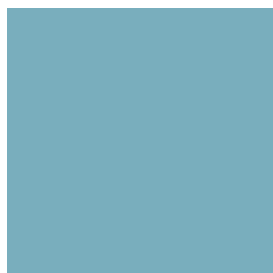


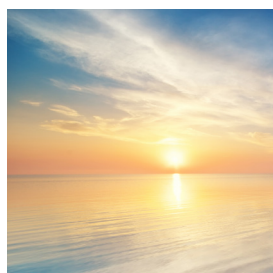
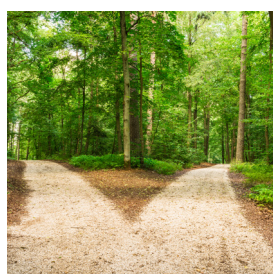
CARE AT THE END OF LIFE:

A guide to best practice, discussion and decision-making in and around critical care

EXECUTIVE SUMMARY



September 2019



This report was produced as part of the Critical Futures initiative, looking to the future for critical care services. www.ficm.ac.uk/criticalfutures

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FOREWORD

Survival rates for critical care patients along with available treatment options have increased throughout the Twentieth and Twenty First Centuries. However, [15-20% of critical care patients continue to die during their hospital admission](#). End-of-life care therefore remains a necessary core skill for critical care teams. Such care includes:

- Symptom assessment and management e.g. pain, nausea, pyrexia, anxiety, delirium, dyspnoea, skin care, thirst and hunger.
- Enabling patients and those close to them to achieve a sense of control, including strengthening of inter-personal relationships.
- Minimising distress.
- Relieving physical and psychological burdens.
- Ensuring patients (and those close to them) are supported (physically and psychologically) through the course of the dying process.
- Meeting spiritual and religious needs.
- Understanding legal and ethical principles related to withdrawal and withholding treatments.

There is also a need for all members of critical care teams to acknowledge and convey uncertainty of prognosis; and depending on circumstances, either lead or support decision-making (Walter et al, 2016.) This is particularly the case when patients have lost capacity and there is a need to determine individuals' (often unknown) best interests. In such circumstances, effective decision-making frameworks are required and involve **collaborative evidence gathering, listening, reasoning and implementing** appropriate, individualised care plans.

Additionally, even if hospital survival occurs after critical care there can be significant physical and psychological impacts on patients and their families. We therefore emphasise **a duty to have open and honest discussions about difficult decisions** with the intention of **increasing public awareness about the burdens as well as benefits of critical care**. Such discourse is intended to enable patients, their families and critical care teams to work through shared-decision making processes and enhance individualised care.

What we know:

- Critical care survival particularly when associated with emergency and prolonged admission (>48-72hours) carries significant physical and psychological burdens impacting on future quality of life (Griffiths et al., 2013).
- More than 80% of critical care patients lack capacity to make important decisions about their care and management at a time when consideration is being given to withholding or withdrawing life-sustaining treatments (Sprung et al., 2018).
- Only 13% of patients dying on critical care have made any pre-emptive statement (Sprung et al., 2018).
- 24% of critical care survivors are re-admitted to hospital within 90-days of discharge from hospital. The reason for re-admission is usually related to chronic health status prior to original critical care admission (Lone et al., 2018).
- One in five critical care survivors die within a year of discharge from hospital (Szakmany et al., 2019).

- [In 2016 approximately 35% of adult in-patients were in their last year of life.](#)

In summary **critical care teams frequently have to deal with uncertainty of prognosis and outcome.** They are required to simultaneously react to changing physiology with resuscitative measures, consider palliative interventions and communicate (with empathy) rapidly changing situations to patients and families during very distressing times. Shared decision-making is regarded as best practice but lack of capacity often precludes this. **If more information about patients' wishes and beliefs were available ICU teams would be better positioned to make Best Interests decisions, enabling individualised care, thereby minimising confusion and conflict** due to clear communications about **advance care planning** (Gross et al 2018.) Such an approach would also have an **additional advantage of reducing stress, anxiety and burn-out in those delivering care.**

This document (full and abridged versions) plus the accompanying lay summary provides recommendations for effective decision-making and resources for clinical teams and the general public. It hopes to encourage open, clear, honest discussions with patients and families enabling improved advance care. Such arrangements will enhance care planning and empower patients, carers and clinical teams to better engage in shared decision-making processes that respect both the philosophical and physiological aspects of individuals' lives.

