



# He Anga Whakaahuru

---

SUPPORTIVE CARE FRAMEWORK

---

# Mihi

‘He kura te tangata’

Kei ngā whānau, koutou ngā whakarurutanga o te mate pukupuku, ka rere ngā mihi maioha ki a koutou. Mei kore ake koutou hei tūāpapa mō He Anga Whakaahuru. Waihoki ki a koutou ngā mātanga, ngā ringa whakaahuru o mua, o nāianeī, e kore rawa e mimiti ngā mihi mō koutou e para tonu nei, e rapu tonu nei i te huarahi mō te noho ora ā-tinana ā-wairua o te hunga mate pukupuku me ō rātou whānau. Kāti rā, ki ngā ringa tōhaunui o te kaupapa, huri noa i te motu me pēnei ake, mā koutou, mā tātou tēnei Anga Whakaahuru e kawē ake, whakamaua kia tina. Inā ia te tūhononga o te whakaaro nui, o te māramatanga, e rite ai te whakataukī nei a ngā tīpuna, āe rā e hika mā ‘he kura te tangata’.

# Contents

## About this document 4-11

<b>Foreword</b>	<b>4-5</b>
<b>Introduction</b>	<b>6</b>
<b>Equity, Māori Health and Pacific Health</b>	<b>7-9</b>
<b>How to Use the Framework</b>	<b>10</b>
<b>Supportive Care Model</b>	<b>11</b>

## Model 12-13

## Standards and Competencies 14-53

<b>Standards and Competencies</b>	<b>16-17</b>
<b>Standard 1. Foundation Standards</b>	<b>18-21</b>
<b>Standard 2. Interpersonal Communication</b>	<b>22-25</b>
<b>Standard 3. Information Support</b>	<b>26-29</b>
<b>Standard 4. Social Support</b>	<b>30-33</b>
<b>Standard 5. Psychological Support</b>	<b>34-37</b>
<b>Standard 6. Care and Support Coordination</b>	<b>38-41</b>
<b>Standard 7. Whānau Support and Involvement</b>	<b>42-45</b>
<b>Standard 8. Wairua and Spirituality</b>	<b>46-49</b>
<b>Standard 9. Living with and Beyond Cancer</b>	<b>50-53</b>

## Quality Tools and Checklist 54-57

<b>Quality Tools and Checklist</b>	<b>54-55</b>
<b>Quality Checklist</b>	<b>56-57</b>

# Foreword

*E ngā mana, e ngā reo, tēnā koutou katoa*

*He mihi whānui tēnei ki a koutou e tautoko ana i te kaupapa nei.*

I acknowledge the work of so many who have contributed to the development of this Supportive Care Framework. Passionate people committed to ensuring the people and their whānau experiencing cancer are supported to access the things that really make a difference to them and their lives.

We have strived to ensure a holistic approach and integrate whānau ora values and principles within the framework. As health providers we have a responsibility to keep it real and ensure the focus remains on the people requiring the care and support.

*“Look at me, see me, ask me, not why I am here, but what matters to me, this day, this time”*

These words remind us of the importance of being present with people and of walking alongside them while they determine their supportive care needs. Our job as service providers is to ensure the care provided is of quality, that our systems, processes and settings are adaptable enough to meet the diverse needs of whānau.

What keeps the mauri of this unique person in front of us going? What is needed to maintain the mana of the person receiving care? What considerations are given to the ōranga of the whānau journeying with their loved one? This Supportive Care Framework provides guidance and process to ensure we keep asking these questions.

*Nō reira, e rau rangatira mā, tēnā koutou, tēnā koutou, tēnā tatou katoa*

---

## Stephanie Turner

*Project Sponsor  
Director Māori Health and Disability  
MidCentral Health*

A cancer diagnosis is often unexpected and is always unwanted. It is crucial that supportive care services are provided at time of diagnosis in a person's care and continue to be available along the whole cancer pathway as we live with or beyond cancer. I need to know what I can expect of my care team and that no matter where I live I can access services.

Supportive care must also consider our loved ones, our whānau, as defined by ourselves. It is a very comforting feeling knowing everyone whom we will come in contact with has all the information to provide the support we need and that there is a point of contact to call if we are uncertain of anything. This will assure me that I am not alone in my journey.

If we are well supported and well cared for, with the help and support of our medical team, we can move forward and work on getting well again.

---

## Marj Allan

*Deputy Chair  
Cancer Consumer New Zealand*



# Introduction

This Supportive Care Framework (the Framework) has been developed to guide service planning and delivery for government, non-government and private cancer care services.

## Supportive Care is described as:

Improving the quality of life for those with cancer, their family and whānau through support, rehabilitation and palliative care ..... the essential services required to meet a person's physical, social, cultural, emotional, nutritional, informational, psychological, spiritual and practical needs throughout their experience with cancer.

(Guidance for Improving Supportive Care for Adults with Cancer in New Zealand, Ministry of Health, 2010)

**This Framework utilises the following wording throughout the document and it is important that the reader has an understanding of this:**

**Person affected by cancer** – this refers to both the person with cancer and those for whom the cancer has an impact.

**Whānau** – this refers to both descent-based whānau and whānau who come together for a common purpose. Metge (1995) defines the two kinds of whānau as whakapapa-based whānau and kaupapa-based whānau. This acknowledges that for people, their whānau can be both their family of descent as well as those people they define as important who make up their support network.

**Health and Supportive Care Workers** – the term within this framework is used to apply to anyone working in the health system and non-government organisations (NGOs) as well as those working in social care agencies who may have contact with a person who is affected by cancer.

## The shared vision is that:

People affected by cancer experience an integrated and coordinated system of continued supportive care, overseen by an educated workforce, to ease the social consequences arising from their experience with cancer and to enhance their quality of life.

# Equity, Māori Health and Pacific Health

Avoidable health inequities are unnecessary and unjust differences in the health of groups of people. In New Zealand, ethnic identity is an important dimension of health disparities. The Ministry of Health (the Ministry) acknowledges that cancer is a significant health concern, particularly for Māori and Pacific people, and has a major and disproportionate impact on their communities. For these populations inequities exist in exposure to risk and/or protective factors for cancer, in incidence and outcomes, and in access to cancer services. Comorbidities are a contributing factor to cancer outcomes so this Framework has relevance to other areas of health which deal with long-term conditions.

## Equity

“For people affected by cancer the social determinants of health play an important role” (World Health Organisation, 2015).

**For example a person's cancer journey can also be influenced by:**

- Distance from treatment centres, which creates access issues
- A person's socio-economic status, which impacts on their ability to access care
- Varying populations' needs including a person's age, gender and sexual orientation, which can influence engagement
- Whether a person can speak and/or understand English which, creates barriers to care.

Supportive care planning and delivery needs to ensure that equity is considered at each stage of the process.

*Avoidable health inequities are unnecessary and unjust differences in the health of groups of people.*

## Māori Health

**The Treaty of Waitangi, New Zealand's founding document, outlines the partnership between Māori and the government. From a health perspective the principles upheld in the Treaty can be described as follows:**

- **Partnership** – working together with iwi, hapū, whānau and Māori communities to develop strategies for Māori health gain and appropriate health and disability services
- **Participation** – involving Māori at all levels of the sector in decision-making, planning, development and delivery of health and disability services
- **Protection** – working to ensure Māori have at least the same level of health as non-Māori and safeguarding Māori cultural concepts, values and practices.

**He Korowai Oranga: Māori Health Strategy 2014 outlines the Ministry and DHB's commitment to improving Māori health and includes the following four implementation pathways:**

- supporting whānau, hapū, iwi and community development
- supporting Māori participation at all levels of the health and disability sector
- ensuring effective health service delivery
- working across sectors.

# Equity, Māori Health and Pacific Health

# Equity, Māori Health and Pacific Health

**Equity of Health Care for Māori: A Framework (MOH, 2014) guides health practitioners, health organisations and the health system to achieve equitable health care for Māori. There are three actions that support the framework:**

- **Leadership** – by championing the provision of high-quality health care that delivers equitable health outcomes for Māori
- **Knowledge** – by developing a knowledge base about ways to effectively deliver and monitor high-quality health care for Māori
- **Commitment** – by providing high-quality health care that meets the health care needs and aspirations of Māori.

The Māori philosophy towards health is based on a wellness or holistic health model. The Te Whare Tapa Wha Model describes the four cornerstones of Māori health as whānau (family health), tinana (physical health), hinengaro (mental health) and wairua (spiritual health) and is a well-recognised model in the health sector. Consideration has been given to this model of health to ensure the four taha outlined in Te Whare Tapa Wha are attended to in this Framework.

**Whānau Ora, the well-being of whānau, is a key government policy area and is described as:**

- an **inclusive approach** to providing services and opportunities to all families in need across New Zealand. It **empowers whānau** as a whole – rather than focusing separately on whānau members and their problems – and requires multiple government agencies to work together with families rather than separately with individual relatives (Ministry of Social Development, 2014).

