

HOW THE NOT-FOR-PROFIT SECTOR CAN ENGAGE AND SUPPORT THE CANCER SURVIVOR COMMUNITY

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Abstract

The increasing amount of research demonstrating the needs of people finishing their cancer treatment brings an increasing amount of discussion within the health sector as how to address these needs in an effective way, regardless of geographic location. The puzzle of how much, when, where and how is a conversation that echoes across Australia, a country which holds a maze of differing health systems across the states and territories. Specialist care is vital for the cancer patient, however what happens afterwards can be a puzzle for many people finishing their treatment. Opening the dialogue between health professionals, consumer groups, cancer charities, government bodies and people affected by cancer has the potential to have a strategic impact for reach and effectiveness with post treatment care. In order to assist the growing number of cancer survivors in this country no matter where they live, we need to have a collaborative approach to post treatment care recognising that 'one size doesn't fit all'.

With the number of people successfully treated for cancer reaching over 65% in most developed countries, there is increasing pressure on the over-burdened health sector to provide quality follow-up service and support.¹ A cancer diagnosis can be a life-changing event and while the number of people successfully being treated is rising, for many, the post-treatment effects can at times be more challenging. These include dealing with the physical effects such as fatigue, changes in cognitive function and pain, as well as the psychosocial sequelae of uncertainty, mood disruptions, anxiety and depression.² Returning to the life experienced prior to a cancer diagnosis can be challenging for cancer survivors with financial and/or legal concerns.^{2,3} Leaving the acute treatment setting can generate anxious feelings of 'being left' and 'what now'?

"I watched one week as a woman attended her last session of chemotherapy and she was surrounded with balloons and loud whistles from her family and she walked out the door to the party. I knew I was finishing my treatment the following week and could not imagine doing anything like that. I felt so alone and I didn't want to celebrate. Who was going to look after me? I didn't even know what had happened." - female cancer survivor, aged 39

It can take time to adjust to a 'new normal'. The time following treatment is often when processing what has happened begins. Up until then, the whirlwind of treatment takes precedence and cancer survivors are in the 'system', proceeding from day to day, focused on their next appointment, treatment or test.

"I am a survivor I feel like I have been through the trenches and some days don't feel like I have made it out the other side very well. No one seems to understand unless you have been through it." - female cancer survivor, aged 62

The term 'cancer survivor' has varied definitions across the world, however for this review it is used as a term to describe someone who has completed their active phase of treatment and does not have signs of active cancer. Many people do not like the term 'survivor', and there are ongoing discussions in the cancer survivor community to find a more acceptable description. It evokes emotion in some and is an individual's choice as to how they refer to themselves - as a survivor from day one of diagnosis, or post treatment, or never at all.

The period after treatment for survivors (and at times their carers) can be a time for reflection and reassessment of what is important in their life. This often brings a strong sense of 'giving back' to the community or their treatment team.

We can talk about people who have successfully finished their cancer treatment and there is a great deal of literature about the challenges involved. What now? How do we reach as many people as possible to assist them into the future? Survivorship care plans, treatment centres, nurse-led care, follow-up clinics and more, are all positive developments in health care. However, often clinicians and health professionals are perceived as not having enough time to effectively communicate with cancer patients and others on the

treating team.⁴ With more people successfully treated, where does all this leave a cancer survivor?

Role of not-for-profit organisations in cancer survivorship

It is not just the formal healthcare system that can offer support and services to cancer survivors. The not-for-profit sector, in particular cancer charities, have essential infrastructure, extensive networks, and a focus on being a pivotal point for accessible and sustainable multi-disciplinary support and information. They also have a growing experience with development of a collaborative approach with treatment and survivorship centres and allied health professionals. These processes are core business of cancer charities.

Cancer Councils across Australia have a range of community-based services to support cancer survivors. They can also be an essential partner to health professionals, offering a range of services that complement clinical care, across all cancers and for the whole cancer journey. The evidence-based information that is delivered by qualified health professionals can be accessed by calling 13 11 20. This information and assistance service also provides access to practical assistance like financial, legal, return to work and other support, as well as emotional support such as peer support and counselling. The service is a primary access point for health professionals and consumers.

Cancer Council Australia's website (www.cancer.org.au) is an extensive and trusted portal, detailing services across the nation that are accessible to people across metropolitan, regional and rural locations. Cancer Council publishes a suite of Understanding Cancer booklets, fact sheets, CDs and DVDs. With advances in technology, we are seeing much more support being available online, which improves access for cancer survivors.

Joining forces

Clinicians and other health professionals working in cancer services know very well the resource constraints and problems in the system that can make life more difficult for cancer patients, or stand in the way of optimal care and treatment. Too often, there is a gap between what evidence indicates should happen and what the system is able to provide. Clinicians are at the frontline of the impact system shortcomings have on patients. Clinicians and health professionals can be very powerful advocates for individual patients and even take up the challenge of making improvements within their own setting. However, sometimes systemic change is necessary to ensure long-lasting benefits to

all who need it, across all service settings at a state or national level. Working alongside one another is a powerful and collaborative way to ensure change is effective and sustainable.

