



## Survivorship

# IMPROVING OUTCOMES FOR CANCER SURVIVORS IN AUSTRALIA

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The most recent national cancer incidence, mortality and prevalence data was reported in 2008.<sup>1</sup> In 2005, for the first time, there were over 100,000 new cases of cancer diagnosed in Australia. This number is projected to grow by over 3000 extra cases per year in 2006–2010, mainly due to the ageing of the population. In 2005 there were over 39,000 deaths from cancer in Australia. Pleasingly though, cancer survival rates have improved substantially over the past two decades.<sup>1</sup> For males, five-year relative survival increased from 41% to 58% (comparing cancer diagnoses made in 1982–1986 and those made in 1998–2004) and for females, it increased from 53% to 64%.<sup>1</sup>

Increasing survival leads to increasing prevalence. At the end of 2004, 654,977 people had been diagnosed with cancer at some time in the previous 23 years (when national data collection began), representing 3.2% of the Australian population (3.1% of males and 3.3% of females).<sup>2</sup> For those aged 50 years and over, 9% (9.3% of males and 8.7% of females) had been diagnosed with cancer during the previous 23 years and were still alive.<sup>2</sup> This proportion was further increased in people aged 65 years and over, at 14% (17% of males and 12% of females). Importantly, in older cohorts, the prevalence of other illnesses also becomes much more common. The most prevalent cancer survivors were survivors of breast cancer (130,000), melanoma (116,000), prostate (98,000) and colorectal (91,000). Next most prevalent are survivors of non Hodgkin's lymphoma, a much smaller group of 26,000.<sup>2</sup>

### Defining cancer survivorship

The term 'cancer survivor' may refer to different populations of people with an experience of cancer. In the US, the National Coalition for Cancer Survivorship suggests that "an individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life." Family members, friends, and caregivers are also impacted by the survivorship experience and are therefore included in this definition.<sup>3</sup> The US National Cancer Institute Office of Cancer Survivorship has adopted the same definition. Advantages of this broad definition are that it emphasises that cancer affects people for the duration of their lives and that family members, caregivers and others are also profoundly affected.

However, and more traditionally, a cancer survivor has been considered someone who appears cured of, or at least free from cancer. Measures such as five-year disease free (or overall) survival have marked long-term survivorship.

A more recent emphasis has been on the period of time following potentially curative treatments for cancer. The influential US Institute of Medicine (IOM) report *From cancer patient to cancer survivor: lost in transition* focuses on this period.<sup>4</sup> In Australia, the term 'cancer survivor' is generally used to refer to people who have completed initial cancer treatments, who are apparently free from cancer. As this definition does not implicitly include family and caregivers, we should be mindful of the effect of cancer on those other than the person immediately affected. Similarly, the post-treatment phase is clearly linked to the diagnostic and treatment phase of a person's cancer experience, as well as potentially, to periods of cancer recurrence, living with advanced cancer and death. It is essential to consider the phase of post-treatment survivorship as part of a continuum, frequently referred to as the cancer journey.

### This edition of *Cancer Forum*

The IOM report made a number of key recommendations, which are very relevant to cancer survivors in Australia, and elsewhere. The first recommendation of the report is to raise awareness of the needs of cancer survivors and to recognise survivorship, and particularly the period after completing treatment, as a distinct phase of cancer care.<sup>4</sup> This edition of *Cancer Forum* includes a number of papers that describe the range of issues and concerns that may be experienced by survivors and caregivers and draws attention to the need to develop strategies to reduce the consequences that cancer and its treatments may have on people. It also considers essential components of quality survivorship care and interventions to improve survivors' health and wellbeing. Papers also review current research activities in Australia and elsewhere and consider the critical issue of measurement – to identify issues affecting survivors, but also to measure the effect of interventions that intend to improve the wellbeing of survivors and carers.

