



# Futile Surgery in NSW

## Lessons from SCIDUA 2010 - 2020

*“Just because we can, it doesn’t mean we should.”*  
**A conversation about non-beneficial procedures**



CLINICAL  
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COMMISSION

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## Foreword

Each year nearly 50% of people who die in NSW do so in acute care facilities. This places doctors and clinicians in the vital role of assisting the community to deal with the reality of death and its consequences, as acknowledged in *Good Medical Practice: A code of conduct for doctors in Australia*<sup>1</sup>.

Yet many hospital incident reports highlight the treating teams' failure to identify patients at risk of dying, and to then develop and document appropriate treatment plans and communicate appropriately with patients and carers.

End-of-life is a part of the human experience that everyone will face. End-of-life is the length of time a person lives with, or is affected or impacted by, a life-limiting condition, even if the prognosis is ambiguous or unknown. This will be different for each person and uncertainty is almost always present.

Clinical decision-making under conditions of uncertainty is influenced by many things including the human tendency to be 'risk seeking' when faced with sure loss. However, in caring for patients towards the end of their life, good medical practice involves:

- Understanding the limits of medicine in prolonging life and recognising when efforts to prolong life may not benefit the patient.
- Understanding that you do not have a duty to try to prolong life at all costs. You have a duty to know when not to initiate and when to cease attempts at prolonging life, while ensuring that your patients receive appropriate relief from distress.
- Accepting that patients have the right to refuse medical treatment or to request the withdrawal of treatment already started.
- Striving to communicate effectively with patients and their families so they understand the outcomes that can and cannot be achieved.
- Communicating bad news to patients and their families in the most appropriate way and providing support for them while they deal with this information.
- Taking reasonable steps to ensure that support is provided to patients and their families, even when it is not possible to deliver the outcome they seek.
- Encouraging advance care planning and facilitating the appropriate documentation, such as an Advance Care Directive (ACD), or similar.
- Respecting different cultural practices related to death and dying.

I hope the four fictitious case examples in this publication encourage meaningful conversations between clinicians and the patients and families they care for and, at an individual clinician level, that it encourages your own reflective behaviour of thinking clearly, honestly, deeply, and critically about your professional practice. In doing so, you will generate a direct positive impact on the quality of care for patients in NSW.

**Adjunct Professor Michael C. Nicholl**  
Chief Executive, Clinical Excellence Commission

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<sup>1</sup> Good medical practice: a code of conduct for doctors in Australia – Medical Board, APHRA, October 2020.

## Introduction

Modern medicine is wonderful. Technological advances give us the ability to offer almost infinite physiological support with increasingly specialised therapies on patients with incredibly complex medical diagnoses. At the core of this is our medical education, which embeds how we practice, through history and examination, investigations, and disease management.

With increasing sub-specialisation of the medical workforce, doctors are able to offer a range of interventions in order to treat a specific diagnosis, often guided by evidence supporting how a treatment works in a population of patients. When looking at an individual patient we need to consider this population-based evidence together with the clinical context, and what the individual patient considers to be important. This may mean that specific population outcome benefits may not be appropriate for an individual patient.

This becomes difficult as management, as taught to doctors in training, is always centred around how best to treat a disease that has been diagnosed. There needs to be a paradigm shift for doctors to acknowledge that occasionally treating a diagnosis should not be offered, rather, alternative treatments should be offered to a patient to support their individual goals.

This booklet does not aim to dictate the management that we should offer our patients but offers a reflection that individual patients have different life beliefs, life experiences and circumstances; such that, treatments we would consider best management for many patients, may not be the best treatment option for that individual patient.

This situation is difficult emotionally for both the health care provider, the patient, and their family. It is time consuming (particularly in an overstretched busy clinical setting) to have a difficult conversation needed to forego a treatment, even when it is in the best interests of the patient (to forego it). It is much easier, and quicker, to offer a treatment - no matter how small the chance of success - while making us feel that we have done all we can.

Behavioural psychologists would consider this an example of a basic human instinct of 'loss aversion', where we risk much more for a potential gain rather than risk a loss - the pain of losing a small amount is much greater than the positive emotion resulting from an equivalent gain, so we do anything possible to avoid that loss rather than aim for a gain.

It takes humility and maturity to understand that the extensive knowledge and skills we have developed through years of training cannot fix a problem; to the extent that some patients are better treated through palliative and comfort care principles rather than curative strategies.

Although we are incredibly lucky to live in an exceedingly advanced and resourced health environment, there are costs associated with everything we offer. While there is no cost that can be put on a human life, the cost of aggressive treatment at end-of-life, particularly if the quality of life post-treatment is not what the patient expected, should be considered. As resource constraints continue to increase in the health system, these factors should become part of the decision-making process in consultation with the patient and family.

The Special Committee Investigating Deaths Under Anaesthesia (SCIDUA) is an expert committee appointed by the Secretary, NSW Health, under delegation by the Minister. Its Terms of Reference are to peer review all deaths occurring while under, as a result of, or within 24 hours, after the administration of anaesthesia or sedation<sup>2</sup> so as to identify any areas of clinical management where alternative methods could have led to a more favourable result.

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<sup>2</sup> These reporting parameters are stated in section 84 of the *Public Health Act 2010*.

This booklet was produced in response to an increase in cases classified as futile by SCIDUA (Chapter 1) leading to patient deaths in NSW hospitals. It will look at fictitious cases which are loosely based on the kinds of clinical issues reported to SCIDUA, or from within the NSW Health system. Although, the cases aren't true patient experiences they aim to outline issues and principles related to perioperative decision-making, with commentary provided by senior clinicians. We will then aim to outline the important principles involved and lessons learned.

Hopefully this booklet will stimulate clinicians to start a conversation about difficult decision-making regarding invasive procedures in complex patient populations.

**Dr Benjamin Olesnicky**

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## Chapter 1 - Deaths reported to SCIDUA and classified as futile

In NSW, all deaths reported to SCIDUA for investigation are classified by a panel of experienced consultant anaesthetists from a variety of backgrounds (public, private, rural, and metropolitan). Part of the classification process involves a determination of whether the surgery performed is in circumstances in which *it is clear before commencement of surgery that the chance of a successful outcome is negligible or non-existent*. For these cases a *futile* suffix is assigned to the classification where the consensus opinion of the expert panel (committee) is that the surgery was non-beneficial in the clinical context.

Figure 1 below, shows the number of cases classified as futile by the SCIDUA committee between 1 January 2010 and 31 December 2020. There was a total of 87 cases classified as futile in the decade to 2020. Both the total number and percentage of total cases reported to SCIDUA has increased over the last decade, with a trend showing an approximate doubling of cases reported over this time.

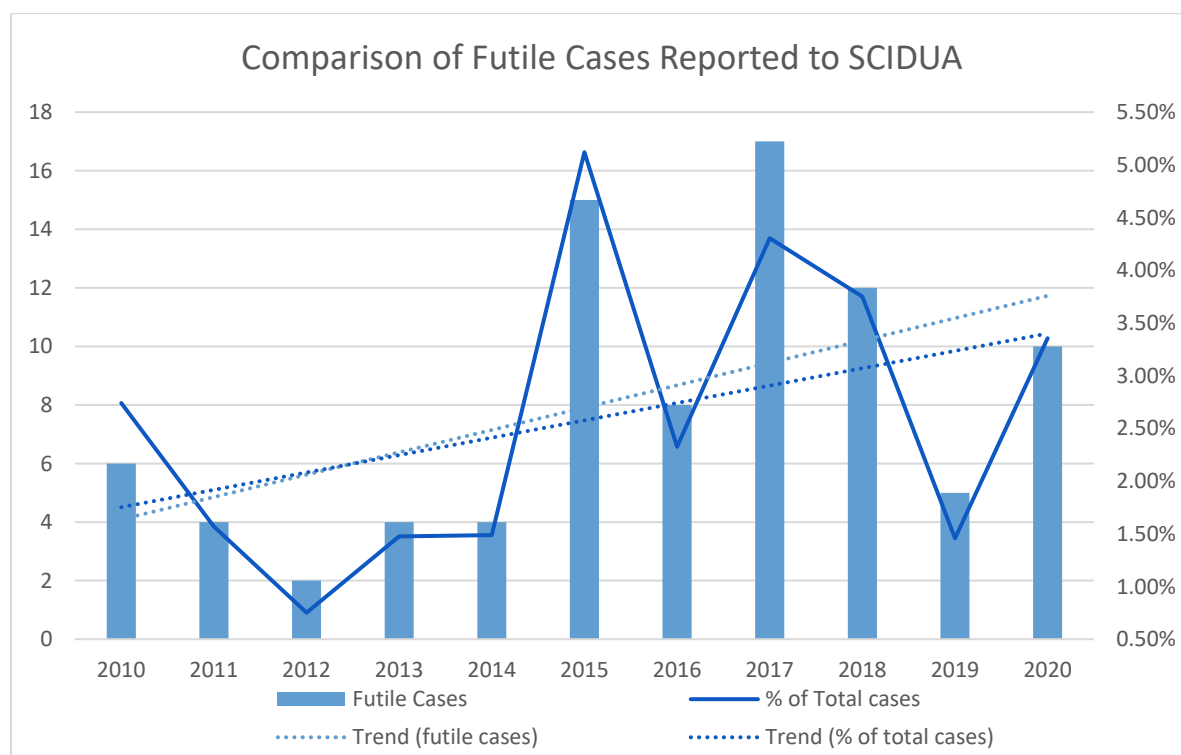


Figure 1: Cases classified as futile and total cases reported to SCIDUA (2010-2020).