As an end-note it should be recognised that discussions surrounding organ donation occur when critical care patients are near the end of their lives. If this occurs it involves teams that are independent to the intensive care team. This document will not cover this extensive topic in death but further information about such processes can be obtained from [NHS Blood and Transplant](#).

Glossary:

The term 'critical care' is used throughout to cover the critical care pathway. 'Intensive care' is only used when referring specifically to Level 3 care.

The terms 'families' or 'family members' are used throughout as the accepted term to refer to relatives or other close friends.

A PATIENT VIEW – ICUSTEPS

We know that a good death, as well as a good life, is important. When asked in surveys, many people say they would prefer to die at home. No-one says they wish to die in critical care. However, about 300,000 people die each year in hospitals in England (roughly 60% of all deaths) and of these, nearly 22,000 die in critical care units; an average of two each week per critical care unit.

We know that critical care treatment, whilst potentially life-saving, can be very distressing for patients. They can be confused, disorientated, and delirious with many interventions being very unpleasant. We can't ask those who die in ICU about their experiences, but it is likely that some find aspects of the care distressing. We certainly know that families can find the experience distressing.

As a healthcare professional, it is perhaps helpful to think about what would be important to you if you were a patient receiving end-of-life care in critical care, or what experiences you would want those close to you to have. We're fairly sure that kindness and compassion from staff would be high up on your list – an empathetic approach can feel like a lifeline and will be remembered by families for a long time afterwards.

From a patient and family point of view, excellent communication from healthcare professionals is paramount. Patients and their families need to know what is happening, especially when there is uncertainty. They may be confused and distressed and they may find it difficult to retain and absorb the information, so it is important to check understanding and have regular conversations.

It is likely that patients and their families will not have been able to prepare and plan for being in critical care. The patient may have been admitted as an emergency, with their condition changing rapidly. Many decisions will have to be made about their care, and unlike most other healthcare scenarios, it is quite possible that the patient may not be able to share in the decision making. What we do know is that family members have to live for the rest of their lives with the decisions that are made on behalf of the patient. So these decisions must be high quality, transparent, evidence based and in the patient's best interests, taking into account their values and wishes. This is a big responsibility. Never be afraid to ask second opinions from patients, their families and your colleagues to make sure the decisions are the right ones.

There is a lot of good practice out there, but it is likely that the experience of dying in ICU is still a poorer experience than dying in a hospice or at home. ICU staff can learn from other practitioners, particularly palliative care colleagues, and exchange ideas and best practice with hospices. We should aim to actively seek feedback from patients and their families, where possible, in order to gain insight into our own practice. Having staff development sessions where family members share their experiences can also help to improve practice.

There is a bigger picture here too, and one that we all have a responsibility for, whether we are healthcare professionals, patients, their families or members of the public. We need to raise the profile about planning for our future care, and start the conversation about what our wishes are in the event of serious illness. A recent survey by *Dying Matters* found that whilst 68% of people said they were comfortable talking about death, less than a third (29%) of people have discussed their wishes around dying. Only 4% have written advance care plans. We need to do better collectively

to start these conversations with our loved ones, and to prompt our healthcare professionals if they don't initiate the conversation. Knowing the wishes of our family members matters – it can provide doctors and nurses with valuable information if there are life and death decisions to be made and it can save us a lot of heartache trying to second guess what the patient would want.

Thank you for reading these guidelines and for your interest in improving the care that ICUs give patients and their families at the end of life.

