

# Palliative and End of Life Care on CCU - Perspectives Across the MDT

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# Why this project...?

- Feedback from staff
- Debriefs
- Relevant research
- *“The language of Medicine, with its priorities of safety and survival...”*
- Atul Gawande, ‘Being Mortal’ (2014).

The Lancet Commissions

## Report of the Lancet Commission on the Value of Death: bringing death back into life

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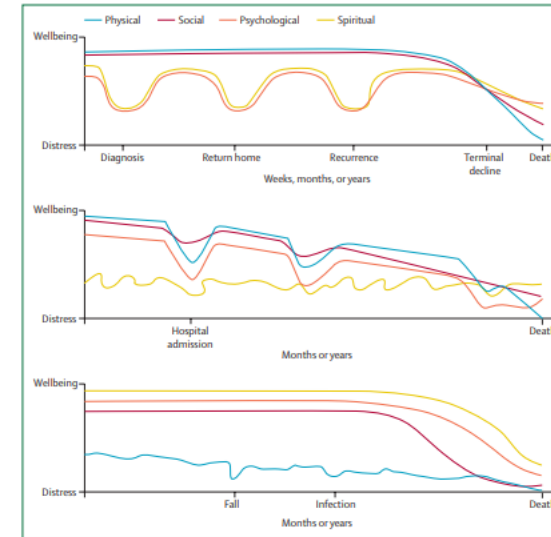


Figure 4: Trajectories of dying with cancer (top), organ failure (middle), and frailty (bottom). Reproduced from Murray and colleagues by permission of BMJ Publishing Group.<sup>24</sup>

Despite this complexity, some distinct patterns can be discerned at a population level in groups of conditions. The trajectories shown in figure 4 capture some of the experiences of people dying from the common conditions of cancer, organ failure, or physical and cognitive decline.<sup>24</sup> Although these models are not predictive for individual cases, they illustrate the types of experiences that people may face.

### “The difficult conversation”: Breaking bad news, communication, and prognostication

The phrase “the difficult conversation” has become shorthand for the honest and wide-ranging discussion that should—but often doesn’t—take place between a dying person and their health-care team. A report from the Royal College of Physicians in the UK, *Talking About Dying: How to Begin Honest Conversations About What Lies Ahead*, reported that only 8% of people with cancer who said that they had thoughts and feelings about their death had shared these reflections with their health-care team. Among those who had, only 19% of the conversations were initiated by the health-care professional.<sup>24</sup> Too often the conversation takes place at a time of crisis, generally during an emergency admission to hospital.

The obstacles to these conversations are many and various. In a busy clinic or ward round, it is easy for

doctors to avoid the conversation by ordering another scan or round of chemotherapy. There may be a fear of extinguishing hope, with doctors worrying that a candid discussion on prognosis could lead to despair. Contemporary hospitals have a “fix-it” approach to acute illness, regardless of the prognosis, often driven by rigid protocols that ignore the likelihood of success. Modern medical care is increasingly splintered and atomised, with poor communication and cooperation between primary and hospital care, and lack of clarity on the responsibility for having such conversations; doctors in acute specialities might regard the difficult conversation as the role and responsibility of specialists in palliative care. Collusion with families might also contribute to the problem: well-meaning relatives may pressurise doctors into not telling dying people that they are dying. Many societies support a focus on communal or relational autonomy rather than individual autonomy—in this setting, families are usually given information first, and discussions then take place about how much to disclose to the patient. In many cultures, it is not acceptable to speak directly of death or to prognosticate when someone may die. Furthermore, some people dying will be unable, cognitively or emotionally, to have this conversation. The conversation may be impossible for people of extreme old age or those with advanced dementia, although members of the Commission report that rich conversations to convey wishes, preferences, and choices can still be had with people living with dementia. It can often be difficult to be sure when a person has begun to die, that they are—to use the oxymoronic term—actively dying, although the time to initiate such conversations would ideally take place before active dying.

