NCFE Level 2
Certificate in Understanding
End of Life Care

Part A
These learning resources and assessments have been reviewed and approved by NCFE as meeting the requirements of the Level 2 Certificate in Understanding End of Life Care.

Disclaimer:
All references to individuals, groups and companies contained within these resources are fictitious and do not relate to any person or company.
Welcome to this Level 2 Certificate in Understanding End of Life Care.

We hope you find all of the information contained in this resource pack interesting and informative. This learning resource and the assessment questions have been approved by NCFE as a great way to meet the learning outcomes for this qualification. (A complete list of the learning outcomes can be found on the last page of this resource.)

The course is made up of two parts (A and B). This is Part A which contains two units:

UNIT 1: Understand how to work in end of life care

UNIT 2: Understand how to provide support to manage pain and discomfort

As you start to read through each page you will be able to make notes and comments on things you have learnt or may want to revisit at a later stage. At the end of each section, you will be asked to go to your assessment booklet and answer the relevant questions.

Once you have answered the questions go to the next section and continue studying until all of the assessments have been completed.

Please make sure that you set aside enough time to read each section carefully, making notes and completing all of the activities. This will allow you to gain a better understanding of the subject content and will help you to answer all of the assessment questions accurately.

Good luck with your study. Now let’s begin!
Unit 1: Understand how to work in end of life care

Welcome to unit one.

This unit is split into four sections. These are:

- Section 1: Different perspectives on death and dying
- Section 2: Aims, principles and policies of end of life care
- Section 3: Communication in end of life care
- Section 4: Accessing support services

Section 1: Different perspectives on death and dying

Within this section you will learn about:

- The factors that can affect an individual’s views on death and dying
- Your own views on death and dying
- How factors affecting views on death and dying can impact on practice
- How attitudes of others may influence views on death and dying.
The factors that can affect an individual’s views on death and dying

Many different factors can affect an individual’s views about death and dying, and therefore their needs and preferences for their end of life care. These factors include:

- Social factors
- Cultural factors
- Religious factors
- Spiritual factors
- Psychological or emotional factors.

Social factors

Social factors that can influence peoples’ views about death and dying are:

- **Age**: Most young adults and adult people prefer to be cared for at home as long as high quality care can be assured and as long as they do not place too great a burden on their families and/or carers. However research has shown that some people, particularly older people who live alone (65 years onwards), wish to stay at home as long as possible, although they wish to die elsewhere so they are not alone when they die. Attitudes to death and dying can change over the course of a person’s lifetime. As people grow older, death becomes more relevant and people may become less comfortable discussing these issues.

- **Gender**: Gender is a factor in how people view death and dying because research has indicated that the greatest worry for females is being a burden to their family and carers, whilst males worry more about the financial implications of their death and dying for their family.

- **Social attitudes to death**: People tend to live longer and often die in hospitals or hospices, so death has become ‘hidden’ in today’s society. It is removed from everyday life and people become more reluctant to talk about it or plan for it.
**Cultural factors**

Q. What is ‘culture’?

A. *Culture in its broadest sense, refers to the worldview, values, norms and behaviour guidelines shared by a group of individuals.*

Some of the cultural factors that affect peoples’ views on death and dying include:

- Culture may define how a person acts and grieves when death has occurred – for example, in some cultures death is not viewed as the end but a new beginning.
- Some cultures believe that open discussions about dying and death are disrespectful and impolite, whilst other cultures believe that speaking about death makes it ‘real’.

**Religious factors**

Q. What is ‘religion’?

A. *Religion is an established system of symbols, beliefs, rituals and text shared by a community of faith.*

A person’s religion can be an enormous source of support and strength for dying people and their families. In relation to end of life care, an individual’s religion may define how they deal with the process of dying, death and bereavement. Some religions believe in an afterlife, whilst some religions believe in re-incarnation. These beliefs will have an important effect on how they view their own death.
**Spiritual factors**

Q. What is ‘spirituality’?

A. **Spirituality is related to human needs for the meaning and purpose of life, hope, forgiveness, for acceptance and peace of mind.**

There is a close association between religion and spirituality, but even those without religious beliefs may have spiritual needs related to regret, the meaning, value and purpose of their lives. Ways in which spirituality can affect peoples’ views of death and dying include their feelings about:

- The meaning, value and purpose of their life. Some people may look back and feel a sense of pride in their life achievements. Some people may have regrets about their life, the things they wanted to achieve and never had.

- Important relationships they have had in their lives - for example; being a father, mother, a wife, a daughter. Their sense of well-being and purpose revolves around these roles.

- Any pets they may have had – giving them a feeling of being needed and loved unconditionally.