**Whānau Ora is about transformation of whānau with whānau who set their own direction. It is driven by a focus on six whānau outcomes identified by the Taskforce on Whānau-Centred Initiatives:**

1. that whānau will be self-managing
2. living healthy lifestyles
3. participating fully in society
4. confidently participating in te ao Māori (the Māori world)
5. economically secure and successfully involved in wealth creation, and
6. are cohesive, resilient and nurturing (Te Puni Kokiri, 2013).

Whānau Ora promotes integrated service delivery and a seamless and coordinated approach to meeting multiple needs (Ministry of Health, 2010). The health and disability sector continues to promote a whānau-centred and holistic approach to quality service delivery. The outcome of the Whānau Ora approach in health will be improved health outcomes for whānau through quality services that are integrated (across social sectors and within health), responsive and whānau-centred. This document supports the use of the Whānau Ora Assessment Tool as a measure of success.

*The Māori philosophy towards health is based on a wellness or holistic health model.*

## Pacific Health

**Ala Mo'ui: Pathways to Pacific Health and Wellbeing 2014–2018 is the Government's national plan for improving health outcomes for Pacific people. The plan's long-term vision is:**

- Pacific 'āiga, kāiga, magafaoa, kōpū tangata, vuvale and fāмили experience equitable health outcomes and lead independent lives.

**Ala Mo'ui seeks to achieve the following four priority outcomes:**

- Systems and services meet the needs of Pacific people
- More services are delivered locally in the community and in primary care
- Pacific people are better supported to be healthy
- Pacific people experience improved broader determinants of health.

The Fonofale Model designed by Fuimaono Karl Pulotu-Endemann in 2001 is a recognised holistic model of Pacific health and incorporates values and beliefs important to Pacific people. It builds on the Te Whare Tapa Wha model and incorporates values and considerations. Together with Whānau Ora it aims to support the vision for Pacific families “Prosperity for all Pacific families in Aotearoa/New Zealand by supporting and building 'āiga, kāiga, magafaoa, kōpū tangata, vuvale, fāмили, family capability” (Ministry of Pacific Island Affairs, 2013). This model has also informed our thinking in the development of this Framework.

**The Supportive Care Framework seeks to address equity for all peoples and improve Māori health and Pacific health by:**

- Ensuring equity considerations are included in all components of the Framework
- Mirroring the levels of the Equity of Health Care for Māori Framework by identifying actions to improve equity at the health system, health organisation and health practitioner levels
- Embedding the concepts from the Māori and Pacific health models and Whānau Ora
- Promoting culturally appropriate care considerations and competencies at all levels, i.e. workforce, service/organisation and system
- Inclusion of equity-focused tools and resources
- The use of person centred care philosophies and values
- Increasing the profile of working with whānau to improve overall health
- Working intersectorally in line with the principles of Whānau Ora
- Outlining key practice points for groups at risk.

# How to Use the Framework

There are several components to the Supportive Care Framework which are interlinked and inform each other to support both government and non-government supportive care service providers and the workforce to plan and deliver quality care.

## Model

To begin your understanding of the work we recommend you review the model first. A model is a visual representation of the factors required to provide effective care. Models provide the hooks to hang the components needed to deliver and measure this care, and supports the system to maintain a common focus and sense of united direction. This will increase your understanding of the concepts around supportive care and the principles of the model need to be kept in mind when utilising the standards.

## Standards and Competencies

Looking to the tabs at the top of the document you can then move to the standards and competencies section.

Standards describe the type of services that a person affected by cancer should have access to and provides a benchmark for high-quality care. The standards apply to any person or organisation that provides care and services to people affected by cancer in NZ. They can be used to form a basis for measurement of how well a service is doing and highlight areas of improvement.

Workforce competencies are matched to the standards to provide the health and supportive care workforce with information on the skills and knowledge required to give optimum supportive care for people affected by cancer. These are best viewed online where direct links to education and training about these skills can be found.

## Quality Tools and Checklist

Adoption without adaptation will not contribute to resources which increase equity or maximise engagement. The resource links in this section provide an understanding of the considerations needed when developing a new tool or information. A template of questions based on these resources can be used by project groups to consider what principles need to be adhered to when adapting resources to the NZ context.

## Iconography

Icons have been used to highlight specific areas of the Framework. Below is a key for the icons that will guide you through the Framework.

-  **Standard**
-  **Competencies**
-  **Person affected by cancer**
-  **Online resources**
-  **Equity statement**

 The full document including references and background work can be found at [www.centralcancernetwork.org.nz](http://www.centralcancernetwork.org.nz)

# Supportive Care Model

The koru (Māori for 'loop') is a spiral shape based on a new unfurling silver fern frond and symbolises new life, growth, strength and peace, all aspects which are important to people affected by cancer.

The white circles over the koru reflect the premise that supportive care isn't a linear process and the needs of the person affected by cancer should be considered continuously.

Te Whare Tapa Wha reminds us that these interdependent aspects of a person all require attention in order for wellness to be maintained. The four taha need to all be attended to or each is affected, taha wairua (the capacity for faith and wider communication), taha tinana (the capacity for physical growth and development.), taha whānau (the capacity to belong, to care and to share where individuals are part of wider social systems) and taha hinengaro (the capacity to communicate, to think and to feel, mind and body are inseparable).

The person affected by cancer and the provider statements remind us that it is the partnership between the two that will deliver the best outcomes. The model seeks to empower the individual in decision-making. The principles of the model, identified by key stakeholders, are concepts integral to delivering person centred care.

**The following principles provide the cradle for, and are important to be upheld when delivering, supportive care:**

<b>Whānau Ora</b>	Meaning 'family health' Whānau Ora is an inclusive approach to providing services and opportunities to all families in need across New Zealand, working towards overall family health.
<b>Compassionate Communication</b>	Seen by the sector as being the core of supportive care. The ability by the workforce to communicate with people affected by cancer in a way that they feel heard and valued.
<b>Resilience</b>	The ability to tolerate and adapt, to cope with difficult events.
<b>Collaboration of Care</b>	Collaborative care is when the system works together to support people affected by cancer with shared understandings and established processes.
<b>See Me as a Whole</b>	A reminder that a person is more than a cancer diagnosis and this needs to be responded to by using an understanding of Te Whare Tapa Wha. This is based on the training of Lisa Cherrington and colleagues in the course 'See me as a whole – I am more than my cancer'.
<b>Manaakitanga</b>	Behaviour that acknowledges the mana of others as having equal or greater importance than one's own. It is the need to preserve this mana in all interactions with a person who is affected by cancer.
<b>Rangatiratanga</b>	Self-determination and management of one's self.
<b>Va</b>	A Pacific concept about the space that exists between people – the relationships that support and interlink all parts of a person.

# Te Whakaahūru

He matatini te pāpā mai o te mate pukupuku ki te tangata. Ko tā Te Whakaahūru, he whakatakoto i ēnei āhuatanga matatini hei whakaaroaro mā te tangata i a ia e mohimohitia ana, haere ake nei.

# Supportive Care

People are affected by cancer in many different aspects of their lives. Supportive Care enables people to consider these aspects while having treatment and beyond.

## When you're affected by cancer

Knowing that I am not alone in my journey, that help is available at your right time in the right way.

I have a trusted point of contact to support me & my Whānau.

I can ask any questions and receive answers in a way that I can understand.

People working with me listen to my concerns and help allay them.

