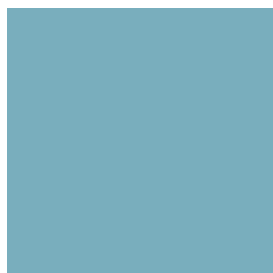


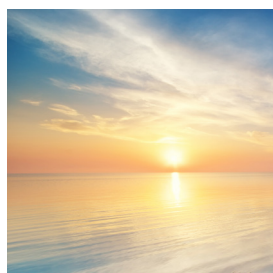
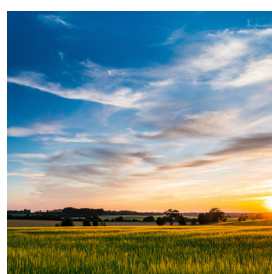
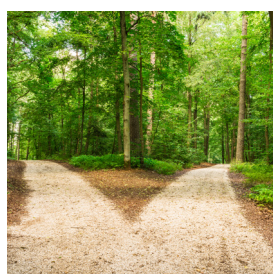
CARE AT THE END OF LIFE:

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

SUMMARY FOR PATIENTS, RELATIVES AND THE PUBLIC



September 2019



This document is a summary of the best practice guide about adult Care at the End of Life from the Faculty of Intensive Care Medicine (FICM) for patients, relatives and the public. The aim of this document is to explain the role of critical care teams that care for people at the end of life and the guidance these teams should follow.

The best practice guide consists of five chapters:

- The success and dilemmas of modern critical care medicine
- Guidance on best practice for providing care at the end of life in critical care units
- Conflict, confusion and communication in critical care medicine
- What needs to be considered when making decisions for acutely ill patients
- Advance Care Planning (ACP)

Each chapter includes key points, recommendations for best practice, discussion about the main issues and information about extra resources.

The full best practice guide is [here](#).

There is also a summarised version of the best practice guide, which contains key points, recommendations and flowcharts for each chapter, it can be found [here](#).

Note:

Hospitals may call their ward Critical Care Units or Intensive Care Units, and there may also be separate High Dependency Units. This document will use critical care as a general term meaning all of the above.

The terms 'families' or 'family members' are used as a term to mean those who are important to the patient and includes relatives, partners and close friends.

Critical care teams means the many different healthcare professionals who are looking after the patient, which include doctors, nurses, physiotherapists etc.



Executive Summary

Due to new treatments and technology in critical care units, more patients now survive critical illness. However, even with this help, 15-20% of UK critical care patients die in hospital. End-of-life care therefore remains a necessary core skill for intensive care teams. Such care includes:

- Assessing and managing symptoms e.g. pain, nausea, anxiety, delirium,
- Enabling patients and those close to them to take part in care decisions;
- Understanding legal and ethical processes for withdrawal and withholding treatments
- Minimising distress
- Ensuring patients (and those close to them) do not feel abandoned
- Meeting beliefs and religious needs

Moreover, critical care teams have to deal with changes to the patient's condition while communicating complex situations to distressed patients and those close to them. When patients are unable to make and communicate their own treatment decisions, the teams have to gather information about patients' wishes and beliefs so that care can be provided.

This document summarises key elements of critical care at the end of life so that patients, carers and clinical teams are better able to have honest conversations and engage in shared-decision making about care and treatment. This is so that the end-of-life care provided for each individual is right for them and in line with their wishes and values.

We know that surviving critical illness can have significant physical and emotional impacts on patients and their families and it is sometimes not clear which patients will be helped by critical care treatments. Patients are often too ill to decide and tell critical care teams what treatment they want to have. This is called *lacking capacity* when discussions to withhold or withdraw treatments are happening.

Only a small number of patients will have already had discussions about end-of-life care, but if healthcare professionals know what a patient would want to happen, they can give the right care to that patient. Advance Care Planning (ACP) is where patients can say how they would wish to be cared for should they become seriously ill and unable to make decisions for themselves.



