

RECOVERING FROM AND SURVIVING CANCER: A CONSUMER PERSPECTIVE

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Abstract

This article describes the evolving experience of recovering and surviving cancer from the survivors' perspective. What matters, what helps, what else is needed? Contrasting pictures of emotionally fragile, frightened, isolated and physically-damaged survivors is overlaid by happy, fit and healthy survivors achieving wellbeing irrespective of their cancer prognosis or health challenges. Many 'positives' are reported by survivors, wrought from the cancer experience, with contributing factors including social support, information, complementary therapy use, lifestyle changes and physical activity. Routine monitoring of the physical, emotional and practical issues experienced by survivors may enable better understanding of the essential elements contributing to recovery after cancer. Cancer survivors and their families are an under-utilised source of information, inspiration, knowledge and ideas about survivorship challenges and solutions. What are the opportunities and gaps in our care systems to better support survivors?

Achieving wellness (and being cancer free) is what most people want from the moment they are diagnosed with cancer. A cancer diagnosis rocks a person's physical, psychological, social, economic and spiritual foundations. There are few conditions where the treatment can be so damaging, requiring a period of recovery and ongoing vigilance for both disease and treatment effects. Despite growing numbers of cancer survivors, measures of the impact and duration of cancer or treatment effects on quality of life are poor.¹ Most survivors would agree that "cancer may leave your body, but it never leaves your life,"² or in clinical terms "being disease-free does not mean being free of your disease."³

What is 'survivorship'?

'Survivorship', 'remission', 'five year survival' – the meanings vary and are unclear to many. 'Survivorship' in practice generally refers to the period after primary treatment ends. This one directional depiction of cancer fails to capture the sometimes circuitous trajectory of many living with cancer, its ongoing treatment, recurrence or progression.³ Many ask: "Can I call myself a survivor if my prognosis is not good?" "Am I a survivor only after five years?" "Did the 'five year survival' clock reset when I relapsed?" "What do I call myself, if I'm not a survivor?" Considering a 'survivor' as anyone diagnosed with cancer, from the time of diagnosis to the end of life, would overcome these concerns.

Each person's cancer experience is different, but the end of intensive cancer treatment is frequently reported as difficult. However, individuals are often unaware and unprepared for this and left feeling uncertain as to how

to recover and reintegrate back into the community. People, their communities and workplaces need to be better prepared for this transition.

Use of individual cancer treatment summaries and survivorship care plans (mapping follow-up schedules and possible side-effects) is sporadic. Survivorship care plans can give guidance on what requires monitoring, when to come back early, things an individual can do for themselves and the follow-up to meet their needs. These should be used routinely.

Survivorship challenges are not routinely recorded or reported. A picture of what these are, how they change over time and what else impacts them is being developed. However, consideration of what supports recovery and what is learnt from people who have made good recoveries is needed. Are survivorship concerns avoided by healthcare professionals because they lack interventions and information to address these concerns?

An international survey of 'survivorship concerns' received 3129 responses, with 98% of reporting at least one post-treatment concern.² These included problems with fatigue, concentration, fear of recurrence, grief and identity issues, sexual dysfunction, and pain and/or neuropathy that caused day-to-day functional impairment.²

How do cancer survivors recover?

Achieving acceptance is not linear; processing anger, fear and grief can be iterative. 'Survivors' may emerge exhausted with cumulative toxicity and stepping into an

environment where people expect them to be ‘fixed’ and back to normal. They can be left feeling isolated and vulnerable. As physical recovery progresses, the emotional impact takes many by surprise. Why some people sail through treatment then don’t cope post-treatment is unknown.

Our expectation of how survivors should feel, think and act underpins the experience. Getting life back to normal with its predictability and control can be comforting. Milestones can be highly anticipated and celebrated. Five year survival is a disease outcome measure significant across all cancers.

