



# Cancer as a chronic disease

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## KEYWORDS

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## Summary

**Background:** Over the past two decades the number of people living with cancer has increased. Many cancer survivors end up with long term disabilities requiring ongoing care and support. For many people, cancer survival now means living with a chronic and complex condition.

**Aim:** The purpose of this paper is to provide an overview of the long term management issues for cancer survivors and strategies to enhance their care.

**Discussion:** Cancer survivors require ongoing support in four key areas: prevention; surveillance; intervention for consequences of cancer and its treatment; and coordination between specialist and generalist providers.

**Conclusion:** Cancer survivors experience significant physical and psychological morbidity which makes minimising their burden of disability and distress an important priority. Survivors require ongoing care that is well co-ordinated, focuses on prevention, provides going surveillance whilst minimising and managing the long term effects of treatment and other co-morbidities.

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## Introduction

Better identification of risk factors, earlier diagnosis, new technologies and improved treatments has resulted in increasing numbers of Australians' affected by cancer living longer. Cancer data are collected at two mandatory census points, at diagnosis (incidence) and at death (mortality). Over the past two decades there has been a growing gap between cancer incidence and mortality (Australian Institute of Health and Welfare, Cancer Australia, & The

Australasian Associations of Cancer Registries, 2008). At the end of 2004, there were some 655,000 Australians who had been diagnosed with invasive cancer (excluding all non-melanocytic skin cancer diagnosis) who were still alive (Australian Institute of Health and Welfare et al., 2008). The most prevalent survivors of cancer were people with breast cancer (130,000), melanoma (116,000), prostate cancer (98,000) or colorectal cancer (91,000) (Australian Institute of Health and Welfare et al., 2008).

However, what is not reflected in this survivorship data is the presence of two distinct sub-populations: one composed of disease free survivors of cancer and another composed of people living with cancer from the time of diagnosis or with recurrence of disease. It is not possible to quantify the actual number of people living with recurrent disease

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because the prevalence of metastatic cancer is not routinely collected in Australia (Cancer Australia, 2008) or around the world. It is also difficult to accurately identify the growing number of adults in these data who are survivors of a childhood cancer as it is estimated that 80% of children and adolescence diagnosed with cancer will go onto be long term cancer survivors (Oeffinger et al., 2006). Another limitation of existing cancer data collection systems is that there are few opportunities, at a population level, to monitor cancer survivors' quality of life, the effects of new treatments or the intermediate and long term toxicities associated with various therapies (Cancer Australia, 2008).

Cancer treatment is complex, involving many disciplines and treatment modalities delivered in a variety of care settings across the country. Despite every effort being made to minimise the medical and social hazards associated with cancer treatments, many treatments have been found to have long term consequences (Hewitt, Greenfield, & Stoval, 2006). Some of these long term effects include persistent neuropathies decreased immune functioning, cardiac toxicity and weight gain, which in turn can contribute to the development or worsening of several co-morbid conditions (Pinto & Trunzo, 2005). Some survivors of cancer experience a range of other disabling effects which impact on their day to day functioning, such as endocrine dysfunction, infertility, functional decline and psychosocial morbidity (Hewitt et al., 2006). Although many of these effects gradually improve over time, for some people they will live with the effects of cancer or its treatment for the rest of their lives. Many survivors of childhood cancers who received treatment in the 1970s and 1980s now experience a range of serious health problems which require ongoing monitoring and management (Oeffinger et al., 2006).

However, cancer is essentially a disease of ageing, mirroring patterns of non-malignant disease. Older people newly diagnosed with cancer often present with other chronic and complex conditions requiring ongoing management – both pharmacological and non-pharmacological. Polypharmacy can be an issue for many older people complicating their cancer management and requiring the ongoing involvement of other clinical specialities (Lane, Christ, Khan, & Backus, 2001). These pre-existing co-morbidities may also be exacerbated by cancer itself or its various treatments.

Various definitions are ascribed to a 'cancer survivor'. For the purpose of this paper a 'cancer survivor' is someone who has experienced cancer and who is still alive (Morgan, 2009). This broader definition is appropriate because many people who have completed treatment will remain disease free but require ongoing support to manage disease recurrence fears, long term treatment side effects and a range of co-morbidities (Lotfi-Jam et al., 2009). However, an increasing number of survivors will live with recurrent cancer, requiring ongoing monitoring, treatment, care and support. Their management frequently involves the use of long term therapies. Consequently, for many people cancer survival, regardless of their disease status, increasingly means living with a chronic and complex condition.

The purpose of this paper is to provide an overview of the long term management issues for cancer survivors and strategies to enhance their care.

## Cancer as a chronic disease

Chronic diseases impact on the quality of life of individuals, families, and communities and are the leading cause of illness, disability, and death in Australia and other resource rich countries. Similar to other chronic diseases, providing adequate support and care for cancer survivors is challenging in our current health care system which is often: orientated towards the management of acute illnesses; fails to emphasise the person's own role in self management; provides inconsistent disease specific follow-up; and overlooks the importance of secondary prevention.

Australia's National Services Improvement Frameworks (NISF) attempt to address these limitations by providing outlining the action required within the health care system to minimise the impact of various chronic conditions, including cancer (National Health Priority Action Council, 2006). The NISF developed for cancer follows the patient journey from prevention through to end-of-life care and in doing so, acknowledges that the needs of people with cancer extends beyond the initial diagnosis and treatment phase (Lotfi-Jam et al., 2009). The '*care after and between periods of active treatment*' acknowledges that a range of strategies are needed to identify and address needs, provide appropriate supports and information about follow-up, practical issues, support services and self care (National Health Priority Action Council, 2006).

During the time after and between periods of active treatment cancer survivors' concerns are often primarily relate to issues associated with: recurrence, secondary malignancies and long term consequences of cancer treatment (Morgan, 2009). A landmark United States Institute of Medicine (IOM) report '*From cancer patient to cancer survivor: lost in transition*' (Hewitt et al., 2006) advocates for a number of changes to ensure that cancer survivors are better supported in four key areas: prevention; surveillance; intervention for consequences of cancer and its treatment; and coordination between specialist and generalist providers. These essential components of survivorship care are discussed below.

## Prevention

Cancer survival increases the risk of developing a second cancer, which makes the integration of relevant cancer prevention information into all follow-up care a priority (Watson, Sugden, & Rose, in press). The cancer risks include: a new primary in the same site or organ system (given the person's original risk factor(s)); a cancer as a result of therapy; or a cancer unrelated but with increasing risk because of age. Emerging evidence suggests that cancer survivors will often benefit from a range of information about various health behaviours that could reduce their cancer risks such as: smoking cessation, regular cancer screening, healthier eating, reducing alcohol intake and increasing physical activity (Pollack, Adamache, Blythe Ryerson, Eheman, & Richardson, 2009). As survivors contemplate their life post treatment, there is a window of opportunity for health professionals to support and inspire them to take action to reduce their modifiable cancer risk factors (Lotfi-Jam, Schofield, & Jefford, 2009).

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