CHAPTER 1

Twenty First Century Critical Care: Success and Dilemma, Intertwined

Key Points:

- Critical care medicine has been able to save more lives since the 1970s.
- As more lives are saved, people may believe that critical care units may be able to stop all patients from dying. However, up to 20% of critical care patients die in hospital. It is therefore important that critical care teams know how to provide good care at the end of life.
- Some critical care treatments can be distressing for patients. It is therefore very important to know what individual patients would wish to happen. For example:
 - Would they want critical care treatment if it meant they would only live a short time longer than if they didn't have it? These treatments could lead to patients being less awake and not being able to talk with their families.
 - If they had critical care treatments and survived their illness would they have a very poor quality of life afterwards?
- When medical teams do not tell patients and families about the uncertainties of critical care treatments actually helping the patient, it can lead to conflict between patients, families and healthcare professionals.
- There is less conflict when healthcare professionals show empathy towards patients and family and communicate clearly. This is helped when the medical teams understand legal and ethical backgrounds of the decisions that need to be made. It can also mean patients may be able to tell the medical team about their own values about the quality of life that they would want to have.

There have been many improvements in critical care medicine since the 1950s and many lives have been saved. However, for some patients, it is not clear that treatment in a critical care unit is going to be the best care for them. This uncertainty can make the decisions about care very difficult. Critical care teams have a duty to talk about such uncertainty with patients (if they're well enough to understand) and their families. It can be very upsetting for patients and families to realise that even with critical care treatments, the patients may still die. This is why it is important that there is clear communication with patients, families and critical care teams so that they can work together to provide care that an individual patient would wish for and avoid conflict and disagreement.

Talking about these uncertainties is not a means of removing hope or giving up on a patient. It is a means by which patients, their families and clinical teams can have honest discussions about the uncertainty of survival and then provide good care for individual patients.

Legal and Ethical Considerations

Critical care treatments are known as *Serious Medical Treatments*. With these treatments, it is possible that they may harm the patient more than they might help them. It is therefore important that critical care teams are aware of legal and ethical frameworks when making decisions for patients who are too ill to say what they wish to happen.

In law, patients have the right to refuse treatments but they are not able to insist they have a treatment. For patients who are able to make decisions about their care (known as having capacity), healthcare professionals must provide them with good quality information to allow them to make an informed decision about whether they want to have particular treatments. For patients who are too ill to do this (i.e. they lack capacity to make the decision in question) the medical team should first look for any advance care plans (see chapter 5) and in the absence of such documentation the medical team have a duty to find out what their wishes would be and make a decision in the patients' best interests.

The *European Convention on Human Rights* has sections (called Articles) that are important in guiding such decisions about care at the end of life.

These articles provide principles to be discussed, but they do not provide the answers for care of an individual patient. Medical teams have to weigh up what is in patients' *best interests* (England, Wales and Northern Ireland) or *least restrictive* (Scotland.)

Inappropriate Treatments

It is very important to weigh up if treatments that are supposed to help patients may cause harm. If harm will happen, the treatment is described as *inappropriate* or sometimes *disproportionate*. For example, a patient may only have a few months to live. They are offered chemotherapy that may allow them to live for up to a year but the side-effects could well mean that they have a very poor quality of life compared to a life that is shorter but better quality.

Therefore, when considering what is in a patient's best interest, critical care teams consider different types of information. They look at how ill patients are and what other health conditions they have in case these could affect the chance of recovery. They may think about:

- How will critical care treatments help patients in the short and long term?
- Could treatments offer a quality of life that is acceptable to a patient?
- Could treatments help achieve a patient's goals for a good life?
- Are there non-critical care treatments that may help the patient and be more comfortable for them?

Teams may also use information from data systems (e.g. Intensive Care National Audit and Research Centre Case Mix Programme) which contain information on how acute illnesses are affected by patients' longstanding medical conditions. The information that these systems provides can be very useful in allowing teams to explain how life-threatening a condition is, although they do not predict how an individual will respond to specific treatments.

Sometimes critical care teams may try a specific treatment for a short time to see if patients improve. For example, they might give antibiotics for 48 hours and see how a patient is after that. This is called a trial of treatment.

If the patient has capacity the critical care team should talk with them about their wishes. If patients lack capacity to make a decision about treatment, the team should look for any advance care plans setting out the patients' care preferences and in the absence of such documentation should speak with the family to see if they can provide information on patients' wishes and beliefs.



Capacity means the ability to make a particular decision. A person lacks capacity if they are unable, because of an impairment or disturbance of the mind, to understand information relating to a decision, remember the information and use it to make and communicate their wishes on the matter.

Recommendations: (taken from the full guidance document)

- *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.*

CHAPTER 2

The Provision of Effective End-of-Life Care on Intensive Care

This chapter looks at areas that are important for patients who are having End-of-Life Care in critical care units. It makes suggestions for best practice in how this care can be given.