‘Learned helplessness’ can develop during treatment and has to be overcome. So many survivors have had this experience, yet outside of the hospital each muddles through, discovering resources by word-of-mouth or the internet, often by chance. Survivors don’t expect oncologists to have all the answers, but increasing knowledge may reasonably be expected after so many years. Survivorship apps are one way to provide tailored information and structured programs. Whether these improve outcomes is not known. While potentially helpful supporting self-care, we need to ensure they are available to disadvantaged groups.

What are survivor priorities?

Cancer may be relegated as professional and home roles as well as relationships and finances are reassembled, while making sense of the experience. Life and lifestyle are often reassessed and priorities changed. It is a time of healing and learning to either ‘sit with’ or seek out solutions to physical and emotional concerns. Many grieve the loss of function, fertility, or a predictable future. Adolescents and young adult survivors can feel out of step with their peers. There is uncertainty about which healthcare professional looks after which concerns. For example, should problems be discussed with the GP or saved until oncology check-ups? Are there other practitioners who can be trusted to know enough about cancer?

‘Scanxiety’, a heightened fear of cancer recurrence at the time of follow-up, is well recognised and particularly difficult for those who have had cancer recurrence or progression. It can be unsettling for survivors who felt unwell yet had a clear result, or felt well when the scans show recurrence. Instincts can’t be trusted. Some survivors find their way into counselling, but not all know, would accept, or can afford this. Anxiety is exacerbated by long waits for follow-up appointments to receive results. Immediate access to test results should always be possible. Cancer survivors learn a lot about interpreting, keeping track and using our own data for self-care, given the opportunity and desire. One hopes that e-health records will enable this soon.

With time ongoing problems can be compounded – “cancer takes its toll, and is cumulative”.⁴ Coupled with ‘survivor’s guilt’ can be a lack of trained support or access to multi-disciplinary medical teams for the complex health issues that arise. While survivors can feel lucky to be alive, many would not say they are thriving. They may have survived cancer and have a good ‘living’ prognosis, but their life has changed dramatically.

The road to wellness

Despite this gloomy outlook, there are examples of happy, fit and healthy survivors who have achieved a good level of wellbeing. Many positives are reported by survivors, with modifiable contributing factors being social support, access to information, complementary therapy use, lifestyle changes and physical activity.⁵

By addressing strategies for wellness and coping skills as a shared responsibility, with ‘prescription’ during treatment, some post treatment concerns may be averted. This is highlighted in the blog ‘Survivorship is not a passive sport’.⁶ Discussion of lifestyle changes including physical activity, diet, alcohol, smoking and stress need to be initiated early after diagnosis. Despite the known benefits of physical activity for cancer survivors, translating this knowledge into practice is difficult. Survivor-led exercise initiatives can provide insights into this challenge.⁷ The health system is not organised to address these components of wellness. Health professionals need training to do this and referral pathways to be established. Many survivors do not expect to be involved in their healthcare in this way, even in the best chronic disease management systems.

We know the prevalence of chronic conditions is significantly higher among people with a history of cancer. This supports the importance of chronic disease management as routine care after a cancer diagnosis.⁸ Involving GPs and other practitioners during treatment and beyond is a challenge. Patients are often the communication conduit between clinicians, but are not involved in discussions. More research into survivorship health concerns is needed to identify effective intervention and management strategies.

Survivorship issues needing further research include: fatigue; bowel problems; neuropathy; sleep disturbance; anxiety; physical deconditioning; health impact of work; financial concerns; self-esteem; impact on relationships; impacts on body image and sexuality; and impacts on carers and families.

Returning to work and giving back

Employment is associated with higher levels of health and wellbeing. There is evidence that long-term work absence, work disability and unemployment impact negatively on

mental health, physical health, sense of worth and financial position.⁹ Recently, returning to work has been recognised as an important issue for recovery and wellbeing, supported by fostering partnerships outside of the traditional health sector pathways. Resources are in development.^{10,11}

Survivors, whether in good health or not, often want to 'give back' and help others engage in personally meaningful activities. This can aid personal recovery while supporting others. Examples include: peer support groups; teaching; research; health system planning and improvement; information provision; hope and encouragement; motivation for personal growth and lobbying; as well as collaboration in design and development of research, policy, position statements, information sharing and fundraising.