Table 1 below, shows the surgical specialty involved with cases classified as futile. From this table we can see that, while General Surgery (abdominal) is the largest single contributor (n=24), procedural specialties (Cardiology, Endoscopy and Radiology) combined, account for almost one third (n=24) of futile cases.

<b>Surgical Specialty</b>	<b>No. of futile cases 2010-2020</b>
<b>General Surgery (abdominal)</b>	24
<b>Vascular</b>	14
<b>Procedural - Endoscopy</b>	12
<b>Orthopaedic</b>	10
<b>Procedural - Cardiology</b>	10
<b>Cardiothoracic</b>	7
<b>Neurosurgery</b>	3
<b>Urology</b>	2
<b>Procedural - Radiology</b>	2
<b>Multi-Trauma</b>	1
<b>Obstetric</b>	1
<b>General Surgery (non-abdominal)</b>	1
<b>Total Cases</b>	<b>87</b>

**Table 1: Number of futile cases according to surgical specialty (2010-2020).**



Table 2 below, outlines patient and surgical factors involved in cases that were classified as futile by the SCIDUA committee for the period 1 January 2010 – 31 December 2020.

Characteristic	Number of Cases
<b>Anaesthetic Type*</b>	
General Anaesthesia	69
Sedation	14
Regional Anaesthesia	8
Local Anaesthesia	2
<b>Surgery Classification</b>	
Emergency	60
Urgent Non-Emergency	20
Scheduled	7
<b>ASA Status</b>	
ASA1	0
ASA2	0
ASA3	1
ASA4	41
ASA5	44
<b>Sex</b>	
Male	47
Female	40
<b>Age (Mean +/- SD)</b>	76.7 +/- 13.2 years

**Table 2 – Characteristics of cases classified as futile by SCIDUA (2010-2020).**

*\*Total frequency count >87 cases as some cases had a combination of >1 anaesthetic type.*

## Chapter 2 – Practice in Futility – Case Studies and Commentary

The following case examples aim to outline some of the principles in assessment and management of complex patients undergoing surgery. Several senior consultants were asked for their opinions and a summary of these are presented.

**Dr Linda Sheahan** is the Clinical Stream Director, Palliative and End-of-Life care, and is a Clinical Ethics Consultant, and Lead for the SESLHD Clinical Ethics Support Service. She has fellowship in Clinical and Organisational Ethics with the Joint Centre for Bioethics in Toronto and holds academic appointments with Sydney Health Ethics at the University of Sydney and UNSW Medical School. She is a Fellow of the Royal Australian College of Physicians (RACP) and the Australian Chapter of Palliative Medicine. She also works clinically as a palliative Care Physician in the consult service at the St George Hospital Cancer Care Centre.



**Dr Michelle Mulligan OAM** is a Specialist Anaesthetist at Royal North Shore Hospital and in the private sector. She has previously acted as the Clinical Director of the Division of Surgery and Anaesthetics and chairs the Surgery and Anaesthetic Clinical Network. Her qualifications include an MBA, Fellowship of the Australian Institute of Company Directors, and Associate Fellowship of the Royal Australasian College of Medical Administrators (RACMA). Michelle has served on several Boards including the Australian Medical Council, Australian and New Zealand College of Anaesthetists (ANZCA) and is a member of the Northern Sydney Local Health District Board.



**Dr Raymond Raper AM** is the past Head of the Intensive Care Unit of Royal North Shore Hospital and past President of the College of Intensive Care Medicine of Australia and New Zealand (CICM).

He has a long association with the Royal Australasian College of Physicians - chairing the Joint Specialty Advisory Committee in Intensive Care for several years. He served on the Executive of ANZICS (NSW), is a Foundation Fellow of the Joint Faculty of Intensive Care Medicine, and an inaugural member of their Board.

Dr Raper has a long-standing interest in the ethical aspects of medical practice. He has a BA from Macquarie University majoring in social philosophy, and has participated on numerous Hospital, College, Department of Health and AHEC initiatives in this arena.



**Mr Robert Samut** is a Principal at Barry Nilsson Lawyers and heads the firm's national Health Law practice. He works with large hospital groups, insurers, and large corporates in the defence of medico-legal and other claims, regulatory and disciplinary proceedings, and in providing general and risk management advice.

Heading the national health team, Mr Samut acts in large litigation and disputes for public and private hospitals, doctors, and allied health care workers. He is also involved in providing advice in non-contentious matters, and acts for insurers, self-insureds, government agencies, underwriters, and brokers.

Mr Samut has an excellent understanding of the operations of large hospitals, including the management of public health claims, and has achieved outstanding outcomes in highly publicised matters.



## Collaborating Hospitals' Audit of Surgical Mortality

The Collaborating Hospitals' Audit of Surgical Mortality (CHASM) audits patient deaths which occur within 30 days under the care of a surgeon at some time during their hospital stay, regardless of whether an operation was performed. Several members were approached to provide their opinion on the case relative to their speciality.

- **Case 1 - Dr Robert Costa (MBBS, FRACS)** is a Cardiothoracic Surgeon based at Westmead Hospital.
- **Case 2 - Dr Kate Gibson (MBBS, FRACS, BSc Microbiology, MSc)** is a General Surgeon (Colorectal) based at Liverpool Hospital.
- **Case 3 - Associate Professor Brett Courtenay OAM (MBBS, FRACS)** is an Orthopaedic Surgeon based at St Vincent's Private Hospital.
- **Case 4\* - Dr Rodney Allan (BSc, MBBS, FRACS)** is a Neurosurgeon and Endovascular Neurosurgeon based at the Chris O'Brien Lifehouse, at the Royal Prince Alfred Hospital.

\*This case is an example of an interventional neuroradiology (INR) procedure. INR is a subspecialty of clinical radiology which involves using medical imaging tests in diagnosing and treating disease of the central nervous system, head, neck, and spine<sup>3</sup>. Treatment is generally minimally invasive and should avoid the need for traditional surgery, lowering the risk to patients and reducing recovery time.

## Hierarchy for Persons Responsible

In NSW, the *Guardianship Act 1987* defines a 'person in need of a guardian' as meaning, a person who, because of disability, is totally or partially incapable of managing his or her person. There is a hierarchy of persons from whom the 'person responsible'<sup>4</sup> for another person (other than a child) is to be ascertained. It is, in descending order:

1. A guardian or enduring guardian (if any), legally appointed to provide consent<sup>5</sup> for minor or major medical or dental treatment on the person.
2. The spouse (if any), with whom the patient has a close and continuing relationship.  
*[In this instance, 'spouse' means the person to whom a person is legally married (including the husband or wife of a person), or a de facto partner i.e., a relationship as a couple living together; but where more than one person would so qualify as a spouse, it means only the last person so to qualify.]*
3. The person's carer - This is a person who provides ongoing, regular care (such as domestic services and support) - and is not a paid care worker or volunteer.  
*[A person residing in an institution (such as a hospital, nursing home, group home, boarding-house or hostel), is to be regarded as remaining in the care of the person who was immediately providing care for them before residing in the institution.]*
4. A close friend or relative of the person, who maintains both a close personal relationship and a personal interest in the other person's welfare. (This person should not be receiving remuneration for, or have a financial interest in, any services they perform for the person in relation to their care).

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<sup>3</sup> Neuroradiology

<https://www.insideradiology.com.au/neuroradiology/#:~:text=Neuroradiology%20is%20a%20subspecialty%20of,%20range%20of%20neuroimaging%20techniques.>

<sup>4</sup> *Guardianship Act 1987* - Part 5, Division 1, Section 33A, Person responsible.

<sup>5</sup> *Guardianship Act 1987* - Division 2, Section 36, Who may give consent.

## Substitute Decision-making

In situations where medical treatment is required for a patient - when they are confused, or lack decision-making capabilities regarding the decision at hand, and where they have no ACD in place concerning their wishes or preferences - medical practitioners rely on *substitute decision-makers*. These are persons who are able to bring the patient's voice to the table. Who that is, is context dependent. At the very least, the 'person responsible' should be involved in the consent<sup>6</sup> process for the medical treatment to be conducted on the patient.

Consent can be given by the medical practitioner (or dentist) carrying out, or supervising, the treatment on a patient if the treatment is considered necessary, as a matter of urgency to save the patient's life, or to prevent serious damage to the patient's health.

In some instances (except in the case of special treatment), consent may be given by the medical practitioner for treatment to prevent the patient from suffering or continuing to suffer significant pain or distress.

Some minor treatments may be carried out on a patient without consent given if there is no person responsible for the patient, or that person cannot be contacted, or they are unable or unwilling to make a decision concerning the treatment of the patient.

It is important to note that, the medical practitioner providing the treatment is required to certify in writing in the patient's clinical record that: *the treatment is necessary and is the form of treatment that will most successfully promote the patient's health and well-being, and the patient does not object to the carrying out of the treatment.*

However, under the Act, any person may apply to the Tribunal (NCAT) for consent to carry out a medical or dental treatment on a patient. Whenever such an application is made for consent, the treatment cannot be carried out without that consent, and not until the Tribunal has determined the application, and is satisfied that the treatment is the most appropriate form of treatment for promoting and maintaining the patient's health and well-being.

