



Cancer Survivorship in New Zealand - Consensus Statement

*Living with, through and beyond cancer
(Te reo wording under development)*

Why is a consensus statement needed in NZ?

There are a number of survivorship focussed services and programmes being delivered in New Zealand. However, at this stage there has been limited policy and research work undertaken. This consensus statement provides a foundation to inform policy development, evaluate existing services and as a guide for establishing new initiatives and services.

This consensus statement has been developed by a wide range of stakeholders, including consumers and health professionals, who have input via literature reviews, a stocktake of current survivorship focussed programmes and services and sector workshops.

Background papers can be accessed via the following link..... **(to be completed once statement confirmed)**

Consumer perspectives on survivorship

Cancer survivorship is a day-to-day, on-going process that is constantly changing.

People are not defined by their cancer diagnosis. People affected by cancer, including the individual and their whānau /family, will all experience their cancer journey differently. Similarly, every person affected by cancer will define survivorship differently, and it is important that any cancer care acknowledges and considers this in care planning.

People affected by cancer should be empowered to make informed decisions that enable them to access the right care, at the right time and in the right place. What is important to a person affected by cancer should help determine what support they access, with the understanding that needs may change over time. The relationship between health care professionals and people affected by cancer is a partnership, where people affected by cancer are experts of their own lives and health care professionals are experts in their field.

People's lives may be forever changed by cancer. This consensus statement focuses on how to maximise quality of life for people affected by cancer, from the point of diagnosis. Specifically, it will focus on ways to ensure a person affected by cancer has their survivorship needs assessed and addressed as they transition through the pathway. All people with cancer, including those on both a curative and non-curative pathway, should have their needs assessed and addressed.

For people affected by cancer the survivorship pathway is well lit, smooth under foot and clearly sign posted. People are provided with plenty of options to pause, reflect and assess what is now needed and are able to connect with services as and when these are required.

Expert Advisors Workshop



How is cancer survivorship described?

Although survivorship is an integral part of care from the point of diagnosis, it should be considered, as much as feasible, at every stage of the cancer continuum, including; maximising healthy living to reduce the likelihood of getting cancer and diagnosing early to maximise treatment options and outcomes.

Survivorship assumes a collaborative process is in place to monitor changing priorities and ensure delivery of appropriate on-going care.

Survivorship is not a term that resonates with all people, whether so-called survivors or health professionals. However, it is consistent with international terminology and there has not been an acceptable New Zealand alternative agreed to date.

There are many international models of care and services that provide a template for future work in this area. The international examples highlight the importance of person centred care, support being available across the cancer continuum, with well-coordinated services and support available for all. Services must support survivors and their families to self-manage and provide them with information and support as required, as well as to support them to manage their own wellness.

The existing international examples provide an opportunity to learn from established processes. For example, we may look at their effectiveness if we were to apply them to services being provided or developed in New Zealand. These learnings have been considered in the development of this consensus statement.

Why are survivorship issues important?

As cancer outcomes improve and more people are living longer with, through and beyond cancer, there is a need to consider how best to support these people and their whānau /family. Cancer can have an impact on all aspects of a person's life and these impacts can be intermittent or on-going and chronic in nature. Survivorship signals a shift in cancer treatment to a focus on quality of life.

There has been a shift in cancer care that reflects improved treatments, but not necessarily improved outcomes, when it comes to living well with, through and beyond cancer. As demand for post cancer treatment support services increases it is important that those services are delivered to a high standard and that they are accessible and equitable throughout New Zealand.

People with cancer and their whānau /family may face many challenges, however they may also experience new opportunities. The challenges and opportunities are wide ranging and any survivorship services should seek to support people through this time. These cover many aspects and could include:

- Psychological
- Cultural
- Physical
- Sexual and reproductive
- Relationship
- Work and education related
- Financial
- Spiritual



Why is equity important for cancer survivorship?

Avoidable health inequities are unnecessary and unjust differences in the health of groups of people¹. In New Zealand, Māori have poorer health outcomes than non-Māori across many measures, including heart disease, cancer and mortality². Any cancer survivorship model of care, service or support should be developed with a focus on achieving equity, and recognising New Zealand's unique and diverse population.

A key consideration for survivorship in New Zealand is the Treaty of Waitangi / Te Tiriti o Waitangi:

- **Participation** - Working with Māori to ensure that the Survivorship model of care reflects a Māori world view in participating, contributing, and engaging in cancer services.
- **Partnership** - The Survivorship model of care ensures a process where Māori are equal partners in planning, developing and monitoring the delivery of on-going care.
- **Protection** - Māori values, beliefs, and practices are integral within the Survivorship model and are protected

Principles underpinning high quality survivorship support

- All people affected by cancer benefit from survivorship support whether they are on a curative or non-curative pathway, or where they are in that pathway.
- Survivorship support means that the care coordination, psychological, social, spiritual, medical, supportive care³, cultural and rehabilitative needs are regularly assessed and addressed.
- All health and supportive care workers working with people affected by cancer build on their existing skills, or receive additional training to be both clinically and culturally competent to support survivorship and proactively take responsibility for enabling people affected by cancer to have their needs identified and met.
- Survivorship support is informed by the principles of the Treaty of Waitangi.
- Survivorship support programmes, services and resources should be:
 - Person and whānau /family centred: thinking and doing things that sees the people using health and social services and their whānau / family as equal partners in planning, developing and monitoring care to make sure it meets their needs.
 - Future-focused: ensure approaches reflect the likely direction and shape of the New Zealand health system over the next 10 years; consider clinical and technical developments.
 - Culturally appropriate and responsive: develop approaches that support the Government's priority objective to improve the health of Māori, achieve equity for Māori whānau in cancer outcomes and that engage people of different cultures.
 - Co-designed and tailored in partnership with people affected by cancer.
 - Regularly evaluated to ensure they continue to meet the needs of the target population.

