Helping survivors to adjust after cancer

In this article...
- Defining the concept of cancer survivorship
- The consequences of cancer and its treatment for survivors
- How nurses can help survivors adjust to their new lives

Author Victoria Harmer is team leader clinical nurse specialist, Breast Care Unit, Imperial College Healthcare Trust, London and a trustee for Against Breast Cancer.

The concept of “cancer survivorship” has received considerable attention over the past three years as increasing numbers of people live with and beyond cancer. Previously, attention may have focused more on treatments for cancer and the likelihood of their success. In recent years, interest has moved to the after-effects of treatment, and how people can return to their lives while recovering.

This article discusses the various ways in which cancer and its treatment may affect survivors, and how nurses, in both hospital and the community, can help them to adjust and recover.

Although “cancer survivorship” is a relatively new concept, there is emerging recognition and a growing body of knowledge in this area (Sheppard, 2011).

As treatments become more successful and mortality rates for cancers reduce, an increasing number of people living in the community have completed cancer treatment; this group, along with those living with cancer, are called cancer survivors.

Research by Macmillan Cancer Support (2009) has revealed that around two million people are living with or beyond cancer, and this figure is growing by over 3% each year. Macmillan Cancer Support’s (2009) health and wellbeing survey showed that more than 90% of survivors had asked to be seen by their GP in the last year, compared with 68% in the general population. This suggests they have specific needs which must be addressed.

Given the prevalence of cancer survivors and their needs, Macmillan Cancer Support (2009) argued that cancer follow-up is unsustainable in its current format and leaves patients dissatisfied.

The cancer reform strategy identified the need for an initiative to enhance care and support for cancer survivors (Department of Health, 2007). As a result, the DH, Macmillan Cancer Support and NHS Improvement launched the National Cancer Survivorship Initiative (NCSI) in 2008 (www.ncsi.org.uk). Its aim was to improve support and services for cancer survivors and to establish care and support for all survivors by 2012, enabling them to lead as healthy and active a life as possible, for as long as possible.

New models of care, including cancer follow-up, and attitudes are being scrutinised as part of the NCSI initiative to improve patient experience and reshape cancer care. Survivors’ unmet needs in terms of social, spiritual, financial, psychological, medical and informational aspects of life are being examined and support structures and information discussed and put in place.

Consequences of treatment
Many cancer survivors experience long-term side-effects from previous treatment or from the cancer itself, and may have to overcome a number of psychological and medical issues.

Fatigue is common after cancer treatment

5 key points
1 People who have completed treatment or are living with cancer are called cancer survivors
2 The National Cancer Survivorship Initiative aims to improve support and services for cancer survivors
3 Many cancer survivors experience long-term side-effects from treatment or from having cancer
4 Fatigue is a common consequence of cancer treatment
5 Survivors have to live with the possibility that they may develop unwanted consequences of treatment

Keywords: Cancer/Survivorship/Treatment effects

● This article has been double-blind peer reviewed
A health and wellbeing survey showed that people living with or beyond cancer are seven times more likely to find it difficult to perform personal care tasks, such as washing and getting dressed, than those who do not have a long-term condition (Macmillan Cancer Support, 2009). Fatigue is a common consequence of cancer treatment, and survivors can find this particularly difficult to cope with as it has serious implications and a detrimental effect on quality of life.

The NCSI (2011) found that, after treatment, 60% of cancer survivors had unmet physical or psychological needs and 34% had at least five unmet needs. It defined consequences of treatment as symptoms and/or changes in function that arise after seemingly successful treatment for cancer. It also reported that 50% of patients who had had radiotherapy to the pelvis said they had bowel problems that affected quality of life, and that over one third of survivors described problems with close relationships, issues in performing routine household chores and an inability to fulfil career ambitions.

This area of study is relatively new, and links between previous treatment for cancer and its consequences are only now being discovered and documented; there is limited data about the frequency and occurrence of detrimental late effects.

Although some treatment effects may be considered of low importance, others may be serious, such as the increased risk of breast cancer after mantle radiation for Hodgkin’s lymphoma.

Potential onset of consequences of treatment

Survivors also have to live with the possibility that they may later develop unwanted consequences of treatment.

For example, after treatment for breast cancer, women who have had lymph nodes removed as part of surgical treatment have a life-long risk of developing lymphoedema in that arm. They therefore need to adopt behaviour patterns to reduce this risk such as avoiding having blood pressure measurement or blood taken from the affected arm.

Box 1 outlines the range of possible long-term issues for cancer survivors; while this list is by no means exhaustive, it shows the far-reaching implications of cancer survivorship.

Aspects of life affected

Cancer can affect many aspects of survivors’ lives (Box 2) and it is important to realise that they have probably had to reframe and rethink their lives in some way.

