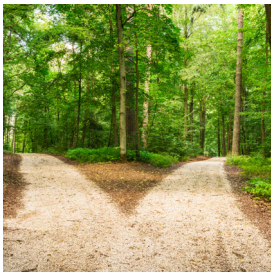
CARE AT THE END OF LIFE:

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

September 2019



The Faculty of
Intensive Care Medicine

CRITICAL FUTURES

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

1 Within the UK

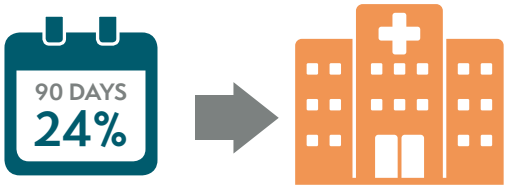
intensive care survival has improved significantly, nevertheless **15–20%** of UK intensive care admissions die in hospital.

2

Intensive care survival, particularly when associated with emergency and prolonged admission (>48–72hours), carries significant physical and psychological burdens impacting on quality of life.

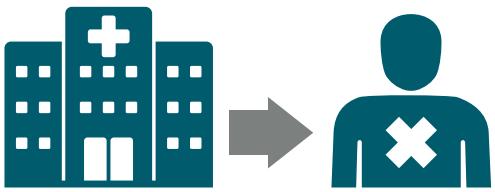
3 Scotland (2005–2013)

24% of intensive care survivors are **re-admitted to hospital inside 90-days of discharge**. The reason for re-admission is usually related to chronic health status prior to original intensive care admission.



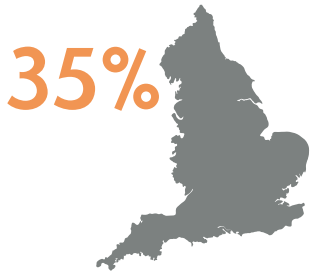
4 Wales (2006–2013)

one in five intensive care survivors **die within a year of discharge from hospital**.



5 England 2016

approximately **35%** of adult in-patients were in their last year of life.



6

Advance Care Planning and the information to the left therefore has the potential to:

Allow patients, those close to them and clinical teams

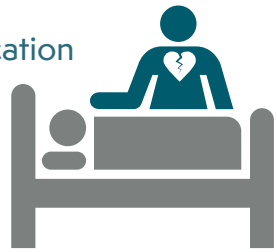
to better utilise **shared decision making when planning care**.

Reduce confusion and conflict

when patients are acutely ill, have lost capacity and have a **high risk of dying**.

Improve clarity of communication

surrounding care at the end of life and **reduce the severity of grief amongst friends and families.**



Reduce the incidence and impact of burn-out

in healthcare professionals.

The Faculty of Intensive Care Medicine is the professional body responsible for the training, assessment, practice and continuing professional development of Intensive Care Medicine doctors and practitioners in the UK.

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 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.

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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

1.1 Context

The General Medical Council's *Duties of a Doctor* notes that clinicians must recognise when a patient is dying. Such decisions are inevitably some of the most challenging faced by health care teams (General Medical, 2018). This section summarises current ethical and legal principles and outlines debates relating to inappropriate or disproportionate treatments.

The primary purpose of critical care is to support patients with (sometimes immediately) life-threatening conditions through treatments enabling survival (Great Britain. Department of Health, 2000). Decision-making is frequently complex and may be emotionally distressing. Nevertheless, it is a central role for critical care teams. Being **honest about uncertainty, utilising collaborative decision-making and clarity of communication are paramount. Failure to act in this manner can compound misunderstandings and fuel conflict**. Understanding debates surrounding concepts of inappropriate treatment and clear communications can significantly improve the delivery of care (Kon et al., 2016). It can also enable decisions to be held up to scrutiny by family members, peers, public bodies and the law.

1.2 What is Care Designed to Achieve? Inappropriate or Disproportionate Treatments

Debate here balances the potential benefits of critical care against its burdens (Schellongowski et al., 2016). Inappropriate treatments are *treatments that do not achieve their intended purpose.* The debate therefore involves analysing both quantitative outcome measures and qualitative aspects of patients' values reflecting physical and holistic aspects of care i.e. some treatments may be physiologically successful, but inappropriate or disproportionate as they fail to provide qualitative benefits.

Quantitative factors include assessing physiological impact of treatments and whether they offer any reasonable chance of survival. This involves collating clinical assessments, investigations and prognostic indices e.g. ICNARC, APACHE II. The scores offer a predictive value for mortality but relate to populations and should not be used as absolute guides in the context of individual patients. Doubt can lead to further discussion and the possibility of trials of treatment within specific, agreed, realistic timescales e.g. change of antibiotics with a 48-72 hour *review*, or a trial period of non-invasive ventilation. These are often referred to as *trials of critical care* (Lecuyer et al., 2007).

Qualitative/holistic aspects of care involve asking the questions **"Do proposed treatments offer a minimum quality of life acceptable to the patient?", "What are the patient's values?" and "Can proposed treatments achieve a patient's goals for a good life?"** Ideally these issues should be discussed (and documented) with competent patients before any acute illness, however this rarely occurs and cannot usually be discussed in acute situations. Where this is not possible, consultation from patients' nominated family members, admitting teams and critical care staff can enable details of a care plan to evolve via a *Best Interests* process e.g. as outlined in legislation such as the *Mental Capacity Act 2005* in England and Wales, and the *Mental Capacity Act (Northern Ireland) 2016* (Chapter 5.) In Scotland there is the *Adults with Incapacity (Scotland) Act 2000;* such discussions lead decisions that consider therapies that will benefit patients and cannot be achieved by other ways. They must consider what actions will be the least-restrictive for patients. Regardless of which legislature teams are working in, a consistent approach with effective and honest

communications can minimise confusion, conflict and complaints. A working knowledge of ethics and relevant law is therefore a major factor in this process.

1.3 Legal and Ethical Considerations

These considerations are based on an understanding and ability to explain the concept of *Serious Medical Treatments* i.e. treatments where there is a fine balance between benefits, risks and burdens, principles of medical ethics, and how law relevant to consent and capacity is shaped. They also include concepts such as *Advance Care Planning* (ACP), *Treatment Escalation Plans* (TEPs), *Emergency Health Care Plans* (EHCP) and *Advanced Decisions to Refuse Treatment* (ADRT). Central to the process are **shared decision making**, ***Best-Interests'* decisions** and **clarity of communication** (Northern Cancer Alliance, 2018; Obolensky et al., 2010).

1.3.1 Ethical Principles and a Link to Current Legal Principles

In law, patients may refuse but do not have the right to demand treatments. For patients who have capacity to make decisions about their own care, healthcare professionals must provide them with sufficient information to make an informed decision about proposed treatments. In patients who have lost decision-making capacity, healthcare professionals have a duty to seek out and take their views into account when considering planning of care. The provision of end-of-life care can be guided by articles from the European Convention on Human Rights:

- Article 2: with the exception of the prevention of criminal acts or lawful use of the death penalty, everyone's right to life shall be protected
- Article 3: no one shall be subjected to torture or inhuman or degrading treatment or punishment
- Article 8: with respect to an individual within the norms of a democratic society an organisation cannot interfere with their rights unless it is to uphold the law or protect the rights and freedoms of others

The articles guide debate case by case, e.g. Article 2 (*The Right to Life*) can present an argument for continuation of life-sustaining treatments. If a patient is dying there could be concerns about the potential for life-prolonging treatments becoming "inhuman and degrading" (Article 3.) Whilst rulings have referred to the *sanctity of life*, this principle is not absolute and planning for a "good death" may provide the final part of a fulfilling, complete life. In cultural and religious contexts where death is regarded as a step towards the "after-life" or reincarnation, a natural death may honour individuals' rights and freedoms (Article 9.) Effective care therefore requires an understanding of these issues and an ability to explain them in discussions, adding clarity to planned care and minimising conflict ("Aintree v James," 2013; "Glass v UK, EHCR - 61827/00," 2004).

Observation, information gathering (physiological and qualitative) with frequent multi-disciplinary communication should enable improved person-centred decision-making around the potential for inappropriate treatments (Chapter 4.) Regular open and unambiguous discussions (with all parties) can build understandings of patients' progress and prognoses. Wherever possible people should be given time to gain an understanding of processes with relevant information and discussion, taking into account patients' and families' cultural, religious and language needs (Marie Curie, 2019) (Public Health England London, 2016).

1.4 Summary

Modern critical care has made significant inroads into the survival of patients, however interventions required to save life can also be physically and psychologically harmful. Consequently, there is potential for dilemma and conflict if survival is uncertain. **In order to be effective, critical care teams must (in addition to managing organ support) be able to appreciate the concept of inappropriate and/or disproportionate treatments administered to the dying.**

Chapter 1: Further Reading

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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.

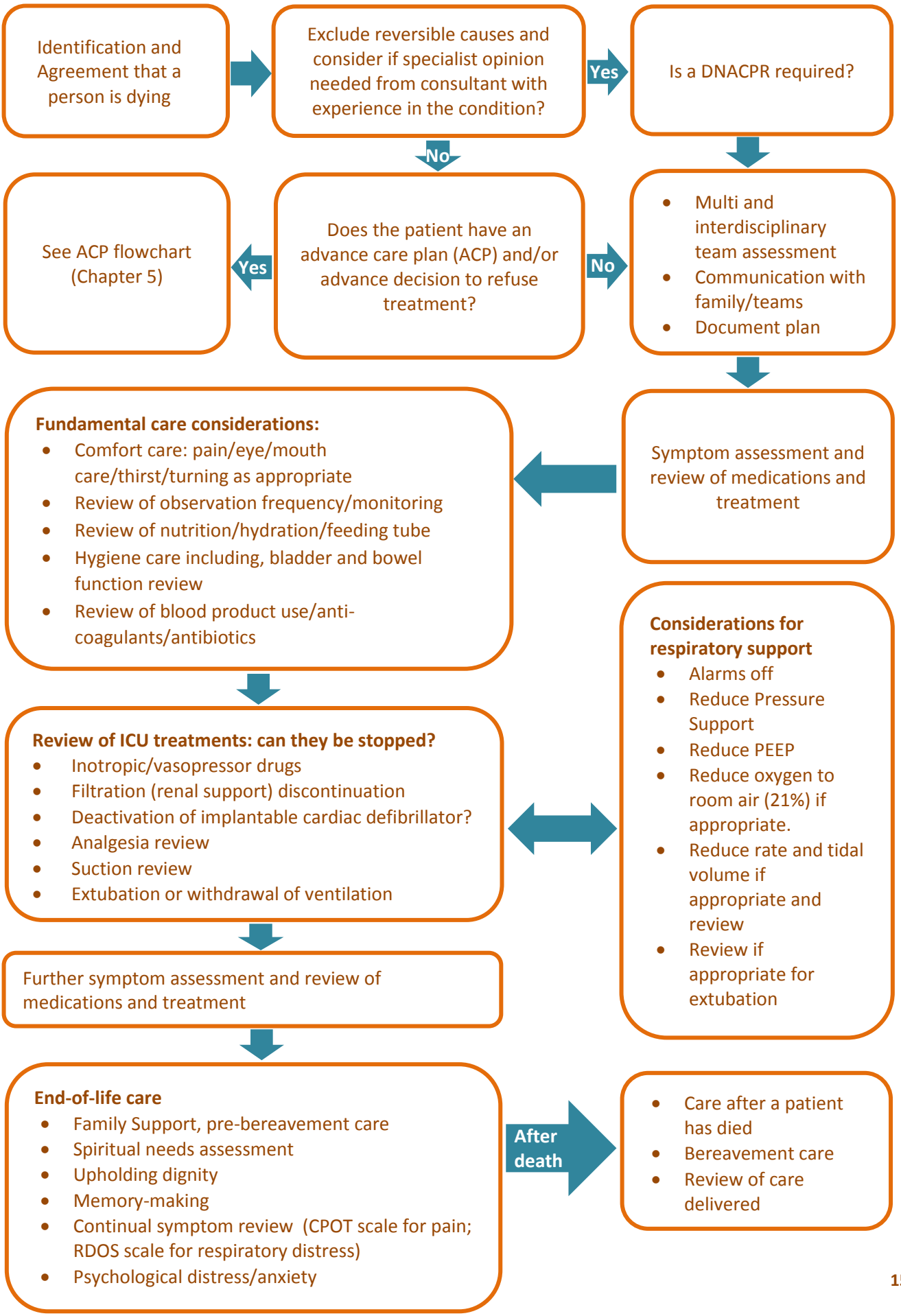
Key Points

- 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



2.1 Care at the End of Life: a practical approach

When critical care patients are in the last days/hours of life a thorough evaluation of therapies is necessary to determine net positive contributions (physical and psychological) to effective care (Truog et al., 2008). Domains for teams to consider are:

