Chapter 13
Surviving cancer

Living with cancer

Improved health promotion and treatments for cancer have contributed to earlier detection and increased chances of survival. Some long-term cancer survivors have a normal life expectancy and others, although not cured, live for a long time with cancer. For some cancers, the treatments needed to control the disease are intensive; for others a ‘wait and see’ policy can intensify the psychological trauma of living with a life-threatening illness. Survival of cancer should be accompanied by an acceptable quality of life for the individual. The trauma of a life-threatening illness and the almost unrecognizable life change are exasperated by our incapacity as a society to address, accept and communicate openly about the fear of our own mortality, which underlies cancer (Petrone 1999).

Problems commonly identified as long-term effects of cancer treatment include:

- fear of death
- fear of recurrence
- a preoccupation with health
- physical problems including fatigue, pain and long-term side effects of treatments
- psychological problems including anxiety and depression
- relationship difficulties.

Rehabilitation in cancer care involves adapting to changing circumstances over time and includes four aims:

1. Prevention: involves care aimed at preventing potential long-term problems, e.g. body image problems after mastectomy for breast cancer.
2. Restoration: returning the patient to a pre-cancer level of function. This might be physically possible but the patient may have psychological difficulties in returning.
3. Support: involves helping patients to adapt to long-term symptoms.
4. Palliation: this involves reducing the side effects of the disease process and treatment, and offering comfort and emotional support.
Several factors will influence individual coping styles, including:

- The nature of the cancer: type, site, extent
- Individual characteristics: age, gender, education, culture, religion, health beliefs
- Family characteristics: roles, responsibilities, communication, relationships, culture and values
- Support network characteristics: availability, flexibility, culture.

The role of the multidisciplinary team is key to supporting patients living with cancer, working together with the patient and the family to promote optimal quality of life – a quality of life that at times measures the difference between the hopes and expectations of an individual and that individual’s experiences.

**Hope**

Many people react to a cancer diagnosis by preparing for death and, no matter what the prognosis, cancer forces people to examine the possibility that they may not live as long as they had thought (Brennan 2004). Suddenly hopes and dreams for the future are threatened, long-standing life goals become clear and at the same time their attainment may seem unlikely and even unrealistic.

Having things to look forward to and goals to achieve is what motivates and structures our lives; the threat of cancer leads people to re-evaluate life’s hopes and dreams. Everyone needs a sense of hope and having hope involves more than just the wish to be cured. Having goals and plans, even if they are treatment related or even if they are made on a daily basis, are vital to people’s sense of hope and meaning (Brennan 2004). The health-care professional who works with the patient and offers hope also enriches the life of the patient living with cancer.

**Spirituality**

Holistic care is based on the physical, psychosocial and spiritual needs of the individual. The multidisciplinary team works hard to meet the biopsychosocial needs of the patient, but often spiritual care is ignored, resulting in a failure to meet the spiritual pain, conflict and needs of the patient.

Patients with cancer experience loss, pain, fear, despair and often quote ‘a search for meaning’ or purpose for their life. Spirituality and a search
for meaning are diverse concepts and encompass an individual’s beliefs and values. Spiritual care can impact on the ability of patients to cope with a diagnosis of cancer, as well as subsequent treatments, providing a sense of purpose and meaning to life as well as preparation for death.

Nursing interventions that 'enspirit' people affected by cancer include:

- giving encouragement
- being quietly and professionally confident
- demonstrating genuine respect for the patient
- remembering the special characteristics of the patient in order to offer individualized care
- trusting the wisdom of struggling, standing by through the experience and protecting personal space and privacy
- being honest and open
- encouraging patients to talk about how they feel.

For some patients, confrontation with death results in a clarification of their understanding of human existence (Kinghorn and Gamlin 2001):

If there is any place that needs any spirituality, it’s here. If there’s a place that needs God’s kindness, it’s here... Because you’re at your end. Some of them are going to die. Some of them are not going to die, but still, in this time of life, you need someone to be able to be kind and show God’s love. Because otherwise it would be hell... I couldn’t stand to be here that many days without some kindness.

Taylor (2003, p. 590)

**Communication**

Nurses are in the privileged position of being able to listen to patients talking about their hopes and fears related to their illness. The nurse’s experience, knowledge and skills can enable patients and families to explore their feelings and adjust in some way to the situation; this may include discussing the situation openly or by using strategies such as humour or even avoidance in order for the individual to cope (Dean 2002).

It should be remembered that ‘social talk’ is also necessary; chatting and joking in a way that people take for granted may help to foster the hope that the illness has not taken over the patient’s life entirely (Dean 2002, Wilkinson et al. 2002). Research evidence supporting *The NHS Cancer Plan* (DoH 2000) highlighted communication skills and the willingness to listen and explain as essential attributes of the health-care professional working in cancer care, along with sensitivity, approachability,
respect and honesty, according to a national patient survey. Some patients went on to say that they received excellent care, with sensitive and thoughtful communication, clear information about their disease and its treatment, and good support when needed (DoH 2000). Other patients reported being given bad news in a deeply insensitive way, being left in the dark about their condition and being badly informed about their treatment and care. Complaints by patients focus not on a lack of competence but more often on the perceived failure of communication and an inability to convey a sense of care adequately (Wilkinson et al. 2002).