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<sup>6</sup> *Guardianship Act 1987* - Division 3, Section 40, Consents given by persons responsible for patients.

## Case Example 1 – Cardiothoracic Surgery

An 87 year old man was booked for insertion of a permanent pacemaker. He had presented to the hospital earlier that day following a syncopal event and was found to be in complete heart block. He had a temporary pacing wire inserted while in the emergency department and had been confused since his admission receiving a diagnosis of *delirium of unknown cause*.

He had a background of Ischaemic Heart Disease with previous coronary bypass surgery and mitral valve replacement 15 years earlier (now unremarkable echocardiogram and symptom free), severe bronchiectasis, with 'occasional' home O<sub>2</sub> when unwell, and chronic mucous plugging with left lower lobe collapse on a chest X-ray. He was living at home with his wife and was recently assessed for higher level care to support his daily living activities.

There was no documented Advance Care Directive (ACD) for the patient, and this was not previously discussed with his wife.

On examination, the patient was frail, had difficulty breathing and clearing secretions and was obviously confused. He was deemed unsuitable for a procedure under local anaesthesia due to confusion and recurrent coughing.

He had a general anaesthetic (laryngeal mask airway [LMA] with pressure supported ventilation). His intraoperative course was uneventful, and at the end of the procedure the LMA was removed. He had immediate airway obstruction, with rapid deterioration. He was increasingly agitated and dependant on assisted manual bag/mask ventilation to maintain oxygenation >90%. High flow nasal prong oxygen support was attempted but failed due to airway obstruction.

The options at that stage were considered to be:

1. Intubate and transfer to ICU
2. Continue with other forms of non-invasive ventilation in a ward environment
3. Palliation / Palliative care

After discussions with the recovery nursing staff, the admitting cardiologist, anaesthetist on duty, respiratory physician, ICU consultant, social worker, priest and patient's wife and son, he was transferred to a single room in the recovery unit and palliated with fentanyl and midazolam. He rapidly deteriorated over the next 30 minutes and passed away.

### Considerations and Comments

- *This was a potentially "small" operation in an acutely unwell patient to treat a potentially reversible condition.*
- *What factors are important to consider when proceeding with this operation?*
- *Does the ability to do a procedure under local anaesthetic make a difference in the decision?*
- *Who is important in determining the need to proceed to an operation in a confused patient (treating team, family, general practitioner, guardianship)?*
- *Where should patients be palliated in a hospital environment? Is a recovery unit appropriate?*

## Raymond Raper

This elderly man underwent a procedure that was potentially inappropriate. It can only truly be classified as futile if: (a) the procedure could not achieve permanent cardiac pacing (as was not the case); (b) there was reasonable certainty that the man could not survive the procedure; or (c) there was a reasonable knowledge that the patient would not have consented to the procedure, (if he was able to do so). If any of these possibilities were options, then I would contend that the procedure was medically negligent or even a form of (involuntary and expensive) euthanasia. It is possible that, as for early fixation of fractures, the urgent procedure offered the patient the best opportunity for at least short-term survival. Certainly, without the benefit of a crystal ball, the appropriateness of the procedure cannot be judged simply on the basis of the outcome.

So, what might have been the reasonable pre-operative considerations, given that this was potentially inappropriate surgery? As for all such cases, this discussion should be founded in the potential burdens and benefits of the procedure in the circumstances, the alternatives and the known or projected values and wishes of the patient. Neither the acute delirium nor the absence of an ACD provides grounds for dismissing any consideration of the patient's values - to the extent that these can be ascertained from those with personal knowledge of the patient, such as the next of kin and other involved medical personnel.

It is clear the patient was facing imminent nursing home placement even before the current crisis. When specifically asked, the majority of elderly citizens express the conviction that they would rather die than be managed in a nursing home. If there was any information available that this value may have been shared by the patient, then surgery would have been, at least, relatively contraindicated. If there was no such suggestion, then an alternative pathway could have been considered, particularly given the significant risk associated with general anaesthesia in a patient with impending respiratory failure.

The immediate risk to the patient was averted by the placement of the temporary pacing wire. If appropriately placed and secured, this could have continued for some days to potentially allow the delirium to clear and respiratory function to be optimised. Such a course may have allowed the patient to make his own decision on surgery and may have enabled the safer conduct of the procedure by optimising respiratory function.

The issue around the type of anaesthesia is only relevant to the extent that it highlights the severity of the patient's comorbidities. General anaesthesia is likely to have a more significant acute impact on respiratory function, especially if an LMA is utilised to provide un-humidified ventilation. The real issue here is the red flag for potentially inappropriate surgery that the anaesthetic decision presages.

The rationale for the terminal management (palliation) of the patient is not provided, but it presumably depends on many of the considerations that should have been discussed before the procedure. As respiratory failure was certainly a possible outcome, the decision-makers should have considered this beforehand. The decision likely entailed a consideration of patient burden versus benefit and (likely) the probable consideration of the patient's projected values - as in *he wouldn't have wanted this, especially if he will end up in a nursing home*. This consideration is valid but no more so than before the procedure was undertaken.

Finally, the patient was transferred to the recovery unit, provided some terminal sedation and analgesia, and was allowed to die without further intervention. This is not an ideal site for terminal management but may have been the only real option given the time course and the circumstances. It was closely proximate to the doctors most intimately involved in the terminal decision-making and enabled some continuity of care - although managing a dying patient is generally outside of the usual scope of practice of the recovery staff. However, the recovery unit is geographically isolated from those essentially involved in the management of a dying patient - such as social workers.

The use of the adjective “palliation” in this context is, unfortunately, becoming more common. This is not an accurate term and does a disservice to the complexity involved in true palliative care. It is far better to say that the patient was allowed to die with comfort and dignity.

## Michelle Mulligan

It is important for clinical teams to recognise this patient is frail and therefore at increased risk for any procedure, including those performed under local anaesthetic.

Given this man’s frailty, severe bronchiectasis, confusion and deterioration over the recent period, a discussion should have proceeded with his wife prior to the procedure. The conversation should be sensitive, directly, and clearly raising the prospect of death, the risk of dying and the prognostic issues. A range of potential outcomes and the approach to their management should also be discussed and the possibility of iatrogenic complications. A plan for respiratory failure perioperatively should be made in advance of the procedure.

The recovery unit is a busy and disruptive clinical area and, even if a private room can be found, it is not an ideal place to provide palliative care for a patient, especially for the family and carers. Palliative care is not a core competency of recovery staff, and the situation is likely to be difficult for them as well.

## Linda Sheahan

As always, when making decisions in clinical practice, the following considerations are of central importance:

- Who is this person (the patient), and what are their goals and values? What is important to them?
- Does the proposed intervention align with these goals, and are they likely to be achieved in this context?
- What are the potential burdens and harms of the intervention, and are these proportional to the expected benefits?

In light of the above, and in discussion with the patient, (and/or their substitute decision-makers where appropriate or required), is it believed that proceeding with this intervention is in the person’s best interests overall? In the case example given here, there are factors of specific relevance to consider, including:

- The proposed procedure has specific palliative and quality of life goals and outcomes, so even where the patient has non-curative priorities, pacing may be indicated.
- Given the patient’s frailty and comorbidities, consideration should pre-emptively be given to the appropriate ceilings of care prior to progressing with the surgery. It is important that the deliberations over proportionality take into account the potential complications and anticipates appropriate responses, so that thresholds of acceptable burden don’t inadvertently blow-out in the acute context.
- Broad consultation with relevant stakeholders and experts allows for both shared, and consensus, iterative decision-making when difficult clinical calls need to be made (e.g., a decision to take a comfort-only approach to the patient’s deterioration). This is the gold standard ethically, which shares the burden of decision-making, and goes some of the way to preventing conflict or complicated bereavement.



From the ethics perspective, the ability to perform a procedure under local anaesthesia lessens the burdens and potential harms of the procedure, and thus effects the assessment of proportionality.

Looking through the ethics lens, the gold standard for determining whether an operation is in the best interests of a specific patient is a shared decision-making process. We bring our general clinical expertise and experience about the procedure and the likely outcomes to the table, and the patient brings their expertise about themselves and what's important to them, and together we come to a decision about best interests in the specific context.

However, where a patient is confused, or lacking capacity for decision-making regarding the decision at hand, and they have not left any ACD as to their wishes and preferences, we rely on substitute decision-making – that is to say, we rely on others to bring the patient's voice to the table. Who that is, is context dependant. At the very least, the 'person responsible' for consenting to the operation under law should be involved in the discussion.

A recovery unit is not ideal for palliation of a patient, but this may occasionally happen in the context of hospital practicalities. Key considerations include: (a) access and room for families and loved ones to be by the bedside; (b) privacy; (c) quiet space; and (d) attention to the non-medicalised aspects of personhood and humanity – as much as this can be achieved in a hospital setting. Consultation with the hospital palliative care service may expedite and facilitate these goals in a time critical context. Access to psychosocial support and referral for bereavement support is essential.

## *Robert Costa*

From a surgical viewpoint, the other option for clinical management would be to transfer the patient to an HDU/ICU setting to manage the delirium and rely on the temporary pacing wire to maintain cardiac rate. If the patient improved, the pacemaker could then proceed along standard lines, with a potentially more beneficial outcome.

## Case Example 2 - General Surgery

A 70 year old female patient was transferred to a major tertiary hospital from an urban community hospital emergency department at 2:30am. Diagnosis was of acute haemorrhage into a metastatic liver lesion. Her transfer was accepted by the general surgeons and interventional radiologists, with a view to perform a CT scan, followed by embolisation of the bleeding metastatic lesion.