- Symptom assessment and management e.g. pain, nausea, pyrexia, anxiety, delirium, dyspnoea, skin and eye care, thirst and hunger
- Avoidance of inappropriate prolongation of dying
- Enabling patients to achieve a sense of control, minimising distress and relieving physical and psychological burdens
- Strengthening relationships with loved ones
- Not being abandoned/being in a familiar place
- Meeting spiritual and/or religious needs
- Processes of withdrawal and withholding treatments

Explicit, individualised care plans minimise confusion and omissions. The aim is to **make dying patients the focus of care, allowing a natural death with minimal interference from medical technology**. Involving families in processes of end-of-life care is also key. Any treatment that does not advance such aims should be considered for withholding or withdrawal (National Institute for Clinical Health and Excellence (NICE), 2014; National Institute for Health and Clinical Excellence (NICE), 2015). In England this guidance is summarised by the **Leadership Alliance for Care of Dying People**. On occasion consideration can be given to discharging patients (ward, hospice or even home) noting the potential for harm (including a sense of abandonment), local resource and discomfort during transfer.

Concerns can exist that symptom control (especially analgesia) can hasten death. There is no firm evidence to support this. Thus, if analgesia is to be administered it is imperative to make clear that the patient is dying and the clear intent is to prevent a painful death even if the act of drug administration is followed by death. This principle is known as the *Doctrine of Double Effect* (DDE) and is aligned with ethics and law across multiple jurisdictions and religions, acting as a channel for effective care (Douglas et al., 2013; Lindblad et al., 2014) In summary, the **main considerations for end-of-life care are clarity of communication, symptom review and management plus the processes for withdrawing or withholding treatments**, particularly ventilatory, cardiovascular and nutritional support (Puntillo et al., 2010). Considerations when dealing with **devastating brain injury** is the focus of a recent FICM consensus statement, so is not covered in this section.

2.1.1 Involving families/patients

Family, and where possible, patients' involvement is central to improved shared decision-making and improved delivery of end-of-life care. It should begin with enquiries as to the beliefs and values of a patient and whether there is any form of advance statement.

Direct involvement in all aspects of care (particularly in comfort care, such as hygiene, eye and mouth care) can help them reach awareness and acceptance of dying. Inevitably the risk of conflict can remain, with families not understanding why certain end of life processes occur. Clear, honest communications are pivotal to minimising disputes, but if they arise resolution becomes imperative (through mechanisms such as mediation, discussed in Chapter 3).

2.1.2 Symptom monitoring review and interventions

Assessing symptoms, and acting to stop them is a cornerstone of supportive care. However, with critical care patients, symptom assessment can be challenging and non-verbal assessments may be necessary (section 2.1.3). Prescribing in palliative care is well described in the **British National Formulary Palliative Care Guidance**. A multi-disciplinary approach is invaluable and colleagues from pharmacy and palliative/supportive care can assist in drug administration conversions between oral/subcutaneous and intravenous routes.

2.1.3 Pain and Pain Control

Pain is common in critical care patients near the end of their life. Visual or numerical pain scales can assess pain in patients with capacity and are easy for staff to use. However, where patients are unable to communicate, assessment relies on observing physiological and behavioural manifestations of pain e.g. the *Behavioural Pain Scale* (BPS) and *Critical Care Pain Observation Tool* (CPOT) (Burns et al., 2015; Gelinas et al., 2017; Kemp et al., 2017).

The main stays of analgesia are opioids and intravenous paracetamol, titrated to provide individualised pain control. Choice of opioid may be determined by the nature of multi-organ dysfunction e.g. in acute kidney injury codeine, morphine and tramadol can accumulate leading to unpleasant side-effects (Barr et al., 2013). Constipation in particular is a frequent side-effect (National Institute for Care and Health Excellence (NICE), 2019), but consideration of laxative use must be balanced against the burden of administration and expected length of survival.

2.1.4 Anxiety/Distress/Agitation/Delirium

These symptoms are very common in patients near the end of their life. If communication is possible, calm reassurance, information, distraction and the presence of family can assist in minimising symptoms. For patients who cannot communicate, or where these approaches are unsuccessful, administration of anxiolytic and sedative medication can be considered after easily reversible causes have been excluded e.g. pain and drug side-effects (Barr et al., 2013). There is some tentative evidence that music therapy can not only support the patient but also help reduce family anxieties (Bradt & Dileo, 2014). Agitation and delirium are common near the end of life with the incidence of the latter being increased in ventilated patients. Furthermore it is not usually effectively managed by sedation alone (**national delirium guidance**) and the use of anti-psychotic medications may have to be considered if patients are distressed (Devlin et al., 2018).

2.1.5 Dyspnoea and Respiratory Secretions

Breathlessness can compound anxiety (Schmidt et al., 2014). Non-pharmacological treatments (including hand-held fans) can assist and opioids can reduce the sensation of breathlessness (Devlin et al., 2018; Puntillo et al., 2014b). With respect to respiratory secretions, non-intubated patients have a build-up of respiratory secretions causing noisy breathing. Suctioning can cause distress so there is a role for anti-cholinergic agents such as hyoscine to minimise secretion production, noting the potential side-effects of a dry mouth (section 2.1.7).

2.1.6 Skin and Eye Care

Skin is at high risk of breakdown from immobility, hypermetabolism, infection, hypoperfusion, steroids, vasoconstrictor medication (Chaboyer et al., 2018). Skin care focuses on infection prevention and control, prevention of pressure sores (pressure-relieving devices) and regular repositioning (Tayyib & Coyer, 2016). Key factors include regular assessment, two-hourly positioning, twice daily washing with soap-free cleanser (which can help manage pruritis), barrier films and moisturising dry skin. Regular eye care with water and liberal use of ointment lubricants to enhance comfort is important, especially where corneal oedema exposes the eyes. Silicone-foam dressing on heels and sacral areas also help with potential benefits coming from phototherapy, specific mattresses and faecal continence systems (Coyer et al., 2017; Pather et al., 2017; Tayyib & Coyer, 2016). **In summary the approach to skin care (as with all end-of-life care) relates to what procedures benefit patients and what may cause discomfort or distress.**

2.1.7 Thirst, Mouth Care, Nausea, Hunger and Withdrawal of Hydration and Nutrition (BMA advice)

Thirst (often difficult to distinguish from xerostomia or dry mouth) has been rated as one of the most distressing and intense symptoms experienced by patients at high risk of dying (Oechsle et al., 2014; Puntillo et al., 2010). Treatment for xerostomia can be found in **BNF guidance**, and involves salivary replacements. Treatments for thirst relate to the use of *thirst bundles* including frequent use of sterile ice (1-2 hours), cold water sprays, wet oral swabs and lip moisturisers (Puntillo et al., 2014a). Ice chips (infection prevention to be considered) and saliva substitutes can also help, as can gentle tooth-brushing.

Hunger in critically ill patients at high risk of dying has been rated as a greater concern than pain and may be difficult to manage (Miller, 2017). However, critical illness may also suppress the action of the peptide ghrelin (Nematy et al., 2006), reducing appetite and artificial feeding may cause discomfort. Once again, the need for nutrition needs to be considered on a **case by case basis**.

Many cultures and religions place significant symbolic value on hydration and nutrition, hence discussions with family about **withdrawal of clinically-assisted nutrition and hydration** (CANH) can be challenging. Nevertheless continuation/institution may prolong the dying process, and the means of providing hydration or nutrition to critical care patients can be painful and distressing (e.g. inserting a naso-gastric tube, gastric distension from enteral feeding, pain from inserting a cannula or tissue oedema from fluid). The consequences of dehydration and electrolyte disturbances may also contribute to ineffective sedation, anxiolysis and analgesia. Once appropriate levels of analgesia and sedation have been achieved, clinically-assisted hydration and nutrition may have to be considered as a treatment that does not necessarily advance the aims of a 'good death.' For patients receiving CANH who are in a permanent vegetative state (PVS) or minimally conscious state (MCS) following sudden-onset of profound brain injury, there is specific guidance from the **GMC/RCP** (British Medical Association and Royal College of Physicians, 2018; General Medical Council, 2017) that consequently means court approval is no longer necessary for withdrawal of CANH.

2.1.8 Extubation and ventilatory withdrawal

With respect to extubation and tracheostomy decannulation, practices and time to death are variable (Robert et al., 2017; Sprung et al., 2003) and should be individualised (Paruk et al., 2014). Regardless of actual practice though, poor conduct of the processes place patients at high risk of respiratory distress. The application of individualised care plans is once again paramount. Effective risk-assessment examines oxygen dependency, risk of air hunger and careful patient/family preparation. Stages may involve the prescription of medications to pre-emptively protect from dyspnoea, reduction of support via adjustment of ventilatory settings prior to withdrawal (Robert et al., 2017). A spontaneous breathing trial may be performed prior to extubation, although this has to be assessed against the risk of significant airway obstruction plus pain and discomfort on extubation.

For patients receiving non-invasive ventilation, air hunger is also a risk, so similar dyspnoea management is required. Replacement with an O_2 mask, or nasal cannula may increase comfort. For patients on high PEEP, again an interim adjustment of PEEP may be needed. Anxiolytics and morphine are also recommended if patients are dyspnoeic, to be commenced hours prior to withdrawal in order to optimise comfort.

2.1.9 Dealing with vasoactive medications and cardiac devices

Stopping vasoactive medications is not known to cause discomfort but should be explained and planned for as death can often follow rapidly. Deactivation of implantable cardiac defibrillators will prevent shock being delivered in the event of a shockable rhythm when dying (see local policies and implantable cardioverter-defibrillator (ICD) manufacturer guidance).

2.1.10 Environment

Minimising clinical interventions and attempting to return the person to as natural a state as possible may help to humanise the surroundings. Removing unnecessary technology and turning off (or turning away) screens may be of benefit, as could providing views of outside spaces and supporting 'trips' to garden areas for fresh air. Other suggested initiatives include wall projections (which can be made to look like home), **pet therapy** (including, where possible, own pet visits) available via local and **national charities**, subtle lighting with lamps, own clothes/bedding, own music, smells and photographs (Pattison et al., 2013). Other supportive measures include offering free car-parking and easily accessible (free) accommodation for families.