## Issues for survivors

Survivors may encounter a range of potential effects as a result of the cancer itself and cancer treatments.<sup>4</sup> These issues are reviewed by Boyes and colleagues.<sup>5</sup> Cancer may cause significant physical, psychosocial, spiritual and existential impacts. There may be a range of practical consequences, including loss of income and change in roles. Effects may pass relatively quickly following completion of treatment (eg. hair loss or nausea), or may be long-term or permanent (eg. infertility). Some effects may not arise for months or years after completion of treatment, so called 'late effects' (eg. heart failure, second cancers).

Social impacts include loss of work and income, changed roles and changed friendships and networks. Physical impacts are strongly influenced by cancer type and treatments (as well as patient factors, including age and other illnesses) and may include fatigue, changed appearance (which may be associated with altered body image and esteem), cognitive changes, impaired mobility and premature menopause.

Many survivors feel anxious about leaving the safety of the hospital system when they transition from the end of treatment to long-term follow-up.<sup>6</sup> Consistent with many international reports, Australian studies indicate that fear of cancer recurrence and uncertainty about the future are common issues that survivors (and indeed caregivers) identify as needing help with.<sup>6-8</sup> In general though, studies indicate that cancer survivors' levels of anxiety and distress generally return to a level comparable to the general population (without a prior history of cancer), around two years post-treatment completion. An Australian study reported this year, found that five years following cancer diagnosis, most survivors had adjusted well and reported levels of anxiety and depression similar to Australian population norms.<sup>9</sup>

There may be additional difficulties for people from particular populations. People with backgrounds different to the dominant cultural and language groups appear to experience additional difficulties.<sup>5</sup>

While the majority of cancer survivors have very good quality of life and live healthy, satisfying and rewarding lives, it is vital that health professionals are aware of the issues that survivors may encounter and have strategies to, where possible, prevent, identify and treat these consequences. The IOM report recommends that healthcare providers "use systematically developed evidence-based clinical practice guidelines, assessment tools and screening instruments to help identify and manage late effects of cancer and its treatment."<sup>4</sup>

In the midst of potential negative consequences, many survivors (and carers) report positive feelings and describe personal growth. There is an emerging literature describing post-traumatic growth and benefit finding in oncology.<sup>10,11</sup>

## Family members and caregivers

With the shift in healthcare from hospital to more community-based care, increasing demands are placed on informal carers. Family members may find the cancer

experience more stressful than patients.<sup>12</sup> Girgis and Lambert review the issues that face caregivers of cancer survivors.<sup>13</sup> Caregivers may experience negative outcomes, including high levels of distress and depression.<sup>13,14</sup> Caregivers frequently report significant unmet needs, some of which overlap with those reported by people with cancer, including concerns about cancer recurrence and the need for accurate information and practical assistance. A meta-analysis of research studies examining the relationship between psychological distress in cancer patients and caregivers found a moderate correlation between patients' and caregivers' psychological distress.<sup>15</sup> The authors suggest that attention be given to factors other than cancer that may mediate distress in couples. Girgis and Lambert note the paucity of research studies targeting both patients and caregivers and suggest that interventions focus on areas such as information giving, communication between patients, caregivers and health professionals, emotional support, promotion of self care and peer support.<sup>13</sup>

## Issues for survivors of childhood cancers

Wheeler and colleagues review issues for survivors of childhood cancers.<sup>16</sup> As a result of improvements in cancer treatments, around 80% of children with cancer will be long-term survivors. However, such impressive survival figures are a relatively recent phenomenon, seen for only the last 40 years. There has been growing recognition, particularly over the last 20 years, of the many potential complications that may result from cancers themselves and cancer treatments for children. Much of the current data regarding long-term and late complications has derived from the Childhood Cancer Survivors Study.<sup>17,18</sup> This very impressive data set underscores the importance of data collection to allow a full assessment of issues for cancer survivors. Moreover, the studies have led to the development of comprehensive long-term follow-up guidelines (see [www.survivorguidelines.org](http://www.survivorguidelines.org)) that are becoming integrated into program delivery in the US and elsewhere.

