Understanding how death and dying impacts on our social care colleagues

Amanda Young PhD RGN DN RNT
Director of Nursing Programmes
(Innovation and Policy)

Welcome

Acknowledgement

Aims and objectives of the session

Aim is to acknowledge the cultural difference of those caring in social care settings related to end of life care in the UK and the impact this has on residents and staff in this care sector.

Learning outcomes

- To understand what palliative and end of life care means and how we can support residents and staff
- To have knowledge and understanding of the cultural difference related to palliative and end of life care
- For care sector staff to understand the main causes of death in the UK
- For care sector staff to acknowledge the emotional impact of caring for the dying

Language about death

Professional

- Dying
- Terminal
- End of life
- Palliative
- Deterioration
- Poor prognosis
- Deceased

Common phrases

- Poorly
- At death’s door
- On last legs
- One foot in the grave
- Kicked the bucket
- Passed on
- Gone

Definition of End of Life Care

- People are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:
  - advanced, progressive, incurable conditions
  - general frailty and coexisting conditions that mean they are expected to die within 12 months
  - existing conditions if they are at risk of dying from a sudden acute crisis in their condition
  - life-threatening acute conditions caused by sudden catastrophic events.

NICE 2015
GMC guidance 2013

Definition of Palliative Care

- Palliative care is defined by the World Health Organisation as an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-limiting illness, usually progressive. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems whether physical, psychosocial or spiritual.

Definition of Terminal Care

- Terminal care will comprise of extensive physical and medical care within the loved one's own home or hospital setting. During this stage of their palliative care journey, individuals may experience the following physical symptoms:
  - Becoming bedridden
  - Experiencing severe mobility issues
  - A decrease or loss of appetite
  - Difficulty in swallowing solids and medications
  - A severe diagnosis that requires daily medical interventions
- Is an integral aspect of palliative and end of life care

Exercise

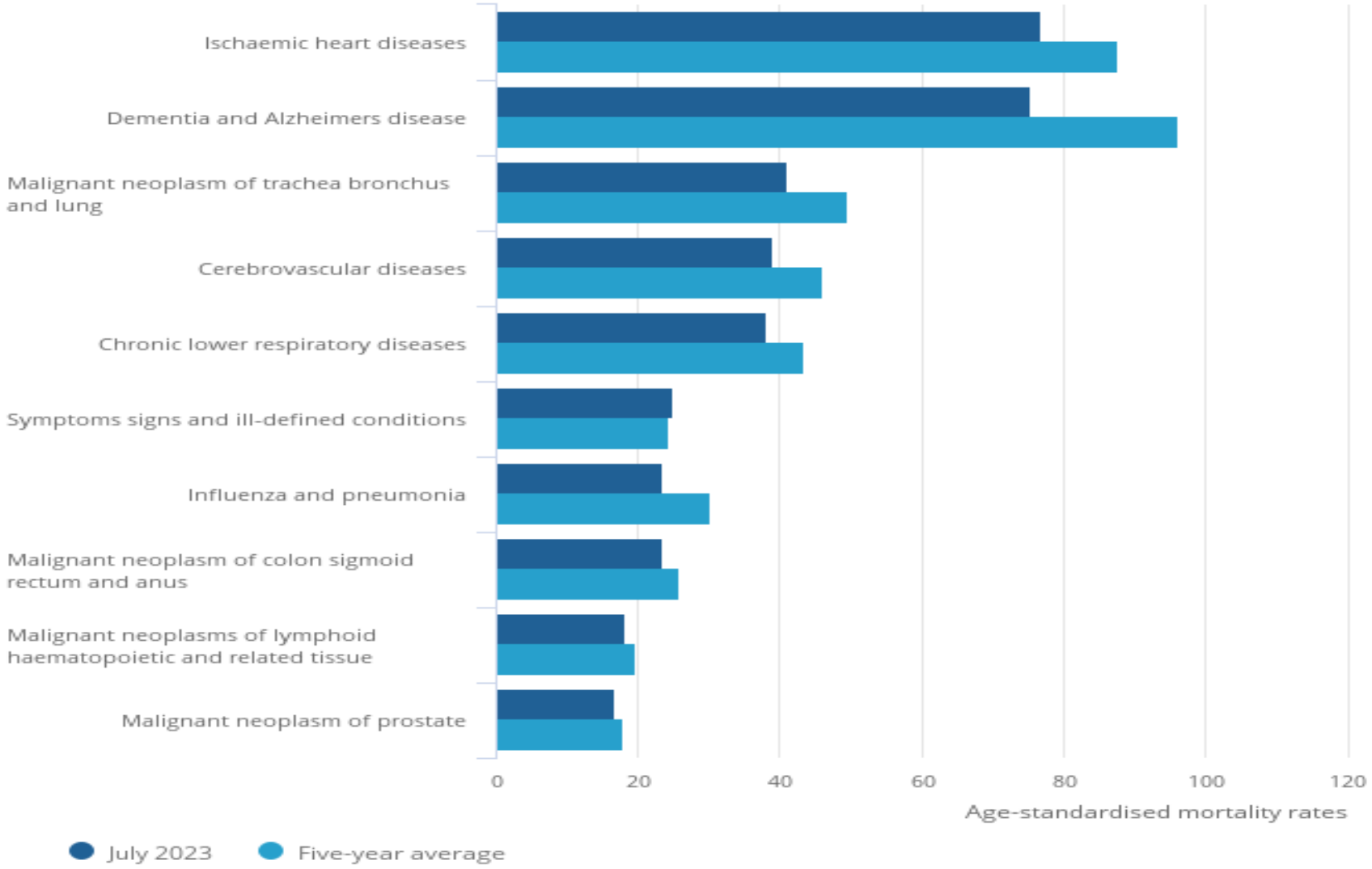
- In the chat box please put any comments, thoughts or fears that you have related to end-of-life care since you have been working in England or in social care.