A potential major environmental problem in these situations (despite **national guidance**) is the management of social media. Broad principles state that photographs and social media posts should not be shared without the explicit consent of the patient; noting that patients are likely to be vulnerable and lacking capacity in the majority of circumstances that critical care teams will face. It can be appropriate to use social media to support family engagement at end of life, such as encrypted video platforms to enable distant family to communicate with patients.

2.1.11 Discharge from Critical Care to Other Areas

Such transfers may be desirable for patients unlikely to die within 24-48 hours of commencing end-of-life care, as they can remove the very clinical and at times intimidating environment of critical care. They do however require significant advance planning and

careful management to prevent any sense of abandonment. Any handovers are critical to the success and involvement of Palliative Care teams can provide significant continuity of care in managing and explaining the rationale for such transfers e.g. different environment, different medical and nursing staff, less invasive monitoring, alternative methods of drug administration.

2.1.12 Discharging Critical Care Patients Home to Die

Approximately 6% of critical care patients are discharged directly home (Intensive Care National Audit and Research Centre, 2018); a small proportion of this group will be specifically transferred home to die, and more may be potentially eligible (Coombs et al., 2017). There may be potential for further numbers of patients to be discharged for end-of-life care but there remains a requirement for patient-by-patient assessment, taking into account multiple practical implications and the family's needs. Such patients tend to be long-stay patients with a clear, expected trajectory to death after treatment withdrawal; it does not include patients wishing to be organ donors or physiologically unstable patients requiring high levels of organ support. Factors to be considered include:

- Accompanying critical care doctor and nurse.
- What are the implications for community and primary care in such circumstances?
    - Is there an actual model for shared care and who retains overall responsibility of treatment decisions?
    - Are they sufficiently experienced and trained in dealing with such circumstances?
    - What support do they require and have their staffing levels been fully considered?
- What are the implications for ambulance services?
- What support is there for the family?

2.1.13 Spiritual Needs and Cultural Sensitivity at End of Life

Spiritual and faith needs encompass belief systems, values, cultural issues and religiosity plus the need for reconciliation towards death and dying in a high technology space. This can include sensitively provided religiously affiliated music, iconography, cultural displays and religious practices. Pastoral care teams are highly valuable in providing support particularly when conflict arises. A range of guidance exists, including Public Health England's **Faith at end of life** (Public Health England, 2016) which provides support for families and offers practical advice to staff during dying and after death.

2.1.14 Bereavement Care

Shared decision-making models for care and discussion can emphasise family involvement and prepare them for bereavement (Downar et al., 2014). The incidence of complicated grief is higher in the families of critical care patients (Kentish-Barnes et al., 2015). Discretion and sensitivity are therefore required from the critical care team in order to guide the family through an understanding of death in terms of both individual and cultural perspectives. Bereavement care services are invaluable at this juncture as families can struggle to understand the death of a loved one compared to deaths in other environments (Jones et al., 2018; Kentish-Barnes et al., 2016; Kock et al., 2014). Dealing with family at this time requires great skill and sensitivity, from both an individual and a cultural perspective. Bereavement care services are important to signpost to at this time with written information being provided for families (Faculty of Intensive Care Medicine, 2019; Intensive Care Society, 1998). Bereavement tools and mementoes e.g. locks of hair, hand-prints can

help those close to the patient. **Organ donation** may also have to be considered in the context of preparing for bereavement with specialised organ donation teams being able to help in this process (National Institute for Care and Health Excellence, 2016). The entire approach requires sensitivity and should be personalised.

2.1.15 Support for Staff

Support for patients and families is a continual thread in this document, but support for staff should be viewed with equal importance given that it is their role to provide compassionate and skilful care (Salvagioni et al., 2017). Furthermore, lack of support for all critical care staff is multifaceted, associated with burnout, compassion fatigue, moral injury, distress and dissonance with end-of-life care conferring added risk (van Mol et al., 2015).

Symptoms that staff may suffer can be both physiological and psychological.

Physiological:

- Cardiovascular disease
- Fatigue
- Gastrointestinal disease
- Pain
- Early death

Psychological and **occupational consequences**:

- Anxiety
- Depression
- Other mental health manifestations
- General job-stress leading to either absenteeism or excess presentism

The consequences of this are reduced quality of care and increased adverse safety incidents (Panagioti et al., 2018; Poghosyan et al., 2010; Rathert et al., 2018). In addition to debriefing sessions (immediate and later, planned) tentative evidence suggests improved support can occur via:

- Fostering positive team culture and team communication (Panagioti et al., 2017)
- Stress management and self-care interventions (West et al., 2016)
- Self-efficacy focussed interventions, such as coaching (van Mol et al., 2015)
- Individual communication skills training (West et al., 2016)
- Grief resolution therapy (van Mol et al., 2015)
- Exploration of moral or emotional distress (van Mol et al., 2015)
- Ethical rounds have also been put forward as possible means to support staff (van Mol et al., 2015)

Peer-support, mindfulness, yoga, meditation and music therapy may also help staff, however, there is a broad evidence base for these to enhance wellbeing in general settings. In ethically challenging cases, externally facilitated and structured debriefing sessions might be appropriate (Hanna & Romana, 2007). Monitoring staff support (through measures such as compassion fatigue scales, compassion satisfaction, mastery and hope, moral distress scales, impact of events, depression, grief, self-esteem) has to be countered with interventions to support staff. Organisational, individual and structural mechanisms are all needed to ensure staff feel supported to deliver end-of-life care.

2.2 Summary

Effective end-of-life care relies on an individualised approach to patients and families. It is intended to provide a respectful and dignified natural death encompassing a series of domains that meet physical, holistic, spiritual and religious needs of patients.

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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.

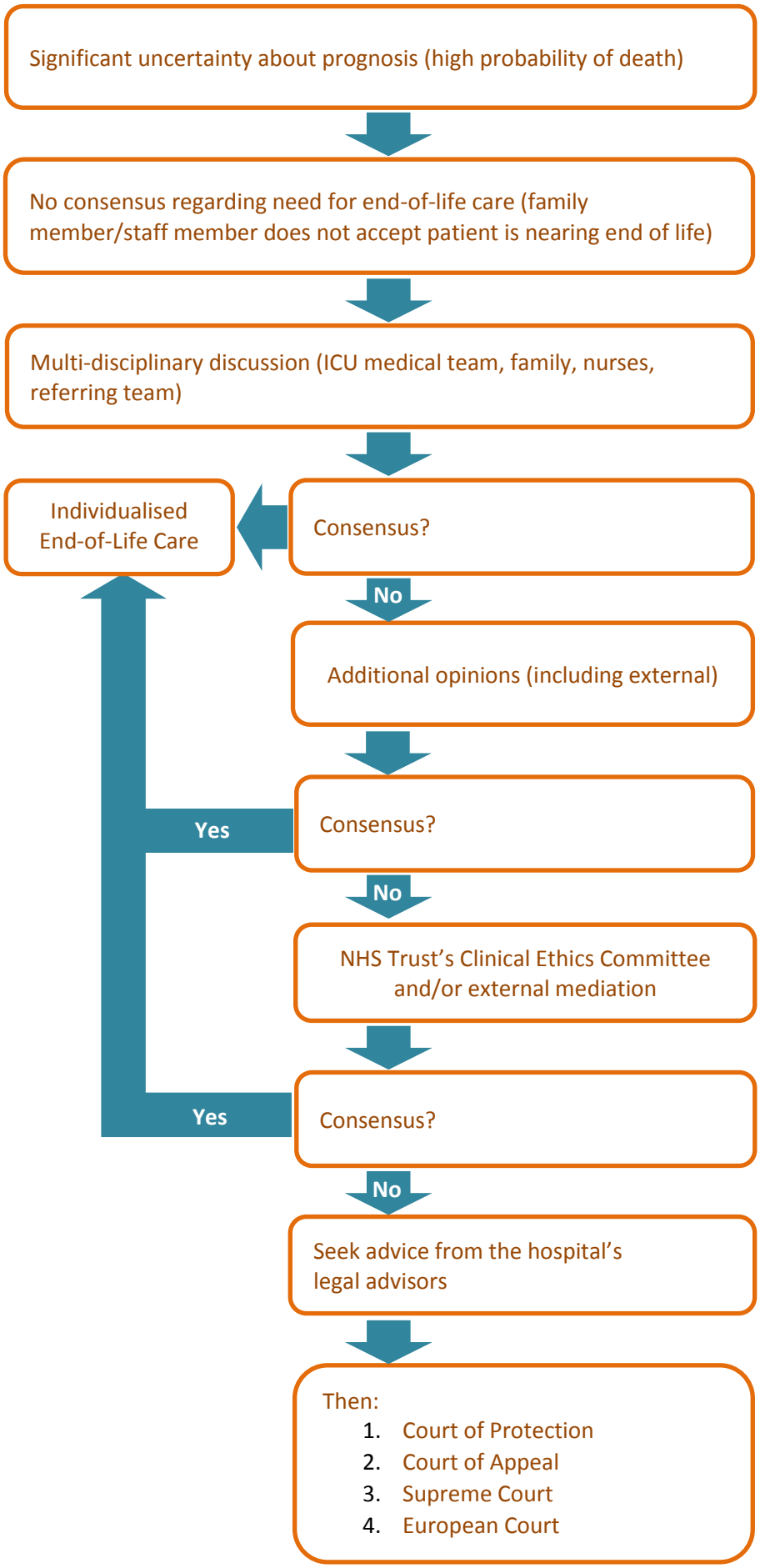
Key Points:

- 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



3.1 Understanding conflict, confusion and communication

Confusion and limited communications about withdrawal or withholding treatments is one of the main causes of both perceived and actual conflict (Azoulay et al., 2009). This can be between ICU teams and families, between different clinical teams or within the same clinical team. **Clear, honest communication from the point of admission onwards can help minimise disputes**. In most circumstances conflict can be resolved by sensitive negotiations, good listening, timely second opinions and other expert opinions. Religious and other external support can also be invaluable if the conflict is between families and clinical teams. It is essential that teams move away from a paternalistic approach and take into consideration the opinions of what families consider the best interests / wishes of the patient would be (Macfarlane et al., 2018).

If difficulties persist a more structured approach becomes necessary with the likely involvement of hospital legal and management teams (Turnbull et al., 2019). Discussions should focus on attempts to lay out plans that families and clinical teams can agree on. Meetings should be clearly documented in case notes and minuted (recording of verbatim comments rather than interpretations of what has been said). Copies should be available to all.

Nevertheless, occasions will still arise where communications completely breakdown with polarised viewpoints about best interests. At such junctures applications may be made to the Court of Protection. This is a long, drawn-out process that may destroy relationships between the parties. It is expensive and takes clinicians away from clinical roles for significant periods of time. For example, the recent paediatric intensive care case of ***Charlie Gard*** took 11-months to resolve, **being finally rejected at the European Court of Human Rights (EHCR)**. After the court case clinicians were back at the bedside having to implement that decision in the presence of the child's family (Mayor, 2017). Inevitably such processes create significant amounts of moral distress for all concerned (Henrich et al., 2017).

Conversely, the use of mediation is a flexible, cost-effective process where a neutral third-party (mediator) *facilitates discussions and negotiations*. The process remains with the parties and if a conclusion can be reached, the implementation is faster and has 'buy-in' from everyone. This greatly reduces the possibility of a post-hoc review (coronial investigation or clinical negligence litigation) where a "forced decision" may have been perceived to have occurred. Accessing mediators is straight forward: NHS Resolution has two approved panels of mediators that can help (**Trust Mediation** and **Centre for Effective Dispute Resolution**). The Faculty of Intensive Care Medicine also has a small database of medical mediators and the **Medical Mediation Foundation** is a not-for-profit organisation specialising in medical mediation.