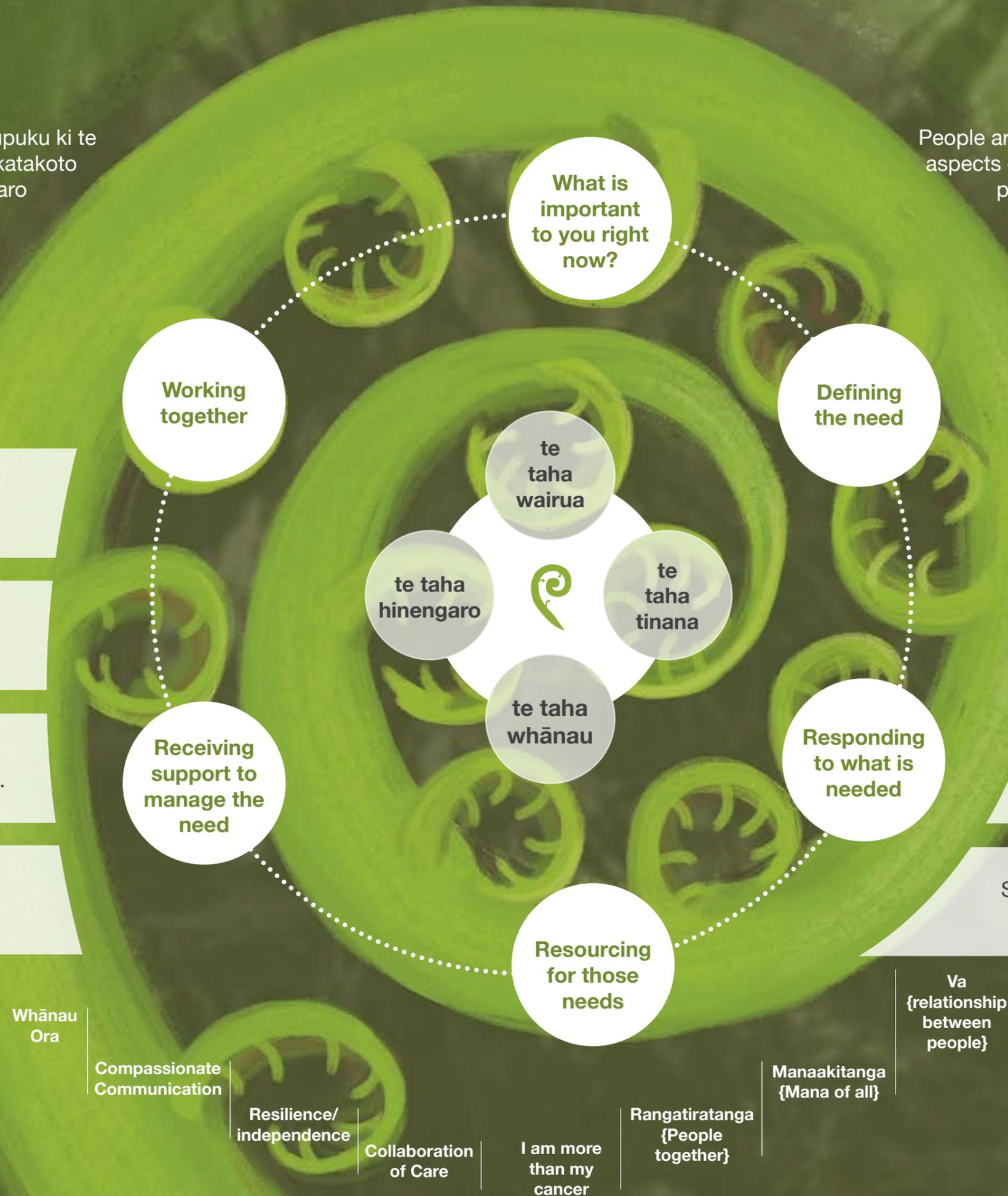
## When you're supporting a person affected by cancer

Supportive care enhances quality of life, before during and after treatment.

People with cancer and their whānau need an integrated and coordinated system of continued supportive care.

Everyone who has contact with someone affected by cancer has a role in supportive care.

Service provision responds to diversity in order to promote equity.



Whānau Ora

Compassionate Communication

Resilience/ independence

Collaboration of Care

I am more than my cancer

Rangatiratanga {People together}

Manaakitanga {Mana of all}

Va {relationship between people}



# Standards and Competencies



*Why are we here?*

*At some time in our lives  
Most of us will need health care  
Some more than others – to be fair*

*Whatever we need, wherever we are  
You can be sure, mostly we don't want to be there  
But sometimes we just need care*

*Look at me, see me, ask me  
Not why I am here  
But what matters to me, this day, this time*

*I will tell you if I know, if you listen openly  
I will tell you what I know about why I am here  
Will you pay attention, hear what I say?  
Know who you are, and who I am  
And who we can both be  
To help each other with my health care  
on this day  
We are both here*

*Chris Walsh (consumer)*

## The Standards

**Standard 1.** Foundation Standards

**Standard 2.** Interpersonal Communication

**Standard 3.** Information Support

**Standard 4.** Social Support

**Standard 5.** Psychological Support

**Standard 6.** Care and Support Coordination

**Standard 7.** Whānau Support and Involvement

**Standard 8.** Wairua and Spirituality

**Standard 9.** Living with and Beyond Cancer

# Standards and Competencies

## Standards

Standards describe the level and quality of service that a person affected by cancer should have access to. They are to be used by DHBs, NGOs, private providers, regional and national cancer networks and the Ministry as the benchmark for high-quality care. They provide the ability to measure the quality, access and impact of services. Currently the national provisional tumour standards contain versions of the following general standards that relate to supportive care:

- All patients with [specific cancer] and their family/whānau have equitable and coordinated access to appropriate medical, Allied Health and supportive care services, in accordance with *Guidance for Improving Supportive Care for Adults with Cancer in New Zealand, 2010*.
- Patients with [specific] cancer have access to a [specific] cancer clinical nurse specialist or other health professional who is a member of the MDM to help coordinate all aspects of their care.

In addition, various services and organisations have developed standards and quality measures that include aspects of supportive care. This work aims to expand on these general standards to support the sector to develop, improve and monitor quality supportive care services specifically for cancer.

The standards apply to any person or organisation that provides care and services to patients with cancer in New Zealand.

It is also the intention that these standards be used to develop key performance indicators that will be audited and used to drive improvements in services.

## Monitoring Requirements

Indicators to measure access to and the effectiveness of supportive care, including understanding the patient's experience of that care, should be identified and included in regional and national reporting.

### Output measures that DHBs and NGOs can implement are:

- Evidence of supportive care needs assessments being undertaken
- Referrals to supportive care services
- Workforce involved in delivering supportive care services
- Involvement of consumers and Māori in service improvement activities
- Evidence of policies and procedures relating to supportive care
- Evidence of the use of care plans.

For all of these measures it is important for ethnicity data to be captured and reported to ensure equity issues are able to be identified and addressed.

Outcome measures can be more difficult to identify and report. However the use of patient experience surveys, case reviews, audits and consumer input can all add to the improvement of supportive care services.

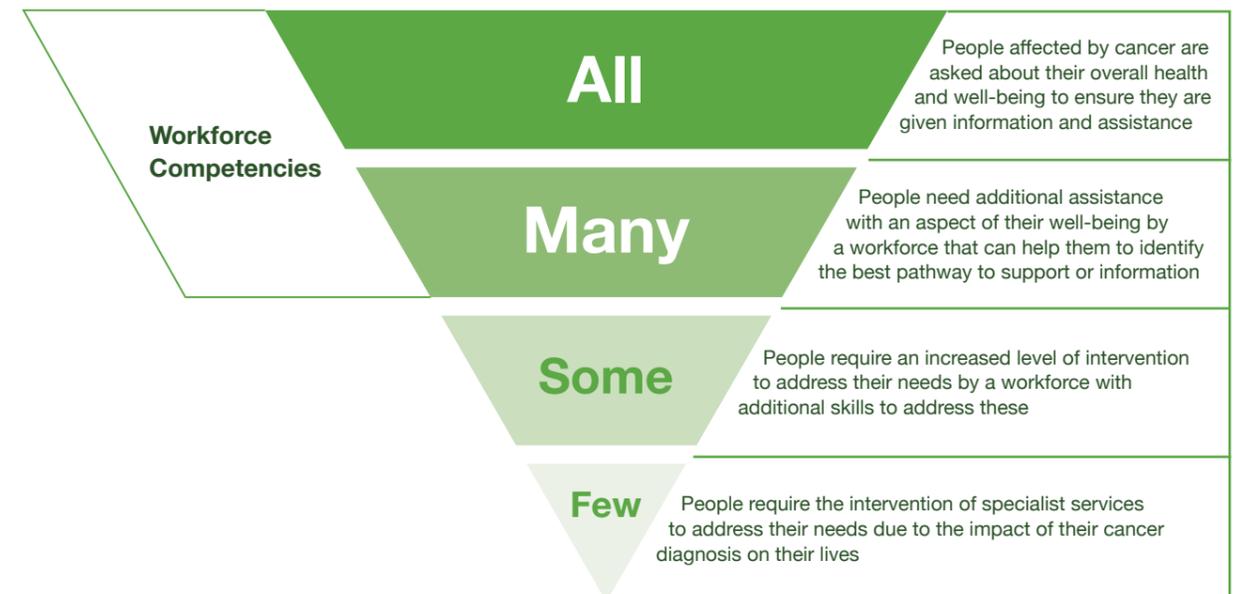
## Workforce Competencies

Workforce competencies are matched to the standards to provide the health and supportive care workforce with information on the skills and knowledge required to provide optimum supportive care for people affected by cancer.

### These can be used to:

- Identify gaps in learning and provide resources to support education in specific areas
- Give guidance for orientation when moving into cancer care
- Indicate competencies for position descriptions
- Provide a focus for aspects of training.

Represented in the diagram below are the varying practice interventions of the workforce in providing supportive care. In applying this understanding all health and supportive care workers, regardless of practice setting, are likely to have contact with people affected by cancer and will therefore require some level of capability in supportive care. This work doesn't set out to provide competencies for the advanced or specialist workforce in this area, but there will be aspects within the competencies which all the workforce can benefit from.



If not viewing this document online please go to [www.centralcancernetwork.org.nz](http://www.centralcancernetwork.org.nz) to find the most up-to-date links to training and resources.



