



Cancer Survivorship in New Zealand - Consensus Statement

*Living with, through and beyond cancer
Te noho ora me te matepukupuku, eke panuku noa¹*

How is cancer survivorship described?

Survivorship is an integral part of cancer care from the point of diagnosis with specific assessments, programmes and services focussed on living with, through and beyond cancer. Maximising healthy living means reducing the likelihood of getting cancer, diagnosing cancer early, accessing quality treatment and appropriate after care services.

Survivorship is not a term that resonates with all people, including those affected by cancer and 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 and adapt or adopt these for the New Zealand context. These learnings have been considered in the development of this consensus statement.

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.

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

¹ Gifted by Hohepa MacDougall; Kaumatua Te Kāhui Matepukupuku o Aotearoa



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 move through their journey. 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

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 for cancer treatment and care to ensure a focus on quality of life.

There has been a shift in cancer care with 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 identify new opportunities as a result of this experience. 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 and physiological
- 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 people². In New Zealand, Māori have poorer health outcomes than non-Māori across many measures, including heart disease, cancer and mortality³. Other evidenced drivers of inequity include socioeconomic, rurality, ethnicity, those with mental health issues and those in LGBTQ community. Any cancer survivorship model of care should address achieving equity, and in particular reducing mortality. In doing so it needs to recognise New Zealand's unique and increasingly diverse population.

² <https://www.centralcancernetwork.org.nz/page/pageid/2145884676/Equity%2c%20Maori%20Health%20and%20Pacific%20Health>

³ https://www.nzcpnm.org.nz/media/58923/2016_11_17_nzcphm_health_equity_policy_statement.pdf



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

- 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 care⁴, cultural and rehabilitative needs are regularly assessed and addressed.
- Services function in an integrated and coordinated manner to ensure people affected by cancer receive continuity of care.
- 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 based on the principles of the Treaty of Waitangi and Maori models of care.
- Models of care for other ethnic groups need to be reflected in the model of care eg Fonofale model for Pacific peoples.
- 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. This must be reflective of the fact that many people may be managing multiple health issues.
 - 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. Kaupapa Māori programmes that are designed and delivered within the Māori worldview by a trained and resourced Maori workforce
 - 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.
 - Delivered in a variety of modes including face to face, online, audio, visual, and multilingual delivery.
 - Inclusive of self- management and health promoting strategies and resources to enable people affected by cancer to live healthy lifestyles and participate fully in society.

⁴ 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 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 and responsible for achieving equity
- Designed and delivered in such a way that there is no inequity in access and outcomes from the beginning.
- 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.

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 Whā⁵ 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 Whā	Components of a Survivorship Pathway	Survivorship Care Plans Care Planning Programmes & Services	Key Informing Documents:
Te taha hinengaro <i>Mental and emotional wellbeing</i>	<ul style="list-style-type: none"> ○ Self-management strategies ○ Appropriate information resources and delivery ○ Psychological support 		<ul style="list-style-type: none"> ○ New Zealand Health Strategy ○ New Zealand Research Strategy ○ Advance Care Plans (HOSC)
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 ○ Support to address financial issues ○ Connections to support groups 		<ul style="list-style-type: none"> ○ Equity of Healthcare for Māori: A Framework (MOH) ○ National Tumour Standards
Te taha tinana <i>Physical well-being</i>	<ul style="list-style-type: none"> ○ Transfer of care or shared care arrangements ○ Appropriate medical follow-up and surveillance activities which take into account assessment of individual needs ○ 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 		<ul style="list-style-type: none"> ○ National AYA Service Standards ○ LEAP programme ○ He Anga Whakaahuru - supportive care framework
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. 		<p>Monitoring:</p> <ul style="list-style-type: none"> ○ Cancer outcome registries - quality of life measures ○ Patient experience indicators (HOSC) ○ Equity outcomes for Māori

⁵ Mason Durie, Te Whare Tapa Whā concept of hauora, 1994



What is important to the delivery of quality survivorship support?

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. The range of services needs to include both health and social support services. Services and support should be tailored to requirements including treatments, symptoms and the resulting impacts of cancer. People affected by cancer are often challenged with loss of income which can impact on peoples' ability to engage with these services if financial support is not able to be accessed.

Care planning

Care planning is an important mechanism for survivorship care delivery and care plans should be developed as early as possible. Ensuring supportive care assessments and referrals are included as part of treatment and care planning means that people will be well supported during this phase of their journey. Then as people transition into the survivorship space these plans are updated to reflect their requirements in this next phase.

Care plans should be developed in partnership with people with cancer and their whānau / family and should consider transfer of care and/or shared care practices, assessment of individual needs and encourage self-management.

Access to information is provided in a format that works

Access to high quality information, across multiple platforms, that allows people the opportunity to develop an understanding of their cancer. This includes knowledge about any treatment and care they might receive in a way that makes the health system easier to understand and to navigate. Information also supports people affected by cancer to ask meaningful questions of their health and social team.

Follow Up and Surveillance

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

Following treatment for cancer, people often have follow-up appointments and surveillance tests to monitor the impact of treatment including disease response, side effects, relapse and recurrence. Any cancer survivorship model of care, service or support should include evidence based standards of follow up and surveillance. Currently follow-up and surveillance practices around the country vary considerably affecting resource provision and utilisation. Importantly, as surveillance for recurrence can create anxiety and distress, people need information on the reasons for the various tests and appointments going forward.

It is also important that the transition from specialist follow up and/or surveillance is supported, so people affected by cancer can move, when appropriate, to greater independence, self-determination and self-management of their ongoing health and wellbeing.

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, nervous



system and digestion. Sexual or reproductive health may change. There may also be fatigue, memory problems, spiritual and emotional difficulties.

Regular follow-up care is needed to prevent, diagnose, and treat these issues along with supporting people to manage long term changes in the persons' health and well being. To note 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 events⁶. 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 / family work in collaboration with carers and health professionals⁷.

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 for support
- to empower them to take the decisions best suited to their circumstances in support of their health and wellbeing.

By service providers (DHB / PHO / NGO):

- to achieve equity and Māori health gain people affected by 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 and Māori health gain is prioritised.

⁶ He Anga Whakaahuru, Supportive Care Framework, Central Cancer Network, October 2016

⁷ 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, Executive Director of Health Improvement and Equity 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