

**CACHE Level 2**

# Certificate in the Principles of End of Life Care

COMMUNICATION SKILLS

CARE PLANNING CYCLE

UNDERSTANDING GRIEF AND LOSS

PALLIATIVE CARE

ADVANCE CARE PLANNING

## Workbook 1

## Section 1: Understand how to work in end of life care

This section of the workbook will help you to develop your knowledge and understanding of the factors that are important when working in end of life care.

### The factors that can affect people's views on death and dying

Please read the following as it will help you to answer questions 1 and 2.

The way in which people respond to death varies considerably. Whilst some people avoid any mention of the subject, others may feel more comfortable and openly welcome discussions about death and dying. These differences in views about death and dying are influenced by the individuality of the person; namely the social, cultural, religious, spiritual, psychological and emotional factors that make up that person.

Dying is a deeply personal experience and it is therefore important to have knowledge of someone's views in order to understand why they respond to the prospect of dying in the way that they do. If you are supporting individuals who are nearing the end of their life, it is important to have a knowledge of the factors that could influence decisions relating to death and how individuals choose to die. We will explore each of these factors in a little more detail.

#### Social factors

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A person's social perspective is influenced by a number of different social factors. The social relationships that an individual has could cause them to worry about the impact their death will have on others such as family, friends, children and colleagues. This worry and concern is often referred to as 'social pain' and may include the following:

- loss of relationships – their social placement within the family unit (as father, mother, grandparent etc.)
- loss of role within their community
- worry about how their family will cope emotionally, psychologically and socially after their death
- worry about how their family will manage financially (especially if they are the main breadwinner)



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These can all influence the choices a dying person makes in relation to planning their death.

An individual may withdraw socially from those they were previously close to – a natural reaction to place distance between them. This often occurs during the anticipatory grieving process as the dying person begins to prepare for their death.

This withdrawal is not only limited to the dying person. Family, friends and care workers may also withdraw and experience the same feelings of anticipatory grief.

Social interaction is important, and maintaining it ensures that the dying person does not feel isolated as the end of their life nears.

### Cultural factors

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As we live in a multicultural 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 the meaning of death, how people who are dying should be cared for, and how grief may be expressed.

Within some cultures, death is viewed as a social event with great meaning for the whole of society, whereas for others, death is viewed as a private, hidden occurrence.

Some cultures openly celebrate death, believing the person who has died has gone to a better place, whilst people from other cultures mourn for extended periods of time.

Some cultures grieve openly with great expression, whilst others will only express their feelings and emotions within a private circle.

Amongst older British people, there remains a strong belief in the 'stiff upper lip'. Men in particular may feel that expressing emotions 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.

### Religious factors

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Religious beliefs and practices play a significant role in the lives of people who are living with a life-limiting condition. Along with spiritual beliefs, religious traditions provide a framework for understanding the experience of death and dying, and the meaning of illness and suffering.

Some people gain comfort from their religious beliefs as they face the end of life, and some find reassurance through a belief in a continued existence after their death.



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However, religious concerns can also be a source of pain and distress, for example, if an individual feels they are being punished or abandoned by God. Furthermore, beyond the role of religious faith in coping and adjusting to illness, religion can also influence the individual's decisions about active treatment and end of life care.

### Spiritual factors

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Spirituality is the part of a person which is concerned with ultimate ends and the search for meaning and existence. This involves searching for answers to questions and generally surfaces at times of emotional stress, illness, loss, bereavement and death. The essence of spirituality is about knowing our true selves and what makes our thoughts and beliefs unique to us.

Most people have a spiritual component to their life at some point, just as they have physical, social and psychological components. In this instance, spiritual needs relate to the needs a person approaching their end of life may have with regard to their religion, culture, values, beliefs and experiences. Spiritualism tends to come into focus at a time of emotional stress, illness, loss, bereavement or death. As with other dimensions of the person, spiritual needs are highly individualised and can change as other dimensions of a person's health changes.

Support for spiritual needs may be especially important at the end of life as an individual starts to consider their own death and dying.

Spiritual factors that can affect a individual's views on death and dying include:

- their expression of religious beliefs within their spiritual values
- the meaning and purpose of their life and whether they have fulfilled their ambitions and needs
- environmental perspectives such as their method of burial
- their reflections upon key life events, love and family relationships
- cultural and family traditions which they would prefer to be upheld during their end of life care
- preferences for music, the arts and self-expression – this could include their views in relation to creative approaches such as art, poetry, meditation, massage and relaxation techniques, which could be used as a part of end of life care

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As a person nears the end of their life, he or she may draw strength from ceremony, ritual or cultural practices. However, a person may struggle to find hope and to make sense of what is happening to them. This could lead to what has been described as spiritual pain. Spiritual pain could also occur as a result of an individual experiencing discomfort with their religious beliefs. They may hold the belief that God is not there for them, or that they are being punished for something they did earlier in life. This may lead to feelings of anger and pain.

### Psychological factors

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Generally, people's reaction to death is that of fear. The process of death and dying are still unknown. No one has ever died and returned to tell us what death is really like. Man naturally fears what he does not understand and cannot control. We can never know exactly what death is, so we can never fully understand it. Therefore most people will continue to fear it. Because of this fear, much of our response to death is avoidance. Death is not a pleasant topic of conversation and when we do talk about it, it is usually discussed in academic terms as talking about death on a personal level usually creates discomfort.

### Emotional factors

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Death brings with it all kinds of emotions such as sadness, worry, fear, anger, shock and confusion. A person experiencing death or the death of a loved one may also feel cheated, relieved, guilty, exhausted or empty. These emotions are usually very intense. Many of us are inclined not to talk about things that upset us. We try to put a lid on our feelings and hope that saying nothing will get us through. We therefore often choose to work through these feelings ourselves in order to protect others.

## Section 1: Understand how to work in end of life care

**Knowledge Activity 1:** Think about an individual for whom you are providing end of life support; what are their views about death and dying in terms of the following contexts?



### ■ Social

### ■ Cultural

### ■ Religious

### ■ Spiritual

### ■ Psychological

### ■ Emotional

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**Knowledge Activity 2:** Outline the factors that can affect your own views on death and dying.



### How factors relating to views on death and dying can impact on practice

Please read the following as it will help you to answer question 3.

Care workers who display negative attitudes towards end of life care may possibly do so because of fear in relation to their own abilities. This could be due to a lack of training, a lack of experience and negative assumptions. This can act as a barrier to the effective delivery of end of life care leading to a situation by where the process of dying is badly managed.

A 'bad death' experience may cause stress to the individual but also to their family and the staff involved in their care. 'Bad deaths' tend to occur as a result of miscommunication, perhaps through fear, a reluctance to talk about death and dying and also as a result of dying unprepared.

A 'bad death' may be experienced by an individual if they suffer a great deal of pain or other unpleasant and possibly avoidable symptoms. This may occur when the individual makes the decision to refuse treatment or medication as they wish to die in a particular way, perhaps through being alert and responsive at the time of their death.

Other experiences of bad deaths occur when individuals prevented from being with their families at the time of their death. Occasionally, family and friends cannot make it to the bedside of the individual in time and this can result in the individual feeling isolated and alone.

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