Key Points

- It is very important that symptoms are assessed to make sure that the best, personalised care is given to each patient.
- It is important that a patients' religious, spiritual and/or cultural needs are met.
- Unless the patient has stated to the contrary involving their families can improve care.
- It is very important that the critical care team communicate clearly. This helps build trust between patients, families and the medical team and can reduce conflict.
- For individuals at the end of their life the ultimate aim is to meet an individuals' needs for a natural death.

When it is not clear if a patient needs end-of-life care, it is possible to combine active and palliative (end-of-life care) treatments for a short time. This gives times to see how a patient responds to treatment and helps begin discussions with patients (if they are well enough) and families about planning care if the patient is dying.

End-of-Life Care

Critical care teams will look at all a patient's treatments and medications to see if they are helping them. Any treatment that doesn't bring comfort to the patient or help towards a good death may be stopped. There is advice for healthcare professionals about this in a document called [Leadership Alliance for Care of Dying People](#). It suggests that patients should have individual care plans and includes:

- What is required for comfort care e.g. pain control, control of nausea, anxiety and delirium, plus management of hunger, thirst, high body temperatures and good skin and mouth care
- How to stop treatment that will make the dying process longer
- Helping patients and families to understand what is happening
- Ensuring patients are not distressed in mind or body
- Ensuring a comfortable care environment (having an individual's own items with them if possible, such as photos etc)
- Allowing patients and families to spend time together
- Meeting spiritual and religious needs

The aim for Care at the End of Life is to ensure the patient is as comfortable as possible, and the critical care team will look closely at how the patient is and what they need, and they review their care and treatments regularly.

The FICM best practice guide gives advice on the following areas:

Pain Control

Pain is common near the end of life, and it is important that critical care teams assess patients for pain. Sometimes patients can't let staff know their levels of pain, so specific assessments should be used to help identify and manage pain.

Anxiety/Distress/Agitation/Delirium

These are common symptoms at the end of life. It can help patients and families when teams explain what is happening and give reassurance about them. Obvious causes can include pain and the side-effects of some drugs. The patient will be assessed and there may be other drugs that can help. Hearing familiar voices and playing familiar music to the patient may also help.

Breathlessness and Noisy Breathing

Breathlessness can be uncomfortable for patients, but it can also make feelings of anxiety worse. Drugs such as morphine can reduce the sensation of breathlessness as can simpler ways such as hand held fans to give the patient a feeling of air on their face.

Near the end of life, mucus can build up causing noisy breathing. Some patients may not find this upsetting and it may not mean that breathing is more difficult. However, if a patient does seem distressed by it, the medical team may clear the mucous by suctioning. If mucus is still causing distress, the patient may be given drugs to dry up mucus production.

Skin care

It is important that critical care teams (particularly nurses and physiotherapists) regularly check patients' skin to monitor for pressure sores. Regularly changing patients' positions (sometimes every two-hours), washing, creams and specialist mattresses can help stop pressure sores.

Thirst, mouth care and hunger

If a patient feels uncomfortable because they are hungry or thirsty, but if they do not want to eat or drink, it can help to use ice, mouth swabs, lip moisturisers and gentle tooth brushing.

Stopping artificial food and fluids (Clinically Assisted Nutrition and Hydration or CANH)

Some patients may want to continue to eat and drink near the end of life, but others prefer not to or find it uncomfortable. Many critically ill patients are unable to eat or drink anyway and they have artificial food or drink through tubes into their stomach or veins. This can be uncomfortable towards the end of life and may make the final stages of dying longer than they would be naturally, and patients may not want this to happen. Also, for some patients, stopping artificial feeding can lead to increased sleepiness and drowsiness, owing to changes in body chemistry and this is more comfortable for patients. Critically ill patients are often too ill to be able to say what they want to happen, and so decisions to continue, stop or withhold food and fluid are made on an individual basis by their medical team based on what is in the patient's best interests. If, however, the patient has a valid and applicable Advance Decision to Refuse Treatment (see chapter 5) then this must be followed. If the person has made a Lasting Power of Attorney for Health and Welfare then the attorney(s) will make the decision, acting in the patient's best interests.

There is [specific guidance](#) for medical teams about taking away clinically assisted nutrition and hydration where patients are in vegetative states or minimally conscious states.

