

## Dying in Intensive Care



Health Education England

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Outstanding ☆



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ENTRANCE

By the end of this session you will be able to:

- Describe the key issues and challenges facing dying patients and their families in an ICU setting
- Describe triggers to conversations about end of life care in ICU and explain how these conversations may be approached
- Recognise the signs and symptoms that indicate that treatment may be becoming futile in dying patients in ICU
- Explain how decisions about ceiling of intervention may be made
- Outline a sensible approach to managing end of life care for patients in an ICU situation

Intensive care units (ICUs) can be frightening places for patients and their families. When treatment becomes futile, the focus of care shifts. Providing care and support for patients and families in this situation can be challenging.

Determining the appropriate levels of medical intervention, recognising when a patient is dying, initiating conversations and decision making about end of life care require skills and sensitivity. Assessing and controlling pain and symptoms in unconscious patients can be difficult.

Through a case study, this session offers some strategies for approaching such clinical situations, illustrates some of the challenges and highlights points for further learning and reflection.



This photo is for illustrative purposes only and the person depicted is a model.

Before looking at the case study in detail, let us look at what is known about death in intensive care units.

Every year in England, Wales and Northern Ireland approximately 150,000 acutely sick patients are admitted to an ICU. The focus of care is to provide organ support to patients aiming for cure and recovery.

In the UK on average, ICU mortality rate is 16% (Fig 1) with an overall mortality rate for patients who have been in ICU of 22% (Fig 2).

The mortality rate for elective surgical admissions admitted to ICU is 8.7%, whereas the rate for non-surgical admissions is 38.5%.

Death and end of life care are not unusual on a typical ICU

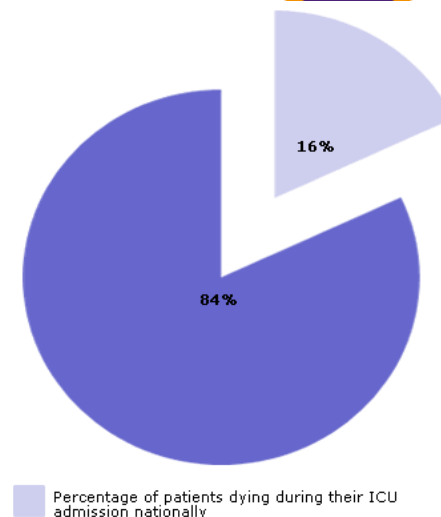


Fig 1 England, Wales and Northern Ireland mortality rate during ICU admission

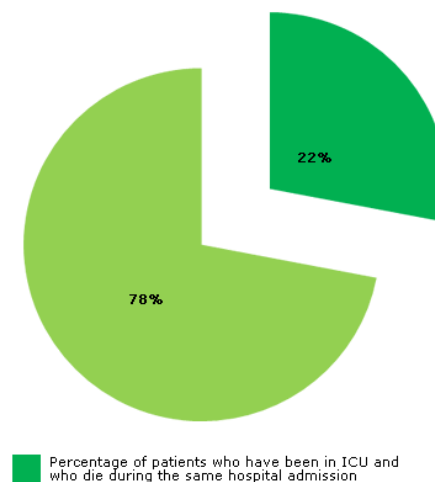


Fig 2 England, Wales and Northern Ireland hospital mortality rate for patients who have been in ICU

**Question:** What do you think are the challenges involved in providing end of life care for a patient on ICU?

**Answer:** There are various challenges involved in providing end of life care for a patient on ICU. These will vary from patient to patient but can include the following:

- Clinical challenges
- Ethical issues
- Communication challenges
- Environment
- Organ donation



## Clinical challenges

- Recognising that a patient is irreversibly dying
- Different views between healthcare teams regarding the likely outcome
- Undertaking assessment of pain and other symptoms in unconscious sedated patients

## Ethical issues

- Treatment in the setting of futility
- When is escalation futile?
- Withdrawing and withholding treatment
- How to assess the best interests or wishes of an unconscious patient
- Ensuring that advance care plans and advance decisions to refuse treatment (ADRTs) are taken into account



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## Communication challenges

- Communication between different healthcare teams involved in the patient's care
- Communication with families and within families, especially large families where information and understanding may not be shared fully or equally between different members
- Families may be unprepared for a sudden acute event, deterioration, or death
- No chance for patients and loved ones to say goodbye
- Patients are often sedated and ventilated and have no opportunity to communicate with loved ones
- Managing expectations and hopes that maximal medical treatment will succeed
- The emotional rollercoaster for families as patients improve then deteriorate repeatedly
- Explaining complex medical situations, treatments and terminology to families

Can we wake her up to say goodbye?

