworks. Clinical directive forms and goals of care frameworks are distinct from advance care directives (see above) which are patient driven legal documents. However, ACDs, may form the basis of GOC and medical treatment decisions recorded on clinical directive forms with consequent medicolegal implications that vary by jurisdiction. Clinical directive forms also enable translation of refusal of treatment decisions documented on ACPs and ACDs into non-escalation instructions that can be easily interpreted in a clinical scenario.

3.2 Considerations in the decision-making process

3.2.1 Identifying patients at the End-of-Life

Identifying patients at the end of life is an important skill for all doctors. People at the end-of-life who are offered surgery may suffer due to a fundamental mismatch between the goals of acute care and the delivery of safe and high-quality end of life care^[28]. Frameworks to assist doctors in identifying patients approaching end of life include the Why Framework^[29], Te Ara Whakapiri Toolkit^[30], Proactive Identification Guidance (PIG)^[31] and the Supportive and Palliative Care Indicators Tool (SPICT)^[32]. A working understanding of illness trajectories and phases at the end of life assists with decision making for patients considered for surgery as it enables doctors to understand the expected course of any patient’s deterioration with and without surgery^[25]. Relevant illness trajectories are short periods of evident decline, long-term limitations with intermittent episodes and prolonged dwindling^[1, 33]. A goals of care framework (see above) is based on curative/restorative, palliative and terminal phases^[27]. Within palliative phases, there are stable (no change in symptoms), unstable (unanticipated or new symptoms) and deteriorating (anticipated worsening of symptoms) phases as well as the terminal phase (imminent death)^[34, 35]. It is particularly critical to differentiate patients who have entered the terminal phase^[25,26], as it is inappropriate to offer surgery for these patients. Although frameworks, illness trajectories and phases were developed for patients under specialist palliative care, all are applicable for patients approaching end of life even if they are not in specialist palliative care. In general, the frameworks provide doctors with questions to identify the illness trajectory and phase which can be used together to provide a longitudinal and cross-sectional assessment of any patient’s presentation at end-of-life.

3.2.2 Intention of surgery and patient-centred outcomes.

Once a patient is identified as at the end of life, balancing the intention and anticipated outcome of surgery against patient-centred outcomes is crucial when contemplating surgery. Doctors may be concerned about proceeding with surgery in patients approaching the end of life due to concerns regarding futility^[3, 9]. Futility is challenging to define in the

medical literature but futile treatment is broadly conceptualised as treatment that cannot achieve the intended goal^[10, 36]. Treatment may have relative futility (*unlikely* to achieve the intended goal) or absolute futility (*definitely* will not achieve the intended goal)^[36]. Futility is a clinical concept (not an ethical or legal one)^[36] and balances the intended benefit of surgery (surgical intention) against the potential benefit to the patient (patient-centred outcome). The intention of surgery can be classified as diagnostic/prognostic, preventative, curative/restorative and palliative/symptom-relieving. Patient centred outcomes are focused on patient stated values and goals, which should direct what care any patient ultimately receives. Meaningful patient centred outcomes following surgery include survival, satisfaction, functional status, well-being, health related quality of life and preparation for a good death.^[23] Surgery that aligns the intended benefit of surgery and the patient-centred outcome is deemed beneficial and non-futile^[10] and the realistic potential to align these two benefits should be explored and explained clearly in a shared-care decision-making process. In clinical practice, non-beneficial treatment (instead of futile treatment) is the preferred terminology in discussion with patients, their families and substitute decision-makers^[19].

3.2.3 Shared-care decision-making (SDM).

In an increasingly complex medical system, the concept of shared-care decision making (SDM), either with the patient or the substitute decision maker is increasingly important so that the patient's stated goals and values can direct what medical care they ultimately will receive. Communication skills training and experience are key as it is important to sensitively, directly and clearly, raise death and dying, risk and prognostic issues.^[2] The Kings Fund document from 2011 titled "Making Shared Decision Making a Reality – No decision about me, without me", defined shared decision making as a process in which 'clinicians and patients work together to select treatments based on clinical evidence and patient's informed preferences'^[37]. The components of SDM include provision of evidence-based information about options, exploring patient-centred outcomes, and explaining procedural risk together with decision support counselling and a system for recording and implementing patient informed preferences. Discussion of "best-case/worst-case scenarios" emphasises the potential patient-centred outcomes instead of procedural risk to allow patients and their substitute decision makers to better understand the decision to proceed with surgery with respect to their preferred outcomes and values. This decision support intervention helps to facilitate difficult decision-making for patients at the end of life considering surgery or other invasive, acute medical treatments^[38].