She had a background of end-stage metastatic colorectal cancer and was recently transitioned to palliative care in the community. The ACD in her medical notes stated that she was “*not for ICU, not for intubation and not for CPR*”.

On arrival, the patient was in severe hypovolaemic shock with severe metabolic acidosis (lactate 14) and progressive multiorgan failure. She was on moderate levels of noradrenaline and vasopressin for cardiovascular support, and high flow nasal oxygen for ventilatory support. She received 4 units of packed cells in the emergency department to treat a blood pressure of 85/50 with little success. She was drowsy, but responsive.

The interventional radiology team were happy to give embolisation a try as a small blush was seen on the abdominal CT. The medical oncologist on-call was contacted, and it was documented in the notes that their opinion was that the embolisation procedure was considered as “treating reversible issues” and therefore should be attempted.

Present in the hospital were the surgical registrar, (in phone contact with a general surgical fellow off-site); the radiology fellow; the anaesthetic fellow; the intensive care senior registrar; and the emergency registrar. A meeting between them was arranged, and at 3am it was decided the patient should be palliated in the intensive care unit, with full support until her family arrived. She rapidly deteriorated on arrival to intensive care and passed away without her family present.

### Considerations and Comments

- *What is the benefit of an advance care directive? Does it help in this situation?*
- *What issues are there when a defined pathway of treatment has already been determined and a patient has been transferred for this treatment?*
- *What other issues are there with transferring end-of-life patients between hospitals overnight for assessment of acute issues?*
- *Is it ethical to provide maximal ICU and cardiorespiratory support to a patient to await the arrival of their family? If so, how long should they be supported? What if their family is overseas?*

## Linda Sheahan

*What is the benefit of an ACD? Does it help in this situation?*

An ACD is a specific type of advance care plan made by a competent patient. ACDs clearly document a patient’s wishes and preferences regarding treatments they would, or would not, consent to in the event they become incapable of decision-making at the necessary time. They empower patients to refuse specific therapies, and if the ACD is valid and relevant to the specific situation, they are legally binding even when the intervention refused is life sustaining. Presuming the ACD is valid in this circumstance, it should have reassured the emergency department clinicians in the urban community hospital that it would be reasonable not to escalate care to intensive care levels, and to consider alternative approaches. Further, once transferred to the tertiary centre, it should have been explicitly respected. This would mean that intensive care admission is inappropriate, as it has been explicitly refused by the patient when they were competent enough to make that decision.

*What issues are there when a defined pathway of treatment has already been determined and a patient has been transferred for this treatment?*

The natural chain of events is to follow through with the planned treatment as the teams and the system have already invested in the decision to proceed down a specific path. From the clinical ethics perspective, decision-making is time sensitive and decision specific – if the situation has changed in any way decision-making should be revisited. Again, we look for the patient's preferences, values, and goals (in this case the ACD helps us significantly). We deliberate over the potential harms and burdens of the proposed intervention, and whether they are proportional to the expected benefits and goals, and we re-assess what 'best interests' looks like to the best of our ability. It may no longer be the best decision to progress down the planned treatment pathway.

*What other issues are there with transferring end-of-life patients between hospitals overnight for assessment of acute issues?*

There are so many, not the least of which is the patient may die during transfer, or on arrival to hospital, which is in no-one's best interests.

Patients approaching end-of-life, who have clearly defined palliative goals, should be assessed based on whether what can be offered in the acute setting is likely to achieve or further those goals. It may be appropriate to transfer the patient to acute facilities for interventions in pursuit of specific palliative goals. However, the decision requires careful evaluation of what we are trying to achieve for the specific person, as guided by what's important to that person as they approach their end-of-life.

*Is it ethical to provide maximal ICU and cardiorespiratory support to a patient to await the arrival of their family? If so, how long should they be supported? What if their family is overseas?*

This is a difficult one ethically, and the answer may be specific to context based on the multitude of substantive variables. So, from the ethics perspective the answer is - maybe; in some circumstances; in very specific contexts; but highly contested. In this specific case, however, the wishes and preferences of the patient were clearly delineated. She explicitly refused ICU level intervention, and this should have been respected.

## *Michelle Mulligan*

Recognising that this patient has transitioned to palliative care in the community and with the availability of an ACD, this should be able to guide the management of the patient. The ACD is an expression of patients' wishes, and in practice it is strengthened if the patient appoints a substitute decision-maker who has a clear understanding of their preferences and is willing to be a strong advocate for them.

Sometimes the issue of recency arises. A more recent ACD may be regarded as more valid because it provides more certainty about its currency and its relation to the current condition. An ACD that considers the current clinical circumstances will reduce doubt.

## Raymond Raper

This is a very sad case that highlights the 'can = must' fallacy, the technological imperative, and it was not without major consequence. The patient was transferred at considerable discomfort and cost (monetary and opportunity), and the principal consequence was that this inevitable death occurred in a 'foreign' ICU without the presence of family. This was undertaken to manage a catastrophic (and terminal) complication of an intractably terminal disease. The 'reverse the reversible' assessment could equally apply to a cardiac arrest and is manifestly ridiculous unless modified by qualifiers like 'easily' or 'simply' in the context of managing symptoms. The (probably inappropriate) transfer for a specific purpose does not justify the subsequent inappropriate decision-making.

The ACD in this case was very useful. It signifies that the patient had some discussion about, and some understanding of, the terminal nature of the underlying disease. It also provides a clear indication that the patient does not value mere survival above all other considerations. It doesn't offer guidance about the specific procedure that was planned, but it surely provides some guidance for the prioritisation of management of profound shock that had already proved recalcitrant to fluid administration, including transfusion.

The issue of keeping the patient alive until the family arrives is somewhat vexed. Even in the absence of a patient's active assent, it is a reasonable assumption that a patient has an interest in the care of their family during and after the dying process. This is highly contextual and is informed by an understanding of the family and of the relationships involved. Other considerations include the patient's comfort and dignity and the actual and opportunity costs of the ongoing management which will depend, in part, on complexity and duration.

The two major ethical concerns are: (1) the use of the patient as the means to the ends of others (the family); and (2) distributive justice. In general, a balance of these considerations could be seen to allow the short-term continuation of even quite major support measures, provided the patient's comfort and dignity can be ensured. Longer continuation of more simple management might be justifiable, but with the same proviso on patient comfort and dignity.

## Kate Gibson

1. Discussion with the patient should have been held at the initial hospital with respect to her wishes re: intervention vs palliation. Had this been the case she could have been kept comfortable and it is possible that family (if they lived locally) would have arrived in time to be with her before she died. Would have avoided costs (time, money, and resources) for transfer of patient to tertiary hospital and her body back to her community.

2. A fully completed ACD is a more detailed document than simply "not for ICU, not for intubation and not for CPR" and refers to interventions, which may have aided decision-making in this case.

3. The Medical Oncologist on-call was probably not the most appropriate person to contact – however, in this situation the patient's regular oncologist would have been more familiar with the patient. Intervention for a reversible problem misses the point that the patient was already being palliated in the community with a very short life expectancy and is currently in extremis.

4. I agree with the registrar/fellow in the decision for palliation, but I think that the on-call surgeon should have been involved, particularly as they had already accepted her care and plan of management.

5. While it may be appropriate to support a patient to allow family time to arrive, it is not appropriate (ethical) to escalate treatment or transfer a patient to ICU specifically for palliation – this is bad messaging psychologically for the family, ICU staff and the patient. Also, it is an inappropriate financial burden for the taxpayer and health system.

## Case Example 3 – Orthopaedic Surgery

A 72 year old female patient presented to the preoperative assessment clinic at a rural base hospital prior to her total knee replacement for osteoarthritis. She was on the waiting list for a unilateral total knee replacement for 14 months and was managing at home with paracetamol and anti-inflammatory medications while waiting for her surgery. She was still managing to play weekly golf, however, now needed a motorised cart as she could not walk the length of the course due to pain and stiffness. She expressed a desire to maintain her golf game.

She had no history of cardiorespiratory illness, but was diagnosed with pancreatic cancer 11 months earlier, undergoing a pancreatico-jejunostomy with minimal complications. Four months ago, she was diagnosed with recurrent metastatic disease after further lesions were discovered in her lung. She had been enrolled in an immunotherapy trial and was hopeful that she would be cured of her cancer. On detailed questioning, she reported a new cough with minimal haemoptysis over the last few weeks. She was adamant she wanted surgery as she had been waiting so long and wanted her “knee fixed”. She did not have an ACD.

The case was discussed with the consultant orthopaedic surgeon, who had not seen the patient since booking her in for her surgery 14 months earlier. He contacted the patient’s oncologist (based in a metropolitan hospital 455km away) who expressed that the response to immunotherapy was unpredictable and therefore, she should be treated as any other patient for an elective operation.

The patient proceeded to surgery and had an uneventful total knee replacement. Post-operatively, she experienced significant pain issues and was unable to fully engage with her rehabilitation program. After 6 weeks, she requires a manipulation under anaesthesia for joint stiffness. At this operation, she expressed that she didn’t know what the operation involved, and she wished she never went ahead with it.

Unfortunately, her metastatic disease progressed rapidly, and she became increasingly cachectic and unwell over the following 12 weeks and was referred to palliative care physicians for further management. She passed away 4 weeks later.

