About the NCFE Level 3 Certificate in the Principles of End of Life Care

> **"You matter because you are what you are. You matter to the last moment of your life and we will do all we can not only to help you die peacefully but to live until you die."**
>
> (Dame Cicely Saunders, founder of the modern hospice movement)

Although working in end of life care can be a difficult and highly emotive experience, supporting dying people to achieve a comfortable, dignified and pain-free death can be a very special experience – the parting gift of a caring society. However, critics have long argued that end of life care provision in this country benefits far too few people. Historically, they have pointed to the fact that end of life care has been largely restricted to hospices and its resources focused on those with cancer.

However, the last decade in particular has seen some considerable investment and important initiatives within end of life care. The aim has been to spread the highly successful hospice model of end of life care to all types of care settings and to supporting people with a range of life-limiting conditions, not just cancer.

A number of barriers still remain. One of these is the need for training in end of life care. Many health and social care workers still say that they find it hard to talk about death and dying, or that they don't feel sufficiently trained to deal with the sensitive and difficult issues that they are confronted with. Hopefully, this course will enhance your confidence and understanding of the topic, and provide you with some of the knowledge and skills needed to effectively support people nearing the end of life.

Aims

On completion of this course, you should:

- Understand the meaning, aims and key components of end of life and palliative care.
- Have an awareness of the range of support services that are available.
- Appreciate the importance of effective communication in end of life care.
- Be able to support people with their physical, psychological, emotional, social, cultural, spiritual and religious needs.
- Understand the nature of grief and loss, and how to support people with their bereavement.

Content

This course has five units:

Unit 1: Understanding end of life care

Unit 2: Communication during end of life care

Unit 3: Assessment and care planning in end of life care

Unit 4: Person-centred approaches to end of life care

Unit 5: Care during the final hours of life and bereavement care

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Unit introduction

In order to learn how to support people nearing the end of life, it is first important to acknowledge that people will have different views towards death and dying. These differing views will be shaped by **social, cultural, religious and spiritual factors.** In Section 1, we will begin the course by examining each of these factors. This will help you to appreciate why people respond to and cope with the prospect of dying in different ways.

There are many misconceptions about end of life care. Therefore, in Section 2, we will look at the **meaning and aims of end of life and palliative care.** We will also explore the important concept and aspiration of a 'good death'.

Although you may understand what end of life and palliative care means, what does it actually look like in action? In Section 3, we will look at attempts to formalise the principles and goals of end of life care into a coherent strategy – the national **End of Life Care Strategy.** We will also examine a number of tools or approaches that have been developed to raise the standard of end of life care.

In the final section, we will consider the **range of support services** and facilities that are available to dying people and their families. We will also look at the 'multi-disciplinary team' – the specialists involved in providing end of life care.

Aims

When you have worked through this unit, you should be able to:

- Outline the factors that can affect an individual's views on death and dying.
- Clarify the aims of end of life care.
- Differentiate between a 'good death' and a 'bad death'.
- Outline the World Health Organisation's definition of palliative care.
- Explain how palliative care is part of end of life care.
- Explain the stages in the end of life care pathway.
- Identify the current approaches to end of life care.
- Evaluate how an approach to end of life care can support the individual and others.
- Explore the range of services and facilities available to an individual and their family.
- Identify the key people who may be involved within a multi-disciplinary end of life care team.
- Identify the potential barriers an individual may face when accessing end of life care to meet their needs.
- Suggest ways to minimise those barriers.

Content

Assessment

Once you have worked through each section, including the learning activities, you will need to complete a series of questions called 'Assessments'. These can be found in a separate booklet within this pack. When you have finished all of the section assessments, you should submit them to your tutor, who will give you feedback on your work. Good luck with your studies!

Did you know?