- Leisure pursuits that have given them a sense of spiritual well-being - for example, music, fishing, the arts.

- Cultural, religious and family traditions. Some people view their spirituality as part of their religion, culture or family traditions and may experience feelings of longing for their family, culture or religion.

- Key life events which gave them feelings of well-being, happiness or achievement. Some people may focus on life events and view them negatively, feeling resentment, guilt or regret about past decisions.

**Psychological or emotional factors**

Psychological and emotional factors can influence how people view death and dying – in particular the experience of the recent death of a loved one. In these circumstances they are more likely to discuss issues around end of life such as planning and preferences.

**Your own views on death and dying**

As a care worker in end of life care, an important way to raise your awareness and understanding of individuals’ views on death and dying is to think about your own views and the factors that influence them.

**STOP AND THINK!**

Think about your own views about death and dying. What would be your wishes and preferences? What factors in your life have an influence on your views? This will help you to empathise with others.
How factors affecting views on death and dying can impact on practice

In today’s society death and dying are still taboo subjects not only for the public but also for many health and social care professionals. Many people have not seen a dead person.

The care of the deceased is now commonly undertaken by funeral directors who perform the care tasks and rituals associated with caring for the deceased, whereas in previous centuries, this was undertaken by the family or the community. This has resulted in a lack of openness and discussion about death which has an impact on practice in the following ways:

• People fear death and the dying process
• Close relatives, or health and social care professionals may not be aware of the individual’s wishes and preferences for treatment and therefore not know how best to support and help them
• People may not want to discuss their funeral wishes
• People die without making a will because they think it is ‘tempting fate’
• There is a lack of public and professional discussion regarding the dying process and death
• There is a lack of knowledge and understanding of death, dying and the grieving process.

Activity 1: How views on death and dying can affect practice in end of life care

Review the information that you have learned so far and jot down some examples of how you think views about death and dying could affect end of life care practice.
Did you consider the following examples?

- **Social factors**, such as attitudes to different diseases, may lead to value judgements about dying and how people are therefore treated – for example, some diseases could be viewed as self-inflicted such as liver failure due to alcohol abuse, whereas a person dying from cancer may be viewed as just ‘bad luck’.

- **Social attitudes towards sexuality** may lead to discrimination in end of life care. When people who are in a same sex relationship have not been declared in a civil partnership, they have no rights in relation to involvement in decision making and in some cases the funeral arrangements.

- **Social attitudes to death** as a ‘taboo’ subject may prevent people discussing and planning for end of life with care professionals.

- **Cultural factors** mean that end of life care workers need to be aware and sensitive to the different cultural needs of the person. The UK is a diverse society in relation to culture and ethnicity. Cultural factors also mean that care professionals must be more aware of language differences. If English is not the first language, the person may experience difficulties in accessing health care and understanding any information given to them.

- **Religious factors** impact on practice because the UK is not a purely Christian community. Healthcare professionals now need to have an understanding of the world religions in order to provide high quality end of life care and decision making. Religious factors also impact on practice because, for those with a strong faith, religious coping can result in less use of end of life care planning and less use of advanced decisions. People may view what is happening to them as the ‘will of God’.
How attitudes of others may influence views on death and dying

The attitudes of others may influence an individual’s choices or perspectives concerning death and dying. The person who is reaching end of life may be influenced by others in the following ways:

- The information that care professionals such as GPs, nurses and care workers tell them about their illness and its prognosis may influence people to make plans in the event of death.
- GPs and Practice and District Nurses can provide information on a one-to-one basis. Raising awareness, both of what is available and why it is important, could influence people to plan for end of life.
- Family, friends and significant others such as partners may have negative attitudes to their approaching death - for example, people who feel comfortable discussing death and their preferences may be prevented by relatives who are unwilling to engage in the discussion.
- Relatives can be reluctant to discuss plans for end of life as they do not want to consider a family member dying. Also, they sometimes prevent plans from being followed if they are not properly informed or supported.

Activity 2: Attitudes towards dying

Use the link below to download a copy of, ‘Attitudes Towards Death and Dying in the East of England - Qualitative Report: Research to Inform the Development of Social Marketing Interventions on Palliative and End of Life Care (Ipsos/MORI 2010)’.

[link]

Key Fact

It is important not to make assumptions about a person’s perspectives on death and dying, but to undertake an assessment in order to be able to provide the person and their significant others with the support and help that they require.

CONGRATULATIONS, YOU HAVE NOW COMPLETED SECTION 1.
PLEASE NOW GO TO YOUR ASSESSMENT BOOKLET AND ANSWER Q1 to Q4.