Taking Away Artificial Help with Breathing

Critical care patients usually need help with their breathing. This is usually from a breathing-tube (called an endotracheal tube). It can be put in the patient's mouth and into the wind-pipe or through the front of their neck (called a tracheostomy). It is usually attached to a ventilator (machine assisting breathing.) When a patient is dying, the medical team will need to decide whether or not to remove these tubes.

They will consider if:

- The breathing tube is causing discomfort and if it can be safely removed, or will taking it away cause pain and discomfort
- The tube will allow mucus to be cleared that would otherwise be uncomfortable for the patient
- The patient will breathe comfortably without the tube

- The patient is comfortable breathing normal air (normal levels of oxygen)

Artificial Support of the Heart and Blood Pressure

Critically ill patients are often given drugs to help their hearts to work and to keep the right blood pressure in their arteries. The medical team will look to see if these drugs still need to be given to the patient.

Some patients also have mechanical or electrical devices to support their heart, for example pacemakers, and implantable defibrillators. When patients are close to death these devices will be turned off because if continued, they could cause them harm.

The Critical Care Environment

The different machines that help critically ill patients can make critical care units the most technical, and even intimidating, areas of a hospital. It is a very different environment than being in a hospice or at home. However, if a patient is at the end of their life in a critical care unit, there are ways to make it as familiar as possible. For example:

- Pet therapy (animals are brought into the unit)
- Softer lighting
- Patients' own bedding
- Familiar music, smells (perfume, after shave)
- Photographs of family and friends

Where practical, machines with monitor screens can be turned away (and alarm volumes turned down) to help patients and their families. Sometimes it may be possible to take patients outside to get some fresh air. It also helps families if hospitals can offer other support at this time such as free parking or a room to sleep in overnight.

Families may want to post messages or photographs on social media for friends and relatives that are unable to visit. It is important that this is only done with the permission of a patient, as they might not want to have pictures or information about them shared.

Leaving the Critical Care Unit

For some patients at the end of their lives, it may be possible to consider if they would wish to be moved to a ward (where they may have been previously), hospices or even home. However, in doing so critical care teams must consider if this is in the best interests of the patient. For example:

- Will the move be uncomfortable for the patient?
- Is the patient likely to die during transfer or very soon afterwards?
- Will the move cause patients or families anxiety?
- Is the specialist team available that is needed if the patient wants to go home? In some cases the team might not be available at that hospital, or may not be available in time.

If patients are having end-of-life care but it is likely that they might live longer than 24-48 hours, they may be moved to a more private area of the hospital. This needs careful planning and discussion with medical teams, the patient and their family. It is very important that the medical team on the receiving ward has a very clear handover and Palliative Care teams can be a great help during this time.

A small number of critical care patients are able to go home to die. Though many patients would want to go home, the nature of critical care support means that discharging some patients home for end-of-life care could cause them distress and discomfort. Also, if a patient wishes to be an organ donor, they will need to stay in hospital. For those patients who may be able to go home, a specialist team is needed to help the transfer happen as well as support from GPs and community nursing.

Due to the complex care that some patients need, it is inevitable that some patients will die in critical care units. The teams caring for them must have appropriate skills and knowledge to care for the dying. They must explain what is happening in terms of care and treatment to their patients (wherever possible) and

their families, answering any questions and noting concerns.

Spiritual needs and cultural understanding by the medical team at end of life

It is important that patients have spiritual and cultural needs met near the end of their life and that critical care teams understand what is important to the patient. Communicating this understanding can offer reassurance to families and help ease anxieties about dying on a critical care unit.

There is [specific guidance](#) about meeting patients spiritual and cultural needs which suggests what hospitals can do to help their patients. This may be by:

- Allowing religious music and icons to be brought in
- Respecting and supporting rituals and cultural practices
- A member of a religious congregation may visit the patient. This can often be arranged by a hospital's Chaplain. Chaplains can also offer non-religious and spiritual support. They can also help in discussions if it seems that there may be conflict between the patient, family and medical team.

Bereavement care

Bereavement care means help given to families after the patient has died. Some families find it very difficult if a relative has died in critical care, rather than in another place and they may need extra support. Many hospitals have bereavement teams and support can be offered to families when patients are in their last stages of life and when discussions about end of life are happening with the critical care team. If patients are donating organs, there will also be a specialist nurse to support the family. Other means of support after death can include offering families:

- Locks of hair from the patient
- Kits to make handprints/fingerprints
- A memorial service for patients who have died in critical care.