The difficult conversation need not be difficult. The conversation should be a process rather than a single conversation: ideally it comprises a series of discussions. In his book *Being Mortal*, the surgeon Atul Gawande suggested that a series of five questions could be used as a frame for these conversations.<sup>46</sup> These questions are: what is your understanding of where you are and of your illness? What are your fears or worries for the future? What are your goals and priorities? What outcomes are acceptable to you? What are you willing to sacrifice and not? And later, what would a good day look like?

The very fact that this conversation is called “difficult” is emblematic of the obstacles to it. This conversation should be termed “essential”, not “difficult”. A cultural shift is required within the medical profession and healthcare more generally so that this conversation is viewed as a professional responsibility for the doctor or health-care professional and a right for all people and families who wish it.

### Withholding or withdrawing treatment

In clinical care—and particularly in intensive care units—decisions often must be made about withholding

# Aims and Objectives

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1. Understand how we provide palliative and end of life care on CCU from a mixture of health care providers.
2. Understand the processes of decision-making regarding end-of-life decisions, including DNAR (do not attempt resuscitation) and TEP (treatment escalation plan) documentation.
3. Identify barriers to collaborative decision making, and sources of conflict across different disciplines regarding difficult conversations.

# Service Improvement Structure

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In the lead up...

- **Debriefs** on recent deaths
- **Survey** preliminary opinions of staff across the MDT
- **Video** introducing the themes and plan for the month

Structure...

- Week 1 – Communication skills (“Am I dying?”), Triggers tool, Referral, Definitions.
- Week 2 – Holistic care, Management of the Patient, Medications, syringe drivers. *Inclusion of DNAR/TEP Audit.*
- Week 3 – Process of Withdrawal of treatment. *Coincided with Mental Health Awareness Week.*
- Week 4 – Last offices, memory boxes, handprint kits. *Inclusion of Rehab Ward Round awareness and feedback*