Question

- What do you think is the most common cause of death in the UK?
- What percentage of deaths happen in a persons place of residence (care home/home)

Figure 5: In England, ischaemic heart diseases was the leading cause of death in July 2023, replacing dementia and Alzheimers disease after 24 months

Age-standardised mortality rate for selected leading causes of death, per 100,000 people, England, deaths registered in July 2023

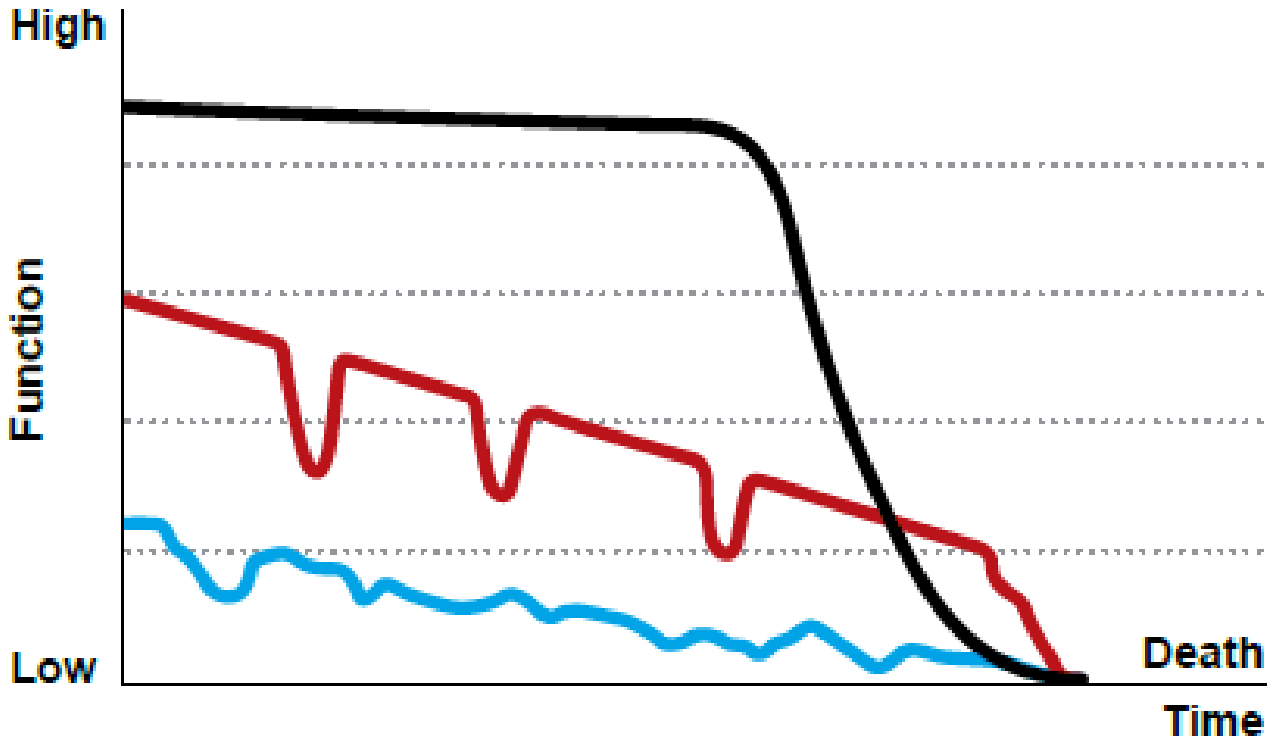


Identifying the last year of life:

1. The surprise question 'Would you be surprised if this patient were to die in the next 6-12months' -an intuitive question integrating co-morbidity, social and other factors.

2. Choice/ Need - The patient with advanced disease makes a choice for comfort care only, not 'curative' treatment, or is in special need of supportive / palliative care eg refusing renal transplant

3. Clinical indicators - Specific indicators of advanced disease for each of the three main end of life patient groups - cancer, organ failure, elderly frail/ dementia



Source: Murray, S.A. et al[1]

Cancer (n=5)

Organ failure (n=6)

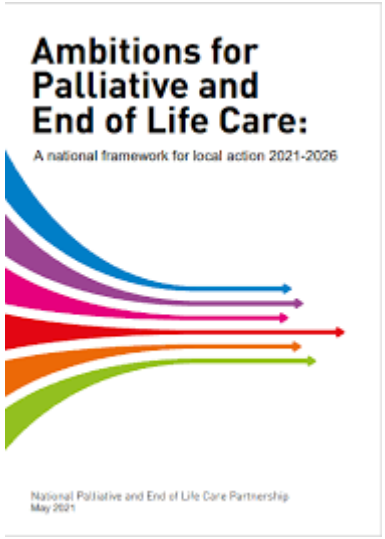
Physical and cognitive frailty (n=7)

Other (n=2)

The End-of-Life Care Strategy 2008

- The Ambitions for Palliative care and end of life care 2021-2026
- NICE guidelines for end-of-life care 2015

The End of Life Care Strategy
(DH 2008)
Promoting high quality care for all adults at the end of life.



MACMILLAN CANCER SUPPORT

NICE National Institute for Health and Care Excellence
Improving health and social care through evidence-based guidance

hospice UK

Dying Matters
'Let's talk about it'

Marie Curie

6 Ambitions

1 Each person is seen as an individual

I, and the people important to me, have opportunities to have honest, informed and timely conversations and to know that I might die soon. I am asked what matters most to me. Those who care for me know that and work with me to do what's possible.

2 Each person gets fair access to care

I live in a society where I get good end of life care regardless of who I am, where I live or the circumstances of my life.

3 Maximising comfort and wellbeing

My care is regularly reviewed, and every effort is made for me to have the support, care and treatment that might be needed to help me to be as comfortable and as free from distress as possible.