Support for critical care team staff

There is a significant strain on medical staff who are supporting patients and their families with care at the end of life. It is important that everyone recognises the stress placed on healthcare professionals and that hospitals offer informal and formal support to their staff.

Recommendations (taken from the full guidance document)

- *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 optimise care.*
- *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.*

CHAPTER 3

Communication, Confusion and Conflict

Key Points

- End of life discussions on critical care can be challenging and can sometimes lead to difficult relationships between clinicians, patients and families.
- Poor communication and actual or perceived lack of empathy are the main reasons for conflict.
- Spending time talking with patients and families can mean there is less time available for other tasks but it is very important to do.
- Mediation (from within the hospital or external) can help minimise conflict. Mediation means when someone independent comes to talk with the patient, family and medical team when there is conflict.
- Sometimes the medical team or patients and families ask for legal help (usually from the Court of Protection).

When a patient is at the end of their life, or when it is not clear what treatment is best for that patient, can be a very difficult time for patients and their families. Clear and good communication is therefore very important to help support patients and families.

When it seems like there could be conflict, it can help if medical teams:

- Spend time talking with patients and families and listening to their views
- Discuss the options and agreeing together what care the patient will have
- Ask different healthcare professionals for their views
- Ask for help from a mediator, if needed

Unfortunately, there are times when patients, families and their medical team cannot agree on what care a patient should have. The hospital's legal and management teams may get involved at this time. Discussions should focus on trying to find a plan that families and the medical teams can agree on. It is very important that what happens in these meetings are minuted (what was discussed is clearly written out) and included in a patient's medical notes. Copies of the minutes from these meetings should be available to patients, families and the medical teams.

In some cases of conflict, it can be very helpful to ask a mediator to help. A mediator is an independent person who can work with the families and the medical team to see if they can find an answer that both can agree to. NHS Resolution have contact details of two organisations of mediators that can help in these situations. These are [Trust Mediation](#) and [Centre for Effective Dispute Resolution](#).

Occasionally patients, families or the medical team feel they cannot agree on what care the patient should have. They may ask for a judge to decide by going to a Court of Protection. This process can take a long time.

In such difficult situations, and when it is not clear what treatment is best for a patient but when decisions may have to be made quickly, it can be hard for medical teams to communicate clearly. The best practice document gives case studies to help medical teams think about how they can communicate in a way that is helpful and supportive for patients and families.

Recommendations (taken from the full guidance document)

- *Avoiding firm predictions (positive or negative) can minimise conflict.*
- *Honesty and empathy in communications are essential.*
- *Clear, contemporaneous documentation can aid future discussions.*
- *Using empathic 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.*



CHAPTER 4

Clinical decision-making in acute situations

This chapter in the best practice document gives information that could be useful for healthcare professionals making decisions in situations where it is not clear if a patient will live.

Key points:

- Healthcare professionals should work with patients and families early on to decide on the best care for each individual. This is called shared decision making. It is very important that every effort is made to find out patients' wishes.
- There should be a structure to the decision-making process (meaning that certain steps are followed in each decision) and these steps should be clearly written down and communicated. The decision should include clear and objective reasoning.
- Healthcare professionals should make sure their decisions follow national medical guidance as well as legal, ethical and regulatory rules.
- Healthcare professionals and hospitals should have a clear process if patients or families disagree with the decisions that have been made for their care.

Critical care treatment can be physically and emotionally difficult for patients. In emergency situations critical care teams have to make decisions quickly and they may only have limited information and they may not know what treatment the patient would wish to have.

Deciding what is in a patient's best interests in these situations is very difficult. For example:

- Even though a patient may have been ill for a long time, they may never have talked with their families about what they would wish to happen if they became very ill. So if the patient is too ill to say what they want, families and the medical team may not know what care the patient would want to have.
- Each patient is different and looking at information about how other similar patients have responded to treatment, cannot tell the medical team what may happen with this individual patient.
- There may be different views as to what the best thing to do is:
 - between the patient and their families
 - between families and healthcare professionals
 - between different families
 - between different healthcare professionals

When a patient becomes sick very suddenly, decisions have to be made quickly to make sure that patient has the care that they need. In these situations, there may not be time to talk about what the patient's wishes are, or they may be too sick to say. If the patient is too ill to say what they want, and if they have not said or written down what their wishes are, then medical teams may (under most circumstances) give the patient treatment to save their life. This is the case even if the treatment may only mean a very poor quality of life afterwards, which a patient may not have chosen. If the patient lives but is still unable to say what they would want to happen, the medical team need to make a decision about what care and treatments they should have next. This is called *Best Interests*.