### Considerations and Comments

- *What difference in risk-benefit analysis exists in non-cancer treatment in patients with metastatic disease (or any other progressive disease process)?*
- *What are the benefits and problems with prognosis in metastatic cancer?*
- *Given significant complications after many elective surgeries are usually unlikely or rare, how much should they weigh in on the decision to proceed to surgery?*
- *Can a patient demand surgery if they feel they have weighed up the pros and cons themselves? What issues are involved?*

## Michelle Mulligan

It is a basic right of each patient to determine what is being done to their bodies and to know the implication of any treatment. Respect for patient autonomy and provision of relevant information are the cornerstones of consent.

Recognising that this patient has a complex medical history and probable reduced life expectancy would be an important part of consent for this patient, with open dialogue about possible outcomes and their impact on quality of life. This takes time. The decision-making process required to proceed prior to surgery needs to be open, honest, and effective. There needs to be consideration of meaningful patient-centred outcomes following surgery including satisfaction, functional status, wellbeing, comfort, and health-related quality of life.

## Linda Sheahan

*What difference in risk-benefit analysis exists in non-cancer treatment in patients with metastatic disease (or any other progressive disease process)?*

A patient's best interests is specific to both the person and their context. This means that a decision about what healthcare interventions are considered to be in a person's best interests, will by definition change if the circumstances change. This is relevant both on the clinician side and the patient side of the decision-making table. The shared decision-making process is revisited wherever the substantive context changes, in this case, the shift from curative-intent treatment of pancreatic cancer to incurable metastatic disease is a substantive shift. Decision-making should be explicitly revisited, and this includes helping the patient understand and appreciate the significance of the decision to proceed with surgery, given her changed context, and how this may impact on her goals and priorities.

*What are the benefits and problems with prognosis in metastatic cancer?*

Prognostication is an imprecise process at the best of times. The emergent therapeutic landscape, in arrival of targeted cancer treatments, has made it exponentially more difficult. The gold standard ethically is to treat each patient, and their cancer, as an "N of 1" (single case study) and engage in a careful deliberation about what's best in the specific context.

*Given significant complications after many elective surgeries are usually unlikely or rare, how much should they weigh in on the decision to proceed to surgery?*

Regardless of the rarity in aggregated risk data, if the complications are potentially significant to the individual person, they are substantive and should weigh in.

*Can a patient demand surgery if they feel they have weighed up the pros and cons themselves? What issues are involved?*

The short answer is no. Ethically, as stated previously, the gold standard is a shared decision-making process, to arrive at a consensus best interests assessment for the specific context. However, from the legal perspective in Australia, capable patients are empowered to refuse even life sustaining interventions, but they are not empowered to demand treatments of any kind. The decision about what interventions are appropriate to be offered to the patient rests with the clinical team. Clearly, this power carries with it both professional duties and obligations, as well as obligations to fair process and a mechanism of appeal.

## Raymond Raper

This case raises several issues. Firstly, while patients do not have an unfettered right to demand surgery regardless of circumstances, neither do doctors have the right to withhold or withdraw beneficial therapies against the patient's expressed wishes.

The second obvious issue relates to informed consent. It is quite possible that the patient was fully informed that the surgery might not be straight forward, especially in the context of progressive metastatic disease and related therapies. It is not clear from the case report if the patient was informed that undertaking the surgery might shorten their remaining life span if complications were encountered, and that complications are almost certainly more likely in this context. The patient may have wished to proceed even if fully informed, but their subsequent disappointment and negative assessment would likely have been mitigated.

Any consideration of elective surgery in the context of chronic or incurable disease demands a different level of forethought, planning and information transfer. Pancreatic cancer has an especially bad reputation and some quantification of the likelihood and significance of any possible response to immunotherapy would be essential.

Characterising the response as unpredictable is simply insufficient and needs to be far more detailed. Also, the possible impact of immunotherapy on the proposed surgery, and the impact of the surgery on the underlying disease, warrant careful consideration. The potential for acceleration of the neoplastic disease, as may have been seen in this case, should be explored as well as the impact of the surgery on the feasibility of the requisite, ongoing oncological therapies.

It is entirely possible that a fully informed patient might still have wished to proceed with the knee replacement. This might create some difficulty for the orthopaedic surgeon if they felt surgery was not appropriate. This can only be resolved with careful discussion that might include a collegial second opinion.

## *Brett Courtenay*

This lady had a knee replacement and sometime later had a manipulation due to stiffness and at that time said she wished she never had the operation. That seemed to be at the time of the anaesthetic. There is nothing about her condition post manipulation under anaesthesia. She had progression of her metastases and after 12 weeks she went into palliative care and passed 4 weeks later.

I am not sure there is sufficient information to be able to comment on the futility of this operation. It is unclear how long it was from surgery to death but seems it could have been up to 6 months. A comment that the patient wished she never had the surgery at the time of a MUA is not, in my opinion, sufficient.

This case could be described as the lady wished to have the surgery, the surgeon was concerned enough to call the oncologist and was given the advice that the lady should be treated as any other patient. The approach was to assist her to enjoy her golf and walking for whatever time she had left.

## Case Example 4 – Interventional Neuroradiology

A stroke call was activated for a 96 year old female who was transferred from her nursing home to the emergency department of a tertiary metropolitan hospital. She was found in her bed (4 hours earlier) with a facial droop and unable to move her left side.

On initial review, the patient was confused and unable to give a reliable history. Her transfer notes show she suffers from dementia and is reliant on nursing staff for all her activities of daily living (ADL). Over the preceding 4 weeks, she had a chest infection and had become bed bound, requiring a hoist for transfer. Her medical history included rate controlled atrial fibrillation (AF) and hypertension.

The patient has an ACD from 6 years ago in her hospital file stating she receives all treatment necessary to treat a reversible condition, including CPR, intubation, and ICU admission. She has no family in NSW, as her two children are interstate and overseas.

The stroke team, consisting of a neurology registrar and an interventional radiologist, assessed her to be appropriate for clot retrieval. The process was activated, and she was transferred to the interventional suite where she was met by a consultant anaesthetist following transfer onto the table, while being prepped and draped.

Initially the plan was for sedation for the procedure, but due to patient movement, she underwent a general anaesthetic with endotracheal tube and arterial pressure monitoring. The clot retrieval was difficult for the neuroradiologists and continued for 3 hours. She was haemodynamically unstable during the procedure, with recurrent runs of rapid AF and the need for significant vasopressor support to maintain a suitable blood pressure.

She was extubated to aid assessment of neurology, and given her haemodynamic instability, an intensive care bed was organised. She showed significant neurological impairment after her procedure with dense hemiparesis and had ongoing delirium and cardiorespiratory impairment post-operatively. She was discharged to the ward the following morning with a directive that she was not for further intervention or intensive care admission. She passed away that morning shortly after her transfer to the ward.

### Considerations and Comments

- *What should be considered when a pathology is identified that is amenable to an evidence based surgical or procedural intervention?*
- *Is it ethical to withhold what would be considered best practice if the patient is potentially going to be left disabled?*
- *Does an old, ACD offer any useful advice?*
- *Who can provide consent to give or withhold treatment when no family members can be found?*

## Raymond Raper

This appears to be another instance of the ‘technological imperative’. If one stands back and reviews this very elderly patient, who is demented and highly dependent with a very negative life trajectory, undertaking any procedure could only be justified on the basis of comfort or dignity, notwithstanding the ACD. Even if the acute neurological deficit could be ameliorated, the underlying dementia cannot and would almost certainly rapidly deteriorate. The overwhelmingly negative life trajectory would steepen. So, the patient would be unable to experience any benefit from the procedure and yet may experience some considerable burden. The ACD makes no mention of, or provision for, the onset of dementia. As the dementia is now present, advanced, and irreversible, the patient’s preparedness to undergo the procedures listed in the directive should be considered as no longer valid. It is a shame that the directive had not been appropriately updated.



The issue of consent in circumstances such as this is quite vexed. Consent for a procedure is not considered necessary if not easily obtained and if life or wellbeing is immediately threatened. At least in NSW, consent to not offer treatment is problematic. Substitute decision-makers, whether relatives or duly appointed guardians, are constrained to act only in the best interests of the health and wellbeing of the patient. Can this neuro-intervention be considered to serve these interests for this patient with severe dementia? Whatever the technicalities, surely the default position in circumstances where the patient cannot currently, or at any time in the future, have any experience of themselves in place, time, or community, should be to not undertake any intervention that isn't solely designed to enhance or maintain the comfort and dignity of the patient.

## Linda Sheahan

*What should be considered when a pathology is identified that is amenable to an evidence based surgical or procedural intervention? Is it ethical to withhold what would be considered best practice if the patient is potentially going to be left disabled?*

This is a huge and complicated question. The key point is that “what is ethical” in circumstances such as these will be context-dependent and individualised to the patient. A couple of key rules of thumb can be flagged:

- The decision-making around what treatments should be offered is the responsibility of the clinical team. We are not obligated to offer treatments considered futile or non-beneficial, though it should be noted that defining these terms is often fundamentally values based, and thus may be contested.
- Our obligation as clinicians is to only offer treatments and interventions thought to be in the best interests of the patient in front of us. As previously outlined, the ‘gold standard’ in best interests assessments looks at generic best practice from a clinician perspective and incorporates specific interests and values of the person being treating in each specific circumstance.
- Care should be taken not to discriminate based on age or disability. We are looking at the substantive features of the individual’s health status and their goals and values.
- Quality of life assessments are both values-based and subjective. While they are clearly always relevant in clinical decision-making, the rule of thumb in decision-making about individual patients is that it is *the patient’s assessment of quality of life* that should be guiding wherever possible.