CHAPTER 1:

Twenty First Century Critical Care: Success and Dilemma, Intertwined

Prologue

Health care professionals within critical care medicine have a duty to recognise when patients are close to death, and to change the focus of care towards comfort at the end of life. However, the evolution of new technologies has meant that critical care teams are faced with continual dilemmas as to whether or not withdrawal and withholding of life-sustaining treatment is depriving a patient of potentially beneficial interventions. This section provides an overview of the development of critical care and legal concepts relating to debates surrounding continuation of treatments or withholding and withdrawing treatments.

Key Points

- Critical care mortality rates for adults have progressively reduced since the 1970s.
- Medical and scientific advances have raised societal expectations with respect to treatment delivery and longevity of life.
- Despite reductions in mortality rates, 15-20% of patients admitted to critical care die before leaving hospital. Critical care teams therefore continue to have a duty to engage in the provision of end-of-life care.
- For patients who have no realistic chance of surviving critical illness and returning to a life they can value, the physical and psychological burdens of invasive and distressing treatments may outweigh potential benefits.
- Outcomes from critical illness are not only measured in terms of survival but also in terms of patient preferences surrounding quality of life.
- ICU teams require a working knowledge of legal and ethical frameworks that discuss the relative benefits and burdens of treatments.

Recommendations

- Critical care teams must recognise patients as individuals.
- Critical care teams should be empathic in their communications to patients and families. If there is significant chance of patients dying, they must be honest in their communications and convey the concept of uncertainty.
- Critical care teams should be aware of the importance of a good death.
- Critical care teams should have an understanding of legislation relating to capacity, consent and end-of-life care.

Dealing with Dilemma at End of Life: An Overview

This page provides a template for assessment when an acutely ill patient is assessed and there is uncertainty with respect to prognosis. It is supplemented by further guidance in chapters 3-5.

Severe Acute Illness and Critical Care Admission

(Uncertain Prognosis)



Be honest and clear about uncertainty. **Avoid firm predictions**
(Absolute predictions create misunderstanding and fuel conflict)



Are there **any** advance statements outlining patients' values and wishes? (Verbal or written)



Do proposed treatments offer a minimum quality of life acceptable to the patient, and can they achieve their goals for a good life?



Preservation of life as a physiological entity is not necessarily paramount. Preservation of patient's preferences and values can enable a good death

CHAPTER 2:

The Provision of Care at the End of Life in Critical Care

Prologue

In the first instance where prognoses are uncertain, combined supportive and active approaches are recommended. This ensures symptom control and simultaneously provides an environment where the possibility of dying can be discussed. It is important that differences between 'palliative' treatments (aimed at symptom control in incurable illness, regardless of illness duration) and 'end of life' treatments (given during the very last days and hours of life) are made clear to patients and families. Fostering an awareness of dying, whilst balancing hope, is an important part of end-of-life care.

