# **CACHE Level 2** Certificate in Understanding Cancer Support INCIDENCE AND PREVALENCE SUPPORT Workbook 2

In this section, you will learn about the role of family members in caring and supporting individuals with cancer and the dilemmas and conflicts that may arise between healthcare workers and family members. You will learn about the roles that other key people can play in a cancer care team and the organisations that can offer information, support and care services. You will develop an understanding of the impact on individuals of living with cancer and how to support emotional and mental well-being. You will also learn about the principles of self-management that can help individuals to monitor and manage their own condition.

# The contribution of family to the care and support of individuals with cancer

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

Cancer affects families as well as individuals and often family members are a major support for individuals with cancer. The contribution of family members in caring for and supporting individuals will vary depending on the stage of cancer and the individual's family situation. Often partners, adult children or parents will want to do whatever they can to help care for the individual, sometimes putting their own lives on hold to do so. Families may discuss and share decisions on treatment and care. Perhaps most importantly of all, family members can be companions for individuals with cancer so that they don't feel alone in facing their illness. Specifically, family members, with the individual's agreement, can:

- Help with practical tasks such as driving the individual to appointments, shopping, making meals etc.
- Supporting the individual at appointments, helping them to understand information and ask the right questions.
- Just be there when the individual needs support.
- Talk to other family members to let them know what is happening.
- Act as interpreter where the individual's first language is not English.
- Support personal care such as washing, going to the toilet, eating and making the individual comfortable.



Of course, some families will be much more involved in care and support than others. This will depend on a number of factors. Factors include:

**The needs of the individual** – some individuals will need more help than others depending on how ill they are with the cancer and what they are still able to do for themselves. Where individuals are hospitalised, the level of care provided by family will be limited, though they can still offer support.

**The complexity of needs** – where an individual needs a high level of care or has complex needs (for example, if they need to be moved regularly to avoid pressure ulcers) family members may not be able to be involved in care as much as they would wish.

**The wishes of the individual** – some individuals may not want their family members involved in their care. This may be because they don't want to be a burden on their family; because they feel embarrassed about letting a family member help with personal care; or because they don't get on particularly well with family members. Alternatively, they may be well enough to continue with their everyday life and want to remain independent.

**The willingness of the family to help** – family members may be reluctant to help; or they may be nervous about helping, worrying that they will do the wrong thing; or it may simply be too distressing for them. Again, the level of support will be affected by the relationship between the individual and family members.

**Other responsibilities** – often family members may have other responsibilities that affect the level of involvement they can have in the care and support of the individual. A family member with small children, for example, may not be able to get involved as much as they would like because of their own caring responsibilities.

**Financial issues and work commitments** – many family members will have full-time work commitments and will need to continue working to support themselves and, sometimes, the individual diagnosed with cancer. This may limit the time they can spend supporting and caring for individuals. This can be made worse if the individual has had to give up work due to their illness.

**Distance** – often family members, especially adult they may be who would like to be involved in care, live too far away to offer any practical help on a regular basis. In this case, the level of support may be limited to short visits and telephone conversations with the individual to offer emotional support.

**Values and beliefs** – sometimes different religious, spiritual or cultural beliefs may make family members less willing to help or the individual less willing to ask for or accept help.

#### Section 1: Introduction to the social housing sector

#### Kathy's story

When I was diagnosed with breast cancer, my family were really supportive, but I had to ask them to step back a bit. My husband was all for giving up his job to look after me, my daughter wanted to move back home. I was grateful for their love and concern but felt overwhelmed. I talked to the Macmillan nurse who was supporting me, and she said I needed to talk to them about what I wanted. I wanted to carry on as normally as possible whenever I could. I knew I'd need help sometimes, but I didn't want everyone giving up their own lives to focus on me. Apart from anything else, while I love them, they can drive me up the wall sometimes! So, I sat everyone down over takeaway pizza one evening and told them what I wanted. Funnily enough, they admitted they were quite relieved. They wanted to support me but were frightened about how everything would change.