*Does an old, ACD offer any useful advice?*

The ACD gives us very specific information about a patient’s wishes and preferences at a particular time. The critical question is whether it is still valid and specific to the current circumstances. In practical terms, particularly in emergent decision-making, this can be hard to ascertain. Importantly, however, an ACD cannot demand a particular treatment if it is not considered to be medically beneficial – under law it can only refuse treatments considered appropriate to offer. In this case, the ACD tells us that 6 years ago this patient expressed a clear wish to accept all treatments. This is ethically relevant and important, but it does not extend to obligating a clinician to offer any treatments not thought to be in the best interests of the patient.

*Who can provide consent to give or withhold treatment when no family members can be found?*

If a doctor finds that a patient is not capable of informed consent, they must seek consent from a substitute decision-maker - This means someone who has the legal authority to make medical treatment decisions on behalf of the patient, i.e., the *person responsible*. However, in most cases there will be a person responsible.

It is important to note that the person responsible hierarchy established by the Act does not directly relate to family members per se. There may be another person involved in the care of the patient who is empowered to provide consent, even if they are not family. There may be situations where an application to the Tribunal (NCAT) is necessary, such as:

- When the treatment required is considered as *special medical treatment*<sup>7</sup>.  
Special treatment means: (a) any treatment that is intended, or is reasonably likely, to have the effect of rendering permanently infertile the person whom it is carried out on, or (b) any new treatment that has not yet gained the support of a substantial number of medical practitioners or dentists specialising in the area of practice concerned, or (c) any other kind of treatment declared by the *Guardianship Regulation 2016* to be special treatment, [i.e. treatment for the purpose of terminating pregnancy; treatment in the nature of a vasectomy or tubal occlusion; treatments involving the use of aversive stimulus, whether mechanical, chemical, physical or otherwise.] but does not include treatment in the course of a clinical trial.
- When the patient is objecting to the proposed treatment (major or minor) and there is no appointed guardian authorised to override objections.
- the Tribunal may confer at the guardian's request, or with the consent of the guardian, to override the patient's objection to carrying out the treatment.

It is the responsibility of the medical practitioner to identify when consent is required for the proposed treatment and the category of treatment – urgent, major, minor, or special. It is also the responsibility of the medical practitioner to identify the substitute decision-maker and to ensure that the substitute decision-maker signs the appropriate consent forms before treatment is carried out. However, it is important to note that in NSW, explicit consent is not required to withhold non-beneficial treatment.

## Michelle Mulligan

In NSW, an ACD cannot require that futile treatment be given, and equally a person's substitute decision-maker cannot demand such treatment. A clinician does not need to obtain consent from a person or a substitute decision-maker to withhold or withdraw futile or non-beneficial treatment. However, in an emergency, time-critical situation, a substitute decision-maker's consent is not required by the law.

In New South Wales, if the medical practitioner believes providing treatment would be futile, he or she does not have to provide such treatment, and the treatment can be lawfully withheld or withdrawn without obtaining consent. (note: this varies by jurisdiction). As a matter of good medical practice, a person or their substitute decision-maker should always be involved in treatment decision-making, including when clinician's think treatment is futile. Futile treatment is also referred to as non-beneficial treatment or potentially inappropriate treatment. On a case-by-case basis factors that will be considered include the person's diagnosis and prognosis, the person's treatment goals and whether these can be achieved, treatment alternatives, and risks and benefits of these alternatives. Given the impacts of these decisions it is often best for these considerations to be done by a team.

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<sup>7</sup> *Guardian Regulation 2016* – Part 3, Section 9, Special Medical Treatment.

## Rodney Allan

This 96-year-old lady has a background of dementia, atrial fibrillation and hypertension and has suffered an embolic stroke, presumably because of her atrial fibrillation. She was assessed by the stroke team, and it was suggested that she was appropriate for clot retrieval.

Unfortunately, because of the patient's pre-morbid modified Rankin score (either 4 or 5 based upon the information available), she was not eligible for clot retrieval based on the NSW Referral Guide (September 2019)<sup>8</sup>. In the NSW guidelines, there is some area for clinician judgement, however, we are dealing with a demented dependent patient in this instance, who is undoubtedly at high-risk of death with any medical complication, including a stroke.

A good reference is the LAST<sub>2</sub> CH<sub>2</sub>ANCE<sup>9</sup> paper which summarises in Table 3, below, the indications for treatment. This patient did not meet the criteria for any of the randomised controlled trials reviewed for this study, as only patients with a modified Rankin score of 2 or less (1) were eligible for inclusion.

**Details of LAST<sub>2</sub> CH<sub>2</sub>ANCE**

Symbol	Meaning	Details
L	Large vessel occlusion	Internal carotid artery or proximal MCA <sup>a</sup>
A	Age	≥18 yrs <sup>a</sup>
S	Symptom	NIHSS score ≥6 <sup>a</sup>
T	Time	Onset to groin puncture time <6 h <sup>a</sup>
T <sub>2</sub>	Thrombocytopenia	PLT ≥40*10 <sup>9</sup> /L <sup>b</sup>
C	Crippled/disabled	mRS <2 <sup>a</sup>
H	Hypoglycemia	CBG ≥2.7 mmol/L <sup>b</sup>
H <sub>2</sub>	Hypertension	BP ≤185/110 mmHg <sup>b</sup>
A	Anticoagulation	INR ≤3.0 <sup>b</sup>
N	Nonsalvageable brain tissue	ASPECTS ≥6 <sup>a</sup>
C	Collateral	ACG >1 <sup>c</sup>
E	Expectancy of life	>90 d <sup>b</sup>

**Note:**—ACG indicates American Society of Interventional and Therapeutic Neuroradiology collateral grading; BP, blood pressure; CBG, capillary blood glucose; INR, international normalization ratio; PLT, platelet count.

<sup>a</sup> Criterion from the American Heart Association/American Stroke Association guidelines.

<sup>b</sup> Criterion from the protocol of MR CLEAN trial.

<sup>c</sup> Criterion we use in our daily practice but without consensus in the literature.

**Table 3 – Indications and contraindications of treatment for patient selection.**

I feel that although pathology can be identified and treated, the underlying patient needs to be carefully considered, which is why a multidisciplinary team is best to assess these patients. In that way we are not left with a proceduralist making the final decision, but a combined decision between the proceduralist, anaesthetist, intensivist and other clinicians who have intimate knowledge of the trials and the likely outcomes in a case such as this. The evidence would suggest that this patient should not have undergone treatment.

In these circumstances, treatment can be withheld ethically, as it is not best practice. Treatment can also be withheld if the patient is going to be left with unacceptable disability, (in particular, if it is known that the patient has left previous directions). So, I do feel that an ACD does offer useful advice in this case.

A doctor can make a decision to withhold or give treatment when no family members are present based upon; the clinical scenario, the likelihood of a good outcome, the likelihood of a bad outcome, and any information that might be known about the patient's wishes.

<sup>8</sup> [https://aci.health.nsw.gov.au/\\_data/assets/pdf\\_file/0007/506617/Stroke-Network-NSW-Referral-Guide-Eligibility-for-ECR.pdf](https://aci.health.nsw.gov.au/_data/assets/pdf_file/0007/506617/Stroke-Network-NSW-Referral-Guide-Eligibility-for-ECR.pdf) Clinical Practice Guide: Eligibility for endovascular clot retrieval – ACI Stroke Network.

<sup>9</sup> *American Journal of Neuroradiology* September 2017, 38 (9) E58-E59, LAST2 CH2ANCE: A summary of selection criteria for thrombectomy in acute ischaemic stroke. P. Yang, Y. Zhang and J. Liu. DOI: <https://doi.org/10.3174/ajnr.A5249>

## Chapter 3 – Futility

While futile medical treatment has no generally agreed upon formal definition, the overarching principle is that it refers to medical treatment that would be considered to provide little or no benefit to the patient.

Importantly, this requires an understanding of what individual patients would consider to be beneficial to them.

A determination of whether a treatment is futile is usually made by the patient's treating team or medical practitioner, so it is important for medical practitioners to be aware of their own beliefs regarding treatment benefits and consider how this relates to the individual patient and their beliefs.

Futile treatment encompasses non-beneficial surgery and, while it can be used to describe surgical procedures for all patients at all stages of their life, it is commonly applied to complex patients and end-of-life decision-making.

The patient's best interests are not served by providing non-beneficial treatment, which can be associated with increased economic costs. A retrospective 2017 study into the costs of futile treatments in Australia estimated that in patients who died during their hospital stay, the annual cost of futile treatments to 'major' tertiary hospitals was \$153.1 million (2). This does not include costs incurred in 'non-major' tertiary or rehabilitation hospitals or primary care.

While there is limited direct published evidence to guide decision-making about the outcomes of aggressive versus conservative management in the complex and/or frail elderly patient undergoing major surgery. Published trials in chemotherapy for non-small cell lung cancer (3), surgery for malignant bowel obstruction (4), or surgery for metastatic prostate cancer (5), indicate that aggressive management may lead to reduced patient satisfaction with their care and either, no or worsened, survival benefit whilst being more costly to the health system.