There is so much I need to plan and ask him. We never thought that this would happen.

We thought he would pull through with all this technology.

## Environment

The high tech environment in ICU can result in:

- Relatives' fear of touching their loved one or dislodging instrumentation
- Lack of privacy for patients and their families
- Alarms, monitors, and noise being frightening and intrusive
- Difficulties for relatives in visiting and staying for long periods of time

I was scared to touch him in case I dislodged something and he died because of me.

How can I cuddle him and say goodbye?

## Organ donation

Awareness of when this may be appropriate, which patients are potential donors, and how to raise this issue sensitively.

Tissue and organ donation is covered in more detail in the following session:

- Communication Skills/Request for Organ and Tissue Donation



Mrs Peters is 70 years old. She used to be a heavy smoker. In the last year, she has had three admissions with shortness of breath related to chronic obstructive pulmonary disease (COPD). Mrs Peters was found unconscious on the floor by her neighbour, who called an ambulance. She was intubated by paramedics and brought to hospital. In the Emergency Department she was diagnosed with a severe community acquired pneumonia. She remained ventilator-dependent and was transferred to ICU for ongoing care.

Her daughter Susan arrived just as Mrs Peters was being transferred from the ward. She is 26 weeks pregnant with Mrs Peters' first grandchild and usually visits her mother daily on her way home from work.

The notes from a previous admission reveal that Mrs Peters is usually short of breath on minimal exertion, such as getting dressed. She has home oxygen for symptom relief of breathlessness on exertion.



1. What factors in the history are important when considering Mrs Peters' prognosis?
2. What other information would be helpful?

## Feedback

1. The following factors are important when considering Mrs Peters' prognosis:

- Mrs Peters has required hospitalisation three times in the past year with exacerbations of COPD
- She is on home oxygen and her exercise tolerance is poor - she is short of breath on minimal exertion

2. A history of previous ventilation, either invasive and non-invasive, is also an important prognostic factor.

Overall the history points towards a poor prognosis.

Prognosis can be difficult to predict, particularly for non-malignant disease. Determining whether an exacerbation or acute deterioration is likely to be a terminal event can be difficult.

**Question:** What prognostic tools can be helpful in determining prognosis in advanced disease?

**Answer:** Tools such as the Gold Standards Framework (GSF) Prognostic Indicator can be useful

You can also use the surprise question:

“Would you be surprised if this patient died in the next 6 months to 1 year?”

These tools can help with initiating advance care planning (ACP) discussions with patients with advanced disease, like Mrs Peters, before an acute event occurs. This allows the patient's wishes to be explored and documented and therefore be clearer to the healthcare team.

Specific features in COPD, such as FEV1<30% predicted and more than three admissions in the preceding year, are associated with a prognosis of less than one year. Features suggesting that the patient may be difficult to extubate and/or wean from a ventilator include dependence on home oxygen for more than 15 hours a day, and muscle wasting.

**More details of indicators – the relative surprise question, general and specific, above**

**Step 1 The Surprise Question**

For patients with advanced disease of progressive life-limiting conditions, should you be surprised if the patient were to die in the next 6 months, or less, or not?

- The answer to this question should be an intuitive one, pulling together a range of clinical, or morbidity, social and other factors that give a whole picture of deterioration. If you would not be surprised, then what measures might be taken to improve the patient's quality of life now and in preparation for possible further decline?

**Step 2 General Indicators**

Are there general indicators of decline and increasing needs?

- Decreasing activity – functional performance (e.g. walking, sitting, standing, eating, drinking, etc.) and increasing dependence in most activities of daily living
- Co-morbidity is regarded as the biggest predictive indicator of mortality and morbidity
- General physical decline and increasing need for support
- Advanced disease – clinically deteriorating complex symptoms/signs
- Decreasing response to treatment, decreasing reversibility
- Choice of no further active treatment
- Progressive weight loss (> 10% in past six months)
- Repeated admission to hospital
- Spontaneous or planned admission to hospital
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**Step 3 Specific Clinical Indicators – flexible criteria with some overlap, especially with those with frailty and other co-morbidities.**

**X) Cancer – rapid or predictable decline**

**Cancer**

- Advanced cancer
- Where used previously for cancer patients are available e.g. PPS (UK solicited Prognosis in Palliative care Study), W, W, W, etc. Prognosis tools can help but should not be applied blindly
- The single most important predictive factor in cancer is performance status and functional ability – patients are spending more than 50% of their time in bed/lying down or require to be nursed 24 hours a day

