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NCFE Level 3
Certificate in The Principles of End of Life Care

Part A

PART A

Welcome to the first part of NCFE's Level 3 Certificate in The Principles of End of Life Care.

We hope you find all of the information contained in this resource pack interesting and informative. These learning resources and assessments 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 divided into two parts (A and B). This is **Part A** which contains **three** units:

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.

Each unit has a number of small sections. 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: UNDERSTANDING END OF LIFE CARE

Welcome to the first unit, Understanding End of Life Care.

This unit is split into **four** sections. These are:

Section 1: Understanding different attitudes to death and dying
In this section you will consider different attitudes to death and dying and how individual's views are affected by social, cultural, religious and spiritual factors.

Section 2: The aims of end of life care
In this section you will consider the aims of end of life care, what constitutes a 'good' and 'bad' death, the World Health Organisation's definition of palliative care and how palliative care is part of end of life care.

Section 3: Current approaches to end of life care
In this section you will be looking at the stages in The End of Life Care Pathway, current approaches to end of life care, and evaluating how an approach to end of life care can support individuals and others.

Section 4: Support services
In this section you will explore services and facilities available to an individual and their family, identify key people in the end of life team, identify barriers to accessing end of life care and ways to overcome these barriers.

SECTION 1: Understanding different attitudes to death and dying

Factors that can affect individual's views on death and dying

Individuals differ and therefore many different factors will impact on their needs and preferences for their end of life care. Some of these factors include:

Social factors

In today's society death and dying are still taboo subjects for discussion not only for the public but also many health and social care professionals. Many people have not seen a dead person due to the 'professionalisation' of death in the western culture.

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. In previous centuries, the dying process and the care of the deceased was undertaken by the family or the community and this is still the case in some societies today. This has resulted in a lack of openness and discussion about death and dying not only within the public but also for professionals which has the consequences of:

- Making people fear the dying process and death
- Close relatives and health and social care professionals not being aware of the individual's wishes and preferences for treatment and therefore not knowing how best to support and help them. This is especially the case with individuals who have lost their ability to make decisions. In October 2007 The Mental Capacity Act 2005 came fully into force making advance decisions with regard to treatment options
- Lack of organ donation
- People not discussing their funeral wishes
- People dying without a will
- Lack of public and professional discussions regarding the dying process and death
- Lack of knowledge and understanding of death, dying and the grieving process
- Lack of knowledge of the financial implications for the bereaved following the person's death. For example; what can be put into place ahead of death to relieve some of the financial burden on the bereaved.

Age

Most young adults and adult people (15 to 64 years) 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 the time comes.

Gender

From research that has been undertaken, there is no significant gender bias in relation to death and the dying process, however research has indicated that the greatest worry for females is being a burden to their family and their carers, whilst males worry more about the financial implications of their death and dying for their family.

Role / relationships

A person's identity is closely linked to the roles and relationships in a person's life. They fulfil our basic need for love and a sense of belonging - for example, being a husband and being a policeman.

Sexual orientation

Research has shown that sexual orientation is the most likely area for discrimination in end of life care. The problem arises when people who are in a same sex relationship have not been declared in a civil partnership, having no rights in relation to involvement in decision-making and in some cases the funeral arrangements.

The legal status of same sex partners in the United Kingdom is set out in the Civil Partnership Act 2004 (Amendments) 2005. It is accepted by health care regulatory bodies that civil partners should be accorded the same degree of consideration in decision-making as a spouse. While next-of-kin status has no legal basis, once in a civil partnership they should be regarded as the next-of-kin.

Other social factors

There are other social factors that can affect people's view on death and dying. These are:

- The nature of the condition or conditions, from which they are suffering and the different symptoms they cause. Society as a whole views different diseases differently, with some diseases being viewed as self-inflicted such as liver failure due to alcohol abuse, whereas a person dying from cancer being viewed as just 'bad luck'
- Living arrangements, for example; whether they live alone or with others, the proximity of close family, in sheltered or extra care housing, in a care home or a nursing home, etc
- Social circumstances such as poverty, refugee, asylum seeker status
- Pre-existing vulnerabilities such as mental health or learning disabilities
- Experiences of health care in the past, especially in relation to the experience of death and dying of others.