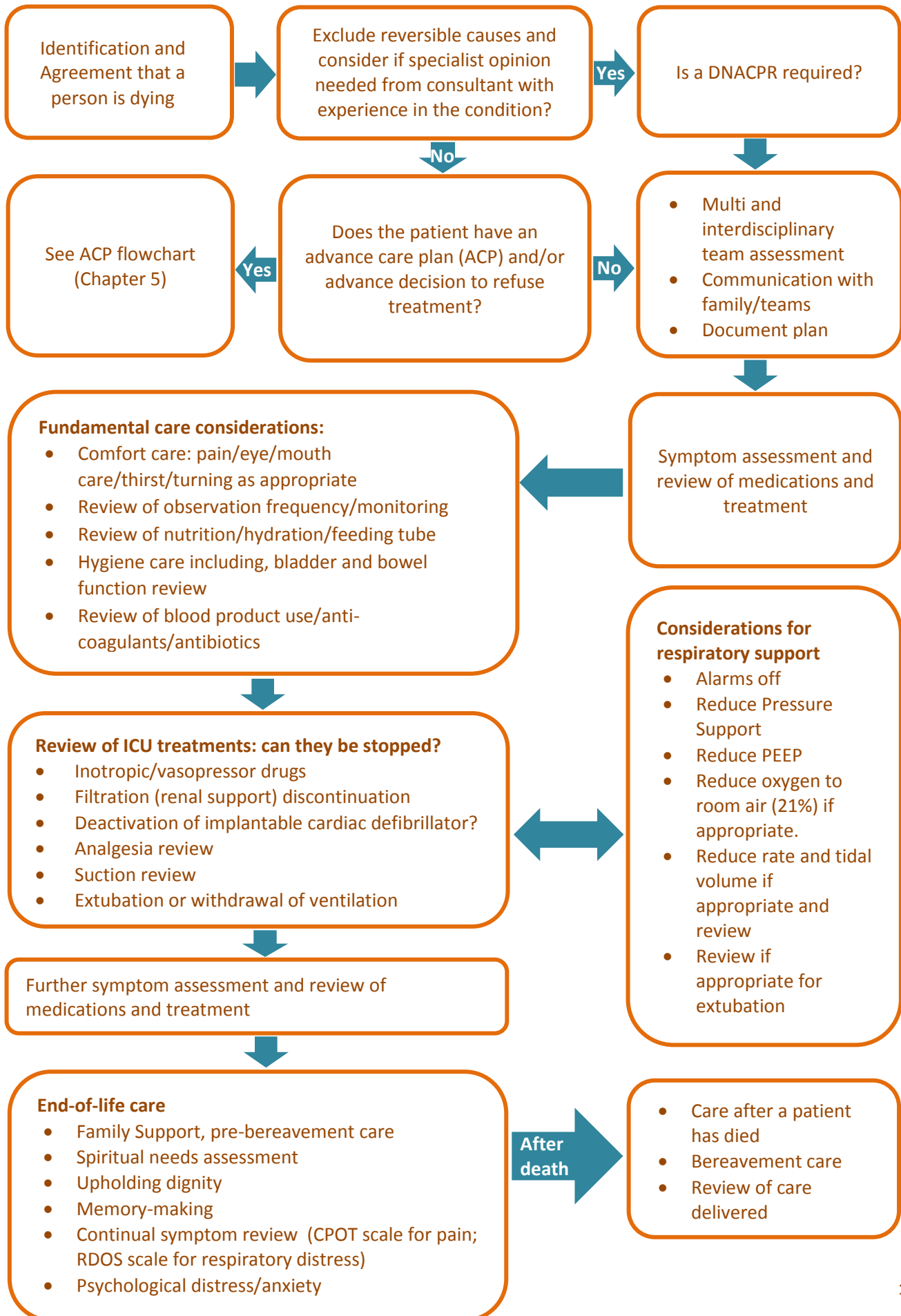
Key Points

- Effective end-of-life care involves individualised symptom assessment and management.
- Effective end-of-life care includes a duty to understand patients' values and beliefs and meet such needs.
- Involving the family of the dying patient enhances care and experiences.
- Clear, non-ambiguous communications are essential.
- The overall aim is to ensure that the patient is the focus of care and allowed to have a dignified, natural death.

Recommendations

- Families should be invited to participate in end-of-life care provision to enhance awareness of dying and develop family-centred care.
- Best practice for symptom management involves routine assessment with active, rapid responses to symptoms. Care planning with symptom experts (e.g. palliative care) can help optimise control.
- Individualised risk assessments and clear plans of care, involving patients/families, will improve processes of withdrawal and withholding treatments.
- Comfort care should take priority with the avoidance of prolongation of dying, tempered with families' needs regarding time to reach acceptance.
- Needs assessment should use recognised tools and encompass spiritual, emotional, practical, physical and psychological needs.

Aide memoire for end-of-life care on the critical care unit



CHAPTER 3:

Communication, Confusion and Conflict

Prologue

Regardless of the specific healthcare environment and application or availability of technology, effective healthcare can only be achieved if medicine and nursing is supported by effective communications with patients and families. This is particularly the case when patients are nearing the end of their life.