# Standard 1

## Foundation Standards

# 1

## Part 1

This section identifies overarching standards that provide the base requirements necessary for all other supportive care activity to be undertaken successfully.

### Standard 1.1

All patients affected by cancer and their whānau have equitable and coordinated access to appropriate medical, Allied Health and supportive care services, in accordance with *Guidance for Improving Supportive Care for Adults with Cancer in New Zealand, 2010*.

### Standard 1.2

People affected by cancer have their supportive care needs regularly assessed at each point in the patient pathway.

### Standard 1.3

Alignment between palliative care and cancer care should occur to ensure a seamless transition for the person affected by cancer which is supported by inter-professional planning and reflects palliative care as a whole system responsibility.

### Standard 1.4

Formalised agreements and processes are implemented to enable primary, secondary and tertiary care services and NGOs to work collaboratively to proactively meet the supportive care needs of people affected by cancer.

### Standard 1.5

Communications between health care providers includes the person's name, date of birth, NHI and contact details and are ideally electronic.

### Standard 1.6

Information about supportive care assessments and interventions is documented in the patient's health record.

**Equity:** Service design incorporates the principles of Whānau Ora, ensuring that an inter-sectoral approach for service provision is utilised.



## Service Improvement Competencies

Can identify actions which improve the delivery of supportive care in their organisation.	Contributes to policy and protocol development for areas within their scope of work which improves delivery of support care.
Participates in wider stakeholder groups and supportive care networks.	Understands and uses co-design principles in service improvement activity.
Utilises the Equity Framework to evaluate change.	Responds to requests for research when able, to improve supportive care overall.
Contributes to supportive care service delivery.	Uses the resources from the He Anga Whakaahuru to further enhance both their individual work and their service.



*He aha te mea nui?  
He tangata, he tangata, he tangata*

*What is the most important thing in the world?  
It is the people, it is the people, it is the people*

### Training and Resources

For up-to-date training and resource links visit [www.centralcancernetwork.org.nz](http://www.centralcancernetwork.org.nz) where education is available which matches the competencies above.

Foundation Standards Part 2 continues on the next page →



# Standard 1

## Foundation Standards

### Part 2

This section identifies overarching standards that provide the base requirements necessary for all other supportive care activity to be undertaken successfully.

#### Standard 1.7

People affected by cancer and their whānau are proactively linked to services which are able to support their cultural and spiritual needs, including Māori and Pacific health providers.

#### Standard 1.8

The person affected by cancer and their whānau are involved with treatment and care planning by all agencies.

#### Standard 1.9

Meaningful and sustained relationships are established with iwi and mana whenua, and taura here, in the area.

#### Standard 1.10

The physical environment enables conversations and therapeutic interventions to be undertaken in a manner that meets the privacy and cultural needs of people affected by cancer.

#### Standard 1.11

Service delivery planning is undertaken in a co-design manner so that it is inclusive of people affected by cancer and the broader health and supportive care team.

#### Standard 1.12

Proposed service changes take account of the potential impact of the supportive care needs of people affected by cancer, with equity assessments undertaken at all stages of the process.

#### Standard 1.13

Ethnicity data is collected by all services involved in a person's care.

**Equity:** In New Zealand, ethnic identity is an important dimension of health disparities.



## Cultural Safety Competencies

Can reflect on how the principles of the Treaty of Waitangi are evident in their practice.	Is able to reflect on their own culture and background (world view) and consider how it impacts on interactions with others.
Can demonstrate an understanding of equity, why it is important and what actions are taken to contribute to its achievement by their service and as an individual.	Considers what professional development opportunities are needed to improve both personal and service capability in delivering equitable care, including the use of innovations which have been shown to improve Māori health outcomes.
Has an understanding of the Code of Health and Disability Services Consumer Rights and how this should be implemented.	Models respect and appreciation for te reo and Tikanga Māori and undertakes education to increase responsiveness and abilities such as learning karakia and greetings.
Is able to identify local iwi and pathways to access further support and information from local Māori services.	

### Training and Resources

For up-to-date training and resource links visit [www.centralcancernetwork.org.nz](http://www.centralcancernetwork.org.nz) where education is available which matches the competencies above.



# Standard

## Interpersonal Communication

# 2

Interpersonal communication is the process through which health and social care professionals in discussion with people with cancer and their carers explore issues and arrive at decisions. It is most effective when there is mutual understanding and respect and an awareness of the individual's roles and functions.

### Standard 2.1

Within service delivery, appropriate time is scheduled to allow for full discussion with the patient and their whānau about what matters to them.

### Standard 2.2

Communication skills training is a core component of all health care workforce training.

### Standard 2.3

Health care workers involved in difficult conversations, e.g. 'breaking bad news', have the required experience and skills.

### Standard 2.4

Organisations have services in place to support health workers to reflect on situations of difficult communications (e.g. supervision, case review).

### Standard 2.5

Interpreter services are available and health and support workers are skilled in their use.

**Equity:** Every consumer has the right to effective communication in a form, language and manner that enables them to understand the information provided.

## Rationale

Communication has been identified as being integral in the provision of quality supportive care. People affected by cancer require interactions where workers engage with them as a whānau as well as one to one. The person being spoken to needs to feel that the health and supportive care worker is engaged in the process, wishes to be asked questions and will take time to explain things in a way that can be understood.

A point of difficulty a person affected with cancer can have is how they are informed that they have cancer, that it is not responding to treatment or that the cancer has returned. Breaking bad news is a skill which must be obtained by those working in diagnostic and treatment teams. It has been shown that effective communication from the beginning of a person's engagement with services enhances their interaction with and satisfaction of services. This includes ensuring that people being treated for cancer are orientated to the variety of diagnostic and treatment services they are going to engage with.

The Health and Disability Code of Consumer Rights identifies that "every consumer has the right to effective communication in a form, language and manner that enables the consumer to understand the information provided. Where necessary and reasonably practicable, this includes the right to a competent interpreter" (Health and Disability Commission, 1996).



*"Take time, be good at answering questions, make the patient know you are interested in them and their wellbeing."*

*Cancer Stories Aotearoa –  
Kahui Korero Taumahatanga o Te Mate Pukupuku*



# Interpersonal Communication Competencies

## Good Practice Points Service/Organisation

- Services need to model good communication as this has been shown to reflect in how health workers respond to the people they are dealing with, i.e. ensure the organisational culture is one of respectful communication.
- An effective way to improve communication is to allow staff to have opportunities to reflect on situations which have been difficult and that have either gone well or haven't.
- Service development needs to factor in time for meaningful dialogue between the person affected by cancer and their treatment team.
- Services need to support training for health workers in cultural competency to increase their communication skills.
- Services need to ensure health workers have knowledge in cultural protocols of communication and engagement.
- Services need to ensure that methods of communicating, i.e. via text, email, phone and face to face, are appropriate and don't increase potential inequities.
- Communication styles need to be adapted to the age and developmental understanding of a person affected by cancer, with consideration of which methods are most appropriate.
- Interactions need to be respectful of additional challenges that a person may face such as hearing loss or English as a second language.
- Services should support and encourage ongoing training for senior staff to maintain their communication skills, including advanced training for staff involved in having difficult conversations.

- Sufficient notice of upcoming appointments is required to enable people affected by cancer to have support people attend appointments with them.

### Organisations should have in place approaches to ensure the breaking of bad news is handled well, including:

- Before the person and their whānau attend the appointment ensure all information is present
- A change in status should not be given over the phone unless agreed prior
- Consideration as to who is invited to the meeting
- Attendance of other professionals who the person affected by cancer considers supportive
- Where possible a second health care professional, e.g. social worker, should be present
- With permission, whānau are informed of the change and agree with the person who they would like to contact them next and when.

## Good Practice Points System

- Communications training is included as a core component of all health workforce training programmes.
- Advanced communication training programmes are developed and promoted.

Is able to engage in dialogue which encourages questions and clarification.	Is able to use interpreters effectively when required and can demonstrate good practice steps in these interactions.
Is able to communicate effectively in times of high distress for the person affected by cancer by being able to explain complicated information in a way that can be understood, and using a variety of mediums to reinforce the information given (written summary, information resources, availability for follow-up).	Is able to demonstrate Te Reo Me Ona Tikanga practices when caring for a person affected by cancer, including the use of karakia.
Is able to clearly communicate and explain the involvement palliative care and its purpose to meet the needs of the person affected by cancer and their whānau.	Demonstrates the use of plain language and terminology, where possible taking into account the age and sensory and developmental needs of the person affected by cancer.
Is able to communicate effectively with those from other services in a collaborative manner.	



## Training and Resources

For up-to-date training and resource links visit [www.centralcancernetwork.org.nz](http://www.centralcancernetwork.org.nz) where education is available which matches the competencies above.



# 3

## Standard Information Support

Information resources may be produced in any medium and may benefit either people with cancer or carers. They may include content specific to either the disease state itself, a particular manifestation or stage of the disease, various treatment, or support and rehabilitation options.