Cultural factors

The United Kingdom is a diverse and varied society in relation to culture and ethnicity. Thus health care workers need to be aware and sensitive to the different cultural needs of the person in regard to their end of life care.

Here are some cultural factors:

- An individual's culture may help people to explain why dying and death has occurred at this time and as a result of their illness. It may define how a person acts and grieves when death has occurred. In some cultures death is not viewed as the end but a new beginning, for example; some Chinese and Tibetan cultures.
- Certain cultures regard seeking care and support from healthcare professionals as acceptable. Whereas some cultures view this as unacceptable and one's care needs should be sought from their family and community, for example; some Hispanic cultures.
- Some cultures believe that open discussion about dying and death is disrespectful and impolite, for example; some Asian cultures. Some cultures believe that speaking about death makes it 'real', for example; Bosnian cultures.
- It may be that English is not their first language and therefore they may experience difficulties in accessing health care and understanding any information given to them.

Religious factors

A person's religion can be an enormous source of support and strength for dying people and their families. A person's religion may define how the person fits into their community, their family and the world as a whole. As previously stated, the United Kingdom is now a diverse society and therefore is no longer a purely Christian community. Health care professionals now need to have an understanding of the world religions in order to provide high quality end of life care. Healthcare professionals should also have an understanding of the importance of religious belief on end of life care and decision-making. Some of the religious factors include:

- An individual's religion may define how they deal with the process of dying, death and bereavement. Some religions believe in an afterlife, while some religions believe in re-incarnation.
- A high level of religious coping can result in less use of end of life care planning and less use of advanced decisions. These people may view it as the 'will of God'.
- There can be wide differences in belief between different forms of the same religion, for example; in Judaism there are three main strands; Orthodox, Conservative and Reformed.
- In some cultures the religious leader is also viewed as the 'healer', for example; some Native American religions and Oriental religions.

Spiritual factors

There is close association between religion and spirituality. However, people with or without faith may have spiritual needs related to the meaning, value and purpose of their lives. This is an essential factor in end of life care. Once a person's spiritual wishes, concerns and / or worries have been established then appropriate support can be offered to the individual and their families.

Common spiritual factors include:

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.

Relationships
Some people may focus their spirituality around important relationships in their life, for example; being a mother, a wife, a daughter. Their sense of well-being and purpose resolves around these roles.

Pets
Some people may view this as a fundamental part of their lives, giving them a feeling of being needed and loved unconditionally.

Hobbies
Some people's feeling of spiritual well-being comes from a passion for a particular hobby, 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. This is especially the case in people who may have moved away from their culture, religion or family over the years. Some people may for example, rekindle family ties that they have severed in the past.

Key moments in a person's life
Some people will gain comfort from a particular or series of life events, events which gave them happiness, feelings of well-being or achievement, for example; having a child or performing a courageous act. Some people may focus on a particular life event and view this negatively and feel resentment, guilt or regret, for example; lost opportunities or past decisions which did not turn out as they had hoped or wanted.

It is important not to make assumptions about any aspects of an individual's social, religious, cultural or spiritual life, but undertake a full assessment in order to be able to provide the person and their significant others with the support and help that they require.

A Activity 1: Priorites

What factors do you consider to be a priority when discussing the dying process and death with an individual, their family / carers / other health and social care professionals? Include reasons as to why you think this.

The individual:

Their family / carers:

Other health and social care professionals:

CONGRATULATIONS, YOU HAVE NOW COMPLETED SECTION 1.

PLEASE NOW GO TO YOUR UNIT 1 ASSESSMENT BOOKLET AND ANSWER QUESTION Q1.