There are important principles for medical teams to think about during this decision-making:

- As well as looking at the medical condition of the patient, they must also try and find out the beliefs and values of the patient

- Wherever possible patients should be asked what they would want to happen
- Families should also be included in discussions and be asked what they think the patient would want
- It is very important that there is good and clear communication, that it is clear how the decision is made and that different healthcare professionals are involved.
- Decision-making processes should follow ethical and legal frameworks

There is information that can help medical teams think about the best way to make such difficult decisions. The best practice document looks at three ways of doing this, the *Warwick Model*, *End of Life Decision-Making Climate* and *MORAL Balance*.

When medical teams follow a decision-making plan, such as one of these models, it means that patient, families and healthcare professionals can trust that the decisions made are fair, consistent and in the patient's best interest. It means that it is very clear what information has been considered and how that has been used to put together a treatment plan for an individual patient.

Involving patients in decision making process

Many critically ill patients are too ill to be able to talk with their doctors about the care that they want to have. However, it is important that medical teams and families try and see if there are ways to communicate with the patient to ask their views. If it is possible to communicate, doctors need to check that the patient has capacity to make decisions, and if they understand what is being asked of them.

When Patients are Unable to Participate in the Decision-Making Process

When patients are too ill to say what they wish to happen and there is no legally binding Advance Decision or Lasting Power of Attorney, families are often the only source of information about patients' wishes, beliefs and values. However, sometimes what a family wants to happen is not the same as what the patient wants, or there may be different views within a family. This is very challenging for healthcare teams. Yet, it remains important that families are asked about what the patients' values are and what they would want to happen. It may help to arrange a time to talk with the family and to discuss what treatment the patient could have and weigh up how this might help or harm the patient.

It is important that healthcare professionals have training or experience in having these conversations with families. Principles that can help during these conversations are:

- Valuing family statements
- Acknowledging family emotions
- Listening to the family
- Understanding the patient as a person
- Eliciting family questions through careful questioning

Transparency and communication

Healthcare professionals must communicate clearly to families any treatment decisions made for a patient. They must say why the decision has been made and what information it was based on.

The condition of critically ill patients can change very quickly, and so it is important that the medical team review any decisions that have been made if the situation changes. For example, if a patient suddenly responds to treatment and becomes less ill, they may need different treatment than was planned for them. This means that decisions can change when new information becomes available, and families need to be kept up to date with this.

Recommendations (taken from the full guidance document)

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



CHAPTER 5

Advance Care Planning within Adult Intensive Care Medicine

This chapter in the best practice document looks at Advance Care Planning (ACP).

Key points:

- Up to one-third of patients in hospital are unable to make decisions about their medical care. This is known as *lacking capacity*.
- Advance care planning seeks to create a record of individuals' wishes, values and preferences that can be considered by healthcare teams at a time in the future should they not have capacity to make decisions about their care.
- In England and Wales ACP is covered by the Mental Capacity Act (2005). Scotland and Northern Ireland have their own legislation.
- Advance care plans can include an Advance Statement, an Advance Decision to Refuse Treatment, a Lasting Power of Attorney for Health and Welfare as well as Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) forms.
- ACP can be done at any time and the conversation may be started by either patients or healthcare professionals.
- The National Institute for Health and Care Excellence (NICE) believes that ACP is particularly important for patients approaching the end of life or at risk of a medical emergency.