While proceeding to invasive interventions may potentially offer what is considered to be the best chance of curative therapy for the patient, or what would be accepted as best practice, the intervention needs to be weighed against the risks involved in proceeding to surgery. This is especially so with the elderly and medically complex patient, as the risk-benefit balance will change, to the extent that non-aggressive conservative management may be preferred.

The aim of treatment should be to return patients to a quality of life that is acceptable to them.

## Chapter 4 – Practice in Futility – Making Decisions

Preoperative assessment and informed decision-making are the cornerstone in effective management of the elderly and medically complex patient to ensure patients get the correct treatment for their situation.

A lot of the research into how we make decisions is published under the umbrella of 'behavioural psychology' rather than within medical journals. This is slowly changing, and doctors are beginning to understand how human factors influence how they assess risks/benefits and treatment decisions.

In making a decision, we are all subject to our personal emotional and cognitive biases. In other words, how we make decisions is impacted by multiple factors beyond our consciousness. As an example, judges (who are presumed to be completely rational and mechanical in their application of legal principles) have been shown to be much more likely to rule favourably immediately following a meal break (6). In medicine, doctors are subject to over 100 biases affecting clinical decision-making (7), which may include having had a long relationship with patients, managing iatrogenic injuries, dealing with a marriage breakdown, being burnt out or being hungry. These factors affect both our fast, easy intuitive (Type 1) thinking and to a lesser extent our slow, analytical, resource heavy (Type 2) thinking.

While there is only sparse evidence examining the accuracy of intuitive thinking in medicine, there have been some smaller studies done, such as the prediction of survival by radiation oncologists has repeatedly been shown to be overly optimistic by about 70% (even worse the closer to end-of-life) (8, 9). The ability for surgeons to pre-operatively predict mortality and major post-operative complications from intuition is, at best, fair in its correlation to actual outcome, and no better than using either the duration of surgery or patient age in accurately predicting outcomes (10).

To try to reduce the effect of bias on decision-making, we can utilise unemotional rule-based or statistical prediction algorithms. In the past, doctors have been reluctant to rely on algorithm-based prediction as it is felt to be an affront to our professional ego, while interfering with our decision-making autonomy. It is also thought to de-humanise the patient-doctor experience. Finally, doctors are reluctant to use predictive algorithms, as the algorithms themselves are not perfect.

Despite this, using statistical methods to support decision-making has repeatedly been shown to improve decisions. A meta-analysis of fifty years of accumulated data into statistical versus clinical judgement showed that statistical prediction is consistently more accurate in projecting outcomes (11). Therefore, when we are dealing with patient's opportunities, we should look to incorporate the statistical algorithms available to us to improve the accuracy of our predictions.

Table 3 below, outlines some validated risk prediction models in perioperative care that can be used to incorporate statistical decision-making into perioperative decision-making.

Risk Prediction Model	Validation in Australian Population
<b>National Surgical Quality Improvement Program (NSQIP) Surgical Risk Predictor (12)</b>	(13-17)
<b>Portsmouth Physiological and Operative Severity Score for the enumeration of mortality and Morbidity (P-POSSUM) (18)</b>	(13, 19-22)*
<b>Surgical Outcome Risk Tool (SORT)(22)</b>	(22, 23)
<b>Canadian Study of Health and Ageing (CSHA) Clinical Frailty Scale (CFS) (24)</b>	(25, 26)
<b>The National Emergency Laparotomy Audit (NELA) Risk Predictor (27)</b>	(13)

**Table 3 – Selected validated examples of Risk Prediction Models used in the Prediction of Perioperative Risk**

*\*19, P-POSSUM statistically over-predicts mortality*

In addition to cognitive biases in decisions, we often make decisions based on our knowledge and experiences. With increased practice, we gain a greater understanding of the patient journey, the risks, the outcomes, and other factors which we see as important to consider in the management of patients. Therefore, a registrar or fellow may be less likely to offer an accurate and informed opinion when compared with an experienced consultant.

Additionally, while specialists are masters of their specific specialty technique, managing possible complications and ensuring good outcomes, they have less understanding over the technique, risks, outcomes, and alternative options of other specialties. Consequently, we should be looking to obtain opinions in a multi-disciplinary manner to offload bias that may exist toward a single-specialty management plan.

Finally, as these four cases have outlined, surgical decision-making is sometimes made under time pressure and the ability to convene a multidisciplinary meeting with all stakeholders is challenging given the urgent requirements for decision-making. We should work to incorporate systems to allow this to happen at short-notice and at any time of the day.

For patients at highest risk of perioperative complications, where time allows, pre-operative decision-making should be led by a multidisciplinary, consultant-level team, and supported by validated statistical prediction models. Particularly where there is a risk of non-beneficial surgery and/or the need for intensive care. It is important to ensure that other management options, focused on what is significant to an individual patient, is offered to patients and their families. (Modified from Choosing Wisely Recommendations ANZCA, 2017) (28)

## Chapter 5 – Not Offering Treatment - Medicolegal Implications

While futility itself is also not defined by law in Australia, a treating medical practitioner can legally not offer treatment that they determine to be futile. When the patient has capacity for decision-making, this holds for all states in Australia, except Queensland - which requires the consent of a substitute decision-maker to withhold treatment when the patient no longer has decision-making capacity (29).

Clinicians have no legal or ethical mandate to offer specific care to a patient they deem to be non-beneficial, even if the patient, or their family, request it.

All registered medical practitioners in Australia are expected (and legally bound) to practice in accordance with the Medical Board of Australia document “*Good medical practice: a code of conduct for doctors in Australia*” (30). Table 1 of the document outlines the expectations for *good patient care* (3.2.7) and *end-of-life care* (4.13.3). Importantly, it provides a standard that all medical practitioners must recognise non-beneficial treatment (and, where your profession’s generally held views would deem that treatment futile) and only recommend treatments when a reasonable expectation of benefit for the patient is warranted.

### 3.2 Good patient care

Maintaining a high level of medical competence and professional conduct is essential for good patient care. Good medical practice involves:

- 3.2.1 Recognising and working within the limits of your competence and scope of practice.
- 3.2.2 Ensuring you have adequate knowledge and skills to provide safe clinical care.
- 3.2.3 Maintaining adequate records.
- 3.2.4 Considering the balance of benefit and harm in all clinical-management decisions.
- 3.2.5 Communicating effectively with patients.
- 3.2.6 Providing treatment options based on the best available information.
- 3.2.7 Only recommending treatments when there is an identified therapeutic need and/or a clinically recognised treatment, and a reasonable expectation of clinical efficacy and benefit for the patient.
- 3.2.8 Informing your patient when your personal opinion (in the context of practice) does not align with the profession’s generally held views.
- 3.2.9 Taking steps to alleviate patient symptoms and distress, whether or not a cure is possible.
- 3.2.10 Supporting the patient’s right to seek a second opinion.
- 3.2.11 Consulting and taking advice from colleagues, when appropriate.
- 3.2.12 Making responsible and effective use of the resources available to you.
- 3.2.13 Encouraging patients to take interest in, and responsibility for, the management of their health and supporting them in this.
- 3.2.14 Ensuring your personal views do not adversely affect the care of your patient or the referrals you make.

### 4.13 End-of-life care

Doctors have a vital role in assisting the community to deal with the reality of death and its consequences. In caring for patients towards the end of their life, good medical practice involves:

- 4.13.1 Taking steps to manage a patient’s symptoms and concerns in a manner consistent with their values and wishes.
- 4.13.2 Providing or arranging appropriate palliative care, including a multi-disciplinary approach whenever possible.
- 4.13.3 Understanding the limits of medicine in prolonging life and recognising when efforts to prolong life may not benefit the patient.
- 4.13.4 Understanding that you do not have a duty to try to prolong life at all cost. However, you have a duty to know when not to initiate and when to cease attempts at prolonging life, while ensuring that your patients receive appropriate relief from distress.
- 4.13.5 Accepting that patients have the right to refuse medical treatment or to request the withdrawal of treatment already started.
- 4.13.6 Respecting different cultural practices related to death and dying.
- 4.13.7 Striving to communicate effectively with patients and their families so they are able to understand the outcomes that can and cannot be achieved.
- 4.13.8 Encouraging advance care planning and facilitating the appropriate documentation, such as an advance care directive (or similar).
- 4.13.9 Taking reasonable steps to ensure that support is provided to patients and their families, even when it is not possible to deliver the outcome they seek.
- 4.13.10 Communicating bad news to patients and their families in the most appropriate way and providing support for them while they deal with this information.
- 4.13.11 When your patient dies, being willing to explain, to the best of your knowledge, the circumstances of the death to appropriate members of the patient’s family and carers, unless you know the patient would have objected.
- 4.13.12 Sensitively discussing and encouraging organ and tissue donation with the patient’s family, when appropriate and consistent with legislation and accepted protocols.

**Table 4 – Expectations of Practice from AHPRA as outlined in *Good medical practice: a code of conduct for doctors in Australia*.**

## A Lawyers Perspective on Futile Treatment

Mr Robert Samut was asked to comment on the medico-legal aspects after reviewing these four cases, and more specifically, to answer a few common questions that clinicians have regarding treatment decisions in potentially futile surgical situations. His commentary and answers are provided below.