According to Petrone (1999, p. 5):

As a community we fail to realise that one lives through illness . . . as an individual the feelings that manifest in us are in fact because we are alive. The feelings of fear, pain, disbelief and anger only give more importance to the feelings of love, happiness and the value of life . . . . Who does not find it difficult to talk to someone who might be dying? The person assumes an aura of fragility that cannot afford a mistake. We are all human, we all make mistakes, how else do we learn and go forward?

**Palliative care**

Sometimes the possibility of dying, gives permission for a way of living not previously allowed.

Petrone (1999, p. 5)

Over 230 000 people in England and Wales will develop cancer each year, and cancer accounts for a quarter of all deaths. The diagnosis of cancer and its subsequent treatment can have a devastating impact not only on the individual’s quality of life but also on the lives of their families and carers. Patients will face having to undergo unpleasant treatment options and they and their families and carers will need access to support from the time that the cancer is first suspected, through all stages of treatment to recovery, or in some cases to death and bereavement (National Institute for Clinical Excellence or NICE 2004).

Research has consistently shown that, in addition to receiving the best possible treatment, patients want and expect to be treated as individuals with dignity and with respect for their culture, lifestyles and beliefs. They want to have their voice heard and be able to exercise real choice about treatments and services. Patients want to receive detailed high-quality information about their condition and possible treatment and to be aware
of the options available to them within the NHS, and the voluntary and independent sectors, including access to self-help groups and complementary therapy services (Cancerlink 2000).

**Definition of palliative care**

Palliative care is:

> The active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.

World Health Organization (WHO 2002)

**Palliative care principles**

Palliative care is based on a number of principles and has a number of aims:

- To provide relief from pain and other distressing symptoms.
- To integrate the psychological and spiritual aspects of patient care.
- To offer a support system to help patients to live as actively as possible until death and to help the family to cope during the patient’s illness and in their own bereavement.
- To be applied early in the course of illness in conjunction with other therapies intended to prolong life (National Council for Hospice and Specialist Palliative Care Services or NCHSPCS 2002, WHO 2002).

Palliative care is recognized in *The NHS Cancer Plan* (DoH 2000) as having a crucial role in the care received by patients and carers throughout the course of their disease. It states that too many patients still experience distressing symptoms, poor nursing care, poor psychological and social support, and inadequate communication from health-care professionals during the final stages of an illness, and it calls for the care of dying patients to improve to the level of the best (DoH 2000).

Palliative care can be provided by those who care for patients on a day-to-day basis; until recently it was categorized as the palliative care approach and has now been redefined as general palliative care (NCHSPCS 2002). Specialist palliative care is delivered by those who specialize in palliative care, e.g. consultants in palliative medicine and clinical nurse specialists (NCHSPCS 2002). The document *Palliative Care in the Hospital*
Setting (NCHSPCS 1996) recommended that the palliative care approach should be an integral part of all clinical practice and should be available to all patients with life-threatening illness. Much of the professional support given to patients with advanced cancer is given by professionals who are not specialists and may have received little training in this area. The NICE (2004) recommends that medical and nursing services are available for patients with advanced cancer on a 24-hour, 7-days-a-week basis, and specialist advice should be available at all times. Staff should receive training and ensure that they have the knowledge and skills needed for their role.

Supportive care

The NICE (2004), in a recent publication, discusses the importance of supportive care, stating that although it is not a distinct speciality it is the responsibility of all health-care and social care professionals. It involves open and sensitive communication. Supportive care begins when the patient is first seen. The NCHSPCS (2002, p. 3) says that supportive care:

\[\ldots\text{helps the patient and their family cope with cancer and its treatment from pre-diagnosis through diagnosis and treatment, to cure, continuing illness or death and into bereavement. It helps the patient maximise the benefits of treatment and to live as well as possible with the effects of the disease. It is given equal priority alongside diagnosis and treatment.}\]

Although the palliative care and supportive care definitions are very similar it is useful to have supportive care defined in order that patients and families can have an idea of the type of care and support that they can expect.

There is both a growing interest and need to expand the provision of palliative care to those with diseases other than cancer. In doing so the potential to relieve suffering is increased.

Conclusion

Supportive care for those people living with cancer whether after curative treatment, during active treatment or in the terminal stages of disease should be addressed by all members of the multidisciplinary team. It is
important that the cancer patient has goals and plans; these might be short or long term or even on a daily basis; they might be treatment related or even psychosocial or emotional (Brennan 2004). The physical, psychosocial and spiritual needs of the patient should be embraced by health-care professionals working in partnership with the patient and his or her family (NICE 2004).

For those patients where treatment is no longer available and no cure possible, and where health-care professionals understand the meaning of the illness for the patient and that patient’s life, there is a sense of healing – in the sense that by understanding the meaning of the illness the patient can overcome the sense of alienation, loss of self-understanding and loss of social integration that can accompany illness. For the health-care professional who is involved in the support of the patient with cancer, involvement and caring can lead to loss and pain; however, it can also make joy and fulfilment possible (Benner and Wrubel 1989).

References