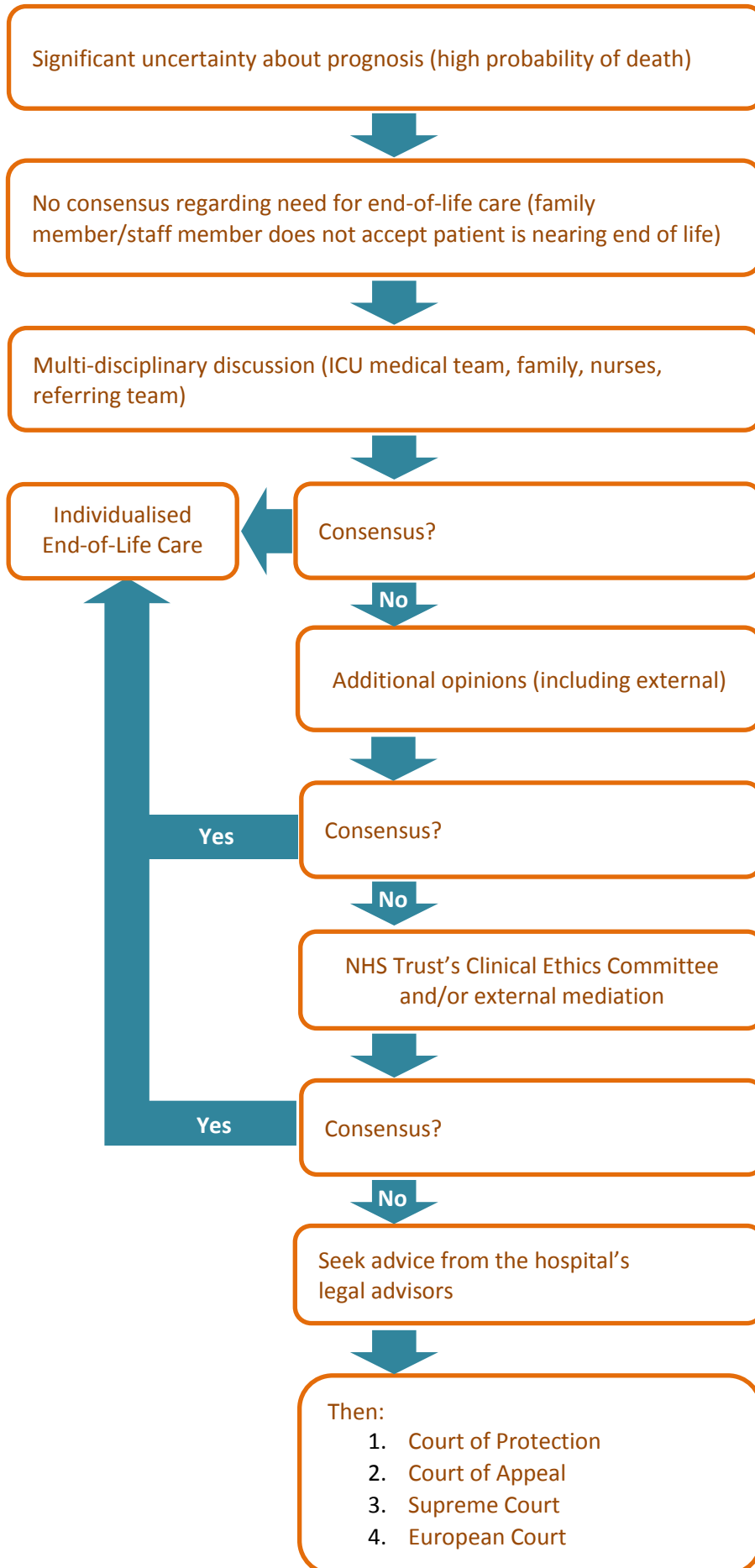
Key Points:

- End of life considerations on critical care can lead to strained relationships between clinicians, patients and families.
- Poor communication and perceived lack of empathy are the main reasons for conflict.
- Sufficient time for effective communication should be planned for.
- Mediation (from within the hospital and external) can help minimise conflict.
- Recourse to legal intervention (usually via the Court of Protection) may occur when an impasse has arisen.