Although not specifically addressed in this edition of *Cancer Forum*, people who develop cancer in adolescence and young adulthood (AYA) may encounter survivorship issues that overlap those seen in survivors of childhood and adult cancers, but also issues that are specific to the types of cancer encountered in this age group and linked to issues around this life stage.<sup>19</sup> Somewhat surprisingly, there is a lack of comprehensive data regarding long-term and late effects from cancer in this age group.<sup>20</sup> Adolescence is recognised as a period marked by risk-taking and experimentation.<sup>21</sup> Hudson and Findlay point out that health promotional counselling should acknowledge the educational needs of the adolescent/young adult age group, recognising the paucity of evidence to guide practice.<sup>21</sup> There is a need to develop greater understanding of survivorship issues and effective management strategies for AYA survivors.

The above brief review underscores the importance of paying attention to the post-treatment phase of the cancer journey. Health care practitioners should be aware of the health consequences of cancer and its treatment, as well

as strategies to address these issues. Comprehensive cancer control plans should include consideration of survivorship care.

### What constitutes ideal survivorship care?

Lotfi-Jam and colleagues consider this question in this edition of *Cancer Forum*.<sup>22</sup> As they describe, the IOM report defines four aims of survivorship care: prevention and detection of new cancers and recurrent cancer; surveillance for cancer spread, recurrence or second cancers; interventions to deal with the consequences of cancer and its treatment, and; coordination between specialists and primary care providers.<sup>4</sup> Arguably, current models of follow-up focus primarily on the second aim, but do not effectively address the other goals of survivorship care. As an illustration, Beaker and Luker studied the nature and content of hospital follow-up for women with early breast cancer.<sup>23</sup> Consultations were generally quite short (mean duration of six minutes) and focused on the detection of cancer recurrence. Unsurprisingly, few opportunities were available to meet supportive care needs. However, patients gained reassurance from these visits, as they were generally very optimistic. Strategies need to be explored that can more fully meet the needs of survivors.

Lotfi-Jam and colleagues suggest that optimal survivorship care should also be patient-centred, multidisciplinary, transition focused, holistic and able to be implemented.<sup>22</sup>

Importantly, optimal survivorship care does not begin as treatment ends. Optimal outcomes for cancer survivors are strongly influenced by experiences and interventions that take place much earlier in the cancer journey, including at diagnosis and during treatment. Identifying and addressing supportive care needs early may result in improved outcomes.<sup>24</sup> For example, meeting informational needs and providing necessary practical and emotional support are likely to reduce distress following treatment completion and into the survivorship phase. Similarly, medical interventions during the treatment phase may prevent later consequences. For example, with appropriate intervention it may be possible to preserve mobility and reduce the risk of premature menopause, infertility, sexual dysfunction and cognitive problems.

Health care providers need to be aware of potential issues for survivors, understanding common survivor concerns and consequences related to treatment of particular types of cancer and particular treatments. As mentioned, the IOM report encourages the development and use of evidence-based clinical practice guidelines, assessment tools and screening instruments to help identify and manage late effects of cancer and its treatment.<sup>4</sup> In Australia, we are currently struggling to routinely screen all new patients with cancer for unmet supportive care needs.<sup>24</sup> Regular rescreening presents an additional challenge. Perhaps considerations regarding screening of survivors for distress and for unmet need might be incorporated into plans to routinely implement repeat screening?

There is a growing push for government and other agencies to recognise survivorship care as an essential

component of high quality cancer care. As with other aspects of clinical care, a set of relevant metrics (that reflect quality survivorship care and survivor outcomes) need to be developed and the results made available, publicly.