### Standard 3.1

Information resources are evidence-based, developed in a collaborative manner, fit for the NZ context and are provided at no cost to the person affected by cancer.

### Standard 3.2

Information resources and services are relevant (in their content, format and dissemination channels) to the needs of Māori, Pacific and culturally and linguistically diverse groups.

### Standard 3.3

Involvement of consumers and subject experts is actively sought in the design, development and evaluation of cancer information resources.

### Rationale

It is vital that people affected by cancer receive information that enables them to make informed decisions along the cancer pathway. It is also understood that when receiving bad news people are not always able to process large amounts of information. This means information needs to be repeated at different times from the time of high suspicion through diagnosis and beyond, and be supported by compassionate communication.

People understand information in different ways so different methods of communication are needed. Particular consideration must be given to format and media (app-based, online, imagery, tone) when developing information that is aimed at adolescents, young adults and children.

In the current era of easy access to large amounts of information it is important that people affected by cancer are directed to information that is evidence-based and appropriate to their situation.

The involvement of consumers in the development of information resources is vital to ensure the information is developed in a way that is appropriate to the audience.



*“I’m given the right information,  
at the right time and in a way  
that meets my needs.”*

⊖ **Equity:** Adoption without adaptation will not promote equity for the NZ population.



# Information Support Competencies

## Good Practice Points Service/Organisation

- Services will utilise information resources which have been evaluated against quality standards.
- Information is available which is suitable for all age and developmental stages.
- Information needs to be in non-technical language and available where possible in different languages.
- Areas for displaying information resources are accessible and the information is continually reviewed and updated.
- People are provided with accurate and clear information about services available to them in a timely fashion, e.g. eligibility for travel and accommodation assistance.
- The setting for information giving is private and comfortable for people affected by cancer to ask questions about the information they are receiving.
- Information which is sourced from outside of the service, organisation or country is reviewed before it is used to ensure the content and language is appropriate for the NZ context and adapted as required.
- Health and supportive care workers need to be aware of what resources exist in the online community and be able to direct people affected by cancer to appropriate sources.
- The use of patient-held diaries is encouraged and engaged with by the workforce.
- Organisations upskill their workforce so they are informed about alternative, complementary and traditional treatment and are able to engage the person affected by cancer about their choices.

- Organisations should have a designated position/role that organises and maintains information and liaises with NGOs about provision of resources.
- To achieve consistency, when information changes all levels of staff and other community agencies need to be informed.
- Resources are developed with Māori so they are appealing to Māori in terms of imagery and content.
- Resources take into account the variety of cultural contexts they may be used in and how they may be received.

## Good Practice Points System

- There is systematic management to monitor and address gaps, overlaps and inconsistencies in the range of information resources and services available.

Remains informed of changes in information that occur.	Familiarises themselves with the information resources available most relevant to their scope of practice.
Is able to evaluate information from alternative sources for its validity and accessibility for people affected by cancer.	Is able to communicate information when significant stressors are occurring, including diagnosis and relapse, in a way that acknowledges the person's ability to absorb information which may be reduced at times of stress.
Is able to provide strategies to counteract the effect of stress to ensure a person is fully informed.	Is able to provide neutral information about traditional and complementary medicines and supports.
Utilises contacts with whānau to give information to increase the health of the whānau as a whole.	

## Training and Resources

For up-to-date training and resource links visit [www.centralcancernetwork.org.nz](http://www.centralcancernetwork.org.nz) where education is available which matches the competencies above.



# Standard 4

## Social Support

Social support encompasses those services that enable people affected by cancer to adjust to and cope with personal, domestic and financial challenges to their everyday lives resulting from cancer.

### Standard 4.1

The social support needs of people affected by cancer are proactively considered and addressed continuously throughout their care.

### Standard 4.2

All health and supportive care workers participate in education and training programmes to increase their awareness and understanding of the impact of social needs on the person affected by cancer and their whānau.

### Standard 4.3

An integrated and coordinated system of continued social support provides timely, accessible services that meet the needs of the full range of populations.

### Standard 4.4

Processes are implemented to enable active identification of populations which are more vulnerable within the cancer pathway.

### Standard 4.5

Health and supportive care workers proactively use evidence-based tools or screening methods to assist in identifying and clarifying social needs from a holistic perspective.

**Equity:** Understanding the causal pathways by which socioeconomic conditions affect health will enable us to identify the most effective interventions.

## Rationale

People affected by cancer can find that many aspects of their lives are affected and changed by cancer.

The awareness of all staff involved in cancer services to social needs will improve the likelihood of these needs being met in a timely and responsive manner, thereby preventing an increase in impact and a crisis response.

For people whose lives already have social challenges or existing stressors, whether at an individual level or within their whānau, the addition of going through a cancer journey can stretch resources even further. Supporting patients to manage the impact of cancer on social factors can be undertaken in a way that strengthens an individual and their whānau's resilience, increases their health literacy and enables them to learn self-management skills in other areas of their life. Navigators and social care agencies may already be supporting the whānau and providing a key role in helping them to manage the challenge that cancer brings.

Information, social care and support are requirements that change dependent on phase, impact and outcome of treatment.

Person-centered care requires people's individuality to be respected and their life choices valued in a way which means they are not marginalised during their care.

Many agencies contribute to addressing social needs. Whānau Ora supports the concept that the best health is achieved by inter-sectoral organisations working collaboratively to address all determinants of health including social factors. The services offered by cancer NGOs and social care agencies provide a valuable role in supporting the person affected by cancer.

Social care is a clinical consideration – the two cannot be separated when considering planning and treatment.



# Social Support Competencies

## Good Practice Points Service/Organisation

- Attendance and engagement in interdisciplinary meetings is expected from all members of the health care team to ensure quality care.
- Referral pathways are well established and utilised to maximise the support needed by the person affected by cancer from their communities.
- Referrals to social support services are undertaken with the consent of the person.
- Information concerning the assessment and interventions related to supportive care is recorded in the patient's medical record and is accessible to all members of the care team.
- Health and supportive care workers require knowledge about what services are able to be offered to ensure that referrals are appropriate. The environment provides space for social care professionals to speak with people affected by cancer in private.
- Organisations need to model that they recognise and value social care input in patient care.
- Respectful language must always be used when describing people with social care needs/additional difficulties so as not to increase stigma.
- The National Travel and Assistance Policy is fully utilised to promote equity of access wherever possible. Its utilisation includes supporting the need for a support person to be with them.

## Good Practice Points System

- Planning for service changes takes into account the potential impact on the supportive care needs for people affected by cancer.
- Investment in social care for patients affected by cancer is prioritised.
- Research is undertaken to identify effective social support services, interventions and measures to support those affected with cancer.
- The development of NZ-based tools for assessment is promoted to ensure the assessment itself does not create an inequity.



*“People involved in my care help me to think about what I might need and how to better cope with what’s happening.”*

Is aware of the social challenges that may impact on the overall well-being of a person affected by cancer and how social determinants impact on overall personal and whānau health.	Utilises established referral pathways to gain additional support for the person affected by cancer and their whānau.
Is aware of their organisation’s risk assessment processes for managing concerns about family violence, child protection, suicidal risk and vulnerable adults.	Is able to identify organisational policy on responding to elder abuse and neglect and know how to gain further assistance.
Is able to identify and understand the roles undertaken by the wider inter-professional team, community and social support agencies and primary care providers in supporting people affected by cancer.	Is able to assist each person to identify support networks based on a personalised assessment of their needs as opposed to an assumption of networks on a cultural basis.
Considers referrals to Māori health and social agencies in a proactive rather than reactive fashion, with the person’s consent.	Works with community agencies which support people from culturally and linguistically diverse backgrounds in a joint partnership with their sharing of cultural knowledge and the health worker’s understanding of cancer.
Is able to provide information and key contacts on accessing support for travel and accommodation.	Is able to identify aspects of someone’s social situation and past challenges that may impact their decision to engage in treatment and refer for support.

## Training and Resources

For up-to-date training and resource links visit [www.centralcancernetwork.org.nz](http://www.centralcancernetwork.org.nz) where education is available which matches the competencies above.



# 5

## Standard Psychological Support

Psychological standards apply in differing levels from those who provide emotional support through to more structured therapeutic interventions such as those delivered by Social Workers, Counsellors, Psychologists and Psychiatrists. Within the requirements for therapeutic intervention there are further specialties which require standards of their own. These standards seek to support access to these specialist services rather than define what form these services should take.

### Standard 5.1

The psychological well-being of people affected by cancer is proactively considered and addressed continuously throughout their care.

### Standard 5.2

All workers participate in education and training programmes to increase their awareness and understanding of the psychological impact on the person affected by cancer and their whānau.

### Standard 5.3

Staff providing advanced psychological interventions are qualified to do so and provided with further training to enhance these skills for the cancer context.

**Equity:** The development of NZ-based tools for screening and assessment is promoted to ensure the tool itself does not create an inequity.