3.2.4 Cultural safety

The needs of New Zealand Māori, Australian Aboriginal and Torres Strait Islander peoples who are approaching end of life are similar to non-Indigenous people regarding holistic person-centred care and clear and respectful communication^[39, 40]. However, Indigenous people in both New Zealand and Australia have a disproportionately high burden of chronic disease, higher mortality rates and lower life expectancy than non-Indigenous populations^[41-43], and therefore, are more likely to be approaching end-of-life at an earlier age. Key preferences identified in Indigenous populations at end-of-life are family and community involvement, dying at home, ensuring their own wishes are known, reconnection with land, provision of cultural and spiritual ceremonies within service settings and availability of Indigenous staff^[39, 44]. Te Whare Tapa Whā represents a Māori holistic model of health with 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 health) and te taha wairua (spiritual health)^[40]. This can provide a framework for discussing patient centred outcomes following surgery in patients approaching end of life. Being mindful of communication styles (particularly unspoken communication),

spokespersons within families and collective societies, and terminology about death and dying are cultural considerations for Australian Aboriginal and Torres Strait Islander peoples^[45]. When considering surgery in Māori, Aboriginal and Torres Strait Islander people who are approaching end of life, it is vital to understand cultural perspectives of health and the end of life, and these key preferences during shared decision-making discussion in order to determine if patient centred outcomes can be achieved following surgery^[40, 45, 46].

3.2.5 Mitigating Clinical Momentum

Clinical momentum describes a system-level, latent property of clinical care that may contribute to the provision of unwanted care^[11]. Described originally for care in the ICU, it describes the automatic offer of a cascade of increasingly invasive interventions without critical evaluation of the benefit of interventions or the consideration of alternative actions. Patients at the end of life are at risk of clinical momentum when offered surgery due to concepts related to surgical buy in^[47, 48] (the assumption that a patient has consented to all post-operative care when consenting for surgery) and treatment escalation if iatrogenic complications occur^[12, 13]. Clinical momentum can be mitigated through shared-care decision making discussions and an alignment between surgical intention and patient centred outcomes. If surgery proceeds, the pro-active implementation of goals of care and limitations on medical treatment to guide post-operative disposition and care provides further barriers to clinical momentum and the implementation of non-beneficial treatment^[14].

3.2.6 Perioperative management of pre-existing Limitations on Medical Treatment.

Management of pre-existing limitations on medical treatment in the perioperative period is required once any decision has been made to proceed with surgery. Limitations on medical treatment (LOMT) may be expressed on a clinical directive form (e.g. Goals of Care Form, Resuscitation Plan) or a legal document i.e., Advance Care Directive. There is general uncertainty amongst anaesthetists around Australia and New Zealand regarding LOMT in the perioperative period with 75% relating their knowledge of advance care directives (ACD) or similar LOMTs as moderate, low or very low and 62% agreed or strongly agreed that there is inadequate training regarding NFR orders and ACDs in the perioperative period^[12].

General strategies for managing LOMT in the perioperative period are suspension, modification or continuation^[49, 50]. Suspension is when LOMT are withdrawn and full resuscitative measures are reinstated in the perioperative period. Although, 37% of Australian and New Zealand anaesthetists responded that operating room staff should always initiate CPR for any arrest in theatre or post-anaesthesia care unit^[12], automatic and unilateral suspension of LOMT in the perioperative period is no longer ethically supported or medicolegally tolerated^[10, 15, 50]. Modification is when specific LOMT are changed to permit the use of medications, techniques or resuscitative measures during the perioperative period. Modification of LOMT may be techniques-based^[49, 50] or values-based^[50]. Techniques based modification allows for routine interventions that are required to administer safe anaesthesia and surgery (e.g., intubation, mechanical ventilation and invasive monitoring) but may prohibit resuscitative measures (e.g., chest compressions and defibrillation). In contrast, values-based modification is when clinical judgement is used to determine which interventions are appropriate in the context of the patient's values and preferred outcomes. Continuation is when LOMT are maintained throughout the perioperative period. This approach is dependent on the LOMT instituted and the anaesthetic and surgical options available.

The final management strategy for pre-existing LOMT in the perioperative period relies on an understanding of the intended benefit of surgery, the preferred patient-centred outcomes, the advantages and disadvantages of suspension, modification, and continuation of LOMT, as well as an assessment of patient decision-making capacity and an understanding of the medicolegal implications of advance care directives in each jurisdiction. Meticulous documentation is required, once a decision has been made.^[10]

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