The butterfly is a symbol that is often used in end of life and hospice care. This stems back to a scientific discovery in the 1960s known as the 'butterfly effect'. The meteorologist, Edward Lorenz, coined the term to describe the significant and unpredictable impact that a small action can have in complex systems. He found that, in the creation of weather forecasts, even tiny changes, 'metaphorically as small as a butterfly flapping its wings', can have a substantial impact on the outcome. In his famous 1963 paper, Lorenz picturesquely explains that a butterfly flapping its wings in Beijing, China, could affect the weather thousands of miles away some days later. The hospice movement first adopted the butterfly to symbolise how the small actions of caring and dedicated people can have a dramatic effect on the quality of life of others. In care settings that deliver good end of life care, there is a 'butterfly effect' going on every day.

Understanding different attitudes towards death and dying

In this section, you will learn about:

- **Social factors**
- **Cultural factors**
- **Religious factors**
- **Spiritual factors**

People will often have very different attitudes towards death and dying. Some people will avoid any mention of the subject, while others may openly welcome the discussion (especially if they themselves are nearing the end of life). Some may intensely fear death, while others may see it as 'divine will'. These differing attitudes will be shaped by **social, cultural, religious and spiritual factors.** Studying each of these factors will help you to understand why people respond to and cope with the prospect of dying in the ways that they do.

Social factors

> **"The word 'dying' – the D-word – carries with it a weighty load. Fear, despair and beauty. Loneliness, dread and hope. Love, remorse and helplessness. Mess, smell, noise and ugliness. Separation, reunion, union. Finality, pain, loss. Controversy, release, relief, grief. Perhaps it is this complex mix which makes it hard for many of us to talk openly and honestly about the dying experience."**
>
> (Brayne, 2010)

Death is often described as one of Western society's **last taboos.** In fact, some argue that society has become **'death-denying'** (Aries, 2000). In other words, although death is inevitable, most people in society are in a form of 'denial', preferring not to talk about it and labelling those that do as 'morbid' or even 'indecent'. As a result, death and dying have effectively been driven into secrecy.

Numerous reasons have been put forward to explain why this might be the case, for instance:

- **The tendency of care providers to 'hide' death and dying** – In hospitals, for example, a person is often moved to a side ward when they are nearing the end of life. In care homes, it is common practice not to discuss the issue of death or the fact that another person may be moving into the last stages of their life with other residents in case it upsets them. Although there may be understandable reasons for doing this, the result is that death and dying almost become 'hidden' or 'invisible'.
- **The 'professionalisation' and 'medicalisation' of death** – In the past, there was often a great deal of community involvement in the dying process and, as a result, death was a more open event. For example, the dead person was 'laid out' for people to visit their house and 'pay their last respects'. Nowadays, a professional firm of undertakers will carry out most of the tasks and rituals associated with caring for the deceased. Furthermore, most people die in hospital rather than at home these days, and this means that people are much less exposed to the dying process than they once were. This is sometimes referred to as the 'medicalisation' of death. For both of these reasons, many people in Western societies have never seen a dead body, except on television.
- **Changing social trends** – The fragmentation of the extended family unit also affects our exposure to death. For example, in the past, it was common for three generations of the same family to live in the same house – children, their parents and their grandparents. Direct contact with death and dying was therefore much more likely as the older generations were cared for and ultimately died at home. This is becoming much less common.

All of these factors combine to directly remove people from the dying process and help to explain society's reluctance and discomfort in discussing, or even contemplating, death and dying.

Did you know?

In 2009, the National Council for Palliative Care (NCPC) set up the **Dying Matters Coalition** to promote public awareness of dying, death and bereavement. By 2010, around 12,000 people had signed up to the campaign. Its mission is 'to support changing knowledge, attitudes and behaviours towards death, dying and bereavement, and through this to make "living and dying well" the norm'. To achieve this, the Coalition believes that a fundamental change in society is required so that dying, death and bereavement are seen and accepted as a natural part of everybody's life cycle.

Dying Matters has produced a useful set of free resources for members looking to raise awareness and promote conversation about death, dying and bereavement. For more information, visit their website (see www.dyingmatters.org).

Activity 1

A good starting point for any course on end of life care is to reflect on your own views towards death and dying. Are they something you fear? Are these subjects that you tend to avoid? Do you encourage others to try not to think about such issues even though they themselves may be nearing the end of life? Jot down your thoughts below.

Why are society's attitudes towards death and dying important anyway?