### Rationale

People are affected by cancer in an emotional as well as physical way. Studies have shown that within the treatment population the level of distress which requires intervention is between 30-60%. It is recognised that those supporting the person with cancer may also be emotionally affected and may have significant psychological needs.

Research has identified various points of screening or assessment linked with the patient moving through treatment stages, or at specific points in the cancer pathway. What is recognised from the workforce involved in this work is that assessment for psychological need has a place throughout the cancer continuum in a systematic fashion, but should also be responded to when there is evidence of need.

Psychological issues which arise can have an impact on the person's engagement with their treatment, the side effects they experience and their recovery. Issues can vary widely from those requiring specialist interventions via psychology or psychiatry to a time limited adjustment reaction which requires a less specialist intervention. It is important for people affected by cancer and the workforce involved in their care that there are processes in place to access this specialist help when needed, but also that all staff have the skills to screen for the emotional impact of having cancer.

It is accepted practice internationally that cancer treatment centres have a screening system in place for distress. Studies have shown that staff cannot always accurately gauge how much distress a person is experiencing or what is causing that distress. Screening is a process which is undertaken on every person with cancer and is a way of identifying potential issues. Assessment is a more in-depth conversation with the person affected by cancer to understand their ongoing needs. This means that the role of all staff is to screen for the need for intervention and for some staff their roles are to assess.



*“Seek help with accepting your diagnosis and then seek help if you're feeling down...”*

*Cancer Stories Aotearoa –  
Kahui Korero Taumahatanga  
o Te Mate Pukupuku*



# Psychological Support Competencies

## Good Practice Points Service/Organisation

- Services utilise a well-developed algorithm defining the referral pathway a person is guided down if and when psychological care concerns are identified. A referral model based on a tiered level of specialist service need is developed for each treatment service.
- Links between services are clear and agreed so that those affected by cancer have access to psychological services appropriate to their needs.
- Service design incorporates the principles of Whānau Ora, ensuring that an inter-sectoral approach for service provision is utilised.
- Services employ health practitioners with the requisite skills and qualifications to meet the psychological needs of people affected by cancer.
- All staff are provided with debrief opportunities after a particularly difficult or distressing intervention.
- Within primary health the use of the Kessler 10 is recommended and should be understood by secondary/tertiary services to allow the transfer of information regarding anxiety and depression which may be present prior to diagnoses. These tools can be found at:  
[www.bpac.org.nz/BPJ/2009/adultdep/assessment.aspx](http://www.bpac.org.nz/BPJ/2009/adultdep/assessment.aspx)  
  
[www.tac.vic.gov.au/files-to-move/media/upload/k10\\_english.pdf](http://www.tac.vic.gov.au/files-to-move/media/upload/k10_english.pdf)

## Organisations implementing distress screening need to consider the following:

- Whole service education and service development to occur if screening tools are to be implemented, to ensure a readiness to respond to referral
- Communication skills need to be part of a distress screening package as a conversation is the best method to capture the information around someone's mood, coping and distress levels
- Monitoring of the use of, and barriers to, screening tools needs to be identified
- Only tools which have been adapted to and validated in the New Zealand context should be used to contribute to Māori health gains. To date, the Distress Thermometer is an accepted screening tool and one for which there has been New Zealand adaptation and validation.

## Good Practice Points System

- Investment in psychological care services for people affected by cancer is prioritised.
- Research is undertaken to identify effective psychological services, interventions and measures that support those affected with cancer.
- The development of NZ-based tools for screening and assessment is promoted to ensure the tool itself does not create an inequity.

Undertakes training and education on the psychological needs of people affected by cancer.	Understands different ages and developmental needs, as well as stages and their impact on responses.
Incorporates the importance of understanding different cultural contexts, including expressions of distress in populations culturally and linguistically diverse from their own.	Recognises individuality and difference in people's reaction to stressful events.
Is proactive in looking for signs of difficulties and gives space for distress to become evident.	Is equipped to respond to immediate distress and provide supportive interventions until/if further specialist intervention is required.
Understands the role, function and access criteria for all members of the interdisciplinary team, and is able to identify reasons for escalation to more specialised support.	Undertakes ongoing training, which increases their understanding of how different cultures grieve and the customs around illness and death.
Is aware of how the social determinants of access to health services may cause barriers to effective psychological care and considers how to overcome them, including past life challenges.	

## Training and Resources

For up-to-date training and resource links visit [www.centralcancernetwork.org.nz](http://www.centralcancernetwork.org.nz) where education is available which matches the competencies above.



# Standard 6

## Care and Support Coordination

Care and support coordination refers to a comprehensive approach that seeks to achieve continuity of care and support, drawing on a variety of strategies that strive for the delivery of responsive, timely and seamless care across a person's cancer service pathway.

### Rationale

Services to people affected by cancer are provided by many disciplines and types of organisations. The person affected by cancer may have complex needs throughout their pathway, which requires the collaboration and coordination of responses to these needs.

Recognition of the value that all services bring is best supported by collaborative care models which incorporate input from a variety of health and supportive care workers in a way that is understood and clear to the person affected by cancer. This cannot be assumed to be occurring, but needs direct intervention and attention to ensure organisations are working together effectively. It is well recognised that continuity of care across providers depends on communication and sharing of information so that the person affected by cancer can be supported in a timely and consistent way.

Care and support coordination is a shared responsibility for the workforce, service and system. For the person affected by cancer the key is that they know who to contact, and how, at any point within their cancer journey.

#### Standard 6.1

People affected by cancer have access to an appropriate health and supportive care provider(s) to coordinate their care, and the documentation clearly states who the identified contact(s) is.

#### Standard 6.2

All health care plans identify what supportive care needs exist for the person affected by cancer and how they will be addressed.

Equity: Working inter-sectorally supports the principles of Whānau Ora.



## Care and Support Coordination Competencies

### Good Practice Points Service/Organisation

- Promote the use of information systems/mechanisms which support the combination of biomedical, psychological, cultural and social care.
- Supportive care is integrated within clinical pathways such as Map of Medicine and Health Pathways.
- People affected by cancer have access to appropriately skilled supportive care services at the point of need.
- In both policy formation and practice, palliative care is recognised as an essential component of the care and support coordination for people.
- Palliative care provision reflects the interdisciplinary skills, communication and understanding of the roles required to deliver a comprehensive service.
- Services actively take steps to ensure they are working together rather than in silos.
- Administration processes and IT support have a role in supporting care coordination.
- Health and supportive care workers communicate with people affected by cancer to develop a plan that identifies how their goals of care, including functionality, wellbeing and whānau stability, are to be addressed.
- The process for transferring care between services is clear and transparent and accompanied by the appropriate documentation.

### Good Practice Points System

- Supportive care providers establish healthy networks which model collaborative practice to support the person affected by cancer.



*“Tell us how people can  
ask questions after  
their appointment.”*

*Cancer Stories Aotearoa –  
Kahui Korero Taumahatanga o Te Mate Pukupuku*

Is able to engage collaboratively with other providers to support the person affected by cancer and their whānau and give information about other providers accurately.

Is aware of the specialist and community palliative care resources which exist and how to utilise them.

Is able to address any concerns about role confusion and overlap with other professions.

Is able to communicate with people affected by cancer to develop a plan that identifies how their goals of care, including functionality, well-being and whānau stability, are to be addressed.

Is aware of the different needs a person has dependent on their age and that these may vary, particularly in childhood, adolescence and when assisting an older person.



### Training and Resources

For up-to-date training and resource links visit [www.centralcancernetwork.org.nz](http://www.centralcancernetwork.org.nz) where education is available which matches the competencies above.



# Standard 7

## Whānau Support and Involvement

# 7

Whānau refers to both descent-based whānau and whānau who come together for a common purpose. Metge defines the two kinds of whānau as whakapapa-based whānau and kaupapa-based whānau. This acknowledges that for some people, their whānau can be both their family of descent as well as those people they define as important who make up their support network.

Statistics New Zealand led by Te Atawhai Tibble (Ngati Porou) “adopts a model that considers both whakapapa and kaupapa whānau valid and leaves it to the individual to define their own whānau.” Kaupapa-based whānau can for the person affected by cancer be their work colleagues, social or sports group, or for some, those who support them from agencies. For others, this network is combined with their whakapapa whānau who again by some is defined as the nuclear family and for others the extended family. The key feature is that the person affected by cancer considers them their whānau.

### Rationale

In line with a holistic understanding of health is an understanding that we are supporting the whānau regardless of who has the cancer diagnosis. Healthy families (Whānau Ora) is a key factor in creating healthy individuals both in terms of lifestyle support as well as care-giving responsibilities. Whānau commitments can impede engagement and need to be addressed in order to minimise distress. Assumptions around the level of whānau support should not be based on cultural stereotyping, but rather an open-minded enquiry into the person’s support network.