**Y) Organ Failure – acute decline**

**Heart Failure**

- At least two of the following factors:
  - Diagnosis assessed by doctors (e.g. ECG, chest X-ray, etc.)
  - Recent hospital admissions (at least 3 in last 12 months due to HF)
  - Difficulty to wean oxygen therapy
  - NYct grade 3/4 – evidence of breath after 300 minutes on this level is confirmed to occur
  - Signs and symptoms of right heart failure
  - Continuation of other factors – i.e. anaemia, previous PAF/atrial fibrillation, etc.
  - More than 4 months of symptoms/signs for HF in preceding 6 months

**Smart (Stroke)**

- At least two of the following factors:
  - CH (MRS) Stage 2 or 3 – absence of breath at rest or minimal exertion
  - Prognosis thought to be in the last year of life by the care team – “the surprise question”
  - Repeated hospital admissions with heart failure symptoms
  - Difficult to wean or extubate or requires complex respiratory support

What are the principles of good communication in an ICU setting?

## **Feedback**

You may have thought of some of the following principles of good communication in an ICU setting:

## **Environment**

Talking to relatives away from the distraction and noise of monitors and in a private, quiet comfortable space is important.

## **Time and introductions**

It is important to introduce members of the team involved in the discussions to the patient and relatives and explain their roles. Allow time for conversations without interruption.

## **Language**

Medicine in ICU is highly complex. Health professionals working in ICU are highly skilled and used to jargon and complex physiological processes. Explanations and information needs to be at the level of the patient or relative's understanding. Medical terminology and jargon should be avoided or explained.

## **Multidisciplinary**

Conversations should be multidisciplinary wherever possible. This provides support to the health professional taking the lead with the conversation (usually a doctor). It also facilitates ongoing support and reiteration from nursing staff by the bedside if necessary. This helps to ensure that the message from all healthcare staff is the same and avoids confusion and miscommunication. Discussions can be difficult and alternative ways of phrasing information can also help.