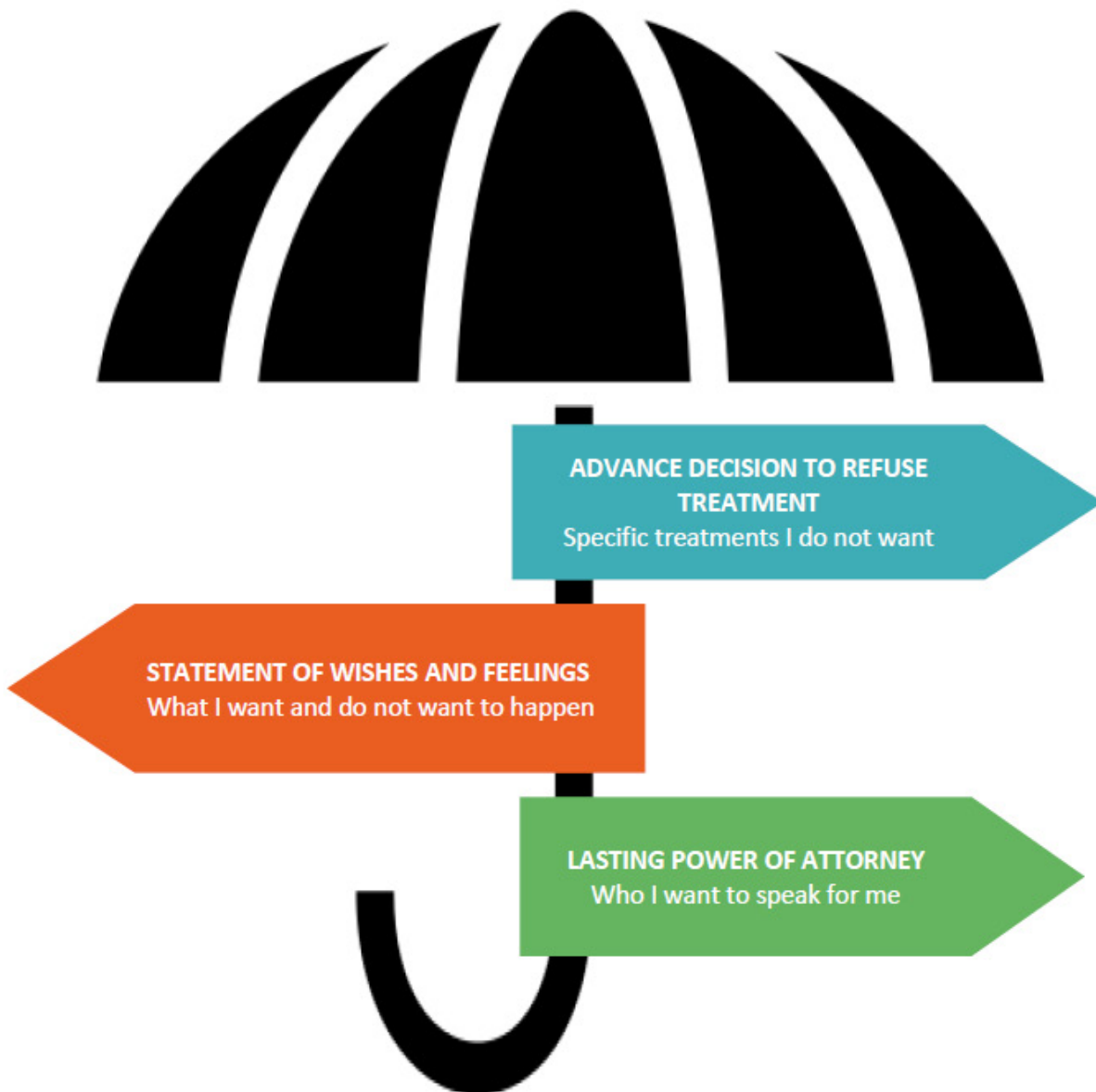
What is Advance Care Planning?

Advance Care Planning (ACP) is where patients can say how they would wish to be cared for should they become seriously ill and not able to make decisions for themselves. Many critically ill patients are too ill to understand and make decisions about their care. They often have not made any clear statements to medical teams or families as to what exactly their beliefs and wishes are. ACP seeks to create a record of patients' wishes, values, preferences and decisions, helping to make sure that the care they have is the care that they want.

ACP can:

- Reduce conflict and confusion when patients have lost capacity and decisions need to be made about their care
- Help dying patients die in a place of their choice e.g. home or hospice
- Reduce conflict during end-of-life care by helping families during the last days of their loved one's life and reduce the strain on health care professionals
- Enable honest discussions between patients, families and critical care teams allowing patients to have the individualised care that they want.

There are different types of Advance Care Planning:



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.

Note: DNACPR stands for Do Not Attempt Cardiopulmonary Resuscitation and is where a patient has said they would not want their heart started again if it stopped.

The best practice guide has a useful summary of questions and answers about ACP.