<b>Knowledge Activity 1:</b> Think about a situation in your own family or a family you know where someone has needed some level of care and support for an illness or other situation such as bereavement. Write down the factors that affected the level of support from different family members.	



# Dilemmas or conflicts when working with family members

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

Care workers who are working in partnership with families may sometimes face dilemmas or conflicts between their duty of care to the individual or the wishes of the individual and what the family wants. Family members may often feel they know what is best for the individual and will try to influence care or support. Dilemmas or conflicts may occur when:

- The personal or cultural beliefs and values of the individual may differ from those of family members, which can cause conflicts over care. For example, if the culture of an older family member is that individuals should only be cared for by same sex care workers, this may lead to problems.
- There may be differences between family members or between family members and care workers about the care provided to the individual. For example, the individual may not feel like eating, and one family member may try to persuade them to eat while another might think they should not encourage the individual to eat if they don't want to.
- Having a family member with cancer can be emotionally traumatic for family members and this will affect their behaviour and attitudes. They may be critical of care provided, feeling that care workers are not doing the best for the individual. Or they may become over emotional about decisions that the individual makes about their own care such as deciding not to have treatment.

When care workers are faced with dilemmas, they must always prioritise the needs and wishes of the individual and provide care accordingly.



## **Key people in the cancer team**

Please read the following as it will help you to answer question 4.

There may be a number of professionals involved in the care of an individual with cancer and they should work together to ensure that support is co-ordinated and meets all individual care needs.

Key people in cancer care teams may include:

- Surgeon as well as having a role in treatment through surgery, surgeons may also be involved in cancer screening, diagnosis and staging, risk-reducing surgery, symptom control and reconstructive surgery. They play an important role in the management of cancer for the individual.
- Medical Oncologist a medical oncologist focuses the treatment of cancer using drugs.
- Clinical Oncologist a clinical oncologist uses chemotherapy and radiation to treat cancer, possibly alongside other drug treatments.
- Radiation Oncologist a radiation oncologist specialises in treatment of cancer using radiotherapy.
- Oncology Nurse an oncology nurse supports the treatment of the individual by monitoring and assessing their medical state. They also give the individual and their families information about treatment and the illness and support individual wellbeing.
- Social Worker an oncology or palliative care social worker supports the individual and their family in a more holistic way than some other professionals. As well as offering emotional and psychological support, they can give practical help with issues such as financing, housing, employment and school issues. They may also act as advocates for the individual within the care team and beyond.
- Nutritionist cancer and cancer treatments can affect the appetite and diet of individuals with cancer. A nutritionist or dietician can give dietary advice to ensure the individual does not become malnourished as a result of their illness or treatment.
- Psychiatrist being diagnosed with cancer and experiencing the illness and treatment can be psychologically challenging. NHS research shows that mental illness is much more common in those with long term illnesses and depression can occur in one in five of these individuals. Anxiety is also common and there may be cognitive symptoms associated with the illness. Psychiatrists can support the mental health of individuals.

- Psychologist/Counsellor psychologists or counsellors can help to support the emotional health of individuals with cancer. They may offer talking therapies so that individuals can work through the fears and anxieties they have relating to their illness.
- Physiotherapist cancer may affect the individual's ability to move and can result in severe fatigue. Physiotherapists can work on exercises with the individual to prevent disability and to alleviate fatigue and other symptoms.
- Occupational Therapist occupational therapists support individuals to maintain or recover the skills they need for everyday living and working. Where individuals find themselves no longer able to carry out specific tasks easily, the occupational therapist can help them to find alternative ways to carry out tasks.
- Patient Navigator a patient navigator helps the individual through the cancer journey. They can give information to the individual about services and support treatment planning so that the individual does not have to attend appointments unnecessarily.
- Haematologist/Pathologist haematologists are the people who deal with blood samples and pathologists deal with cells and other tissue removed from the individual. They will test the samples to help with the diagnosis and treatment of cancer.



STAGES OF GRIEF

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