

BMHP6027_BIRM:

Empowering the Older Person

Week 8- Death, Dying and End-of-Life Care: Choice, Dignity and Empowerment





A Sensitive Subject



Today's session includes discussion of:

Death and dying
Terminal illness
End-of-life decisions
Cardiopulmonary resuscitation
Assisted dying and euthanasia
A real-life end-of-life care video



Some people may find this content upsetting.



You are not expected to share personal experiences.



Please look after your own wellbeing and step outside briefly if needed.



Respectful discussion, please...

Listen without interrupting.
Respect different experiences, cultures and beliefs.
Challenge ideas rather than individuals.
Maintain confidentiality when discussing practice examples.

Learning Objectives of Session

By the end of the session, you should be able to:

- Explain the principles of palliative and end-of-life care.
- Examine how autonomy, dignity and choice can be promoted.
- Apply theory to experiences of death, dying and care.
- Discuss advance care planning, mental capacity and DNACPR decisions.
- Consider inequalities in access to end-of-life care.
- Critically evaluate arguments surrounding assisted dying and euthanasia.

Opening Activity-

What Might Constitute a “Good Death”?

In pairs, discuss what might matter to an older person approaching the end of life.

- Consider:
 - Where they are cared for
 - Who is present
 - Comfort and symptom management
 - Being listened to
 - Privacy and dignity
 - Religious, cultural or spiritual wishes
 - Control over treatment
 - Support for family and friends
- Agree on the **three factors** your pair considers most important.

Palliative and End-of-Life Care



What Is Palliative Care?

Palliative care supports people and families facing problems associated with a life-limiting or life-threatening illness.

It aims to improve quality of life by addressing:

- Physical symptoms
- Psychological wellbeing
- Emotional needs
- Social circumstances
- Cultural and spiritual needs
- Support for families and carers



What Is End-of-Life Care?

End-of-life care is support provided when a person is approaching the end of their life.

It may last for:

- Days
- Weeks
- Months
- Sometimes longer



Key message - Palliative care is not limited to the final days of life.

(WHO, 2020; NHS, 2026; NHS England, 2026)

Principles of Good End-of-Life Care

- **What Should Good Care Look Like?**

Good end-of-life care should be:

- **Individualised**
 - Based on the person's needs, wishes, identity and circumstances.
- **Compassionate**
 - Delivered with kindness, sensitivity and respect.
- **Holistic**
 - Addressing physical, psychological, social and spiritual needs.
- **Coordinated**
 - Shared effectively between professionals and services.
- **Inclusive**
 - Involving the person and, with permission, those important to them.
- **Responsive**
 - Reviewed when the person's health, needs or wishes change.

Central question- Is care being organised around the person, or is the person expected to fit the service?

(NICE, 2019)

Kübler-Ross and Responses to Dying

Elizabeth Kübler-Ross identified five emotional responses that may be experienced by people facing death or terminal illness:

- **Denial:** difficulty accepting the diagnosis or situation
- **Anger:** frustration, fear or a sense of unfairness
- **Bargaining:** attempting to negotiate for more time or a different outcome
- **Depression:** sadness, grief and awareness of impending loss
- **Acceptance:** recognising the reality of approaching death
- **Important point- These responses:**
 - may occur in a different order;
 - may overlap;
 - may be experienced more than once;
 - may not all be experienced;
 - should not be treated as a fixed pathway.

Discussion question - What might happen if practitioners expect every person to move through these responses in the same way?

(Kübler-Ross, 1969; Corr, 1993)

Understanding Death and Dying Through Theory

- **Person-Centred Theory**

- The individual remains a person, not simply a diagnosis.
- Their identity, values, relationships and preferences remain important.
- Care should be provided **with** the person rather than merely **to** them.

- **Continuity Theory**

- People may value continuity in identity, relationships, routines and surroundings.
- This may help explain a preference to remain at home or near familiar people.
- However, familiar care is not always available or clinically appropriate.

- **Activity Theory**

- Suggests that continued involvement, relationships and meaningful activity can support wellbeing in later life.
- At the end of life, activity may need to be redefined rather than abandoned.
- Meaningful participation might include conversation, music, family contact, spiritual practices or involvement in decisions.

Critical question - How might these theories help practitioners support the person without imposing expectations about how they should live or die?

(Havighurst, 1961; Atchley, 1989; McCormack and McCance, 2017)

Empowerment at the End of Life

What Does Empowerment Mean at the End of Life?

- **Autonomy**
 - Having control over decisions wherever possible.
- **Choice**
 - Being offered meaningful and realistic options.
- **Voice**
 - Being included in conversations about care and treatment.
- **Dignity**
 - Being recognised as a person with an identity and history.
- **Inclusion**
 - Having communication, cultural and accessibility needs respected.
- **Advocacy**
 - Receiving support to express wishes and challenge inappropriate decisions.
- **Protection**
 - Being safeguarded from coercion, neglect and avoidable suffering.

Discussion question - Can attempts to protect an older person sometimes reduce their autonomy?