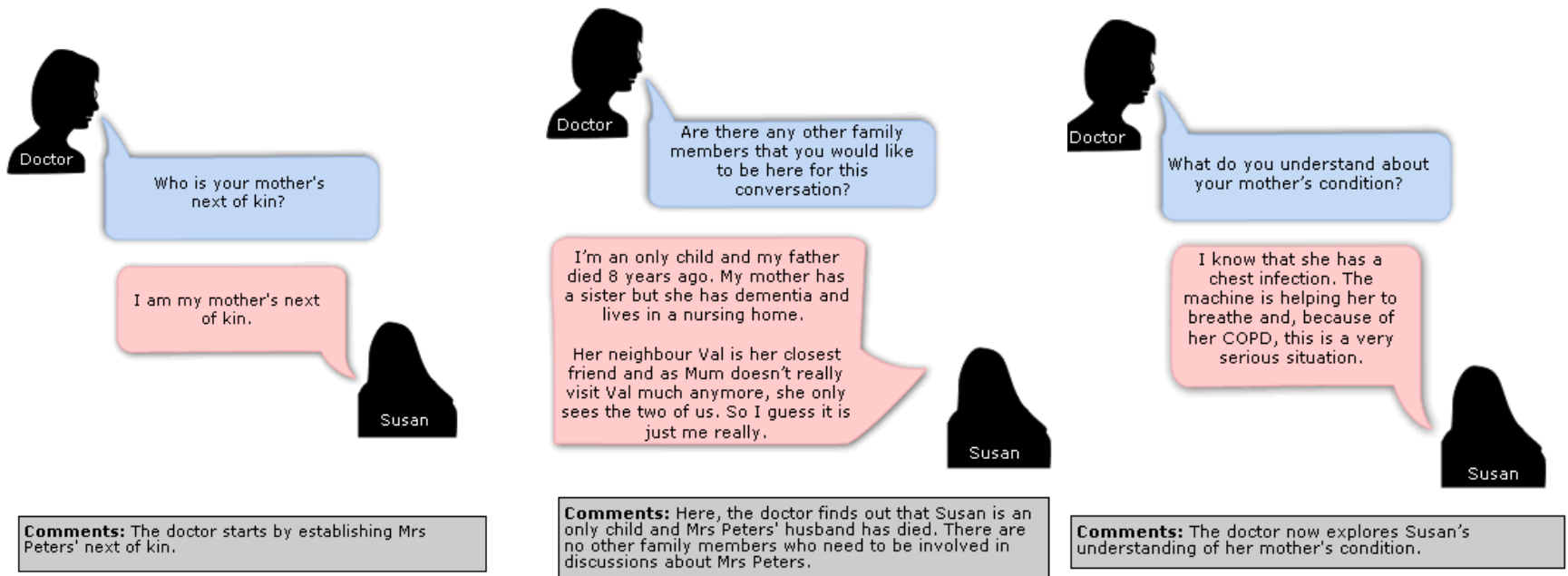
## **Documentation**

All conversations should be clearly documented so that staff subsequently caring for the patient are clear what has been said previously and have an idea of the patient's and/or family's understanding.

# Exploring the Family's Understanding and Patients Wishes

Before the doctor speaks to Susan about her mother, she must first ascertain who is Mrs Peters' next of kin and in particular, which family members should be involved in discussions about her. (See Figs 1-2).

Having established that Susan is Mrs Peters' next of kin, the doctor then needs to explore Susan's understanding of her mother's condition. She needs to find out whether Mrs Peters has any advance care planning documentation, or has expressed what she wants to happen should she become less well. This can be done by asking Susan a series of questions



# Exploring the Family's Understanding and Patients Wishes



Doctor

Yes, I'm afraid she's very unwell indeed. Can you tell me a bit more about your mother's COPD and how it affects her?

She's had it for a long time, but in the past year she has really gone downhill and not been able to do very much for herself. We've both been aware that she was deteriorating but in the past 2 days things have got much worse. I had no idea that she was so sick; I was shocked to hear that Val found her unconscious and she had to come to hospital.



Susan

**Comments:** Here the doctor affirms that Mrs Peters is very unwell, probing to explore her usual level of function.



Doctor

Has she ever been on a ventilator, a breathing machine, before?

No.



Susan



Doctor

So when she is well what can she manage to do?

She can't do very much to be honest. She gets out of breath and exhausted getting dressed. The oxygen helps a bit; she puts that on when she needs to do anything. It is a struggle really getting around her flat or making a cup of tea. She hasn't been out for months.



Susan



Doctor

Things must be quite a struggle for her. Had she talked much about this? Had she talked about getting worse or what treatment she might want if she became less well?

Mum knows she is getting less well. Losing her independence and needing more help has really upset her. She is worried about becoming a burden, especially with my baby on the way, although she is so excited about it. She is very scared of suffocating at the end. She lost her friend Janice to lung cancer who died in terrible pain. Mum is scared of that too, especially with the smoking.



Susan



Doctor

So your Mum knew she was becoming less well. Had she talked about whether she would want to be ventilated? Or if her heart was to stop, whether she would want electric shocks and treatment to try and restart it?

Mum did say to me she never wanted to end up a 'vegetable' on a machine - we never really talked about other things; just not being a vegetable. I think Mum knew something might happen. She kept saying "I hope I will be around when the baby is born."



Susan

**Comments:** In this part of the conversation, the doctor explores Mrs Peters' insight into her condition - had she expressed any wishes about what she would want if she became less well?



Doctor

Sometimes when people have longstanding health problems they write down officially what they would want if they become less well. Has your mother done anything like that?

No.



Susan

**Comments:** Finally, the doctor asks specifically about formal advance care planning documentation.

Having established Susan's understanding of her mother's condition, the team explains to her that her mother is extremely unwell; her lungs were already severely damaged and now she has a bad chest infection (pneumonia). As she was so unwell when the ambulance arrived, and her oxygen levels were very low, she was ventilated immediately.

The team acknowledges that Mrs Peters stated in the past that she did not want to end up as a 'vegetable on a machine', but also that she hopes to be around to meet her grandchild.

The ICU team explains that although Mrs Peters' illness is very advanced, this was an acute event. There is a reasonable chance that she might respond to the antibiotics and recover from the pneumonia.

Overall, the team feels that continued treatment of the acute pneumonia and ventilation are reasonable for the moment to give Mrs Peters a chance of recovering and meeting her grandchild, which seems an important goal for her. However, she will be reviewed on a day-to-day basis and if she deteriorates further, or does not improve at all, this plan can be reviewed.

Susan is then asked if she would like to see her mother.



Before seeing her mother in ICU, Susan might ask some of the following questions. How could you respond?



Is she conscious?

