Anyone who is living after a diagnosis of cancer can be described as a ‘survivor’ or as ‘living with cancer’, and the terms are often used interchangeably. Both encompass patients undergoing primary treatment or in remission, and those with incurable cancer who are receiving treatment to control symptoms or extend life (and who may survive several years). However, many people prefer the term ‘living with cancer’ to ‘cancer survivor’. Adding the word ‘beyond’ (so the expression becomes ‘living with and beyond cancer’) is a way of recognising that whether the cancer has been completely removed or survival is predicted to be limited, it is all about living a meaningful life and achieving the best possible quality of life.

People living with and beyond cancer can face many long-term problems, and some will need ongoing support and intervention. The numbers are continually increasing: today, there are 2.5 million people with a cancer diagnosis in the UK and, by 2030, the figure will rise to 4 million (Maddams et al, 2012). An increasing number of people will need help to cope with the long-term effects of cancer on their lives.

This article explores the long-term problems people living with cancer may experience; how well we are delivering the interventions recommended by the National Cancer Survivorship Initiative (NCSI), which was rolled out between 2008 and 2013; and the role nurses and other health professionals can play in identifying patients’ needs and providing timely support.

Understanding people’s needs
Health and social care providers increasingly focus on managing the burden of long-term conditions in an ageing population. They need to understand the specific problems and needs of people living with cancer, so that they can provide them with the right support and help them live a meaningful life.

Studies of survivors’ physical, emotional and social health are gaining importance but, while there is a growing body of
literature on cancer patients during the first five years after diagnosis, less is known about long-term (five years and beyond) and very long-term (10 years and beyond) survivors.

We already know a great deal about the post-treatment effects of cancer, but it is important to continue to gain insights about how people live after cancer treatment. It is also important to understand that current pressures in the health and social care system mean it can be challenging to ensure people receive the right support at the right time, and change existing models of care.

Living with cancer
As treatments improve, cancer survival is increasing; it is estimated that at least 170,000 people living with cancer were diagnosed in the 1970s and 1980s (Macmillan Cancer Support, 2016a). One in four people living with cancer have ongoing physical, emotional, practical and/or financial problems due to their cancer and its treatment (Macmillan Cancer Support, 2013a). Of the 2.5 million people who have a cancer diagnosis, we can therefore estimate that approximately 625,000 people experience ongoing problems and are likely to need support.

The health and wellbeing of cancer survivors are poorer than in the general population and are comparable to those of people with long-term conditions (Macmillan Cancer Support, 2014). Among the 2.5 million people with a cancer diagnosis, 1.8 million also have at least one other long-term condition – the top four being hypertension (42%), obesity (31%), mental health problems (21%) and heart disease (19%) (Macmillan Cancer Support, 2015).

Cancer survivors can develop physical and psychological problems a long time after treatment, and these often have a devastating impact on their daily lives (Macmillan Cancer Support, 2013b). Problems such as anxiety, depression, fatigue, bowel or urinary issues, impotence or infertility can stop people from working or doing the things they enjoy. They can also remain unresolved, especially if they present several years later, as they are not always immediately connected to the cancer and its treatment.

**Recovery packages**

The NCSI tested interventions that would improve support and care coordination for cancer survivors, foster self-care where possible, shift the focus to recovery, health and wellbeing, and implement person-centred care. These interventions aimed to improve outcomes for patients and help the NHS address the challenges posed by the growing number of cancer survivors. After testing and evaluation, the NCSI recommended as a top priority a recovery package delivered at the end of treatment (see Box 1 for elements in the package).

Following implementation and evaluation, some aspects of the recovery package are now delivered at different points along the disease trajectory – not just at the end of treatment. The recovery package was featured in the Five Year Forward View (NHS England, 2014), the 2015 cancer strategy for England (Independent Cancer Taskforce, 2015) and the Celtic nation cancer plans (Scottish Government, 2016; Wales Cancer Network, 2016; Department of Health, Social Services and Public Safety, 2014).

Implementation to ensure everyone has access to an appropriate recovery package still has a long way to go. For example, in South West England, only 19% of people living with cancer are receiving a holistic needs assessment (HNA). In many areas, progress has been made in delivering the NCSI recommendations, but sometimes only for certain types of cancer – such as breast, prostate or colorectal cancer. The recovery package and redesigned pathways are still not embedded in clinical practice and have not yet become fully commissioned, ‘business-as-usual’ models of care (Macmillan Cancer Support, 2016b).

**Role of health professionals**

Recovery package interventions are delivered in both hospital and community care settings. Clinical nurse specialists (CNSs), practice nurses, chemotherapy nurses, clinical radiographers, clinical psychologists, volunteers, support staff and allied health professionals (such as dietitians, physiotherapists and occupational therapists) can – and in some areas do – play a role in the recovery package. However, the drive to improve cancer care and support and implement the recovery package has been focused on acute hospital settings and specialist cancer teams. Ongoing support in the community is still lacking in many areas. For wider support to become a reality, professionals working in primary care and community settings need to consider how they can better support people living with cancer.

In some areas, practice nurses have taken the lead and are delivering cancer care review consultations in general practice, using HNAs, care plans and treatment summaries.

**Box 1. The recovery package**

The recovery package comprises:

- A holistic needs assessment and care planning, which can be delivered at key points (diagnosis, post-treatment and other transition points) along the care pathway to ensure concerns are raised and addressed in a timely manner
- A treatment summary completed at the end of primary treatment and, ideally after each subsequent treatment, with a copy sent to the patient and their GP
- A cancer care review consultation with the GP or a practice nurse, ideally within six months of the GP practice having been notified of the patient’s cancer diagnosis; this should be the start of an ongoing conversation in primary care
- Attending patient education that focusses on health and wellbeing to prepare for the transition from treatment to recovery and, where possible, enable self-care. The education should include advice on work and finances, on lifestyle and physical activity, and education on monitoring and differentiating between symptoms indicating a recurrence of cancer and those that may arise from treatment
Health needs assessments

CNs have played an integral part in implementing HNAs. Their use of HNA tools to guide their conversations with patients, systematically identify people’s needs, and produce care plans that respond to those needs has improved the support given to people living with cancer (Ipsos MORI Social Research Institute, 2015).

Switching the dynamics of the conversation so that it is driven by the individual’s concerns at that moment in time empowers patients to raise issues they may have previously been too embarrassed to discuss. Seeing anxiety or sexual difficulties listed previously in the HNA can be a step forward to help people living with cancer to access local support services.

The implementation and use of HNAs should be scaled up in acute care for all cancer types, and considered in community settings and linked to community wellbeing programmes for long-term conditions. These events have more generic content but always include advice on diet, support with physical activity and self-help, and psychological support.

Whether HWBEs are delivered in an acute hospital or community setting, they are extremely valued by people living with cancer, as they provide information on relevant topics and open up the possibility of peer support. Some community events have a market stall with information on support in the local area.

Conclusion

Despite areas of good practice and some progress with implementing the recovery package across the UK, there are still many people living with cancer who are not living well or receiving the support they need. All health professionals can use the tools of the recovery package to support people after cancer treatment to cope with long-term issues, better manage their health and achieve better quality of life.

References