Creativity and connection

Creative expression of 'what matters to a cancer survivor' is growing. It is led by survivors via social media and digital platforms, which involve 24 hour access to social interaction from the convenience and privacy of personal spaces. "Many cancer survivors are turning online to find a sense of connection and self-construct ... (which is) therapeutic for the writer (and) reader... For clinicians, care providers and researchers, these narratives provide rich insights into the lived experience of cancer and offer the possibility of improving the patient experience in more meaningful ways."¹³

In a 'Patients as teachers' initiative, survivor narratives reflect on 'what helped or not' during their cancer journey. Survivors valued good clinician communication, authenticity and honesty; rating humour as part of healing, they want an understanding of the multitude of complex challenges. Participants aimed to promote a culture of mutual respect between health professionals and patients.¹⁴

Survivors play an important consumer advisory role in the Australian Cancer Cooperative Clinical Trial Groups. Working closely with clinicians and researchers, our experience can inform development of research concepts, protocols, participant information documents and other trial materials. Community engagement and public information initiatives are supported through our collaborative efforts, e.g. Engage, a survivor led initiative of the Australasian Gastro Intestinal Trial Group.¹⁵

Despite the number of cancer survivors, few are willing to step into consumer advocacy roles. Consumer involvement can be a positive for individuals and to society more broadly. Barriers to survivor engagement include networking with organisations or

individuals who create opportunities for involvement and practical support for participation including financial reimbursement, training, mentoring skills and confidence.

What are the barriers to optimal survivorship?

Stigma around a cancer diagnosis can be a powerful barrier in some communities such as indigenous and sexual minorities, and in respect of some tumour types, exemplified by lung cancer. Some high profile cancers are funded and supported better than their less visible counterparts. Geographical location can limit access to support, with those living in rural and remote areas experiencing poorer outcomes. People from low socioeconomic groups commonly experience barriers to accessing care and support. Increasingly, people without internet access or computing skills find it difficult to access information. Advocates from these groups have heavy demands on their time and energy.

Carers, oft neglected, must be mentioned as their need for access to care is often high. The patient-carer relationship is complex, as each seeks to shield the other from this trauma, at times to the emotional detriment of both. Challenges around emotional disclosure, intimacy and psychological distress in the cancer context can be difficult to acknowledge as needs, and expertise in counseling can be difficult to find.

In conclusion, cancer survivors and their families are an under-recognised source of information, inspiration, knowledge and ideas about survivorship, its challenges and solutions. Survivors have a vision of survivorship care:

- Focus on wellness from diagnosis, in partnership, shared responsibility and open communication with our care team.
- Routine active assessment and reporting of the broad physical, practical and psychosocial needs of cancer survivors, to drive practice improvement and research.
- Build self-care capacity, ensuring survivors know what to expect and where to access care, follow-up, and information when required.
- Help to eliminate stigma, inequality and access to care.

Partnerships between clinicians across all healthcare settings, community supports, researchers and people affected by cancer can achieve effective planning of care and research affecting survivors.¹⁶

Ten things I've learned from cancer:⁴

- Friends matter.
- Optimists have a better quality of life ... anger, frustration, sadness, fear and anxiety ... those emotions don't subtract from the problem, they add to them.
- I've never been big on prayer ... but... it all helps.
- People who practice oncology ... are a cut above.
- Cancer takes its toll, and it's cumulative.
- Patients are just the tip of the iceberg. Family, friends, co-workers, caregivers ... face not only the impact of the disease and its disruption of daily life, but also the burden of emotional support.
- We can do hard things.
- Everyone's cancer is different.
- People's capacity for kindness and compassion.
- Bucket lists are over-rated. ...it's about experiencing what you have, where you are and who you are with.... Life's journey is not a to do list.

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