Not-for-profit organisations can be instrumental in advocating for improvements in the treatment and care of people with cancer, and for public health initiatives to reduce the incidence of cancer in the community and to improve cancer survival. One effective advocacy approach is for not-for-profits to engage those affected by cancer and encourage them to raise issues with decision-makers. The expertise of clinicians should also be drawn upon to understand the problem and to develop appropriate recommendations for improvement. Cancer survivors have powerful stories of personal experiences, which means they are highly motivated and can be very influential advocates.

Over the past decade for example, Cancer Council NSW has worked systematically and deliberately to help cancer survivors find their voice and use their stories to create change. Through the CanAct community and grassroots campaigns, survivors have used their experiences and voice to win policy changes in access to radiotherapy, improvements to patient-assisted transport and subsidy rates, smoke-free legislation, the banning of tobacco displays in shops and increased funding for bowel cancer screening.

A number of survivors have expressed that this has been an important part of their post-treatment experience, helping them to create value from an experience that many would otherwise perceive to have been a burden, or to honour the memory of loved ones lost to cancer.

"At last, long after my own cancer experience had been resolved, I'd found in cancer advocacy a real and meaningful way I could 'fight' cancer. Advocacy helped me recognise that having cancer was far from a weakness, a liability or a waste of time as I had thought before. In fact, having cancer was a valuable set of skills and experiences, which when married with strengths and abilities I already had and others the Cancer Council helped me develop, qualified me to do important and effective work".⁵

We know that politicians are influenced by the personal stories of constituents. Such stories help them understand how a systemic issue affects their local community and turns an abstract policy issue into a very tangible community need or constituent expectation.*

*McNair Ingenuity Survey of NSW Politicians for CCNSW. Unpublished 2006

Not-for-profit organisations have an opportunity and a responsibility to amplify the voices of their supporters to achieve change to benefit the cancer cause. The prospect of change provides an avenue for supporters to be involved in ways other than fundraising, and uses the unique asset that each supporter brings to the cause – their own story. Involving survivors in this way is also consistent with the principles of consumer involvement.

Engaging survivors in the advocacy work of a not-for-profit also helps ensure that the organisation is well-grounded in the issues that matter to supporters, and provides reach into communities and political decision-makers that is not possible through paid advocacy positions alone.

This experience at Cancer Council NSW shows that with the right support, survivors can develop the skills and confidence needed to become strong voices for change. Feedback from politicians confirms that this is an effective way of influencing the way they think about these issues and the likelihood that they will take action.

Clinicians can help in these endeavors by providing insight into the problems within the system, by encouraging people affected by cancer to join advocacy efforts of non-profits, and by collaborating with not-for-profit organisations on campaigns of relevance.

Utilising lived experiences

As evidence-based organisations, Cancer Councils are the leading independent funders of cancer research in Australia. In 2014, research grants through Cancer Councils nationally totalled more than \$65 million. \$42.9 million was directly funded research with a further \$22.2 million contributed by research funding partners.

Research underpins the prevention, information, support and advocacy programs of the organisation and assists with prioritising the areas where it can have the greatest impact, enhancing outcomes across the entire cancer journey. Cancer survivors and carers have the opportunity to be at the heart of research with their insight into the problems faced by those experiencing cancer. Under the Consumer Involvement in Research Program at Cancer Council NSW and acting as representatives of the community that supports the organisation, specially trained cancer survivors, carers and patients analyse all funding applications and identify those that are of greatest value to them as part of the two-stage review process. This consumer review is undertaken after applications have been through a peer-review process. Listening to the experiences of cancer patients is vital to improving the quality of the cancer patient experience and their subsequent survivorship experience.⁴

Cancer survivors and their carers bring high level skills to many roles within not-for-profit organisations across

Australia. The power of their lived experience is unique and they can play a role in assisting people to feel less isolated and increase feelings of well-being while they are 'giving back'.

"Immediately afterwards, of course my wife and I had a lot of re-adjustment to do ... we developed our communication skills and as a result grew very much closer together. I've been involved with Cancer Connect and also with the Ambassador program, and have made huge new friends all over the place ... I'm communicating and passing on information which would hopefully help other guys to make a decision about getting themselves checked out; (helping) gives me a real positive feeling".⁶ - male cancer survivor in Connect and Ambassador program.

Opportunities

While follow-up care with the acute treatment team is vitally important, there are opportunities for cancer treatment centres to work closely with organisations such as Cancer Council. This can be done by informing patients finishing treatment of the supportive care, advocacy and research opportunities that are available within their community. Collaboration has an enormous benefit on an overburdened health sector and the community-based organisations are there to assist when the acute phase of treatment has been completed. A simple referral to the information and support service is the gateway to many services that cancer survivors can access over an unlimited time: information, psychosocial and peer-led support; exercise and nutrition programs; counselling and support groups; legal, financial and returning to work support; advocacy and research; and much more. Why wouldn't these be used more?

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