¹ [https://www.centralcancernetwork.org.nz/page/pageid/2145884676/Equity%2c Maori Health and Pacific Health](https://www.centralcancernetwork.org.nz/page/pageid/2145884676/Equity%2c%20Maori%20Health%20and%20Pacific%20Health)

² https://www.nzcpmh.org.nz/media/58923/2016_11_17_nzcpmh_health_equity_policy_statement.pdf

³ The Ministry of Health defines supportive care as; Improving the quality of life for those with cancer, their family and whānau through support, rehabilitation and palliative care.

<https://www.health.govt.nz/system/files/documents/publications/supp-care-guidance-mar2010.pdf>

- Delivered in a variety of modes including face to face, online, audio, visual, and multilingual delivery.
- Supportive of self- management strategies and resources to enable people affected by cancer to live healthy lifestyles and participate fully in society.
- Delivered in a way that does not present barriers to people affected by cancer including cost, location, and timing.
- Delivered by appropriately trained and resourced workforce that is both clinically and culturally competent
- Accessible and progressively work to create and achieve health equity in cancer outcomes.

In action these principles mean that survivorship services exist, are known, coordinated, and accessible, are available and equitable to all and are ongoing and evolving as the landscape changes. Support for people affected by cancer needs to be empowering, enabling and engaging.

What could a survivorship pathway look like?

The Te Whare Tapa Whā⁴ model is a valuable lens for identifying aspects of life affected by cancer. The four taha provide a structure for survivorship that encompasses all aspects of well-being.

Te Whare Tapa Wha	Components of a Survivorship Pathway		Key Informing Documents:
Te taha hinengaro <i>Mental and emotional well-being</i>	<ul style="list-style-type: none"> ○ Self-management strategies ○ Appropriate information resources and delivery ○ Psychological support 	Survivorship Care Plans	<ul style="list-style-type: none"> ○ New Zealand Health Strategy ○ New Zealand Research Strategy ○ Advance Care Plans (HQSC) ○ Equity of Healthcare for Maori: A Framework (MOH) ○ National Tumour Standards ○ National AYA Service Standards ○ LEAP programme ○ He Anga Whakaahuru - supportive care framework
Te taha whānau <i>Social well-being</i>	<ul style="list-style-type: none"> ○ Social assessment and care planning ○ Return to education and/ or work support ○ Access to survivorship programmes and services ○ Support to address financial issues ○ Connections to support groups 		
Te taha tinana <i>Physical well-being</i>	<ul style="list-style-type: none"> ○ Transfer of care arrangements ○ Appropriate medical follow-up and surveillance activities which take into account a risk stratification process ○ Appropriate cancer rehabilitation and appropriate or prescribed exercise programme ○ Support to lead a healthy lifestyle ○ Nutritional advice and resources ○ Established pathways for rapid specialist reassessment should it become necessary 		
Te taha wairua <i>Spiritual well-being</i>	<ul style="list-style-type: none"> ○ Access to appropriate spiritual care and cultural support that assesses and addresses needs. 		
			Monitoring: <ul style="list-style-type: none"> ○ Cancer outcome registries - quality of life measures ○ Patient experience indicators (HQSC) ○ Equity outcomes for Māori

⁴ Mason Durie, Te Whare Tapa Whā concept of hauora, 1994



How could survivorship support be provided?

Focus on quality of life

Any survivorship pathway or programme has a focus on quality of life. This focus is on guiding people to find their own path in navigating the changes and challenges that arise as a result of living with cancer. This enables the individual and their whānau /family to identify what quality of life looks like for them and what services they want to engage with.

Care planning

Care planning is an important mechanism for survivorship and care plans should be developed as early as possible. Care plans should be developed in partnership with people with cancer and their whānau /family and should consider transfer of care, risk stratification and encourage self-management.

Access to information is provided in a format that works for them

Access to high quality information, across multiple platforms, that allows people the opportunity to develop an understanding of their cancer, any treatment they might receive and what they can do to be in control and seek support that is appropriate for them and their wider whānau /family.

Information also supports people and their whānau /family to ask meaningful questions of their health and social team.

Participating in follow-up care and keeping a medical support system in place is essential for maintaining an individual's physical and emotional health. It also helps many people feel in control as they transition back into their everyday lives.