Even if critical care clinicians have no direct involvement in a case they may be invited to act as expert witnesses. In such circumstances the judge may invite expert witnesses to provide evidence. If called upon to fulfil such roles clinicians must be aware of and declare any potential conflict of interests (General Medical Council, 2019). Conflicts could be financial, professional or personal. Lack of consideration of conflicts of interest can cloud judgement, potentially result in the wrong outcome for patients and create loss of trust between clinical teams and families resulting in significant reputational damage. It is therefore the

professional responsibility of clinicians to maintain high standards of probity by declaring such conflicts (General Medical Council, 2019).

3.2 Useful Phrases

Example 1

A Consultant in ICM was asked to review a frail 82 year-old-patient with chest sepsis who had been in hospital for 10-days after a urinary tract infection. They were hypotensive with an acute kidney injury but continued to have capacity.

"Hello, my name is……. I'm one of the critical care doctors and I've been asked to see you because the doctors and nurses on the ward have noticed that your blood pressure has fallen."

"What's your understanding about what's been happening?"

"How do you feel about that and how have you been over the last few months/years?"

"What do you think might happen if your condition worsens again/further? How do you feel about that?"

Example 2

Talking to the families of patients who are continuing to deteriorate despite escalating ventilatory, cardiovascular and renal support.

"I'm sorry as a stranger to have to talk to you at a time like this, but it's very important that I explain about what is happening to (insert name.) But before I do, have you any queries of your own?"

"I've consulted with my colleagues and it's clear that everything we've done and are doing is no longer capable of saving their life. She is now dying."

"A lot of the things we do to save a patient's life can potentially be unpleasant for the patient. We're very conscious that if we keep doing them to a dying patient, we could be committing a great indignity/unpleasantness towards them."

"Our intention now is to do everything we can to ensure (patient's name) is free from pain and distress and focus on comfort. We may not be able to remove all the tubes and machines as this in itself may sometimes cause discomfort, but we will review as we go along."

"We can't predict an exact time of death but in these circumstances patients who are like (insert patient's name) are likely to die within the next 24-48 hours."

Example 3

A family waiting to see their relative who has been admitted to the intensive care unit as an emergency.

"I'm sorry to keep you waiting, you must be wondering what's been happening. I'll update you on (patient's) condition in a minute but are there any questions you'd like to ask me first?"

"She has been transferred here because she became very unstable. Everything we're doing is aimed at stabilising their condition. I'm hopeful that we can do this but things are likely to continue to be very uncertain in the hours/days ahead."

"I can reassure you that we will continue to care for them at all times."

Example 4

A patient in an open area is dying and all cubicles on the intensive care unit are occupied by patients with infection control issues. There is no prospect of moving the dying patient to a ward-based cubicle. An explanation is given to the family:

"Ideally we'd like to move (patient's name) to a cubicle in order to afford you some peace and quiet together. Unfortunately, we're unable to do this. We'll draw the curtains to afford you some privacy but you may hear us talking to each other as we care for the other patients. We will however try to be as sensitive as possible."

Example 5

A frail 82-year-old man is intubated and ventilated on the haematology ward following a tonic clinic seizure with associated respiratory arrest. He is transferred to the ICU. He has a past medical history of bowel cancer, treated with chemotherapy, and his bone marrow aspirate and trephine from 48 hours ago is suggestive of T cell lymphoma. Treatment options include chemotherapy with palliative intent. A CT brain scan has shown central nervous system involvement (a poor prognostic sign).

A health care professional explains:
"It's clear from the test result we have that your father has a type of cancer (lymphoma) that isn't curable. The lymphoma has spread to his brain and this is why he had a seizure today. When we stop his sedation, he is still having seizures despite the medication we have given him to try and stop them."

"We can try and give more medication to stop the seizures, but we are concerned that your dad is already very frail and the chance of him being able to return to his previous health after a prolonged stay in ICU is very low."

A family member replies:
"When the doctors on the ward told dad he had lymphoma and would need chemotherapy, he said he didn't want to go through chemo again. He found the side effects so awful last time, with the bowel cancer. The doctors said they had lots of ways they could try and reduce the side effects, but he was determined just to enjoy the time he had left".

"Independence was really important to dad and he had been clear to us many times in recent years that being able to live alone and take care of himself was really important to him, and that is what really made life worthwhile for him. We think he would not want any aggressive treatment or more chemotherapy – he had said so, really, in a roundabout way, and that is what dad was like."

Further response from healthcare professional:
"It seems from what you've said that continuing with treatments wouldn't be in keeping with what your dad would have wanted. We can now talk about changing the focus of his care to prioritising comfort."

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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.

PRINCIPLES AND MODELS OF DECISION MAKING

Principles of Decision-Making

Clinicians will inevitably develop individualised practice in their approach to complex decisions. This should be adapted and developed through reflection and patient/peer/family feedback, enabling tailoring to specific circumstances in order to achieve best outcomes. The core principles of best practice are outlined below, as are recognised structured models for decision-making.

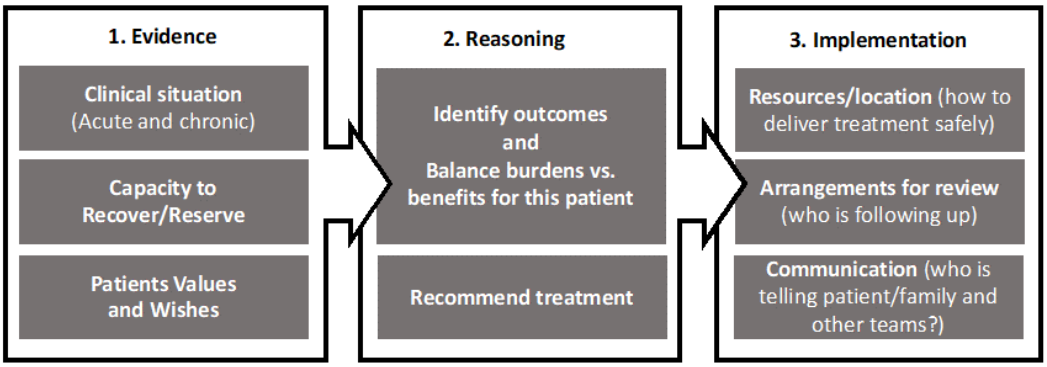
- Wherever possible the patient should be involved in discussions
- If patients are unable to participate directly, families should be involved in decision-making
- Discussions and decisions should focus on the best interests of patients
- There should be multi-disciplinary involvement in these processes
- Processes should be transparent and communicated effectively
- Decisions should adhere to relevant legal and ethical frameworks

Models of Decision-Making

The Warwick Model

Developed by the University of Warwick this model draws on an ethical framework of accountability and reasonableness (Rees et al., 2019). It focuses on evidence gathering that leads to a reasoning process of balancing benefits and burdens for patients before concluding with an implementation of an individualised care plan with arrangements for effective review and communication.

Decision-making for escalation of treatment: Warwick model



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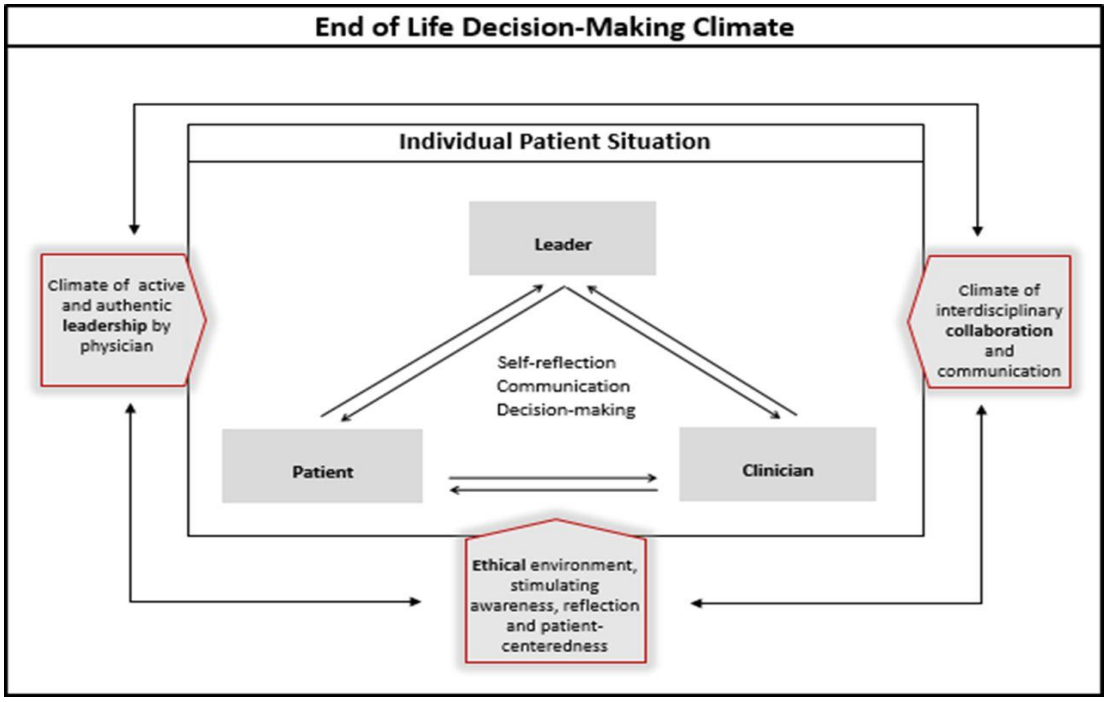
End of Life Decision-Making Climate Model (Van den Bulcke et al., 2018)

The strong ethical components to decision making are particularly influenced by cultural and organisational norms prevalent within environments in which they are made e.g. interactions between patients, clinicians and potential influence from unit leaders. This has been described as a Decision-Making Climate (Van den Bulcke et al., 2018).



MORAL Balance (Nottingham University Hospitals)

In complex circumstances the choice and reasoning for particular treatments requires an extended process. *MORAL-Balance* is an applied ethical technique developed for these circumstances:

- **M**ake sure of the facts surrounding the clinical situation
- Establish **O**utcomes **R**elevant to the **A**gents involved
- **L**evel up options by balancing likely outcomes with and without critical care support

It involves the specific use of the principles of biomedical ethics (beneficence, non-maleficence, autonomy and justice) to describe a situation and to balance burdens and benefits of a particular action in each of these domains.

4.1 Context

Good end-of-life care is reliant on the recognition that a patient is at the end of their life and dying, as highlighted in the **National Audit of Care at the End of Life (NACEL)**. This may be straightforward (with terminal diagnoses), however it may not be so straightforward for patients whose clinical condition deteriorates acutely. Some such patients may have technically reversible conditions but combinations of the severity of acute illness/injury and co-morbidities, can unavoidably lead to their death. Invasive treatments may therefore cause harm in such circumstances as they do not offer a realistic chance of medium to long-term survival. Furthermore, patients who survive intensive care can have significant physical, psychological and cognitive burdens; harms that can extend to families and carers in the form of *complicated grief* and *post-traumatic stress disorder*.

For critical care teams balancing the burdens and benefits of life-sustaining treatments and whether they enhance or diminish care is an everyday occurrence. It is seldom straightforward. Predicting who will benefit is difficult as patients respond differently to similar therapies, have differing co-morbidities, different capacities to recover from a critical illness, and attach different values to their quality of life. This frequently creates doubt, indecision and conflict as clinicians, patients and families reach different conclusions from the available information, particularly in emergency situations. Nevertheless, decisions must be made on behalf of patients. This chapter therefore aims to provide guidance on best practice in how to best ensure that decisions are patient-centred and ethically justified.