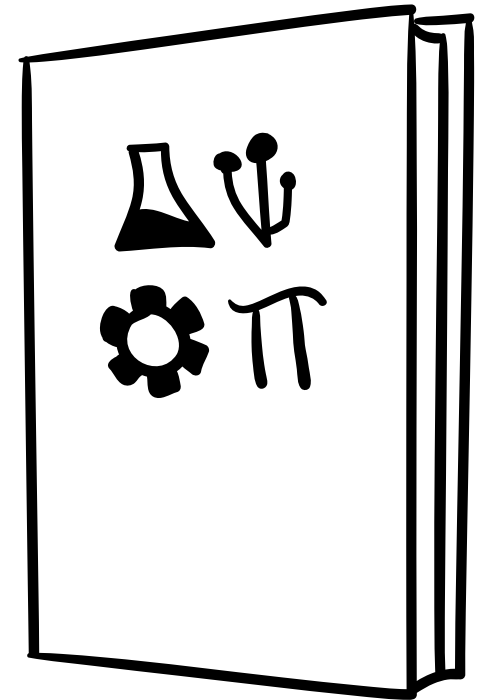
# Service Improvement techniques

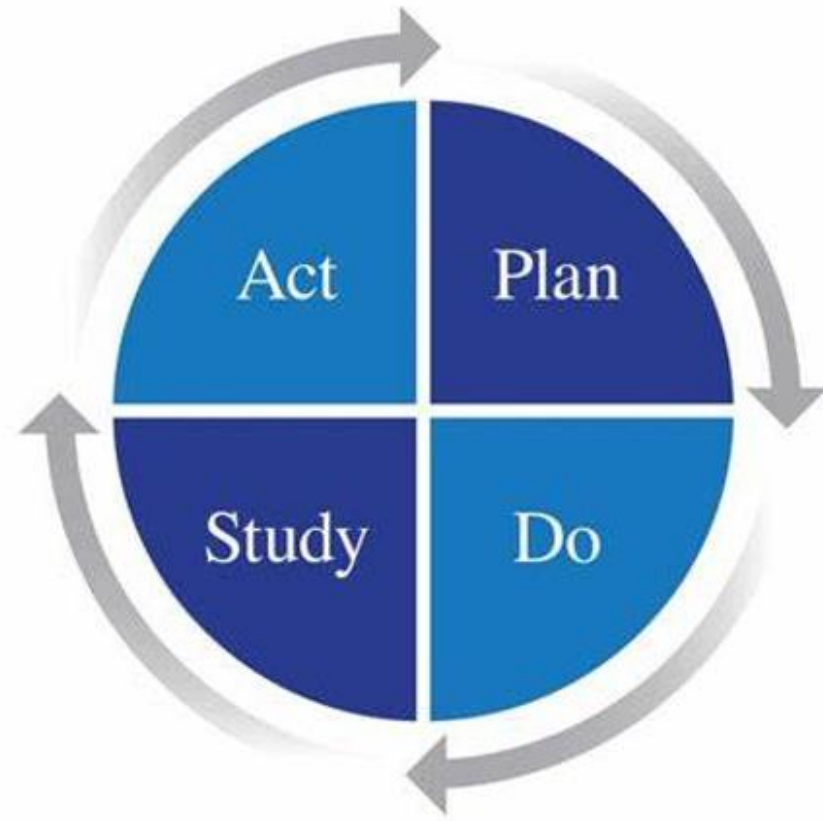
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- Handover Teaching
- Posters
- Bedside teaching – *inclusion of the MDT, such as chaplaincy.*
- Simulation
- Quizzes

## Data Gathering:

- Surveys
- Focus Group





# Survey findings

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Made available to staff on CCU for approximately **six weeks** prior to the service improvement month.

Respondents were predominantly nurses, but also included healthcare assistants and members of the medical and physiotherapy teams.

Key themes:

- **Good knowledge** of the symptoms of dying and their management.
- Positive response to the **quality of care** provided.
- Confusion about **who is responsible for/allowed to make Palliative care referrals**.
- General consensus that **referrals are made too late**.
- Lack of confidence around **starting conversations** about palliative care involvement.



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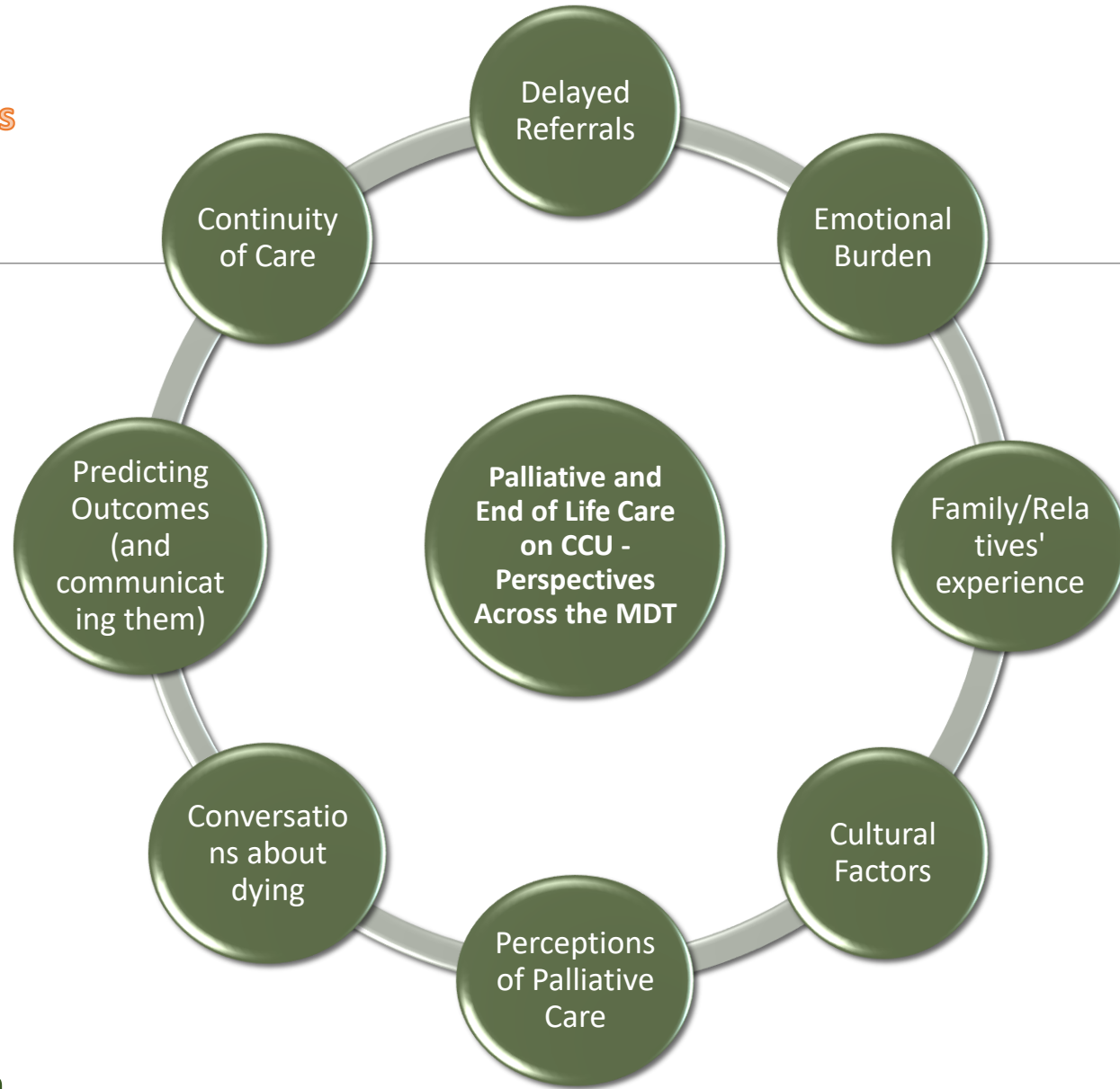
# Focus group findings...