Recommendations

- Avoiding firm predictions (positive or negative) can minimise conflict.
- Honesty and empathy in communications are essential.
- Clear, contemporaneous documentation can aid future discussions.
- Use of key phrases can assist in conveying uncertainty and build understanding between critical care teams, patients and families.
- Learning from previous case examples can help staff deal with new cases and dilemmas and should be incorporated into local clinical governance structures.

Aide memoire for achieving consensus



CHAPTER 4:

Clinical decision-making in acute situations

Prologue

The underlying theme of this document relates to the serious consequences of decisions surrounding care and treatment in the critically ill where there is a fine balance between the need to save life and the burdens that interventions to do so can place upon patients and families. Such decisions often have to be made in a short timeframe where outcomes are uncertain and information incomplete. Furthermore, critically ill patients are vulnerable and are often unable to fully participate in decisions surrounding their care. Therefore, the purpose of this chapter is to guide best practice in decision-making surrounding acutely ill patients with uncertain capacity. The initial few pages summarise principles and frameworks for decision-making in an easy to read format. The subsequent text is used to explore the guidance in greater detail.

Key points

- Where possible clinicians should use shared decision making. Every effort should be made to elicit patients' wishes and take them into account.
- Decision-making should be structured, well documented and communicated, involving clear reasoning that takes into account subjective/objective factors.
- Clinical teams should make decisions in the best interests of patients, in line with current legal, ethical and regulatory frameworks, as well as available national guidance.
- Organisations and individual clinicians should have pre-determined pathways for dealing with conflict and disagreement surrounding outcomes of these decisions (Chapter 3).

Recommendations

- Hospitals should have defined mechanisms for peer review related to treatment escalation decisions.
- Documentation in patients' notes should include clear, structured processes, ideally based on recognised decision-making models.
- Communications of decision-making and the rationale for decisions should be clearly documented.
- Access to support and follow-up should be available for patients and families who have experienced end of life decision-making.
- All members of the clinical team should receive training and feedback in decision-making and having difficult conversations.

CHAPTER 5:

Advance Care Planning within Critical Care Medicine

Prologue

Healthcare decisions should reflect an individual's wishes, values, fears and preferences, and should be made following an in-depth discussion of risks, benefits and likely outcomes between the patient and their healthcare team. When this cannot happen because of incapacity, having previously engaged in a process of advance care planning (ACP) provides a valuable insight into the patient's outlook and can help the healthcare team making the decision.

