

NCFE Level 2

Certificate in the Principles of End of Life Care

COMMUNICATION SKILLS

CARE PLANNING CYCLE

UNDERSTANDING GRIEF AND LOSS

SAMPLE

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

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)



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

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.

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

Fact



Professor Edwin Pugh, a consultant in end of life care says:

“Almost one in five of us are uncomfortable talking about death”

Attitudes of family, friends and community

An individual's choice of where he or she wishes to be cared for may also be influenced by the attitudes of significant others such as family and friends. In the past, younger generations would be far more likely to come across death and dying within their own home as it was probable that their grandparents would die at home. Within today's society, there is a tendency for families to live much further apart. Without family to care for them at the end of life, more people are likely to die in a clinical environment such as a hospital.

In addition, family and friends may find it difficult to broach subjects such as care after death and funeral arrangements with the individual who is dying, for fear of upsetting them.

It is important that people who are dying are afforded the opportunity to make their wishes and preferences known, and that the views and opinions of others should never be allowed to interfere with the decisions made by individuals. Planning in advance, if possible, is the best way of helping individuals and their loved ones to experience a 'good death.'

Explain the aims and principles of end of life care

Please read the following as it will help you to answer question 5.

Quite a few terms are used, sometimes interchangeably, by people when referring to care given to individuals who are nearing the end of their life; 'terminal care', 'palliative care', 'specialist palliative care', 'supportive care', 'hospice care', and 'care of the dying' are a just a few examples. End of life care, however, has become the most popular and widely used term to explain the care given to individuals who are living with a life-limiting illness. But what exactly is it and what are the aims of end of life care?

The answer is to prevent or treat, as early as possible, the symptoms of a disease. The side effects of the disease and psychological, social, and spiritual problems related to the disease are also considered within this practice. The overall aim of end of life care is to support the individual and relieve their symptoms rather than trying to find a cure for their illness. This will ensure that individuals are afforded the best quality of life possible during this time.

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

The goals of end of life care are: to maintain the comfort, choices, and quality of life of a person who is recognised to be dying (in the terminal phase); to support their individuality; and to care for the psychosocial and spiritual needs of themselves and their families. Support for families, if needed, continues after death as bereavement care. End of life care also aims to reduce inappropriate and burdensome healthcare interventions and to offer a choice regarding place of care when possible.

The National Council for Palliative Care and the Department of Health define end of life care as:

‘Care that helps all those with advanced, progressive, incurable conditions to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes physical care, management of pain and other symptoms and provision of psychological, social, spiritual and practical support.’

Source: Department of Health, National End of Life Care Strategy, 2008

Fact



Broadly speaking, the aim of end of life care is to ensure that all of someone's care needs are met in a holistic manner, and that they are cared for, and can face death, in a place of their choosing and in a manner that they choose.

Explain why it is important to support an individual in a way that promotes their dignity

Please read the following as it will help you to answer question 6.

To treat someone with dignity is to treat them with respect and value them as an individual. Within health and social care situations, dignity may be promoted, or equally, it may be compromised by the:

- physical environment
- culture of the organisation
- attitude and behaviour of health and social care workers
- way in which care activities are carried out