*Thematic Analysis. Framework Technique.*





Logistics



Moral Distress

Communication

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Breaking down themes...

# Emotional burden

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*“One of the consultants... she was here and it was clear to everybody that the patient was doing really badly. But there was still some part of her that didn’t want to say ‘yeah, let’s stop.’ Because she felt she was letting the patient down.”*

The moral distress of patients changing their minds.

*“I’d seen him get more and more fed up with what we were doing. And to be honest I felt like what I was doing was cruel. Like, we were constantly having to put new lines in... so it felt like torture.”*

# Family/Relatives' experience

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Rushed/late conversations about dying are distressing for the family

The stress family experience trying to guess what the patient would want. *"I was actually on the phone with his [relative] and she just broke down, she was crying... she was like, 'I don't know what to do anymore'"*

The important of language/vocabulary used. *"...like 'slight improvement', because that seems quite positive. And I think some people hang on to that."*

Balancing the needs of the family and the best interests of the patient. *"You do have to try and mould it as best as you can for that family because withdrawing things too quickly or at the wrong time will completely break a relationship" vs. "... we feel like we're being cruel to the patient because it's what the family want."*

The stress of being in the room with the family for prolonged periods of time.

The tendency of relatives to fixate on monitors.

# Cultural Factors

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Patients consenting to further treatment because they feel that's what their family/parent team would want.

Certain patient demographics are less likely to raise questions/concerns.

## Perceptions of Palliative Care

*"You don't want to take away hope completely, do you?"*

*"Yeah, we would never do that. I don't think that's anyone's role."*

Misconception that Palliative Care can't run alongside active treatment – that it will “interfere” with treatment or hasten death.

Palliative Care are not just involved in the last hours of life – the benefits of early involvement on quality of life; patients can live for a long time with non-curative disease.

Discussion of normalising Palliative Care presence on CCU and integrating them into CCU.

# Conversations about dying

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*“There aren’t very good records on discussions about prognosis.”*

Who actually receives training to have these conversations?

Conversations about dying are had too late.

There is a misconception that these conversations can’t be had while the patient is receiving active treatment. This has led to confusion in the past, among clinicians, patients and relatives.