Key Points

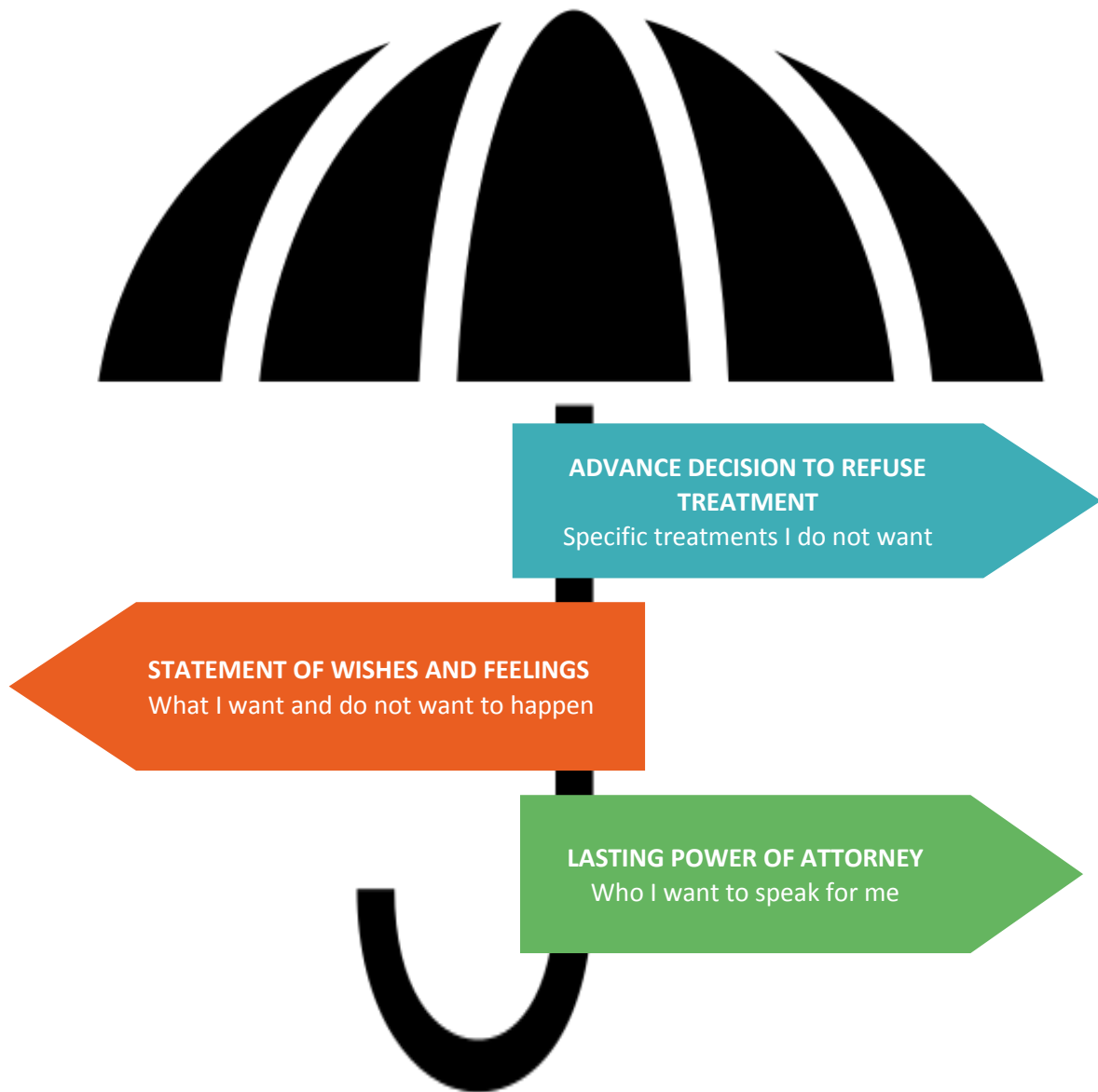
- One-third of adult in-patients may lack a level of decision-making capacity.
- ACP seeks to create a record of individuals' wishes, values and preferences so they can be considered by healthcare teams should the patient subsequently lose decision-making capacity.
- In England and Wales ACP is codified by the Mental Capacity Act ("Mental Capacity Act," 2005). Scotland and Northern Ireland have separate legislation.
- ACP can occur at any time (even in complete health) and may be prompted by either patients or healthcare professionals. Often major events like the death of a loved one, a new diagnosis or major surgery trigger discussions.
- ACP is supported by the National Institute for Health and Care Excellence (NICE) for patients approaching the end of life or at risk of a medical emergency.

Recommendations

- All critical care teams should have a basic understanding of ACP and be able to answer patients' initial questions.
- For patients that lack capacity, critical care teams should enquire about the presence of any ACP or advance statements to better understand the values and beliefs of the individual.
- At critical care discharge plans for future treatment should be documented along with patients' wishes, values and preferences and included in discharge summaries to GPs.
- During perioperative care, teams should review any advance care plan with patients and, if necessary, make alterations prior to anaesthesia and surgery.

Advance Care Planning: An Overview

This visual, informed by the Deciding Right model, is presented here and expanded in detail in Appendix 1 below.



ADVANCE DECISION TO REFUSE TREATMENT

Allows you to tell doctors what treatments you definitely do not want.