A Clear understanding of any custodial issues and parental responsibilities need to be documented where appropriate. Consideration of the provision of resources which fit the context and age of the children involved is required. Staff need to have an understanding of whānau-based policies such as Enduring Powers of Attorney (EPOA) and Advanced Care Planning (ACP). Assisting with anticipatory guidance around whānau issues can be beneficial for the person affected by cancer and staff, especially in times of unplanned admission.

Research has also begun to indicate that at times it can be the partner or main caregiver, including those who are in a relationship with young people with cancer, whose needs are not recognised (these needs may be significant). The needs of this group require ongoing consideration and input.

Whānau make up a large portion of our unpaid care-giving workforce and require input as part of the support network. With societal shifts, the whānau network can be geographically spread, so consideration needs to be given to new methods of engagement for information giving and support.

#### Standard 7.1

A culture of whānau inclusion in decision-making is embedded in all services and organisations that provide supportive care to people affected by cancer.

#### Standard 7.2

Services provide training to the health and supportive care workforce to implement whānau-related policy and undertake effective whānau engagement.

**Equity:** For people affected by cancer the social determinants of health play an important role (WHO).



# Whānau Support Competencies

## Good Practice Points Service/Organisation

- Work needs to be undertaken by the organisation to ensure a standard of practice is followed for whānau meetings including, the facilitation and recording of outcomes.
- The workforce treats every health encounter as an opportunity to improve overall whānau health.
- Systems are in place which proactively address issues that arise about family violence and an awareness of the organisation's policies and procedures for response, if required, is promoted.
- Policies around death and dying should be reflective of Tikanga practices and the inclusion of whānau in decision-making and service provision.
- Policies need to reflect that information is shared, with consent, with whānau in a way that they can also understand and be supported with, to help with decision-making.
- Elderly couples, in particular, need to be assessed in terms of their dependence on each other and systems need to be in place to identify and respond to this population proactively.
- Adolescents and young adults need to be considered in light of their age and development to ensure that their whānau involvement is in line with their wishes.

## Good Practice Points System

- Include Whānau Ora concepts in supportive care service policy development and research.



*“Close family support is very important – whānau and aroha.”*

*Cancer Stories Aotearoa – Kahui Korero Taumahatanga o Te Mate Pukupuku*

Undertakes interventions which support whānau functioning and needs.	Is aware of the importance of Enduring Power of Attorney and who to refer to for additional advice and assistance.
Undertakes Level One Advanced Care Planning training and is able to identify appropriate staff to assist the person further.	Proactively addresses issues that arise about family violence and is aware of the organisation's policies and procedures for response.
Is aware of the signs of abuse, including elder abuse and neglect, and is able to refer appropriately.	Is aware of resources to support the wider whānau including children, adolescents and older adults.
Is aware of the impact of age and capability on consent giving.	Participates in family meetings and is aware of their role and function.
Knows how to access support for complex family dynamics appropriate to their role.	



## Training and Resources

For up-to-date training and resource links visit [www.centralcancernetwork.org.nz](http://www.centralcancernetwork.org.nz) where education is available which matches the competencies above.



# 8

## Standard Wairua and Spirituality

Wairua is a Māori concept which recognises the spiritual essence of a person and their life force. This determines us as individuals and as a collective, who and what we are, where we have come from and where we are going. The capacity for faith and wider communication.

Spirituality means different things to different people. It may include (a search for): one's ultimate beliefs and values; a sense of meaning and purpose in life; a sense of connectedness; identity and awareness; and for some people, religion.

### Rationale

Increasingly wairua and spirituality are being recognised by the health sector as important facets of a person's well-being that need to be understood. Spirituality is not just about religion. People with cancer have their sense of meaning, identity and sometimes faith challenged.

*"There is however, strong evidence that if the human elements of compassion and hope, understanding and relationship between carer and cared for are ignored, then we are forgetting and losing a crucial element of the healing process"* (NHS, 2009). Health and supportive care workers' acknowledgement of a spiritually-based issue/need for the person affected by cancer and attention to the existential questions has been shown to improve overall health, both mental and physical. *"Patients and physicians have begun to realise the value of elements such as faith, hope and compassion in the healing process"* (NHS, 2009).

The spiritual care needs of the workforce are also important as they are integral to maintaining a sense of compassion and hope. A patient's death, in particular, needs to be acknowledged within a workplace and can affect staff in a variety of ways. While it is an expected event in health care it can have a cumulative effect on the workforce. A workforce that pays attention to their own sense of compassion, hope and meaning will be a more responsive workforce to these issues and deliver more responsive care.

#### Standard 8.1

The spiritual needs of people affected by cancer are proactively considered and addressed along the journey or at each intervention point.

#### Standard 8.2

Systems are in place to ensure people affected by cancer and their whānau are fully informed of their right to be cared for in a manner which is in agreement with their spiritual beliefs.

⊖ **Equity:** Person centred care requires a health system which supports a inclusion of spiritual care.



# Wairua and Spirituality Competencies

## Good Practice Points Service/Organisation

- There is an organisational approach to how a need for spiritual care is identified and there is a referral pathway to how this need will be addressed.
- Health and supportive care workers are encouraged to participate in spiritual awareness education.
- A level of cultural competency within the health workforce is maintained to ensure they are able to integrate the spiritual beliefs of Māori into care and are aware of where to access additional support.
- To facilitate the broader needs of people in terms of spirituality, expertise from nga hahi Māori (Māori churches) should be identified and made available.
- There is the provision of spiritually-enhancing spaces within the buildings of the organisation, including designated space for contemplation and reflection from a religious or spiritual stance.
- Spaces and time for reflection will increase the health and well-being of the workforce as well as that of the person affected by cancer.
- People affected by cancer should be asked about their spiritual care needs and guided to the appropriate services.
- Policies and procedures for cultural safety in relation to Tikanga practices are in place, e.g. the use of karakia before procedures or meetings.
- People affected by cancer should be able to seek support from their own spiritual advisor, as well as the help offered by the pastoral care services.

## Good Practice Points System

- Spiritual support services are included in relevant health care contracts and service specifications.
- Research is undertaken to identify effective spiritual support services, interventions and measures that support those affected with cancer, including Māori.



*“It was probably that type of healing, the wairua, that I didn’t realise I needed.”*

*Cancer Stories Aotearoa – Kahui Korero Taumahatanga o Te Mate Pukupuku*

Ensures those affected by cancer are offered spiritual support at a time they need it.	Is familiar with, and knows how to, access both spiritual information resources and spiritual leaders.
Is aware of and able to participate in a discussion with the person affected by cancer about their spiritual needs like existential concerns such as mortality.	Has an understanding of how their own beliefs and spiritual beliefs may be challenged within the work environment.
Maintains a level of cultural competency that ensures they are able to integrate the spiritual beliefs of Māori affected by cancer into care and are aware of where to access additional support.	Is able to utilise self-care techniques to ensure that their own sense of hope and compassion is maintained.
Has an understanding of the different religious and cultural rites around death and where to access additional advice and assistance.	

## Training and Resources

For up-to-date training and resource links visit [www.centralcancernetwork.org.nz](http://www.centralcancernetwork.org.nz) where education is available which matches the competencies above.



# Standard 9

## Living with and Beyond Cancer

The terminology 'living with and beyond cancer' used in the Framework reflects recognised survivorship and rehabilitation concepts. Rehabilitative support following the treatment of cancer attempts to maximise the ability of those who have been treated for cancer to: function as fully as possible in their everyday life; promote independence, dignity and quality of life; and generally assist them to adapt to living with cancer long term.

Survivorship refers to the period of time extending from the time of diagnosis through to death. The period is divided into acute, extended and permanent phases.

### Rationale

Living with and beyond cancer identifies the ever-increasing need to ensure people are being assisted with next steps and direction once active treatment is completed. Evidence shows that many people affected by cancer have unmet needs at the end of active treatment or struggle with the consequences of treatment that need to be managed. More people are living longer with cancer and it is now considered a chronic disease. The impacts of increasing treatment options and the disease process itself will result in new challenges for people affected by cancer and the system. Inter-professional, in particular, Allied Health involvement is important as treatment ends to maximise the person's return to functioning or managing with new limitations.

All people affected by cancer have a need for their physical, psychological and social care needs to be recognised and responded to regardless of age. Within this area there are differences in how children with cancer are supported, e.g. an acknowledged set of services and input (Late Effects Assessment Programme). Similar services are required for adolescents and young adults who receive treatment through the adult cancer service and do not have access to the LEAP programme. This is an area that needs addressing.

This is an emerging space in NZ and as such these standards do not seek to cover all aspects which need to be considered, acknowledging this is work that needs more considered attention.

People's needs in survivorship are as unique as they are in treatment, so solutions need to be as flexible as possible.

#### Standard 9.1

People affected by cancer moving from intervention into follow-up have a planned approach to their continued medical and supportive care needs which is clearly documented, reviewed regularly and understood by the person and their whānau.

#### Standard 9.2

The follow-up care plan is communicated to Primary Care and other community-based care providers.