### **Is she conscious?**

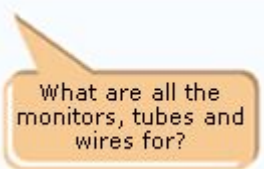
It is important to explain the level of support a patient is having, whether or not he or she is conscious, can communicate, speak or recognise his or her relatives and friends. Depending on the level of sedation, patients may be able to hear or have some awareness of their surroundings.



Can I touch her?

### **Can I touch her?**

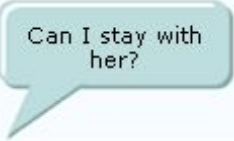
It is important to allow and encourage relatives to touch and talk to their loved ones. Reassure them about displacement of lines or monitoring equipment.



What are all the monitors, tubes and wires for?

### **What are the monitors, tubes and wires for?**


Explain about the monitors, catheters etc. and the care that is being given. Also explain what Susan should not touch and how to call for help if she needs to.



Can I stay with her?

## Can I stay with her?

Outline the facilities for relatives such as waiting areas and visiting times (leaflets can be helpful). In end of life care situations, try to be flexible and allow families to be with the patient as much as possible. This may be their last opportunity.



What other support is there?

## What other support is there?

Spiritual care is important to many people at times of crisis and sickness. Support for patients of different faiths is usually available through chaplaincy services and can be offered even if the patient is not dying.

## **Mrs Peters' current situation**

Mrs Peters stabilises initially. However, she has a further episode of deterioration due to a ventilator associated pneumonia, and after three weeks, she fails to wean from the ventilator.

She then has a further episode of infection and requires additional drug support in the form of inotropes to maintain her blood pressure (BP).

Her urine output then reduces significantly. A renal ultrasound scan is done revealing no renal obstruction, but showing bilaterally small kidneys, so a diagnosis of acute on chronic renal failure is made.

## **The ICU multidisciplinary team's concerns**

The ICU multidisciplinary team is concerned that Mrs Peters is deteriorating despite active management.

Because of the good communication with her daughter Susan, at the start of Mrs Peters' ICU stay, the team is aware of Mrs Peters' expressed wish not to end up attached to a machine and on a ventilator long term.

The team feels it is important to reassess what is an appropriate level of care for Mrs Peters.

## **The decision-making process**

To help the decision-making process, the ICU team asks the renal and respiratory specialists for their views on Mrs Peters' future prognosis.

The renal team feels that Mrs Peters is likely to require ongoing haemodialysis once this is started, as her kidneys are very unlikely to recover.

This will require her to attend a dialysis unit three times a week for 4-hour dialysis sessions. There are concerns that Mrs Peters may not tolerate this well because of her severe COPD, breathlessness and dependence on oxygen. Overall, the renal team feels she is not a good candidate for long-term haemodialysis due to significant comorbidity.

The respiratory specialists feel that Mrs Peters has very severe underlying COPD and lung damage. Her treatment has been optimised from a respiratory point of view. There are no further strategies they can suggest to improve her respiratory function and aid weaning from the ventilator.

# Escalation of Treatment and Futility When Deemed Futile?

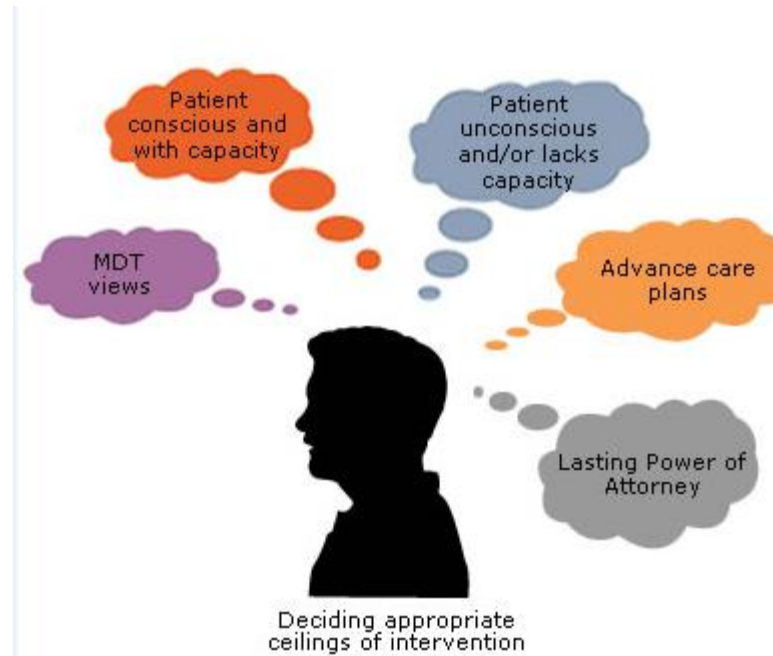
**Question:** When is escalation of treatment deemed futile?