Ensure access to supportive care to manage symptoms and impact of cancer and treatment

High quality supportive care contributes to a person's quality of life, a key focus for a survivorship model. People with cancer and their whānau /family should have equal access to supportive care services that are person centred. Services and support should be tailored to requirements including treatments, symptoms and the resulting impacts of cancer.

A cancer diagnosis can impact on every facet of a person's life. Supportive care services do not focus solely on biomedical factors, psychological, social and spiritual impacts must be considered of equal importance as part of the cancer care plan.

Follow Up and Surveillance

Following diagnosis and treatment for cancer, people often undergo surveillance for relapse and recurrence. Care plans for surveillance around the country vary considerably affecting resource utilisation. Additionally, surveillance for recurrence can create anxiety and distress. Any cancer survivorship model of care, service or support should include appropriate framework for and standards of follow up and surveillance.

Managing Long-term Side Effects and Late Effects

Most people experience some type of side effects during the treatment period. However, people are often surprised that some side effects may linger after treatment is over—called long-term side effects—and that new changes and problems can appear later on. A late effect is a side effect that shows up months or years after treatment ends. Cancer treatments are intense, and nearly any treatment can cause long-term and/or late effects. When or if someone is affected varies from person to person. Physical late effects include problems with the heart, lungs, bones, and digestion. Sexual or reproductive health may change. There may also be fatigue, memory problems, spiritual and emotional difficulties. Some treatments may cause another type of cancer to occur, called cancer recurrence.



Regular follow-up care is needed to prevent, diagnose, and treat these side effects. And as people grow older, late effects can be similar to the normal aspects of aging.

Cancer Rehabilitation

In cancer care, rehabilitation is a process that helps a person adjust to and overcome changes due to the effects of cancer or its treatment. Goals may include increasing the ability to move around easily, restoring the body's functioning, and increasing a person's independence. Rehabilitative services can help a person improve the physical, social, psychological, recreational, educational, and work-related aspects of their lives. Rehabilitation improves many aspects of health, including: physical strength, flexibility, and abilities; coping with difficult emotions; energy level; and sense of well-being.

Enhanced resilience throughout life

Resilience is the ability to tolerate and adapt, to cope with difficult events⁵. Providing the tools to support resilience in people with cancer and their whānau/family is an important part of survivorship.

'Self-management' refers to any way in which a person manages their condition by themselves. Learning and practising self-management is an ongoing process; it is not achieved in a single step. Self-management is a continuum of learning experiences and opportunities, where a person and their whānau and family work in collaboration with carers and health professionals⁶.

Any survivorship support should facilitate a person to self-manage, self-refer and enhance resilience.

How this consensus statement be used?

For people affected by cancer and their whānau / family:

- to raise their awareness of potential impacts of treatment and challenges they may face
- to provide direction for expected services people and whānau / family may want to access
- to provide sign posts for services that they should be able to access to support them.

By service providers (DHB / PHO / NGO):

- to achieve equity for Māori whānau / family experiencing cancer
- to inform the development of appropriate programmes, services and resources
- to inform the evaluation of existing programmes, services and resources
- to promote a partnership approach between providers
- to advocate for a focus on survivorship across the health sector.

By the health system:

- as foundation work to inform policy development, national cancer programme planning and research, ensuring equity for Māori whānau experiencing cancer is prioritised.

⁵ He Anga Whakaahuru, Supportive Care Framework, Central Cancer Network, October 2016

⁶ Ministry of Health. 2016. Self-management Support for People with Long-term Conditions (2nd edn). Wellington: Ministry of Health.



Appendix: Advisory Group Members

Organisation	Advisors
Consumers	Jo Stafford Raewyn Curren Jess Weller Cancer Consumer NZ members
Hei Āhuru Mōwai	Pat Bodger Pauline Wharerau Joanne Doherty
Regional Cancer Networks	Jo Anson, Manager Central Cancer Network (project team member) Tim Dunn, Central Cancer Network Rachael Crombie, Southern Cancer Network
Cancer NGOs	Vicky Shuker, Cancer Society NZ (project team member) Inga O'Brien, Cancer Society NZ (project team member) Anna Sandall, Cancer Society NZ (project team member) Jenni Moore, Cancer Society NZ Janice Wood, NZ Breast Cancer Foundation Tim Maifeleni, Leukaemia and Blood Cancer NZ Cancer Society Supportive Care Managers Group
Cancer Nurses College	Judy Warren, Chair (member project team)
Ministry of Health	Dr Scott MacFarlane, paediatric oncologist, Cancer Team Clinical Advisor Natalie James, clinical nurse specialist, national Cancer Nurse Coordinator Initiative lead, Cancer Team Clinical Advisor Juliet Ireland, psychologist, national Psychological and Social Support Initiative Lead
National Adolescent Young Adult Network	Heidi Watson, Clinical Lead
National Child Cancer Network	Dr Scott MacFarlane, Clinical Lead
DHBs	Dr Andy Phillips, Allied Health, Scientific & Technical Director HBDHB (project team member) Dr Chris Atkinson, Radiation Oncologist
Research	Dr Richard Egan
General Practice NZ	Dr David Wilson
Psycho Oncology NZ	Kathryn Taylor
Workshop facilitators	Sue Ellis Dr Chris Walsh