Place of Care and Place of Death

- **Where Can End-of-Life Care Be Provided?**

- At home
- In a care home
- In a hospice
- In hospital

- **Factors Affecting the Decision**

- The person's wishes
- Symptom management
- Available services
- Family and carer capacity
- Housing conditions
- Access to equipment
- Safety
- Cultural or spiritual needs
- Changes in the person's condition

Critical question - Does a preferred place of care always remain the best or safest place?

(NHS, 2026; NICE, 2019)

Talking About Death and Dying

Why Are These Conversations Difficult?

- Professionals and relatives may fear that discussing death will:
 - Remove hope
 - Cause distress
 - Feel insensitive
 - Damage relationships
 - Make the situation more real
 - Lead to questions they cannot answer
- **However, avoiding discussion may mean:**
 - The person's wishes remain unknown.
 - Decisions are made during a crisis.
 - Families are left uncertain.
 - Unwanted interventions occur.
 - The person is excluded from their own care.
 - Opportunities for preparation or reconciliation are lost.

Reflection - Can honest communication preserve hope rather than remove it?

(NHS England, 2026)

Communicating Sensitive

Sensitive and Compassionate Communication

- Helpful approaches
 - Find an appropriate and private space.
 - Ask what the person already understands.
 - Establish how much information they want.
 - Use clear and compassionate language.
 - Avoid unexplained medical terminology.
 - Be honest about uncertainty.
 - Allow silence.
 - Listen to fears and questions.
 - Check understanding.
 - Arrange further conversations.
- Avoid
 - Speaking only to relatives
 - Giving false reassurance
 - Making assumptions based on age
 - Rushing to fill every silence
 - Using vague euphemisms
 - Treating one conversation as sufficient

Key principle - Include the person in conversations about their own life and death.

(NICE, 2015)

Communicating About End-of-Life Care

Case Study Activity

Margaret is 82 and lives with advanced heart failure. She has recently been admitted to hospital following a further deterioration in her health.

The medical team believes that Margaret may be approaching the end of her life. Her daughter asks staff not to tell her, saying: “It will destroy her hope. Just speak to me about it.”

Margaret later asks a support worker: “Everyone is whispering around me. Am I dying?”

In Small Groups, Discuss:

- How should the practitioner respond to Margaret?
- What information should be given, and how?
- How can Margaret’s daughter be supported?
- What assumptions are being made about Margaret?
- How can honesty, hope and sensitivity be balanced?
- How could Margaret’s communication, cultural or spiritual needs be explored?

Be Prepared to Share:

- One helpful response the practitioner could give
- One communication approach that should be avoided
- One way Margaret could be empowered

Preparing to Watch “A Graceful Dying”

Content Warning

- The following video, “A Graceful Dying,” follows a person approaching the end of life.
- It includes:
 - Images of visible physical decline
 - Scenes of close family care and presence
 - Photographs from earlier in her life with music, but no spoken words
 - Some people may find this upsetting.
 - You may step outside or choose not to watch.
 - You are not required to explain your decision.

While Watching, Consider:

- How are dignity and personhood represented?
- What do the photographs communicate about her identity and life?
- How is care shown through touch, presence and relationships?
- What appears to make the video empowering rather than purely distressing?
- What can practitioners learn from the way the person is represented?

“A Graceful Dying.”

<https://www.youtube.com/watch?v=EckVDi1RxJM>

Advance Care Planning

Planning Ahead

- Advance care planning is a voluntary process through which a person can discuss:
 - What matters to them
 - Their values and priorities
 - Their understanding of their condition
 - Their preferences for future care
 - Treatments they may or may not want
 - Where they would prefer to be cared for
 - Who they want involved
 - Cultural, religious and spiritual wishes

Advance Care Planning Is:

- Personal
- Voluntary
- Ongoing
- Reviewed as circumstances change

Critical question - Does advance care planning always empower, or could it sometimes feel frightening or pressurising?

(NICE, 2019; Office of the Public Guardian, 2026)

Mental Capacity and End-of-Life Decisions

Mental Capacity Act 2005 - The Act applies to decision-making in England and Wales.

Five Core Principles

- **Presume capacity** unless it is established otherwise.
- Provide all practicable support to help the person decide.
- An unwise decision does not prove a lack of capacity.
- Decisions made for someone lacking capacity must be in their best interests.
- Choose the least restrictive available option.

Capacity Is:

- Decision-specific
- Time-specific
- Capable of fluctuating
- A person must be able to:
 - Understand relevant information
 - Retain it long enough
 - Use or weigh it
 - Communicate their decision

Key message - A diagnosis of dementia does not automatically mean that a person lacks capacity.

(Legislation.gov.uk, 2026c; Office of the Public Guardian, 2026)

DNACPR and Refusing Treatment

A **DNACPR** or **Do Not Attempt Cardiopulmonary Resuscitation** decision relates specifically to CPR if the heart or breathing stops.