**Answer:** Determining whether a medical intervention or treatment is futile involves weighing up whether a treatment is likely to improve the patient's clinical state or outcome, or whether the burden of such treatment significantly outweighs the likely benefit.

The patient's views on what would be a reasonable outcome, or a burden, greatly impacts on this decision-making process.



How can decisions around appropriate ceilings of intervention be made on ICU?



### **MDT views**

In an ICU setting, determining the appropriate ceiling of intervention and organ support provided to the patient is usually facilitated by the multidisciplinary ICU team caring for the patient. This includes specialist advice from relevant medical or surgical teams (in this case renal and respiratory teams) regarding what the treatment options are and the likely outcomes following them.

### **Patient conscious and with capacity**

If conscious and with capacity, the patient can participate in the decision-making processes. Frequently in an ICU setting this is not the case.

### **Patient unconscious and/or lacks capacity**

Patients who are unconscious and lack capacity may have an advance decision to refuse treatment which is valid only in the exact circumstances it describes, or they may have appointed a Lasting Power of Attorney to make healthcare decisions on their behalf.

### **Advance care plans**

A written statement of wishes or an advance care planning document may provide a patient's previously stated wishes as to what they want to happen if they become extremely unwell. If there is no documented evidence, relatives can be asked their views on what the patient would want. In the absence of family, friends or unpaid carers, an independent mental capacity advocate (IMCA) can be assigned to act on the patient's behalf.

### **Lasting Power of Attorney**

It is vitally important that relatives understand that, unless they are appointed as a Lasting Power of Attorney, they are not ultimately responsible for any medical decisions made, but they will of course be consulted and involved. Decisions are made by the treating team, based on the status of the patient and the relative harms and benefits of treatments. Relatives should not be left feeling guilty that they are responsible for the death of their loved one.

Advance decision to refuse treatment (ADRT) and the Mental Capacity Act are covered in detail in the following Advance Care Planning sessions:

- Advance Decision to Refuse Treatment: Principles
- Advance Decision to Refuse Treatment: In Practice
- Mental Capacity Act: Aims and Principles
- Mental Capacity Act in Practice

# Escalation of Treatment and Futility

## A Clinical Approach

The following outlines a clinical approach that the ICU MDT can use to help determine whether escalation of organ support is appropriate or not in an unconscious patient who lacks capacity.

### Point 1

What is the cause of the organ failure?

### Point 2

Is this cause reversible?

### Point 3

What comorbidities does the patient have and are these likely to impact on the overall outcome?

### Point 4

Is the patient physiologically able to tolerate escalation of organ support?

### Point 5

Does escalation of organ support increase the likelihood that the patient will survive?

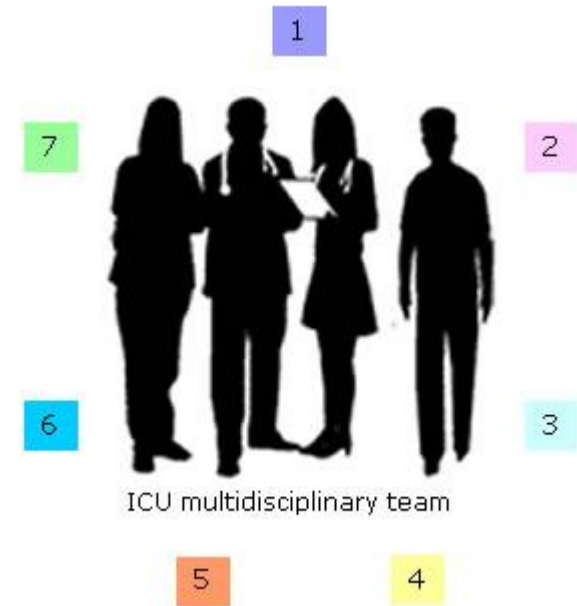
### Point 6

Would the patient want to receive an increase in organ support - if so under what circumstances? Do they have:

- An advance decision to refuse treatment?
- An advance care plan?
- Family and friends who know their wishes?
- A Lasting Power of Attorney?

### Point 7

Finally, is increased organ support appropriate?



The ICU multidisciplinary team reviews Mrs Peters, taking into account the opinions of the renal and respiratory physicians.

The team concludes that Mrs Peters has advanced COPD and is likely to remain ventilator dependent.

She has renal failure which is unlikely to improve and she will require ongoing renal support which will be extremely difficult because of her ventilatory dependence.