4.2 Structuring the decision-making process

In making decisions whether or not to initiate or continue with organ support, clinicians must (as outlined in the models described at the start of this document) balance the burdens and benefits of relevant treatment options and develop management plans tailored to individual needs.

4.3 Involving patients in the decision-making process

Critically ill patients who (frequently) lack capacity present major challenges for shared decision-making. However, whenever possible such an approach should be used. Consideration should be given to how patients' wishes can be elicited (e.g. communication aids, adjusting sedation and optimising mental capacity where possible and appropriate.) Previous statements, whilst not binding, should be taken into account and even though wishes may have changed this can form the basis of initial discussions. Assessments of quality of life before hospitalisation and what patients perceive as being acceptable can aid decisions. It is important to consider that capacity in critically ill patients will fluctuate. Even if patients are able to take part in conversations, it is important that capacity assessment is made and retention of information is checked at a later point, or to determine if they think differently about their treatment at a different time.

4.4 When patients are unable to participate directly

When considering patients' wishes, beliefs and values, families are often the only source of information, although their wishes may not directly reflect those of the patient. Eliciting information can be challenging but it is vital to ensure robust decisions are made for patients. Members of staff seeking this information should be sufficiently trained or experienced; with specific time being set aside for family conferences to outline diagnostic and prognostic activity. Written information and resources for families can be useful in this

process (Jain et al., 2015; Staszewska et al., 2017; Wieringa et al., 2017). Techniques available to support family conferences include using the **VALUE** mnemonic (below):

- **V**aluing family statements
- **A**cknowledging family emotions
- **L**istening to the family
- **U**nderstanding the patient as a person
- **E**liciting family questions through careful questioning (Lautrette et al., 2007)

Such challenging conversations require high-level communication skills, so formal training can be very helpful (Oczkowski et al., 2016). It is also important to regularly seek feedback from families regarding their experiences of this process and what could have been done differently. Tools exist to review the quality of such interactions and consideration should also be given as to when the best time to approach grieving families is; a process supported by bereavement services.

4.5 Decisions should focus on the best interests of the patient

Making Best Interests decisions involves establishing what the likely outcomes are for patients and balancing the relative probabilities (with and without organ-supporting interventions) against individual values and preferences. Whilst survival is frequently the outcome of the greatest immediate concern, there may be other patient-centred outcomes i.e. comfort, dignity, bodily integrity, consciousness, cognitive impairment, quality of life and quality of dying; all of which may outweigh survival as the main goal of treatment.

Establishing the outcomes most relevant to patients should therefore be a clear, early focus of communications. This should enable the burdens of organ support to be balanced against the likelihood and extent of any beneficial outcome. This process should be articulated and documented. It is important that it is conveyed to all that decisions not to pursue additional life-supporting treatments is not necessarily a sign that other interventions will be removed and critical care admission refused.

4.6 Multi-disciplinary involvement in the decision-making process

Anyone involved in treatment escalation can reference this guidance and offer input. It is applicable to all involved in the potential escalation of treatment, such as critical care outreach, (Pattison et al., 2018) and consideration should always be given to this engagement, as failure to do can lead to protracted dying, **poor end-of-life care, inappropriate treatment and resource use and complicated grief for families** (Hinkle et al., 2015; Visser et al., 2014). **They also adversely affect staff increasing the likelihood of moral distress and burn-out**. Involving and preparing the whole team is therefore paramount and the quality of communication can be enhanced by outlining what will be discussed and agreed prior to family conferences (Davidson et al., 2017; Kon et al., 2016). If there is a concern about the potential for conflict the presence of independent staff to support discussions can help e.g. pastoral care staff, clinical ethicist.

4.7 Transparency and communication

Transparency is an ethical obligation. The NHS constitution is clear that no decisions regarding a patient should be made without their involvement (**no decision about me,**

without me) (Department of Health, 2012) and this is only possible with adequate sharing of information (Section 4.3). A duty of candour surrounding patient safety is both an ethical requirement and statutory/contractual requirement for NHS organisations. Despite these ethical norms, numerous studies of communication surrounding admission to ICU have shown that patients and families frequently feel that communication is inadequate. Clinicians should communicate their decisions and the supporting rationale to patients and their families, adhering to legal and regulatory frameworks (Chapter 5).

Whatever decisions are made there should always be an openness to review, particularly if new information may change the outcome. This requires ongoing conversations with patients and families where there should be clear articulation of the evolving nature of some decision-making processes, including how sometimes a prognosis will only become clearer after days of critical care e.g. return of spontaneous circulation after cardiac arrest.

4.8 Supporting the decision-making process

It is acknowledged that clinical decision-making surrounding escalation of treatment and end-of-life care may be influenced by factors not directly related to the values or clinical condition of individual patients e.g. patients are less likely to be admitted to an intensive care unit in circumstances of limited bed availability, and that patients with a "surgical" rather than a "medical" condition are more likely to be admitted (Iapichino et al., 2001; Intensive Care National Audit and Research Centre, 2018).

To mitigate against such potential bias teams should be aware of their personal decision-making mechanisms and preferences minimising any bias influenced by the beliefs, heuristics (decisions based on experiential pattern recognition), previous experiences, and the similarity of previous decision-making circumstances to a current process (cognitive bias) (Ozdemir & Finkelstein, 2018; Power et al., 2018). Structured approaches (outlined earlier) can reduce bias and promote consistency and transparency, and formal training can also assist. Exemplars include:

Exemplar 1: University College London Hospitals (UCLH)
Talking DNACPR is a teaching initiative for clinicians run by UCLH, focusing on providing a framework for conversations in serious illness. The course encompasses legal perspectives, ethical and philosophical context, religious context, relational care and the use of high-fidelity simulations to support learning around having conversations.

Exemplar 2: Deceased Organ Donation Simulation
This two-day course is designed primarily to prepare clinicians for the challenges of approaching families in the process of gaining consent for organ donation. It includes training in the relevant ethical and legal principles surrounding organ donation. Simulation sessions with professional actors are used to train delegates in their interactions with families and how to guide decision-making in these circumstances.

RESOURCES:
Guidance and support for emergency decision-making surrounding end-of-life care

Initiative	Supporting organisation	Summary
Consent: patients and doctors making decisions together	General Medical Council (GMC),UK	This document provides a generic guide for doctors on how to approach making decisions with patients.
Treatment and care towards the end of life: good practice in decision making	General Medical Council (GMC), UK	This document outlines a generic approach to patients nearing the end of their life. It outlines decision-making models for involving patients in decisions surrounding their care.
Choosing wisely	American Board of Internal Medicine (ABIM) Foundation, USA	The purpose of this initiative is to promote conversations between clinicians and patients and to help patients opt for care that is supported by evidence, not duplicative of other tests or procedures already received, free from harm, and truly necessary.
ICU Admission, Discharge, and Triage Guidelines.	Society of Critical Medicine (SCCM), USA	This document makes suggestions as to the organisational frameworks and structures that should underpin policies for admission to ICU and prioritisation of cohorts of patients. It does not offer recommendations on how decisions for individual patients should be made.
Deciding Right	Northern England Clinical Networks, UK	This initiative was developed in the North East of England to promote shared decision-making and partnership between patients and their health care providers. It focused on advance care planning for patients with complex health needs.
ReSPECT process	Resuscitation Council (UK)	The Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) process is designed to develop personalised treatment plans for patients in circumstances where they are unable to participate in discussions surrounding their care. It is intended to replace the traditional do not attempt resuscitation process, and to include treatment options other than cardiopulmonary resuscitation.
AMBER care bundle	Guys and St Thomas NHS Trust, UK	The AMBER care bundle is an initiative designed for use in hospitals to allow structured communication and decision-making surrounding patients who may be approaching the end of their life. It recognises the uncertainty inherent in predicting recovery for some patients and promotes open and frank discussion.

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Shared Decision Making Box

Shared decision-making models: involvement of families and patients
Approaching decisions relating to end of life transitions and care, a shared decision-making model is regarded as best practice, where collaborative decisions involve all parties: health care teams, families and patients (Kon et al., 2016; White et al., 2018). Shared decision-making underpins NHS values. Individual values, goals and preferences must be considered, with overall planning of treatment goals through information exchange, deliberation and decision-making. Excellent communication skills are critical to the success of shared decision-making (SDM), and outcomes of good SDM include improved affective-cognitive outcomes for patients/families (specifically, knowledge, attitudes and emotions) (Shay & Lafata, 2015).

Involvement of patients, where they are able and have capacity, and families is paramount to SDM and family-centred care (Davidson et al., 2017). Interaction and developing a connection can be achieved through a culture of facilitating involvement by encouraging partnering in care activities (Mitchell et al., 2016).

Recommended core elements to facilitate involvement include:

- family presence in the ICU (open visiting)
- family support (access to leaflets, education, psychologists, use of patient diaries, places to sleep)
- structured communication tools (such as VALUE (Lautrette et al., 2007), SPIKES (Baile et al., 2000) and family conferences
- specific consultations with ICU teams (including chaplaincy, social workers, psychologists, ethicists, and family navigators) (Davidson et al., 2017; Lautrette et al., 2007; Pattison et al., 2013)

Nurses (and AHP) involvement in SDM is a critical part of the process (British Medical Association the Resuscitation Council (UK) and the Royal College of Nursing, 2014; General Medical Council, 2010), as nurses will be present at the bedside 24/7, are likely to have developed strong family rapport and support families/patients through the processes of transition to end of life.
Particular issues related to SDM include: difficulties in communicating with critically ill patients, lack of capacity to make an informed decision, and conflicting decisions. Patients' families may reflect their own wishes rather than the patients' wishes. Currently, decisions can be made about the best interests of the patients with no consultation with those who will be most affected by the decision, even though the consequences of those decisions are profound for patients and families. There are significant risks for complicated grief, increased anxiety, depression and PTSD in families where there is no consultation or poor communication from health professionals. Moreover, while the emphasis in SDM is on shared decisions, families may feel under pressure to help make a decision, and this approach does not suit all cultural backgrounds and beliefs (Charles et al., 2006). In the case of conflict in SDM, decision-support tools may be useful, as might ethics consultation (Davidson et al., 2017). Doctors lacking confidence in their own judgment of patients' conditions, lack of communication training and skills, as well as personal attitudes towards death and dying were all identified barriers in promoting family and patient-centred care at end of life (Visser et al., 2014), emphasising the need for guidelines and education.