### Exploring different models of care

Current models of follow-up care are inadequate and inefficient. Other models of care might more fully meet the goals of optimal survivorship care. Oeffinger and McCabe present a very useful review of models of survivorship care.<sup>25</sup> Currently, the majority of follow-up care, particularly in metropolitan areas, is provided by oncology specialists (surgical, medical, radiation oncologists). Other options might include GP care, alone or in partnership with oncology specialists (shared care), and nurse-led care. Follow-up need not be face-to-face, but may be telephone-based or, by video linkage (traditional video conferencing or using the internet). Follow-up may be according to a recommended protocol or patient initiated. Each of these models should allow easy referral to other health professionals (for example, psychology, social work, dietetics, physiotherapy) as necessary, and also allow easy referral for specialist review (for example, if there is concern regarding possible disease recurrence). There is a pressing need to develop and test different models of care. It is likely that different models will suit different settings. What works in a metropolitan setting may not be applicable or feasible in a rural environment. With this, it will be necessary to work with government to fund various models of follow-up. Current funding models favour medical and face-to-face models of review. Yet it may be more feasible, acceptable, cheaper and more effective to use non-medical models and/or models that do not require face-to-face review.

In this edition of *Cancer Forum*, Brennan and Jefford discuss GP based models of care.<sup>26</sup> Several randomised control trials have evaluated GP versus oncology specialist review for patients with a history of early breast or colorectal cancer.<sup>27,28</sup> The studies suggest that GP based review is a safe, reasonable alternative to hospital specialist review. A recent systematic review compared GP versus hospital based review of patients with cancer.<sup>29</sup> The authors found no statistically significant differences regarding cancer recurrence rates, survival, patient wellbeing or patient satisfaction.<sup>29</sup>

Gates and Krishnasamy review nurse-led models of care, particularly nurse-led clinics.<sup>30</sup> Advantages of nurse-led review include a focus on patient centred care, an emphasis on the detection and management of distress and unmet need (including provision of information and support), effective symptom management, promotion of self-care strategies and patient empowerment, and also cost considerations (relative to specialist medical staff). A systematic review of nurse-led versus hospital specialist follow-up identified four randomised control trials.<sup>31</sup> There were no statistically significant differences in cancer outcomes including survival and disease recurrence, nor regarding psychological morbidity. Beaver and colleagues have recently reported results from a randomised control trial in which women with early breast cancer were

randomised to traditional hospital follow-up or telephone follow-up with a specialist nurse.<sup>32</sup> Again, there were no differences regarding detection of cancer recurrence or levels of anxiety, though women in the telephone group reported higher levels of satisfaction. Interestingly, the telephone group was more expensive. The authors' conclusions were that this strategy may be suitable for women "at low to moderate risk of recurrence and those with long travelling distances or mobility problems" and that the intervention "decreases the burden on busy hospital clinics".<sup>32</sup>

Hospital-based multidisciplinary clinics represent another option for follow-up. This model has most commonly been utilised to follow survivors of childhood cancers considered at high risk of late effects, or with complex physical, psychosocial or practical issues. It is discussed by Wheeler and colleagues<sup>16</sup> and by Oeffinger and McCabe.<sup>25</sup>

These and other models of care need to be developed and evaluated. Furthermore, strategies to promote empowerment and greater self efficacy should be explored, where appropriate.

## Survivorship care plans

The majority of survivors want to be informed of strategies to remain well and many wish to be active partners in their long-term follow-up. GPs appear willing to manage patients in the survivorship phase.<sup>26</sup> A key requirement is that they be informed of key issues and advised regarding recommended follow-up. A key recommendation from the IOM report (indeed, the second of its 10 recommendations) is that survivors, GPs and other specialists be provided with a comprehensive care summary and follow-up plan.<sup>26</sup> This should summarise details of the cancer diagnosis, treatments, adverse reactions to treatment, current and potential future medical and supportive care issues and strategies to deal with these, strategies to maintain and improve health and a list of support services. The care plan should ideally be discussed with the person (and family/caregivers) and used as a living, working document. There are resources to assist with the development of care plans.<sup>33</sup> While the use of care plans might make intuitive sense (have good face validity), their impact has not been formally evaluated. There are a number of challenges to their routine use, most obviously who will produce the document, how can it be easily tailored to an individual person, who will discuss the document and how should it be used to enhance outcomes for survivors? Some centres have begun to use and evaluate survivorship care plans.<sup>34</sup> We await further evaluation and publication.