The team is also aware that Mrs Peters expressed a wish in the past not to end up dependent on machines. They therefore feel that escalating treatment to provide renal support and continuing to ventilate her long term would not be in line with her wishes, or likely to change the outcome that she will probably die from her advanced disease.

The team decides to arrange a family meeting to discuss this with Susan and her husband.



ICU multidisciplinary team

**Question:** How should the team approach the family meeting?

**Answer:** The team should:

## **Clarify the family's understanding of the situation**

The team should first clarify the family's understanding of Mrs Peters' condition. How do they feel she is?

The nursing staff looking after Mrs Peters have kept the family informed of the situation throughout her ICU stay. Susan is aware of the renal failure, the difficulty weaning from the ventilator and the fact that specialist opinions have been sought to help determine the best way forward.

## **Explain the current situation and give their expert advice**

The ICU team explains the current situation:

1. They feel that it is very unlikely that Mrs Peters will improve enough to be able to breathe independently again. All treatments to improve her underlying lung disease have been tried and expert respiratory opinion confirms that she is likely to remain dependent on a ventilator
2. Her kidneys are failing. The ultrasound scan suggests that she has underlying kidney disease which has worsened because of the infections she had. The renal specialists feel that her renal function is unlikely to recover. If her renal function were to be supported by haemofiltration now, this would need to be continued indefinitely. Long-term dialysis would be a particularly difficult undertaking for Mrs Peters

## **Discuss the patient's wishes and best interests**

Finally, the team should discuss their concern that as Mrs Peters stated clearly in the past that she did not want to end up attached to machines, escalating her treatment with renal support and continuing ventilation would not be in her best interests.

# The Family Meeting

## Supporting the Family

On hearing the latest information about her mother's condition, Susan is very tearful.

**Question:** Figs 1-3 show Susan's concerns. What are the key issues for Susan?



I just don't know what to do. For a few days now, I've felt that mum was deteriorating but I know she wouldn't be happy being kept alive by machines. I'm really torn.

I know how much both Mum and I would like her to meet her first grandchild but I also know this is probably not going to happen. This is not what Mum would feel a 'life worth living'.



My husband is great. I am worried about work though – I haven't told them about Mum. I just told them about the baby. I'm worried I will lose my job.



OK, if you think it may help. Thank you.



This is really hard – can I ask where are you getting support from? You look very tired.



Would you like a letter explaining the situation to work, perhaps asking for some compassionate leave? In our experience, it is usually better if key people at work know – they can support you and plan in case you need time off. If you just feel sad or are not yourself at times, they would understand why.



We have a chaplain here on ICU – is your mother a spiritual person at all? Even if you are not religious, some people find him helpful to talk to. Shall I mention you and your Mum to him?



OK. Thank you.

The ICU team emphasised that the medical decision was based on Mrs Peters' deterioration despite full active management.

Escalating her treatment with renal support and continuing ventilation was not likely to improve her outcome medically as she was unlikely to recover. This decision was also consistent with her previously expressed views about her quality of life.

The team decided it was appropriate to treat this episode of sepsis with a seven-day course of intravenous antibiotics and to maintain Mrs Peters' blood pressure with fluids and inotropes. However, if her renal function deteriorated further, the team would not increase the organ support; it was felt this would be a terminal event and they would then focus on keeping her as comfortable as possible.

Unfortunately, her renal function got worse. She became anuric and acidotic. The decision was made to develop an end of life care plan for Mrs Peters.



ICU multidisciplinary team

Once it is determined that further escalation of treatment is futile and treatment is failing, decisions are made regarding future intervention.

Treatment that is failing may be withdrawn or a ceiling of intervention determined which is not exceeded. This will vary from patient to patient - it is not possible to generalise. Such decisions should involve the multidisciplinary ICU team, specialist teams as appropriate and where possible, the patient and their family.

Once a decision has been reached to withhold a life-sustaining treatment such as haemofiltration, the rationale for continuing other life-sustaining treatments should be critically evaluated.

When the goal of care switches from cure to comfort, all treatment modalities including IV antibiotics, inotropes or haemofiltration should be considered in terms of whether each one contributes to the comfort of the patient.

Discontinuation of most treatments apart from ventilation seldom results in acute discomfort. However, rapid withdrawal of ventilatory support can cause acute dyspnoea, so ventilation may be continued, reduced or weaned to control the dyspnoea through the titration of medication.

Units vary nationally with 16-70% of ICU deaths being related to withholding further treatment escalation, and 5-70% of deaths following treatment withdrawal.