- It does **not** mean:
 - Do not provide care / Stop all treatment
 - Do not provide pain relief
 - Do not offer food, fluids or comfort
 - Abandon the person

Refusing Treatment

- A person with capacity may refuse treatment, even when refusal could result in death.
- A valid and applicable advance decision may also refuse specified treatment if the person later lacks capacity.

Key distinction

- Refusing treatment is not the same as euthanasia or assisted dying.

Activity question

- An older person refuses hospital treatment that may prolong their life.
- What information should be provided?
- How should capacity be considered?
- Does an unwise decision mean that capacity is absent?
- What should practitioners document?

(NHS, 2023; Legislation.gov.uk, 2026c; Office of the Public Guardian, 2026)

Policy, Rights and Inequalities

End-of-Life Care Is Also a Matter of Rights and Equality

- **NICE NG142 Emphasises...**

- Personalised care
- Advance care planning
- Coordination between services
- Support for carers
- Regular review
- Access across care settings

- **Mental Capacity Act 2005**

- Protects decision-making rights and provides a framework for best-interests decisions.

- **Human Rights Act 1998**

- Relevant considerations include:
 - Life
 - Privacy and family life
 - Freedom of belief
 - Protection from degrading treatment

- **Equality Act 2010**

- Services must avoid unlawful discrimination and make reasonable adjustments

(NICE, 2019; Legislation.gov.uk, 2026a, 2026b, 2026c)

Policy, Rights and Inequalities

Who May Experience Barriers?

- People with dementia
- Minority ethnic communities
- LGBTQ+ older people
- People with learning disabilities
- People experiencing poverty or homelessness
- People in rural areas
- People with non-cancer diagnoses
- People with language or communication needs

Critical question

- *Is choice meaningful when suitable services are unavailable?*

(NICE, 2019; Legislation.gov.uk, 2026a, 2026b, 2026c)

Assisted Dying and Euthanasia

Clarifying the Terms

- **Euthanasia**

- Another person deliberately administers the means that causes the individual's death.

- **Assisted Suicide**

- A person is intentionally helped to end their own life but performs the final act themselves.

- **Assisted Dying**

- A term often used for a proposed legal process limited to defined circumstances, commonly terminal illness and mental capacity.

- **Current Position in England and Wales**

- Assisted dying and euthanasia remain unlawful.
- The **2024–26 Terminally Ill Adults Bill** did not complete its parliamentary stages before the session ended.
- A new **Terminally Ill Adults (End of Life) Bill** was introduced in June 26 and is due to receive its second reading in September 2026.

- **Why Is This Relevant to Empowerment?** - The debate involves a tension between:

- Autonomy and protection
- Choice and coercion
- Relief of suffering and preservation of life
- Individual rights and professional responsibilities

(UK Parliament, 2026)

Euthanasia and Assisted Dying - The Debate

The Central Question - Should assisted dying be legal for terminally ill adults in England and Wales?

- **Arguments Supporting Legalisation**

- Respects personal autonomy and choice
- May prevent prolonged or intolerable suffering
- Allows greater control over the timing and circumstances of death
- May support an individual's understanding of dignity
- A regulated system could provide safeguards
- May provide equality for people physically unable to end their own lives

- **Arguments Opposing Legalisation**

- Older or vulnerable people may experience coercion or subtle pressure
- Some people may feel that they are a burden
- Prognosis and life expectancy can be uncertain
- Capacity, depression and coercion may be difficult to assess
- Safeguards may not remove every risk
- It may affect trust within healthcare relationships

Euthanasia and Assisted Dying – Discussing the Motion

- **Discussion Questions**

- Does autonomy include the right to choose the timing and manner of death?
- Can a decision be fully voluntary if the person feels like a burden?
- Should high-quality palliative care be universally available before assisted dying is considered?
- How should capacity, coercion and prognosis be assessed?
- Can legislation adequately protect vulnerable people?
- How should individual rights be balanced against professional and social responsibilities?

- **C-E-R Activity**

Claim

- State whether you support or oppose the motion.

Evidence

- Use research, law, policy or professional guidance to support your position.

Reasoning

- Explain why the evidence supports your argument.

Critical Final Question - Can genuine choice exist when access to palliative care, social care and family support is unequal?

Conclusion- Death, Dying and End-of-Life Care

Key Messages

- A good death means different things to different people.
- Dignity, identity and relationships remain important.
- Honest communication supports trust and choice.
- Advance planning must remain voluntary and responsive.
- Capacity is decision-specific and should not be assumed absent.
- Protection should not automatically remove autonomy.

Returning to Theory

- **Kübler-Ross** may help identify possible emotional responses, but dying should not be treated as a fixed sequence.
- **Person-centred theory** keeps the individual's identity, wishes and relationships central.
- **Continuity Theory** highlights the importance of familiar people, routines and surroundings.
- **Activity Theory** reminds practitioners that meaningful participation can continue, although activity may need to be redefined.

Final Reflection- What does it mean to empower someone when they cannot control the fact that they are dying?

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