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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

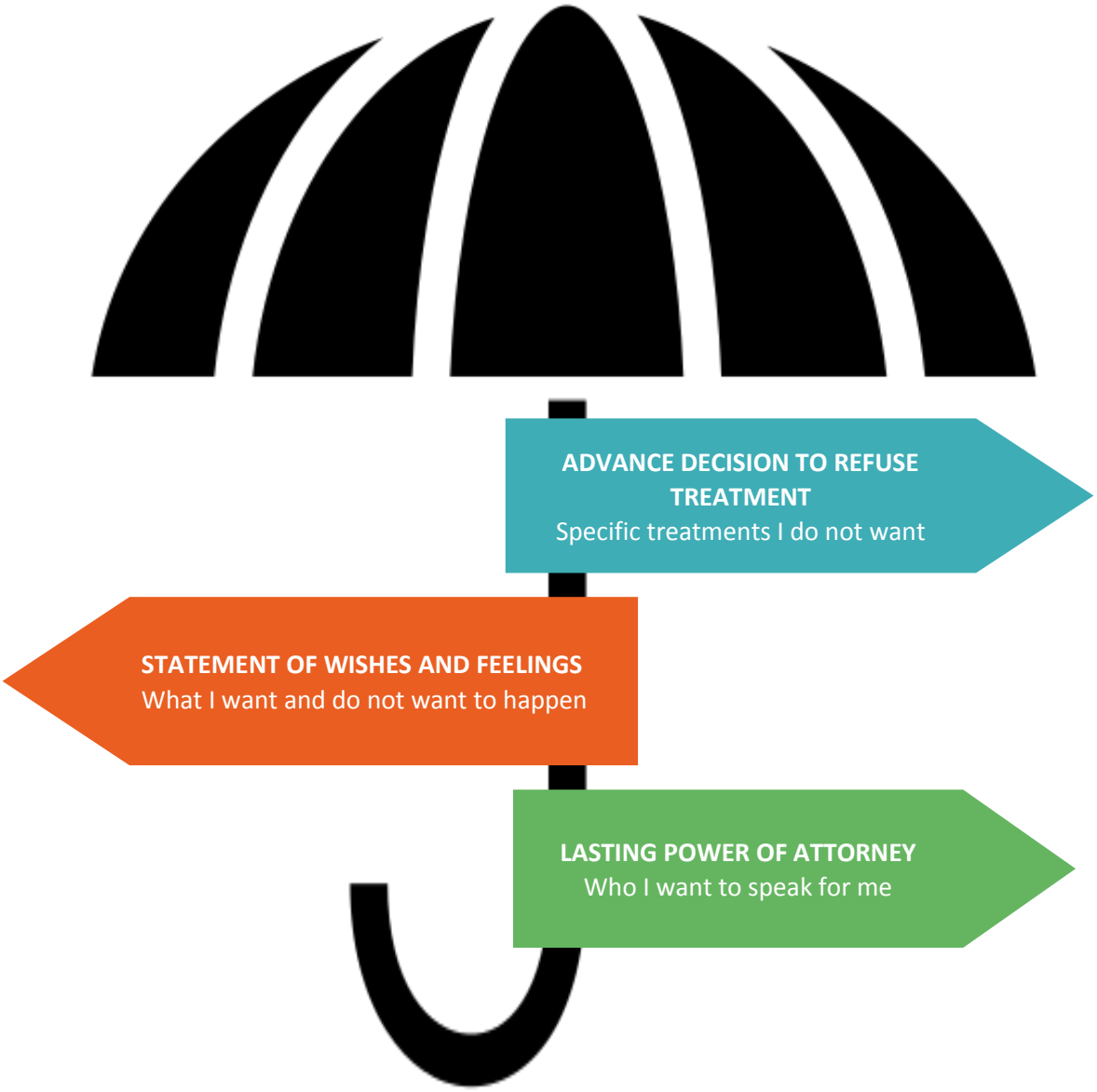
- One-third of adult in-patients may lack a level of decision-making capacity.
- ACP seeks to create a record of individuals' wishes, values and preferences so they can be considered by healthcare teams should the patient subsequently lose decision-making capacity.
- In England and Wales ACP is codified 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.

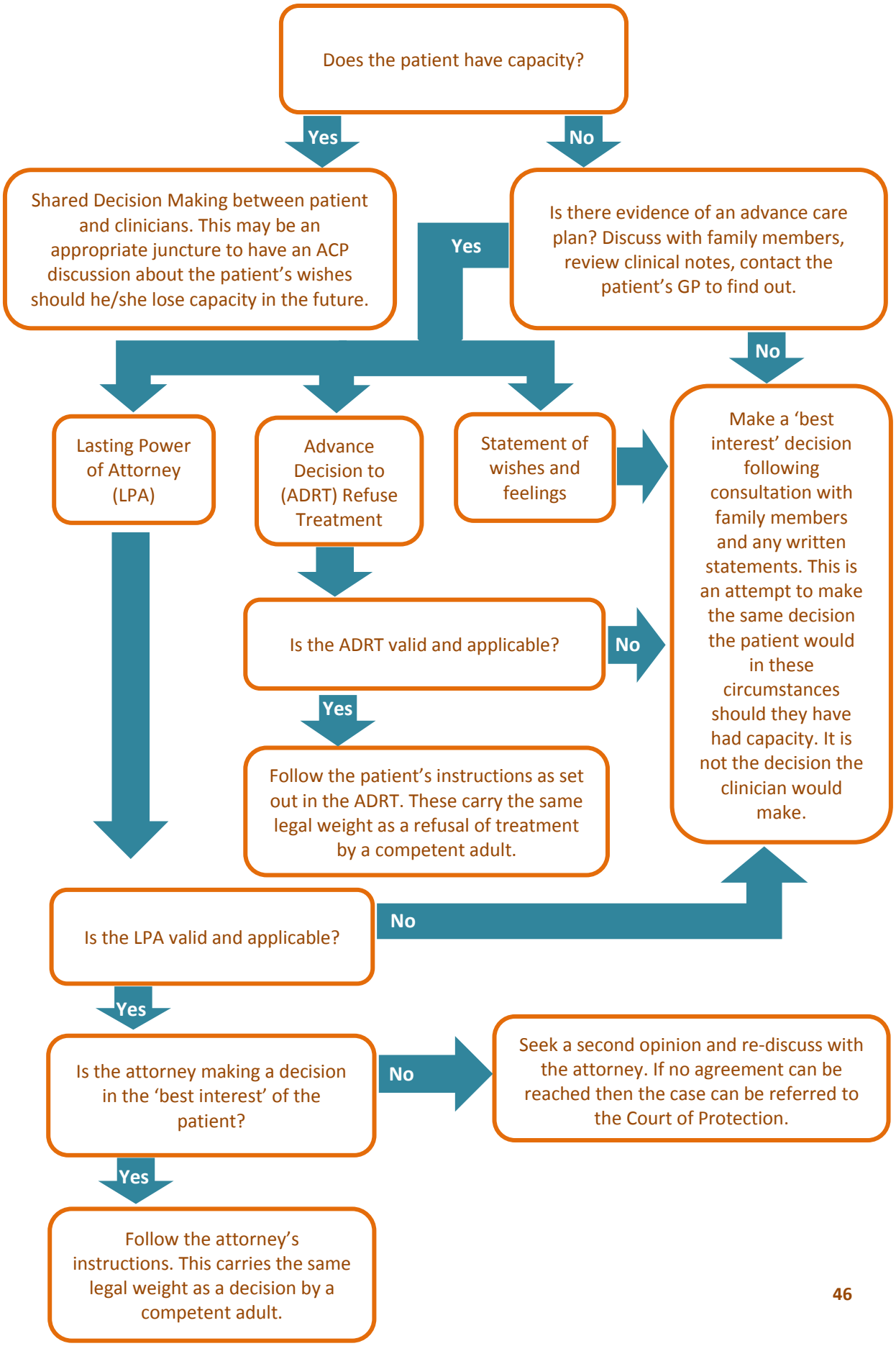
Advance Care Planning: An Overview

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



5.1 Frequently Asked Questions about Advanced Care Planning

Who should have Advance Care Planning Discussions with patients?
All staff should be open to such discussions and be able to respond to initial questions.
Questions beyond their knowledge should trigger the involvement of experienced colleagues.
Who should be present for Advance Care Planning Discussions?
Encourage patients to have others (friends, family, carers, potential Lasting Power of Attorney) present should they wish**.**
Staff should be aware in some circumstances this can inhibit patients from expressing their views.
How to have Advance Care Planning Discussions?
Timings and settings should be appropriate for comfortable and unhurried private discussions.
Information should be free of ambiguity and in *"Plain English"* (Academy of Medical Royal Colleges, 2018).
Health professionals should look for cues that patients want to end conversations.
What if patients do not want Advance Care Planning Discussions?
The ACP process can challenge coping styles or raise issues that patients are unwilling to consider. This should be respected. If treatment is subsequently required and there's a loss of capacity, a best interests process is applicable.
What if others want to withhold information from a patient?
Apart from when patients decline to hear information, clinical teams should not withhold information at the request of family members or friends.
It is helpful to acknowledge that family members may want to protect patients but it should be sensitively explained that there are ethical, legal and professional obligations to prioritise discussions with patients.
Recording Advance Care Planning Decisions
A copy of this record must be made available to patients and (if patients agree) shared with others involved in the care.
Patients should be encouraged to review documentation (contemporaneously or later) to ensure it matches what they understand was agreed.
Patients should be encouraged to share the plan with those close to them as well as health and social care staff. It should be explained that if healthcare teams do not have access, then they may be unable to put plans into action.
In England, Electronic Palliative Care Co-ordination Systems (EPaCCS) are becoming the most important way to document ACP decisions as they enable enacting decisions in an emergency setting.
What if a patient changes their mind?
Patients should be made aware that they can change their mind and advance care plans will be reviewed, and if appropriate, altered as situations and views change.
If revisions are made all copies in notes etc. must be altered.

5.2 Introduction

Investigations and audits over the last decade highlight variabilities and at times inadequacies in end-of-life care (Neuberger, 2013; NHS Benchmarking Network, 2019; Office for National Statistics, 2016; Parliamentary and Health Ombudsman, 2014; Royal College of Physicians, 2016). A consistent theme within national strategies (Department of Health, 2008; Department of Health Social Services and Public Safety, 2010; NHS Wales Health Board, 2013; Scottish Government, 2008, 2018), independent reviews (Neuberger, 2013; The Choice in End of Life Care Programme Board, 2015) and reports from organisational partnerships (Department of Health, 2015; Leadership Alliance for the Care of Dying, 2014; National Palliative and End of Life Care Partnership, 2015) has been the importance of good quality communication and the necessity of ensuring individuals are offered care that focuses on *'what matters to them'.* One route to improving this could be advance care planning (ACP). It is supported in the General Medical Council's (GMC) guidance *Treatment and Care Towards End of Life* (General Medical Council, 2010)(General Medical Council, 2010) and has recently been recommended by the National Institute for Health and Care Excellence (NICE) for all patients approaching the end of life or at risk of a medical emergency (National Institute for Health and Care Excellence (NICE), 2018).

5.3 What is Advance Care Planning?

Between 30-40% of in-patients lack capacity to make treatment decisions (Raymont et al., 2004; Silveira et al., 2010), and this will inevitably be higher in the critically ill. Previous engagement with ACP allows better decisions to be taken with greater understanding of the patients' wishes, values and preferences (Aw et al., 2012).

ACP is a global term which has been adopted to include the broad process of communication surrounding end of life decisions and to not solely focus on written directives or statements (Teno et al., 1994). The GMC define ACP as:
"discussing the type of treatment and care that a patient would or would not wish to receive in the event that they lose capacity … [it seeks] to create a record of a patient's wishes and values … ensuring that care is planned and delivered in a way that meets their needs" (General Medical Council, 2010).

ACP is a process of decision-making about *future* care which aims to be relevant over a wide range of treatment decisions and unforeseen circumstances. It allows patients' preferences, personal circumstances, goals, values and beliefs to be known to healthcare professionals even if patients are unable to communicate at the time a treatment decision is made. Like shared decision-making, it aims to bring together health professionals' expertise with patients' values and goals.

5.4 Having Advance Care Planning Discussions

ACP can be initiated at any time by either the patient or staff. Indeed, everybody regardless of age or illness should consider having a conversation about what is important to them with a friend or loved one, but most often discussions are triggered by one of the following occurrences:

- Life-changing event e.g. death of spouse, friend etc.

- New diagnosis of a life-limiting/ life-threatening illness.
- Significant changes in the treatment of an illness.
- Repeated or prolonged hospital admission(s) (National End of Life Care Programme, 2008; NHS Improving Quality, 2015).