Breast Cancer Care has produced an information pack for cancer survivors, which considers five aspects of life:

- Managing the effects and consequences of treatment;
- The person and their relationships;
- Improving wellbeing;
- Finance, work and practical issues;
- Watching for signs and symptoms of the cancer returning.

These sections are examined individually below.

Managing the effects and consequences of treatment

This may involve getting used to any new symptoms experienced after cancer treatment.

Some people may have thicker skin in areas due to radiotherapy. Chemotherapy can cause hair to grow back with a different texture; it can also prompt early menopause, which can cause confusion about personal identity.

Whatever the symptom, survivors need to redefine and reframe what is now their “baseline” or “norm”, to be more aware of their health and, more importantly, whether something is different and needs to be reported to their GP or hospital specialists.

The person and their relationships

Social support literature demonstrates that interpersonal relationships play an important part in adapting to serious illness (Pistram and Barker, 1995).

Partners of cancer survivors may also face a period of readjustment after their loved one has completed treatment and need time to accept what has happened. Some may take an overly protective role, trying to do everything and protect the survivor from further distress, while others may not be able to come to terms with the new situation and may reject their partner emotionally, either temporarily or permanently.

Some couples become closer as a result of one having gone through cancer treatment, although it can put additional strain on the relationship (Macmillan Cancer Support, 2011a). A partner may not wish to mention or initiate sexual activities for fear of upsetting or hurting the survivor, yet failing to do so may compound the survivor’s worries about their attractiveness.

Although health professionals’ main responsibility is to their patients, providing holistic care does involve supporting relatives, which also helps patients (Brewin, 1996). Nurses can encourage communication between couples, as both partners may be making assumptions about how the other feels without realising it.

The age of cancer survivors may have implications. Those who are older and have retired are likely to have different concerns from those who are still working. Likewise, survivors who have small children at home have different problems from those with grown-up children. The age of children is important in terms of what is communicated to them about a parent’s cancer diagnosis and treatment, although in general children are more at ease when they have been informed of the situation and the plans ahead (Breast Cancer Care, 2010).

Improving wellbeing

Exercise has many benefits (Box 3), and there is a growing body of evidence supporting a link between exercise and cancer survival.

In breast cancer, exercise after diagnosis may reduce the risk of death from the disease (Holmes et al, 2005), and programmes of supervised group exercise...
provide psychological and functional benefits both at the time and six months later (Mutrie et al, 2007).

Survivors can also help by ensuring they eat healthily and avoid or cut down on alcohol and smoking as these have been linked to an increased risk of some types of cancer.

A diagnosis of cancer is life changing; life will never be the same again. It is important for survivors to adjust psychologically over time, which in turn allows this new, initially frightening situation to become less so and more the new normal (Rogers and Turner, 2011).

**Box 2. ASPECTS OF LIFE AFFECTED BY CANCER**

- Finances
- Employment
- Emotional issues
- Sexual issues
- Life plans
- Body image
- Relationships
- Children

Survivorship courses may cover issues such as regaining confidence and intimacy problems, as well as more practical sessions on work and financial issues.

They are a form of rehabilitation that survivors can attend to make slotting back into life easier. Nurses should be knowledgeable about these opportunities and pass on this information when appropriate.

**Nurses’ role**

Because cancer survivors are increasing in number, it is likely that most nurses will come across them – often in situations not directly related to their cancer.

It is as important as ever to ask these patients to describe their past medical history and to keep this in mind if they present with new symptoms.

Nurses are ideally placed to play a central role in ensuring cancer survivors receive high-quality care tailored to specific needs and are referred to appropriate health professionals promptly when needed.

For more information on cancer survivorship, both patients and nurses should consult Goodhart and Atkins (2011).

The future

The NCSI is concentrating on nine areas:

- Assessment and care planning;
- Health and wellbeing clinics;
- Managing active and advanced disease;
- Supported self-management;
- Consequences of cancer and its treatment;
- Survivors of childhood and young people’s cancers;
- Work and finance;
- Vocational rehabilitation;
- Physical activity.

It is expected that the work resulting from these will add to the knowledge base and produce some good-practice principles that nurses can adopt to help survivors develop “a new normal”.

Victoria Harmer is editor of Breast Cancer Nursing Care and Management published in 2011 by Wiley Blackwell

**References**

- Breast Cancer Care (2010) Moving Forward for People Living With and Beyond Breast Cancer. tinyurl.com/Breast-forward
- Macmillan Cancer Support (2011a) Cancer, You and Your Partner. tinyurl.com/Macmillan-partner
- Macmillan Cancer Support (2011b) Prescriptions. tinyurl.com/Macmillan-prescriptions

"For articles on cancer care, go to nursingtimes.net/cancer"