#### Standard 9.3

All patients are assessed for their rehabilitative needs and referred appropriately to Allied Health, irrespective of the patient's age.

**Equity:** The Equity of Health Care for Māori Framework identifies actions to improve equity at the health system, health organisations and health practitioner levels.



# Living with and Beyond Cancer Competencies

## Good Practice Points Service/Organisation

- When discussing treatment options which may have long-term quality of life impacts, these potential impacts are explained to assist with decision-making.
- Planning for service delivery includes post-treatment provision and clinical reasoning for follow-up processes.
- Transfer of care service plans are evident and audited for consistency.
- Services and health professionals utilise patient contacts to promote secondary prevention strategies, i.e. healthy choices.
- Organisations consider the work undertaken already within the LEAP programme for children as a valuable resource to inform service development for adults, in particular, the adolescent and young adult population.
- A response to survivorship issues is based within the community and primary setting where possible to support the person's return to community services.
- Health services which focus on rehabilitation should be utilised at the earliest opportunity to maximise the physical improvements a person can make post-treatment. Rehabilitation still has a role even when the prognosis is non-curative as this period of time can extend for a number of years.

## Good Practice Points System

- Chronic care modelling should be utilised to inform developments in survivorship practice and service design.
- Transfer of care to primary care is evident in all pathway and service development.



*“I’m now living with a different person. I’m not the person I was. My body is not the body it was ...”*

*Cancer Stories Aotearoa –  
Kahui Korero Taumahatanga o Te Mate Pukupuku*

Demonstrates an active intent to ensure the person and whānau transitioning out of secondary and tertiary treatment services does not feel dismissed or abandoned.	Continues to assess the support needs of the person affected by cancer, regardless of the place on the pathway.
Understands the concepts of rehabilitation and is able to articulate the need for, and the referral pathway to, rehabilitation services.	Considers the needs of carers and parents and how to link to appropriate supports to re-enter the workforce.
Uses contacts to promote secondary prevention strategies.	Is aware of how to incorporate the primary care provider in ongoing work or at transfer of care.
Has an understanding of the consequences of treatment and key considerations in working with a person living with or beyond cancer.	Considers the impact of treatment long term on a person affected by cancer in relation to their age and development and the different considerations which need to be addressed.
Is aware of how to access resources that are age and developmentally appropriate to support a young person or child.	

## Training and Resources

For up-to-date training and resource links visit [www.centralcancernetwork.org.nz](http://www.centralcancernetwork.org.nz) where education is available which matches the competencies above.

# Quality Tools and Checklist

This section provides information on quality processes and a quality checklist that can be used to evaluate tools and resources for use in supportive care service delivery. The health and supportive care workforce is always seeking to improve service delivery by developing new resources or adopting/adapting resources already in use in other parts of the country or internationally. Caution needs to be taken when seeking to implement resources/tools which have not been validated for the population they will be used with or when seeking to adapt already validated tools without additional research. Using this checklist in project groups when changing tools and resources the service uses will give a framework to assist in decision-making.

Listed below are key tools which can be used by the sector to ensure that the resources they are seeking to develop or implement meet quality standards. They also support the development process itself by providing guidance on approaches that maximise engagement.

## Health Equity Assessment Tool (HEAT)

The Health Equity Assessment Tool (HEAT) aims to promote equity in health in New Zealand. It consists of a set of 10 questions that enable assessment of policy, programme or service interventions for current or future impact on health inequalities.

### The questions cover four stages of policy, programme or service development:

1. Understanding health inequalities.
2. Designing interventions to reduce inequalities.
3. Reviewing and refining interventions.
4. Evaluating the impacts and outcomes of interventions.

[www.health.govt.nz/publication/health-equity-assessment-tool-users-guide](http://www.health.govt.nz/publication/health-equity-assessment-tool-users-guide)

## Whānau Ora Health Impact Assessment

The Whānau Ora Health Impact Assessment (Whānau Ora HIA) is intended for use by sectors that have a role to play in the wider determinants of health. The tool can also be used by communities or groups affected by the other sectors to inform their input into the development of policies. The particular focus of the Whānau Ora HIA is how the policies of these sectors can support Māori health and well-being and reduce inequalities.

[www.health.govt.nz/our-work/health-impact-assessment/Whānau-ora-health-impact-assessment](http://www.health.govt.nz/our-work/health-impact-assessment/Whānau-ora-health-impact-assessment)

## Health Service Co-Design Toolkit

This guide will help you work with patients to understand their experiences and make improvements to health care services. It provides a range of flexible tools for working effectively with patients in service improvement work. While the focus is on patients themselves, the tools can be equally applied to other groups such as frontline staff, whānau and carers.

[www.healthcodesign.org.nz/](http://www.healthcodesign.org.nz/)

## Engaging with consumers: A Guide for District Health Boards

This practical guide was developed by the NZ Health Quality and Safety Commission to help DHBs, and the health and disability services they fund, to engage better with consumers. It covers consumer engagement in the design and delivery of services, as well as the development of policy and governance procedures.

[www.hqsc.govt.nz/our-programmes/partners-in-care/publications-and-resources/publication/2162](http://www.hqsc.govt.nz/our-programmes/partners-in-care/publications-and-resources/publication/2162)

## NHS Change Model

The NHS Change Model provides a useful organising framework for sustainable change and transformation that delivers real benefits for patients and the public. It has been created to support the NHS to adopt a shared approach to leading change and transformation. The NHS Change Model is not rocket science – it brings together what we know helps make change happen and who needs to be involved.

[www.nhs.uk/capacity-capability/nhs-change-model.aspx](http://www.nhs.uk/capacity-capability/nhs-change-model.aspx)

## Ensuring Quality Information for Patients (EQIP Tool)

The aim of EQIP is to provide a method of assessing, in a fair and rigorous manner, the quality of consumer health information according to published quality criteria. EQIP can be used by anyone, although it was originally designed for use by information producers and providers in an audit setting. It can also be used by information producers as a quality check tool.

[www.centralcancernetwork.org.nz/file/fileid/30183](http://www.centralcancernetwork.org.nz/file/fileid/30183)

## A Framework for Health Literacy

The Ministry of Health developed this framework because it is committed to a health system that enables everyone living in New Zealand to live well and keep well. Building health literacy is an important part of this, and the Framework outlines expectations for the health system, health organisations and the entire health workforce to take action that:

- supports a 'culture shift' so that health literacy is core business at all levels of the health system
- reduces health literacy demands and recognises that good health literacy practice contributes to improved health outcomes and reduced health costs.

[www.health.govt.nz/publication/framework-health-literacy](http://www.health.govt.nz/publication/framework-health-literacy)



# Quality Checklist

Name of the Tool/Resource:		Date:
Comments		
<b>Co-Design/Consumer involvement</b>	Is there evidence in the document or the background information which indicates that consumers have been part of the development?	
	Does it use person centred language?	
	Who is the language aimed at – workforce or consumer?	
<b>Māori Health Outcomes</b>	Does its use support the components of the Equity Framework?	
	In implementation, is consideration given to the use of tools such as HEAT to ensure it supports Māori health gains?	
<b>Pacific Health</b>	Is it reflective of Pacific understandings of health?	
	Does it take account of the words not available to describe technical aspects of the disease?	
<b>Evidence-based</b>	Has it been reviewed against the EQIP or Write Mark?	
	Is the resource from a recognised provider of information?	
	Are the references present or accessible?	
<b>Culturally Appropriate</b>	Is the use of language appropriate to the audience?	
	Is the use of imagery appealing and reflective of the local population?	
	Has the imagery and its meaning been considered for its meaning in other cultures?	

		Comments
<b>Age/Developmentally Appropriate</b>	Is the content suitable for all ages?	
	Does it have relevant and engaging imagery aimed at each age group?	
	Is the language suitable for all ages?	
	Is the format accessible by different technologies, i.e. app or website?	
	If for children, does it come with a parent/teacher guide for use?	
<b>IT-enabled</b>	Is the format adaptable and compatible to being IT-enabled?	
	Is it available and accessible online?	
	Is it changeable and able to be updated?	
	Is it available at no cost?	
<b>Empowering People</b>	Does it reflect self-care/management strategies?	
	Does it encourage questions and dialogue?	
	Is it readable by the population it is aimed at?	
<b>Standardised</b>	Does it reflect the standards that currently exist in the New Zealand system?	
	Can it be used by all client groups?	
	What was the thinking behind its creation – was it to target only a certain population?	
	Is it accessible by all?	
<b>Understood</b>	Can you understand all it says?	
	What level of cancer knowledge would you need to have to understand it?	
	Are the medical terms explained adequately?	
<b>Works in Team Approach</b>	Does the language support an interdisciplinary/team approach?	
	Is it a resource that everyone within the team can understand?	
	Does it give information a team member may not agree with?	

**Decision about the Tool/Resource:**

- Suitable for use as is
- Requires adaptation
- Not suitable for use – look for alternative