Whilst much of ACP occurs via primary care or in outpatient settings, there will be occasions where critical care teams can initiate the process. This may be the case when reviewing patients on the ward or, upon discharge from critical care where patients' functional decline and experiences may trigger a reappraisal of future goals and wishes. Tools are available such as '**The Gold Standards Framework'** (National Gold Standards Framework, 2018) and the **'Supportive and Palliative Care Indicator Tool'** (SPICT, 2018) to help identify patients who are at greatest risk of deterioration and therefore most likely to benefit from ACP.

5.5 Statutory Framework for Advance Care Planning

When a patient lacks capacity health professionals must act in their *best interest* and this requires that they make efforts to discover information which will help them understand what the patient would have chosen had they been able to make the decision.

The Mental Capacity Act ("Mental Capacity Act," 2005) established a statutory framework for decision making for incapacitated patients including for advance decisions. Although the term ACP is not used in the Act, it does allow for three possible outcomes of ACP which can come into effect when a patient loses capacity:

- Statements of wishes and feelings
- Advance decisions to refuse treatment (ADRT)
- Lasting Power of Attorney (LPA)

Scotland and Northern Ireland have different legal frameworks to England and Wales, and therefore the MCA (2005) does not apply. Scotland and Northern Ireland both have separate legislation covering ACP which are detailed in Appendix 1.

5.6 Responsibilities of Health Professionals

- If a patient lacks capacity healthcare professionals should make 'reasonable efforts' to find out if a patient has a statement of wishes, ADRT or LPA i.e. asking the GP and family members for evidence of a written ACP, searching for electronic records within hospital, and externally, or discussing with family and asking if they have ever had conversations with the patient which might help identify their wishes, values or beliefs.
- Special care should be taken if the statement, ADRT or LPA has not been reviewed or updated for some time.
- Once discovered healthcare professionals must determine if an ADRT or LPA is valid and applicable to the proposed treatment.
- If healthcare professionals are not 'satisfied' that an ADRT or LPA is both valid and applicable they should treat the person in their best interests. They should make

clear notes explaining why they believe the ADRT or LPA is either invalid or inapplicable. The ADRT or LPA may be useful as a guide to the patient's values and beliefs and may be helpful in informing the best interest decision.

- The Court of Protection can settle disagreements about the existence, validity or applicability of an ADRT or LPA. Healthcare professionals can give necessary treatment to stop a person's condition getting seriously worse whilst the court decides.
- In an emergency, healthcare professionals should not delay treatment if there is no clear indication that an ADRT or LPA exists. If it is clear that an ADRT or LPA exists they should review its validity and applicability as soon as possible.

5.7 Advance Care Planning in the Perioperative Period

Despite reassuringly low mortality rates, ~2%, the high volume of surgery now conducted in the UK means that around 100,000 people die each year within 90 days of a surgical procedure involving either general or regional anaesthesia (Abbott et al., 2017). A high-risk population exists that whilst accounting for 12.5% of operations equates to >80% of perioperative deaths (Pearse et al., 2006). 'High-risk' patients are characterised by being older and having more co-morbidities and in addition to greater mortality rates, they have a higher incidence of post-operative complications (Story et al., 2010).

The nature of surgery and anaesthesia mean that a modification of ACP specifically for the surgical setting is required. Current advice surrounding DNACPR orders at the time of surgery explain that, in almost all cases, they require either suspension or modification to allow surgery to proceed (The Association of Anaesthetists of Great & Ireland, 2009). This provides a starting point for perioperative ACP. Firm treatment limitations, like DNACPR, will normally be inappropriate given the necessities of anaesthesia and the physiological changes inherent to surgery. Anaesthesia and surgery may precipitate deterioration, e.g. bleeding, anaphylaxis or cardiovascular instability, requiring significant medical intervention. These interventions may well be appropriate in the perioperative setting because the cause is believed to be temporary and reversible, whilst the same intervention would be inappropriate in a different context. Because of this, perioperative ACP should focus on ultimate outcomes as opposed to treatment limitations allowing for more flexibility for the perioperative team.

Similar to AAGBI guidelines regarding DNACPR orders in the perioperative period any advance care plan should be reviewed and discussed by the anaesthetist and/or surgeon with the patient prior to proceeding with anaesthesia and surgery.

RESOURCES

Initiative	Supporting organisation	Summary
Support Tools for Advance Care Planning		
Advance Care Planning Animation	Macmillan Cancer Support	This animation about advance care planning shows someone who has been told that their cancer is spreading. It describes how, with the support of a health professional, she goes on to make plans for her future care.
Supporting Your Choices	Compassion in Dying	This organisation provides packs, free of charge, to guide you through writing an advance decision or statement. There is also a free nurse-led telephone line available to discuss advance care planning.
Deciding Right Initiative	NHS Northern England Clinical Networks	This initiative was developed in the North East of England to promote shared decision-making and partnership between patients and their health care providers. It focuses on advance care planning for patients with complex health needs.
Lasting Power of Attorney Forms	Gov.uk	These are the forms and guidance you need to make and register a Lasting Power of Attorney.
Looking Ahead	St Christopher's Hospice	This document has been produced to help care home staff open up discussions with families about resident care needs towards the end of life for people with dementia.
Planning for your Future Care	National End of Life Care Programme, Dying Matters, University of Nottingham	This booklet provides a simple explanation about advance care planning and the different options open to you.
Preferred Priorities for Care	National End of Life Care Programme	This is a document for you to write down what your wishes and preferences are during the last year or months of your life.
Thinking and Planning Ahead	National End of Life Care Programme, Dying Matters, University of Nottingham	This is a volunteer training programme. It is designed to help people understand what advance care planning is, how to do it and how to assist others with advance care planning.
For Health and Social Care Professionals		
Advance Care Planning e-learning toolkit	Macmillan Cancer Support	This is an e-learning module exploring when and how to start conversations; how you can help someone discuss what's important to them and how to help them plan ahead for their future care.
Advance Care Planning: A quick guide for registered	National Institute for Health and Care Excellence (NICE)	This is a quick guide for managers of care homes and home care services outlining

managers of care homes and home care services		the key components of advance care planning.
Advance decisions to refuse treatment: A guide for health and social care professionals	National End of Life Care Programme, National Council for Palliative Care	This guide is designed to help health and social care professionals understand and implement the law relating to advance decisions to refuse treatment, as contained in the Mental Capacity Act 2005.
Capacity, care planning and advance care planning in life limiting illness	NHS Improving Quality	This guide covers the importance of assessing a person's capacity to make particular decisions about their care and treatment and of acting in the best interests of those who are assessed as lacking capacity to make these decisions.
End of Life Care for All e-learning (incldues modules on ACP)	e-ELCA, Association for Palliative Medicine of GB and Ireland	This e-learning programme aims to enhance the training and education of the health and social care workforce so that well-informed high-quality care can be delivered by confident, competent staff and volunteers to support people wherever they happen to be.
Mental Capacity Act 2005: Code of practice	Department for Constitutional Affairs.	This document is the code of practice giving guidance for decisions made under the Mental Capacity Act 2005.
Treatment and care towards the end of life: good practice in decision making	General Medical Council	This document outlines a generic approach to patients nearing the end of their life. It outlines decision-making models for involving patients in decisions surrounding their care.

APPENDIX: Statutory Framework for Advance Care Planning
The Mental Capacity Act (2005) England & Wales

Statements of wishes and feelings

Note should be taken of the patient's prior statements of wishes and feelings should they lose capacity e.g. types of medical treatment they would or would not want, or how they would like to be cared for (Department for Constitutional Affairs, 2007; NHS Improving Quality, 2014). These can be written or verbal and, although not legally binding, health professionals are required to take them into account when considering *best interests* if the patient lacks capacity to make decisions about treatments. In particular, any relevant written statements must be taken into account (Department for Constitutional Affairs, 2007). There is no set format for written statements, but they would include advance care plans, emergency care plans / treatment escalation plan (TEP) or even a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decision, so long as it has been appropriately discussed and agreed with the patient.

Emergency Care Plans / Treatment Escalation Plans

There are advisory documents designed to make communications easier in the event of healthcare emergencies for patients with complex healthcare needs. They are intended to be clear statements that ensure appropriate care and treatments are delivered in keeping with individuals' preferences. Relevant current resources for such documents include:

- ReSPECT a process supported by the Resuscitation Council (UK) that has been introduced to a number of regions in England and Wales.
- Deciding Right used in North-East England and Cumbria
- Compassion in Dying

Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Decisions

Quantitative success of CPR (return of spontaneous circulation) has to be balanced against the qualitative outcome of survival. This will be affected by hypoxic brain injury and other associated long-term adverse neurological outcomes, particularly when cardiac arrest is preceded by hours of deterioration in association with severe chronic illness. Considerations have to be given to clear discussions with patients and their families about the appropriateness of CPR i.e. it is a very undignified way to treat the newly deceased and denies those close to the patient from having quiet moments after death. **In discussions it should be made clear that DNACPR does not prevent other active treatments being given** e.g. administration of oxygen, intravenous fluids, antibiotics etc. **DNACPR is not a signal for neglect but a means of withholding an inappropriate treatment, minimising unnecessary harm and enhancing care near the end of life.**

Additionally, DNACPR decisions need not be permanent i.e. DNACPR decisions can be written during a period of severe illness when cardiac arrest would be non-survivable. If the patient recovers and survives, the decision can be reviewed and if appropriate revoked. There is now clear legal guidance for health care organisations when considering DNACPR discussions. The orders have to be patient-centred with policies that are "clear and accessible" and compatible current legislation ("Re: Tracey vs. Cambridge University Hospitals NHS Trust and Others," 2014).

In all circumstance's health professionals should revisit these documents with the patient and/or those close to them ensuring that the patient has not changed their mind, done something contrary to the advance statement (suggesting a change of mind) or that there has been a change of circumstances that may have influenced the patient's views.

Advance Decision to Refuse Treatment (ADRT)

The MCA 2005 recognises that adults have a right to say in advance if they wish to refuse treatment even if that refusal results in their death. Similar to contemporaneous decisions when a patient has capacity, the decision does not have to appear wise to others. Whilst people can make an advance decision to refuse treatment, nobody has the right to demand specific treatment i.e. no one can insist on being given treatments that healthcare professionals consider unnecessary, inappropriate or disproportionate (Department for Constitutional Affairs, 2007).

An ADRT cannot refuse actions that are needed to keep a person comfortable (basic or essential care) including warmth, shelter, actions to keep one clean and the offer of food or water by mouth. However, it can refuse clinically assisted nutrition or hydration as these are not included in basic or essential care (Department for Constitutional Affairs, 2007).