6 Ambitions

4 Care is coordinated

I get the right help at the right time from the right people. I have a team around me who know my needs and my plans and work together to help me achieve them. I can always reach someone who will listen and respond at any time of the day or night.

5 All staff are prepared to care

Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and compassionate care.

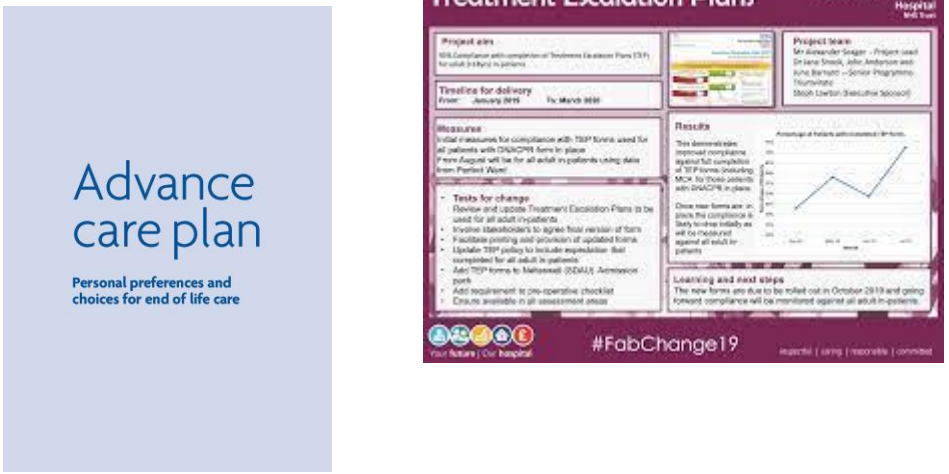
6 Each community is prepared to help

I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways.

Advance care planning Documentation

- Statements of wishes and preferences (eg Preferred Priorities for Care document, Information About Me form)
- Advance decisions to refuse treatment (ADRTs)
- Appointing a Lasting Power of Attorney(health and welfare and/or finance)
- Treatment escalation plans
- DNACPR

Office of the Public Guardian



All People approaching the end of life, and their carers, should be entitled to:

- Have their needs assessed by a professional with appropriate expertise.
- Have a care plan which records their preferences and the choices they would like to make. The plan should be reviewed as their condition changes
- Be involved in decisions about treatments prescribed for them and having option to say no. (DNACPR)
- Know systems are in place to ensure that information about needs and preferences can be shared with permission. (Palliative care register)

What to say to a dying person

Common Symptoms

- Pain
- Nausea and vomiting
- Terminal restlessness/agitation
- Retained respiratory secretions
- Dyspnoea
- *Poor alimentary absorption*
- Dysphagia
- Reduced fluid and nutrition intake

Anticipatory prescribing

- What anticipatory drugs should be prescribed at EOL?
- “Just in case meds”:
- Analgesics- morphine
- Anxiolytics- midazolam
- Anti-emetics-levomepromazine/ haloperidol
- Anti-secretaries- glycopyrronium

What if I was told I had a week to live?

- Would those around me know how best to support me? Would they know about any strong wishes I have about how I want to be cared for? Would I have made a will?
- Would those I love know how I feel about them?
- Would relatives know about any plans I've made for after my death?
- Do you want to spend your final days worrying about sorting all that out?
- The earlier you talk about dying wishes, the easier it is emotionally and practically for everyone.

References

- https://www.england.nhs.uk/publication/ambitions-for-palliative-and-end-of-life-care-a-national-framework-for-local-action-2021-2026/
- https://www.nice.org.uk/guidance/ng142
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- https://www.resus.org.uk/public-resource/cpr-decisions-and-dnacpr
- https://www.nhs.uk/conditions/end-of-life-care/planning-ahead/advance-decision-to-refuse-treatment/

Any Questions