When should Advance Care Planning Discussions happen?

It is helpful for all of us to talk to family and friends about our future wishes, particularly where healthcare and serious illness are concerned. Anyone can start such conversations at any time; but it usually comes from patients or healthcare professionals at GP visits, out-patient appointments or during inpatient care.

Legal Framework for Advance Care Planning

In England and Wales, the legal framework that covers ACP is the Mental Capacity Act 2005. There are different laws for Scotland and Northern Ireland. There is more information in the best practice guide.

ACP allows a person to communicate their treatment preferences when they lack the capacity to make a decision themselves.

If a person lacks the capacity (see definition on page 5) to make a decision and they do not have a valid and applicable Advance Decision or a Lasting Power of Attorney, then the critical care team must make a decision in the person's best interests. This means that in addition to clinical information they must try to discover other matters which will help them understand what the patient would have chosen had they been able to make the decision for themselves.

It is very important that even if there is a written document, or there has been a conversation about a patients' wishes in the past, that the critical care team makes efforts to find out whether or not a patient has changed their mind.

Advance Care Planning: Professional Responsibilities

If a patient is too ill to say what treatment they want healthcare professionals should make 'reasonable efforts' to find out if a patient has written an Advance Decision to Refuse Treatment (ADRT) or if someone has Lasting Power of Attorney (LPA) for Health and Welfare. For example, they can ask the patient's GP and family members for any evidence and look at the patient's medical notes.

If there is an Advanced Decision that is valid (i.e. signed, witnessed, made by an adult whose capacity at the time is not in doubt, and the circumstances and treatments to be refused are clearly set out) and applicable (i.e. the refusal covers the current circumstance and there is no evidence that the person has changed their mind), healthcare professionals have a legal obligation to follow it.

If a Lasting Power of Attorney for Health and Welfare has been made which grants the attorney(s) authority to make decisions about life-sustaining treatment, then they (the attorneys) become the legal decision-maker.

If healthcare professionals are not satisfied that an ADRT or LPA is valid and applicable they should treat the person in their 'best interests'. The healthcare professional should make clear notes in the patient's medical records explaining why they believe the ADRT or LPA is either invalid or inapplicable. However, it may still be useful as a guide to the patient's values and beliefs and may be helpful in informing the best interest decision. There is more information about what makes an ADRT/LPA valid and applicable in the best practice guide.

Occasionally the Court of Protection needs to 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 check its validity and applicability as soon as is possible.

If none of these two documents exist then, healthcare professionals need to make a decision in the person's best interest by looking at clinical information and gathering information from advance statements and family and friends (see Chapter 4 for more information on best interest decision-making).

Advance Care Planning before, during and the days after major surgery (Perioperative Period)

Up to 1.5 million patients undergo major surgery every year in the UK. ACP is an important part of the discussions and consent that happens before surgery. Some patients may already have some form of ACP when they are referred for surgery. However, there are special points to consider before having an anaesthetic and surgery, and patients may want different treatment during this time than they would normally. For example, they may have said they would not usually want their heart started if it stopped (called Do Not Attempt Cardiopulmonary Resuscitation) but they may want their heart to be restarted if possible if it stopped during surgery. Therefore, it is very important that ACP is discussed before surgery so medical teams know what care a patient wishes to have.

Recommendations (taken from the full guidance document)

- *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 and to ensure that the treatment they provide is legal.*
- *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.*

Conclusion

Many patients receive care at the end of life in critical care units. It is therefore very important that medical teams have the knowledge, skills and experience to provide good care during this time. It can be a very distressing time for families, and good, clear and empathetic communication from healthcare professionals is very important.

Making decisions about the best care for an individual, when they are not able to decide themselves, is very difficult. The FICM document *Care at the End of Life: A guide to best practice, discussions and decision-making in and around critical care* sets out the areas that medical teams need to consider to provide good end-of-life care to their patients.

The best practice guideline was produced by the Care at the End of Life Working Party. This was a group of healthcare professionals and patient and relative representatives who worked with the Faculty of Intensive Care Medicine (FICM) between November 2017 to September 2019.

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

Care at the End of Life: A guide to best practice, discussion and decision-making in and around critical care summary for patients, relatives and the public is endorsed by the following organisations:



The following reviewed and fed into the guidance during its creation:

- Dying Matters
- The Royal College of Anaesthetists Lay Committee

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