The Australian and New Zealand College of Anaesthetics (ANZCA) have published Guidelines for the care of patients at the end-of-life who are considered for surgery or interventional procedures (31), which defines futile treatment as:

*“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.”*

A recent study into the attitudes of Anesthesiologists towards ‘medically futile care’ concluded that *“Complete agreement on a definition of futility does not exist. Even when some agreement exists, there is great difficulty in predicting outcomes in individual cases. (32)”*

While *futile treatment* is not a legal term and is, according to the ANZCA definition, a clinical concept; there are several legal issues which may arise when it comes to determining in a particular case whether treatment is futile or not.

Legal issues relating to futile treatment most commonly arise when one is considering withholding or withdrawing life-sustaining treatment, but not always. Recent cases are instructive and are summarised below for context.

### Case A – Barts Health NHS Trust v Dance and Battersbee

NCN: [2022] EWHC 2098 (Fam) - Case No. FD22P00346

In 2022, the UK Courts were called upon to decide whether care being provided to a young person<sup>10</sup> could be withdrawn. The principles were the same as those applied in Australia.

Archie Battersbee was a 12-year-old boy, found unconscious by his mother in April 2022. He died following his participation in the TikTok “blackout challenge”. He was taken immediately to hospital where he was found to have suffered a significant brain injury. Initial orders were made by the High Court authorising brain stem testing without the parent’s consent, and further orders were made authorising MRI scans of Archie’s brain when the specialists were unable to administer the brain stem tests. The MRI’s showed significant brain damage and the High Court was asked to consider whether Archie’s life support treatment should continue.

On 13 June 2022, the UK High Court ruled that Archie was legally “dead” based on the MRI scan results and that treatment could be withdrawn. The family appealed to the Court of Appeal which held the judgement to be incorrect as the MRI scans weren’t seen to be conclusive. The matter was sent back to the High Court for a new hearing to determine whether ongoing life support treatment was in Archie’s “best interests”.

On 15 July 2022, Mr Justice Hayden in the UK High Court ruled that life support treatment should end saying that its continuation was futile and not in Archie’s best interests. The family appealed to both the Court of Appeal and the European Court of Human Rights and asked the United Nations to intervene. All appeals were unsuccessful. Justice Hayden’s decision regarding Archie’s best interests was allowed to stand. He held that continuation of the life sustaining treatment was not in Archie’s best interests i.e., it was futile.

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<sup>10</sup> <https://www.ibanet.org/Family-law-Archie-Battersbee-case-raises-questions-on-legal-reform-for-family%E2%80%9393clinician-disagreements>



On 6 August 2022, Archie passed away at the Royal London Hospital after treatment was withdrawn with the family at his bedside. In her conclusion, Mrs Justice Theis reasoned that Archie's life sustaining treatment was [as described by Mr Justice Hayden on 15 July 2022] *'futile, it compromised Archie's dignity, deprives him of his autonomy, and becomes wholly inimical to his welfare. It serves only to protract his death, whilst being unable to prolong his life'*. That bleak picture remained the position three weeks after that conclusion was reached.

Mr Justice Hayden's application of the best interests' criteria was ultimately based upon the weight of the medical evidence.

## Case B – The Hospital v S (a minor)

Ref: [2019] NSWSC 642

In 2019, the NSW Supreme Court was asked to decide on similar issues in a case which involved a 3-year-old boy who was struck by a motor vehicle. He suffered a traumatic brain injury and a spinal cord injury resulting in ventilator dependent quadriplegia. He was mechanically ventilated, receiving artificial hydration and nutrition, and remained in an unresponsive coma.

Consensus among the boy's doctors was that he had no conscious awareness, and that it was unlikely that he would ever achieve any awareness. They also believed that prolonging his life was inconsistent with his personal dignity, and that continuing the treatment would be unethical.

An application was brought by The hospital to withdraw life sustaining treatment from the boy and commence palliative care. His parents opposed this decision. The NSW Supreme Court ordered that the boy's life sustaining treatment be removed, and palliative care commenced. The Court was persuaded by the unanimity of the medical opinion. The Judge remarked that stopping treatment was justified due to the possibility that the boy may be suffering pain and discomfort; and could suffer further ailments if life sustaining treatment continued.

The Court also noted that in the absence of any possibility of consciousness existence, the dignity of the person is a real and significant factor which the court should protect in the person's best interests.

## Case C – Messiha v South East Health

Ref: [2004] NSWSC 1061

In 2004, the NSW Supreme Court upheld a decision to withdraw life-sustaining treatment from a 75-year-old man with severe hypoxic brain damage. This decision was made by the clinician without the consent of a substitute decision-maker. No formal ACD was prepared.

In this case, the patient had a complete absence of cortical activity (requiring mechanical ventilation, an indwelling catheter, and suctioning of saliva by nursing staff), and efforts were made to communicate the poor prognosis to the family. The treating clinician had determined that the current treatment regime of the patient should cease, he should be removed from ICU and placed under palliative care. The clinician accepted that withdrawing treatment in the ICU would have the effect of reducing his life expectancy from possibly weeks to possibly days.

The substitute decision-maker and the family generally disagreed with the diagnosis and continued to do so, even after an independent neurologist reviewed the case and agreed with the decision to withdraw active treatment. The court upheld the clinical assessment of the patient's best interests, finding that there was unanimous medical opinion that continuity of ICU treatment was not medically justified, and it would be unusual for the court not to give effect to the medical opinion.

## Questions and Answers

### *Who decides whether treatment is futile or non-beneficial?*

Generally, the treating clinical team or medical practitioner will answer this question on a case-by-case basis. Factors that will be considered include the person's diagnosis and prognosis, the person's treatment goals and whether these can be achieved, treatment alternatives and risks and benefits of these alternatives.

### *What can patients or families do if they disagree with the medical team about whether treatment is futile or non-beneficial?*

They can raise the issue with the dispute resolution procedures that operate within the hospital or health service. They may also look to challenge the decision by seeking a second opinion.

If the dispute cannot be resolved at a local level, it may need to be taken to the Supreme Court, Family Court, or NSW Civil Administration Tribunal (NCAT) to decide on whether or not the treatment should be provided and/or maintained. It is for the Court or Tribunal to then decide upon whether the treatment is deemed futile.

### *Do you have to give all treatment options to patients, even where you believe them to be futile?*

When obtaining a patient's consent, you not only need to outline the nature of the procedure and/or treatment, but also provide alternatives. There is no legal obligation to provide a treatment option which is considered to be futile. Where there is potential for differing views on the futility or otherwise of the procedure and/or treatment, then the patient should be given the option of obtaining a second opinion. There is however no legal requirement to refer a patient to a colleague, or to obtain a second opinion if it is within the treating doctor's scope of practice, to determine whether the procedure and/or treatment is futile and therefore should not be offered. The consequences of the decision will determine whether a senior treating doctor should make the assessment.

Best practice and the AMA Code of Ethics suggest that a second opinion is desirable where determining the appropriate diagnosis or treatment is difficult.

While there is no legal duty to provide futile treatment, if a dispute arises between the treating clinicians and the patient or their family, in relation to a treatment decision, then it may be appropriate to refer the matter to the relevant court or tribunal. When managing end-of-life care it is important to make decisions with a view to avoiding conflict, future civil claims, or complaints to the Health Care Complaints Commission (HCCC) and/or the Australian Health Practitioner Regulation Agency (AHPRA).

*Can a patient or their family demand that treatment be given, even if a clinician believes that the treatment would be futile or non-beneficial?*

The answer to this question is no. Under the Common Law, a patient, their family, or substitute decision-maker, cannot demand treatment that is futile or non-beneficial.

There is no legal duty to provide futile treatment regardless of whether the patient has capacity, and a family member or other substitute decision-maker has no right to demand that futile treatment be provided.

In 1992, the High Court of Australia gave approval for the application of *Gillick competent*, aka Marion's case. In deciding whether a person has legal capacity there are certain issues that must be considered, which include:

- A child (15 years or under) or a young person (aged 16 or 17 years), as classified under the *Children and Young Persons (Care and Protection) Act 1998*, is presumed not to have legal capacity except where they are deemed to be Gillick competent (or a Mature Minor), or when the specific advice and/or treatment provided by a clinician meets the criteria set out in the Fraser Guidelines.
- A child or young person will however be able to provide or withhold consent to certain medical treatments when they have sufficient understanding and intelligence to understand what is involved in receiving, or not receiving, such a treatment (Gillick competence). Note: The NSW Health *consent to medical treatment (adults and mature minors) form* should be used in public hospitals and health facilities.
- An adult may not have the legal capacity to make decisions regarding their treatment because of a severe illness, their age, or due to a mental illness which affects their decision-making capacity. In this situation, the treatment will be provided in accordance with any binding authority, such as an ACD, or by using substitute decision-makers.

## Chapter 6 – Practice in Futility – Summary Points

- Just because we can, it doesn't mean we should offer a treatment for a diagnosed condition, particularly when that treatment is not in the patient's best interests.
- Outcomes of population-based evidence-based medicine fail to individualise treatment decisions to patients.
- The aim of any treatment should be to return a patient to a quality of life that is acceptable to them.
- Understanding what is important to patients requires us to ask what is important to them.
- A multi-disciplinary team expert approach to complex patients being considered for invasive procedures allows for consideration of different treatment options and limits of care to be discussed prior to surgery.
- Clinicians should aim to incorporate validated statistical methods and scores to support decision-making and reduce bias.
- Clinicians have no legal, or ethical, mandate to provide care to a patient which they deem to be futile or non-beneficial.

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