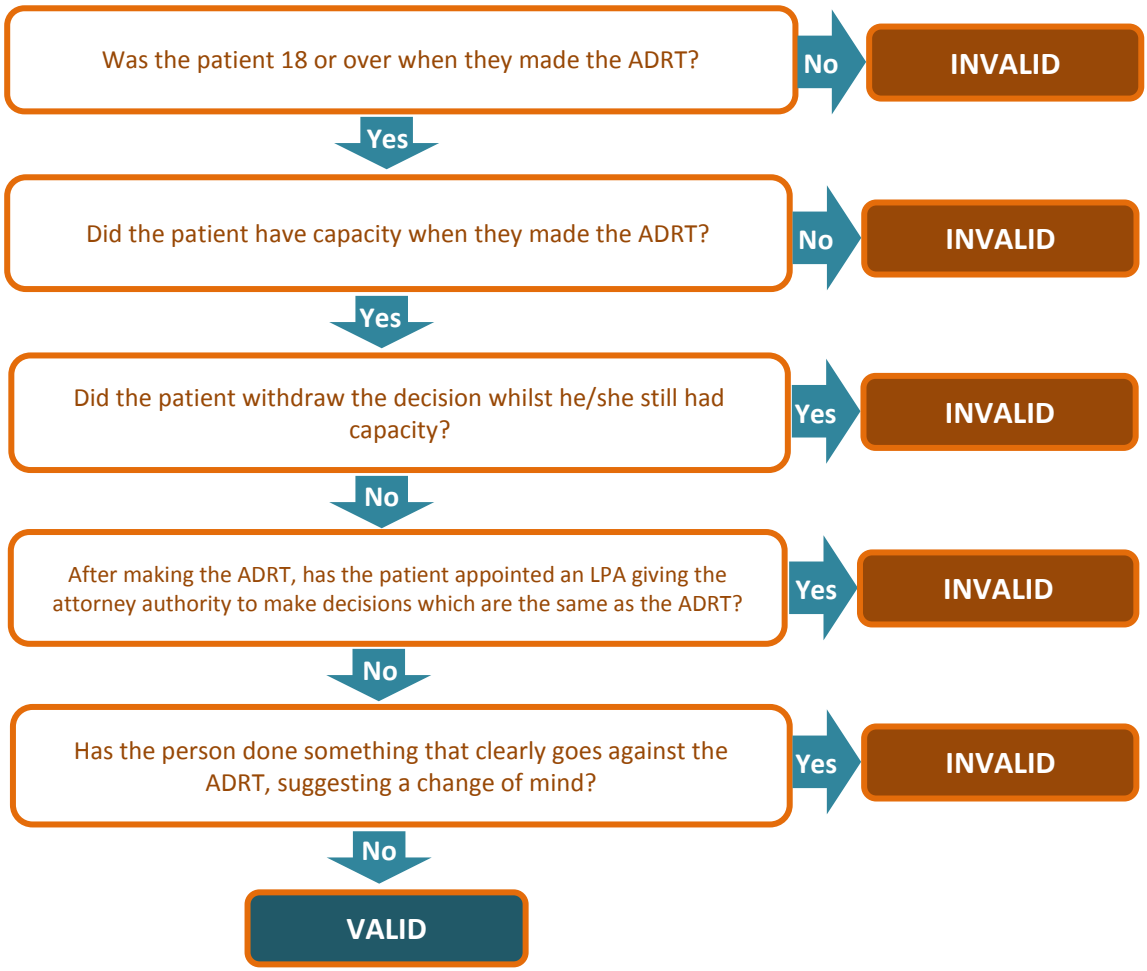
ADRTs can be written or verbal and can use medical or everyday language. It is recommended that people get advice from healthcare professionals e.g. their GP and/or an organisation that can provide advice on specific conditions or situations, but this is not mandatory (Department for Constitutional Affairs, 2007). An ADRT which includes decisions to refuse life-sustaining treatment has particular requirements:

- It must be in writing.
- The person must sign the ADRT (if they are unable to sign directly a proxy can sign on their behalf in their presence).
- A witness must be present to witness the person (or proxy) sign and then must sign the document.
- It must include a clear, specific, written statement that the ADRT is to apply even if life is at risk.

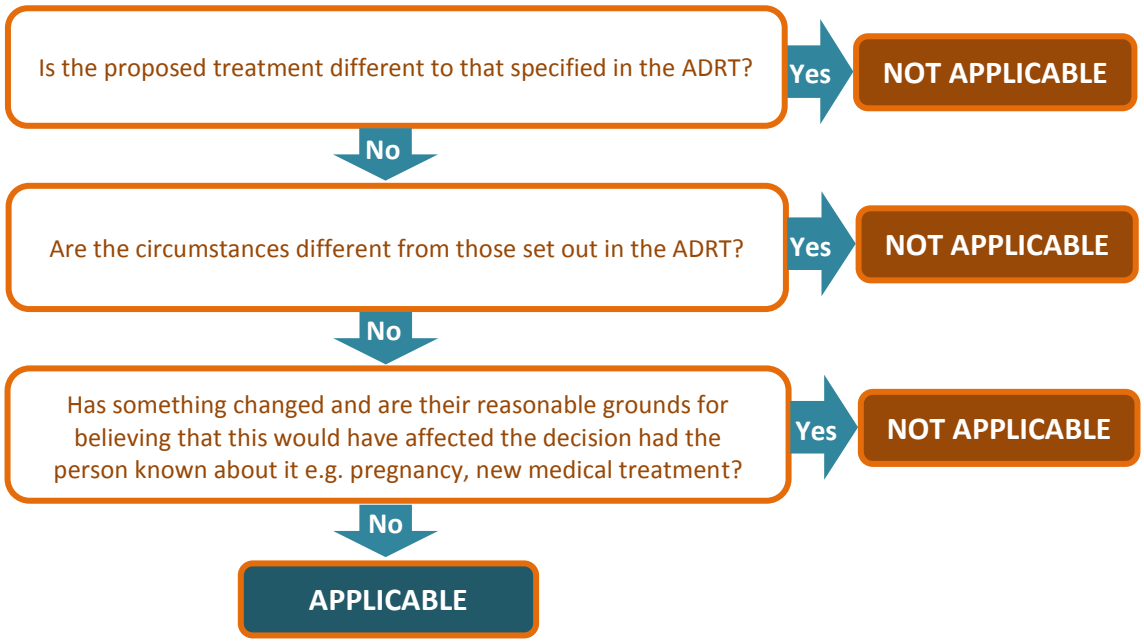
A person can cancel or alter an ADRT at any time whilst they still have capacity to do so. There are no formal processes to follow, they can cancel their decision verbally or in writing and they can destroy any original written document. Clinicians should document a verbal cancellation in healthcare records. An ADRT can refuse any kind of treatment, including psychiatric treatment, however a decision to refuse psychiatric treatment can be overruled if the person is detained under the Mental Health Act (1983) (Department for Constitutional Affairs, 2007). An ADRT refusing treatment for conditions or illnesses for which they are not detained under the Mental Health Act remains valid regardless if the person is detained in hospital under the Mental Health Act.

Any health professional who is to make a decision about medical treatment for a patient who has lost capacity is legally obliged to establish **the validity and applicability of an ADRT** (NHS Improving Quality, 2014). Even if ADRTs are not valid or applicable they should still be considered as part of a 'best interests' assessment if they are thought to be true expressions of a persons' wishes (Department for Constitutional Affairs, 2007).

Is the ADRT valid?



Is the ADRT applicable?



Lasting Power of Attorney

Sometimes a person will want to give another (an *attorney*) authority to make decisions on their behalf. *Power of Attorney* is a legal document allowing such a process. The MCA (2005) replaced *Enduring Power of Attorney* (EPA) with *Lasting Power of Attorney* (LPA). In addition to financial and property matters the option of *LPA for Health and Welfare* includes *consent to medical treatment.* LPAs must be registered with the Office of the Public Guardian before they are used (Department for Constitutional Affairs, 2007).

Similar to ADRTs, LPAs can only be created if the adult has capacity and is 18 years or older. It must be a written document set in a statutory and regulated format. The forms (which can now be completed online) allow LPAs to make decisions about personal welfare including decisions to accept or refuse treatments. Some restrictions are placed on LPAs by law and others may be added by the patient:

- Patients can add restrictions for areas where they do not want LPA to act.
- Attorneys do not have right to demand clinically inappropriate treatments.
- Attorneys do not have the right to consent/refuse treatments where:
  - Patients have capacity to make decisions for themselves.
  - Patients have made ADRTs (after nominating an LPA) that refuse proposed treatments.
  - Decisions relate to immediately life-sustaining treatments, unless, when making the LPA, the patient has specifically stated that they want the attorney to have this authority (Department for Constitutional Affairs, 2007).

Attorneys must always act in patients' best-interests. This means that they should always strive to make the same decision that the patient would have made for themselves if they had had capacity. In some circumstances a patient may have both an LPA and an ADRT. The ADRT may help the attorney illustrate decisions already made by the patient. Healthcare professionals are obliged in law to support the decision the patient would have made, and the views of the attorney are central to discovering what this would have been. This may and does include making decisions that could be considered unwise. If healthcare professionals disagree with an attorneys' assessments, they should discuss the case with other medical experts and potentially seek formal second-opinions before discussing the matter further with the attorney. If they cannot settle the disagreement, they can apply to the Court of Protection. Whilst the court is coming to a decision, healthcare staff can give life-sustaining treatment to prolong the patient's life or stop their condition deteriorating (Department for Constitutional Affairs, 2007). The court will endeavour to support the decision that best represents the patient's values and beliefs.

Adults with Incapacity Act (Scotland) 2000

The Adults with Incapacity Act (Scotland) 2000 applies to those aged 16 years or older. It places obligations on healthcare professionals to take into account past and present wishes of patients under their care who have lost decision-making capacity for medical treatments. In England and Wales an ADRT must fulfil certain requirements in order to be valid however this is not the case in Scotland. There is no specific provision within the Act for advance decisions, or directives as they are referred to in Scotland. This information does not need to be in writing. To date, such directives have not been challenged in court. It is likely that a clear and applicable advance directive would be supported as binding. As in England and Wales, advance directives cannot be used to demand treatment, only to refuse it.

The Act has provisions to allow a person with capacity to appoint a *Welfare Power of Attorney* (WPA). A WPA has the power to make decisions about personal welfare, healthcare decisions and treatment. In order to be valid, such Power of Attorney must be written, signed and registered with the *Office of the Public Guardian.*

Mental Capacity Act (Northern Ireland) 2016

The Mental Capacity Act (Northern Ireland) 2016 aims to support ACP in a similar manner to the England and Wales legislation.

Advance decisions to refuse treatment

Whilst the Mental Capacity Act (Northern Ireland) 2016 recognises that ADRTs exist (termed *statutory recognition*), it contains no *statutory provisions* relating to how ADRT should operate, nor is there any case law specific to ADRTs. A decision was made to await further common law developments and an on-going review is scheduled for presentation to the NI Assembly by May 2019 (Thompson, 2015).

Current legal positions in relation to ADRT (derived from common law) are summarised below (Law Centre (NI), 2017):

- ADRTs can be written or verbal (unlike the MCA (2005), where ADRT relating to life sustaining treatment must be written).
- ADRTs can be modified or revoked by the patient in writing or verbally.
- The existence, validity and applicability of ADRTs must be established as fact. The common law in relation to this point closely reflects the principles already set out above.
- Health care professionals should go to reasonable lengths to establish the existence, validity and applicability of an ADRT.
- Proof of the existence, validity and applicability of ADRT must be greater when it relates to life sustaining therapy.
- Where doubt exists regarding the existence, validity and applicability of ADRT the default position is on preservation of life. This allows for emergency or life-sustaining treatment to be provided until a decision is made regarding the ADRT.

When an ADRT is found to be invalid or unenforceable it should still be used to help determine a patient's best interests. Where disagreements or uncertainty exist regarding ADRTs, the High Court may act as the final arbiter.

ADRTs decisions made by patients aged 18 or over who have capacity are valid, however there is a lack of clarity in the role of ADRT for 16 and 17 years-olds with capacity (Thompson, 2015).

Lasting Powers of Attorney

Creation of LPA follows the same format as the MCA (2005), however the legal age for creating an LPA is 16. LPAs only have the ability to refuse life-sustaining treatment if this is explicitly stated within the scope of their powers.

Chapter 5: Further Reading

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