## Behavioural strategies

A cancer diagnosis and completion of cancer treatments can represent an opportunity to make changes to improve health and wellbeing, a so-called 'teachable moment'.<sup>35,36</sup> Stopping smoking, regular exercise, eating well and maintaining a healthy weight are all strategies that may improve wellbeing, quality of life and may reduce the risk of cancer recurrence.<sup>35,36</sup> Pollard and colleagues review the evidence regarding behavioural strategies, particularly

around exercise and diet.<sup>37</sup> Much Australian research is underway (and reviewed by the authors) to add to the evidence base, particularly regarding exercise. Physical activity recommendations for the general adult Australian population (a minimum of 30 minutes of moderate exercise per day, five days per week) appear appropriate for cancer survivors. It will be important to conduct further work to define strategies, applicable across a range of settings and to the breadth of the cancer survivor population, that lead to the adoption and maintenance of healthy lifestyle behaviours. These strategies may include advice and coaching from a broad range of health professionals, as well as from peers, volunteers or through self-directed learning.

## Measurement

Determination of survivors' concerns and needs is crucial to patient centred care. Survivors (and caregivers) are best placed to report issues that are of concern to them. However, they may not be aware of all potential consequences of their cancer and its treatments. We need assessment tools and screening instruments to help identify and manage late effects of cancer and its treatment.

Sanson-Fisher and colleagues, note that, "while there has been an expansion in the development of unmet needs scales for cancer patients, survivors and significant others, there remains a need to ensure that these measures are psychometrically robust".<sup>38</sup> Also, "a driving impetus behind the assessment of unmet need is the goal of intervening and reducing needs".<sup>38</sup> We need measures that are able to detect issues that are of importance to survivors (and carers). Interventions should be able to improve outcomes and we need to be able to measure this change, so that we can demonstrate that the intervention is effective. A major problem arises if an intervention is effective, however improvement cannot be measured using the available measures. Related to the ability to detect change on a measure, is the relationship of this change in measurement to what survivors and health professionals consider to be clinically meaningful. Although an intervention may produce a statistically significant improvement, compared to usual care, is this change actually meaningful? The authors also discuss the various instruments that have been developed to assess the needs of survivors and carers.<sup>38,39</sup>

## Research

There is a need to further understand experiences of cancer survivors from the paediatric, AYA and adult populations. We also need to further understand issues affecting people from different cultural backgrounds and other groups. Although much is known, particularly about the physical sequelae of cancer, some cancers and cancer treatments are under researched. Effective strategies to deal with the consequences of treatment and improve wellbeing need to be developed. As previously discussed, we need to investigate models of care delivery. As Girgis and Butow note, there is considerable consensus internationally regarding priority areas for research.<sup>40</sup> Priorities include: the investigation of long-term effects of



cancer diagnosis and treatment on patients, their families and caregivers, as well as needs and characteristics of unique or disadvantaged populations; the influence of lifestyle factors and behaviours on the health and wellbeing of survivors; development of evidence-based clinical practice guidelines for survivorship care; development of tools and instruments for use in clinical care and in survivorship research; development of effective care models and interventions, and the development and implementation of measures of quality of survivorship care. As the authors point out (and as illustrated in the papers in this journal), Australian researchers have been and remain, very active in cancer survivorship research. It makes good sense to define a coordinated research agenda that acknowledges internationally agreed priorities, while recognising circumstances that are particular to the Australian setting. For example, models of care that suit the US health care system may not translate effectively to an Australian setting.

We hope that you will enjoy this edition of *Cancer Forum*, that brings together papers that cover many aspects of cancer survivorship, from some of the key leaders in this area.

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