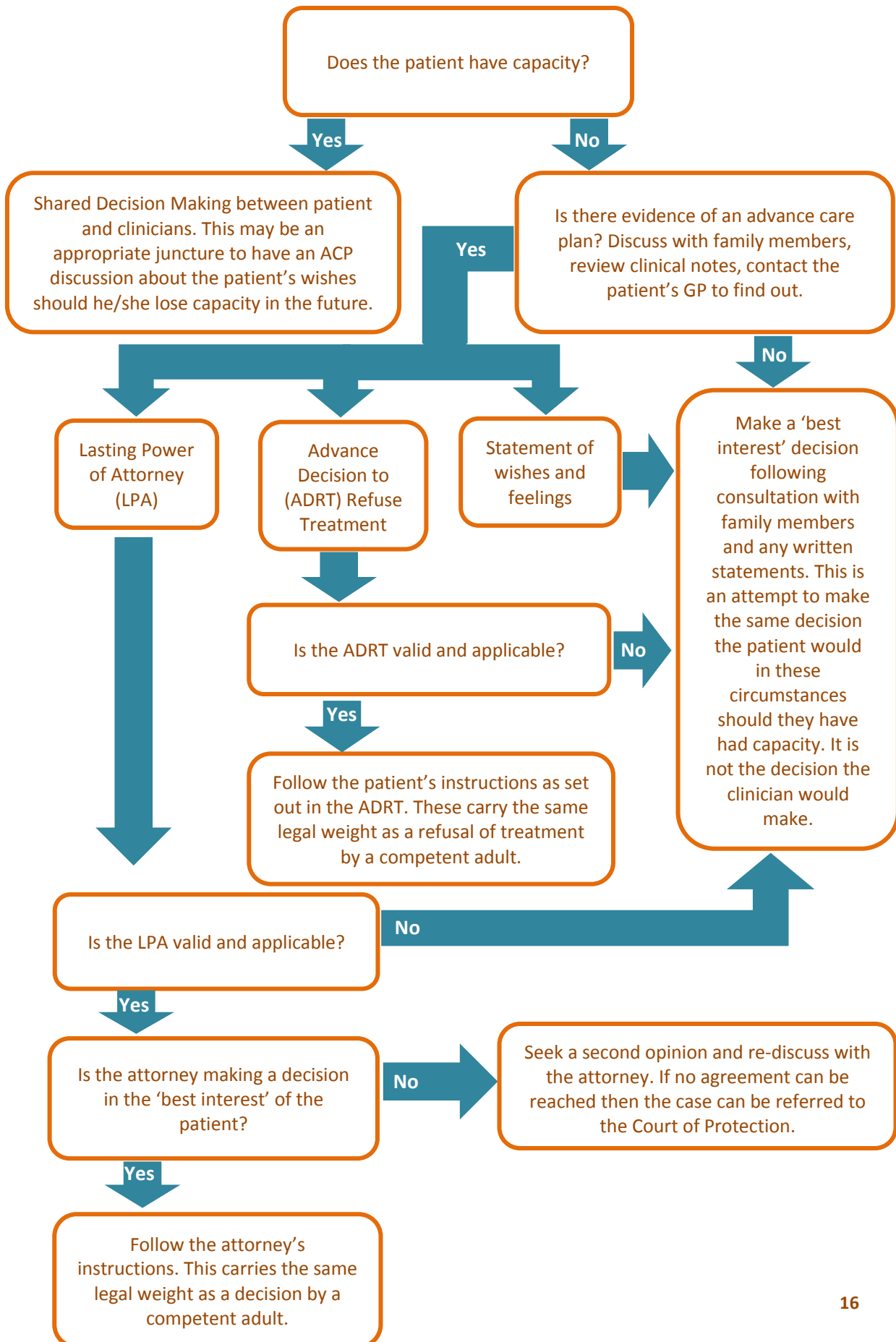
STATEMENT OF WISHES AND FEELINGS

Any record of your views or wishes including general beliefs and values. This could be a treatment escalation plan, DNACPR, or even a conversation with a loved one.

LASTING POWER OF ATTORNEY

Allows you to tell doctors who you want to speak for you.

Aide memoire for assessing and responding to a patient's Advance Care Plan



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