Assessing comfort in sedated ventilated patients is a challenge. When patients cannot self-report symptoms they are often undertreated by clinicians. Over 50% of seriously ill hospitalised patients report pain.

In ICU, pain is often procedure related. Minimising iatrogenic causes of pain should be part of the pain management plan.

Susan is aware that her mother is dying and is worried about pain (Fig 1).

What signs should you look for in assessing pain and distress in ICU patients?



I'm concerned that mum might be in pain and not be able to express it.

Susan

### Feedback

Signs of distress in sedated ventilated patients like Mrs Peters include:

#### Body movements

- Immobility
- Purposeless or inaccurate body movements
- Protective movements including withdrawal reflex
- Rhythmic or rubbing movements
- Agitation

#### Facial expressions

- Clenched teeth
- Wrinkled forehead
- Biting of lower lip
- Widely opened or tightly shut eyes

#### Sympathetic nervous system activation

- Increased pulse, respiration, diastolic and systolic BP
- Cold perspiration, pallor, dilated pupils, muscle tension

Pain and symptom management at end of life on ICU is an essential part of care.

### **Pain Management**

Patients should be assessed for pain at the end of life on ICU by looking for the signs described previously.

Anticipatory prescribing of 'as required' analgesia is important for breakthrough pain.

Unnecessary or pain-provoking interventions should be avoided where possible.

Opioid analgesics are the main method of pain control at the end of life on ICU, with morphine being the most commonly used opioid. However fentanyl, oxycodone or alfentanil are all used in renal impairment.

The intravenous route is commonly used if available.

A background infusion of opioids is usually titrated according to need with additional bolus doses as required

### **Dyspnoea Management**

Dyspnoea is the subjective awareness of altered or uncomfortable respiration.

Behaviours correlated with respiratory distress include tachypnoea (increased respiratory rate), fearful facial expression, use of accessory muscles, paradoxical breathing (diaphragmatic) and nasal flaring.

Dyspnoea may be a symptom if patients are weaned from a ventilator but it can be managed proactively by the use of benzodiazepines and opioids.

Where possible, treat the cause and then palliate symptoms using benzodiazepines and opioids.

### **Delirium Management**

Delirium is disturbance of consciousness characterised by both acute onset and fluctuating course. Delirium is common in ICU secondary to medication use, the underlying medical condition and the environment.

Patients have an impaired ability to receive, process, store or recall information. This is commonly associated with motor activity as seen in agitated delirium.

To manage delirium:

- Remove or treat the cause if possible; review the sedating medication
- Manage background light, noise and calm environment if possible
- Orientate the patient regularly about the time, date and place
- Medication such as levomepromazine, haloperidol or midazolam can be helpful in controlling agitated delirium which is common at the end of life

Pain and dyspnoea can exacerbate delirium and their treatment should be considered

### **Respiratory Secretions**

Management of respiratory secretions is particularly important especially in ventilated patients.

Suctioning is often described by patients as the worst experience of their ICU stay as it is so stimulating and deeply uncomfortable. Suctioning should be avoided at the end of life on ICU if at all possible.

Secretions should be managed proactively by:

- Positioning the patient
- The early use of antimuscarinic antisecretory agents, such as glycopyrronium or hyoscine as appropriate. But remember, these can cause excessively dry mouth

Mrs Peters died peacefully on a ventilator with her daughter and her son-in-law at her bedside.

Susan was able to take compassionate leave to remain at her mother's bedside, reassured by her employer that her job was safe.

The family had been given privacy through the use of screens, and monitors were turned off.

Spiritual support was provided by the chaplain who gave Mrs Peters the blessing of the sick at her daughter's request.

Sadly Mrs Peters did not meet her first grandchild.



- Patients at the end of life on ICU have the same needs as any other patient receiving end of life care in terms of pain and symptom control, family, social, spiritual and psychosocial support
- Determining the patient's wishes regarding the level of medical intervention and establishing likely prognosis at the beginning of the admission can ease decision making later on
- Clinical decisions need to be frequently reviewed with consideration of future events and the realistic ceilings that might be put in place
- Family support and communication are essential in end of life care in ICU with jargon free, clear explanations of complex medical situations. Families should feel they are involved in decision-making processes but know that they are not ultimately responsible
- The patient and their family's comfort and dignity is maintained by pain and symptom assessment and management, nursing care, avoidance of unnecessary interventions such as suctioning wherever possible and maintaining an environment of privacy and quiet as far as is achievable