If people avoid talking or thinking about death and dying, the following situations are more likely:

- Without communication and understanding, death and terminal illness can be a lonely and stressful experience, both for the person who is dying and for their friends and family. Dying people and their families can experience a tremendous sense of isolation and can feel shut out of social circles and distanced from their communities.
- A lack of conversation is perhaps the main reason why people's wishes go ignored or unfulfilled; if we do not know how to communicate what we want, and those around us do not know how to listen, it is almost impossible to express a clear choice.
- It has been said that what we fear most about dying is the associated loss of control. By empowering people to express their wishes, that sense of control can be restored.

(Source: Dying Matters website, 2010)

www.dyingmatters.org

Key point

Death remains a taboo subject within our society. However, greater openness and communication around end of life care issues mean that people are more likely to achieve a 'good death' experience should they be diagnosed with a life-limiting illness.

Cultural factors

As the United Kingdom is a multi-cultural society, it is important that those involved in end of life care understand and respect the different cultural influences and practices associated with death, dying and bereavement. Different cultures may have differing beliefs about, for example, the meaning of death, how the sick should be cared for, and how grief may be expressed.

Public expression of grief

Some cultural groups may feel it important to publically express their grief and sadness when someone dies, whereas other groups may consider a display of strong public emotion as unacceptable. In so-called Anglo-Saxon (north European) cultures, people may be encouraged to 'stay strong' and 'keep positive'. Similarly, amongst older British people, there remains a strong belief in the 'stiff upper lip'. Men in particular may feel that weeping in public is inappropriate. However, in Hindu and Sikh cultures for example, there is much more acceptance of very vocal and public expressions of grief and this can sometimes come as a shock to those that are not aware of these social norms.

Take the example described by Firth (2000) below of a Hindu lady expressing her grief and the effect it had on others.

> **"The English nurses thought she was being very extreme because she was expressing her grief very loudly. A couple of her relatives and her mother-in-law were also wailing and 'making a scene' in a way which would be regarded as quite normal and the 'done thing' in a village setting at home but was regarded as abnormal here. The nurses, not surprisingly perhaps, kept telling them to 'keep your voices down', but a Sikh nurse explained that they needed to get it out of their system and work it out."**

Attitudes towards disclosure

There are also sometimes different cultural views towards the issue of disclosure, in other words whether the person concerned should be told that they are dying. In the UK and the USA, there is a strong belief amongst health professionals in the patient's **'right to know'.** However, this is not the case in various cultural groups where the family is seen as 'knowing best' and amongst whom there is a deeply held belief that discussing illness is **disrespectful and impolite** and that disclosing a life-limiting condition will lead to a **loss of hope** and **unnecessary anxiety.**

Unit 1 assessment
Understanding end of life care

After completing your assessment please return it to your assessor/tutor

ADVICE TO ALL CANDIDATES

- Please complete your personal details and candidate statement below.
- Complete all questions in this assessment.
- Write your answers in the spaces provided. Add any additional work for any of the questions on plain paper and attach to this assessment.
- You do not need to return your completed activities in the unit – just this assessment.
- If you require any assistance or guidance please contact your assessor/tutor.

PERSONAL DETAILS

Name _____

Contact address _____

_____

Postcode _____

Telephone no. (evening) _____ (day) _____

Email (home) _____ (work) _____

CANDIDATE STATEMENT

I certify that I have read Unit 1 and completed all sections in this assessment.

I confirm that this is my own work.

Signature _____ Date _____

For office use only
Candidate ref:
Assessor:
IV:

Passed
Date
Re-submit
Date

Tutor feedback:	
Written	☐
Telephone	☐
Personal tutorial	☐

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Section 1: Understanding different attitudes towards death and dying

1. Some commentators argue that society is 'death-denying'. What does this mean? *(1.1)*

2. Outline three factors that might explain Western society's attitude towards death and dying. *(1.1)*

a)

b)

c)

3. **Outline two ways in which a person's culture might affect their views on death and dying.** *(1.1)*

   a)

   b)

4. **In what ways might an individual's religious faith determine their attitude towards death and dying?** *(1.1)*

   a)

   b)