\*There is an expectation in this Trust for consultants to have all these conversations. *“There is not a situation where you can go and have a conversation behind the consultant’s back.” ... “They advocate on behalf of the patient. But... if the consultant disagrees then that is sort of the end of the conversation.”*

Scope for having these discussions at the point of consent.

Why do conversations not happen? *“I guess for them, they have in their heart and minds ‘will it change the relationship?’”*

Taking our cue from the patient.

The challenge of denial. *“... the family did say they wanted us to stop giving bad news.”*

# Predicting Outcomes

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The acceptance that a CCU admission will involve a degree of suffering... *“it is very difficult to balance when to draw the line, when is it going one way... it is notoriously hard to pick which patients will thrive and which won't...”*

There is a window of time where active treatment may make a difference, and this window is shaped by many factors - such as the stage and type of cancer... *“you'd constantly be falling short if you call it too soon.”*

Discussion of Nursing perspectives being more pessimistic than Medical perspectives. This may be due to the length of time spent at the bedside. **Both experiences are valid and share an overlap of emotional burden and moral distress. Empathy is key.** (Oberle & Hughes, 2000).

Do patient really know the impact that a CCU admission can have on their quality of life?

Who knows? Who has been told? *“We all feel things are going one way, even if we see it very strongly, stuff still isn't happening even though there's stuff we organise and do. You are just in a moot point, you're stuck...”*

# Continuity of care (Team Structure and Task Delegation)

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\*The challenge of scheduling meetings/conversations with changing consultant schedules.

Maintaining trust between teams/specialists – avoid causing “division.”

The challenge of sharing perspectives between clinicians who spend differing lengths of time on CCU/with the patient.

*"...this is probably the topic that is discussed the longest of all the things."*



# Delayed referrals

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There is an *“absence of early discussion in terms of prognosis, treatment outlines, and where you’re going.”*

Who is responsible for referrals? – \*There is an expectation in this Trust for consultants to have all these conversations, which differs from other Trusts.

The impact of delayed referrals – distressed relatives; lack of time to make decisions.

What factors delay a referral? – The challenge of scheduling important conversations with Consultant schedules.

Are some teams less likely to refer than others?

Concerns around awareness and efficacy of the Triggers tool.

# Follow up

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- Palliative presence at Rehab ward round
- MDT presentation
- E-folder resource collation
- Staff welfare – *prizes; gifts; therapy animal*
- BACCN conference
- Discussion with other specialists about findings...

# Wicked Problems in Healthcare

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*“Culture has tremendous inertia... that’s why it’s culture. It works because it lasts. Culture strangles innovation in the crib.”* —  
Dr Bill Thomas in Atul Gawande’s ‘Being Mortal.’

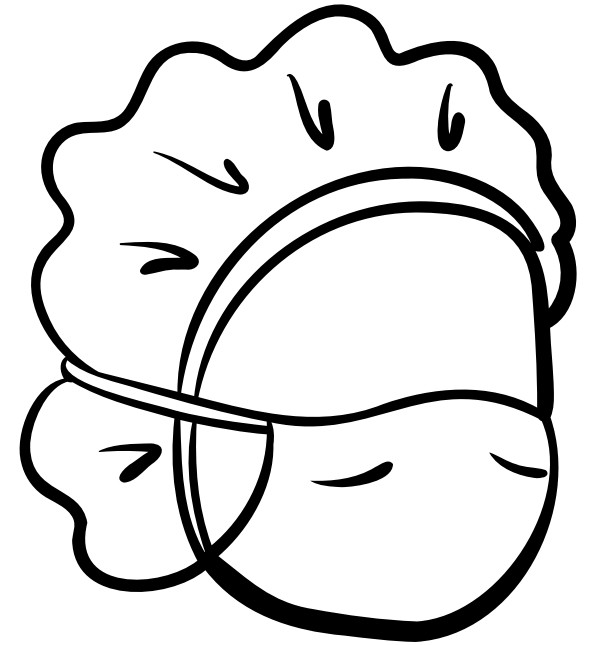
# Key points & Interventions

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Barriers – stigma and euphemisms

Differing and valid perspectives – maintain trust

Collaborative moral discourse – incorporating the nursing perspective



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