

**Guidance for Improving
Supportive Care for Adults
with Cancer in
New Zealand**

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MANATŪ HAUORA

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1. Introduction

1.1 Purpose

The aim of this guidance document is to improve the quality of life for people affected by cancer by improving access to and the quality of supportive care in New Zealand. It provides clear objectives based on the best evidence, and suggests best-practice service approaches that will help to ensure that adults with cancer, their families and whānau have access to the supportive care they need throughout the various stages of cancer, from diagnosis onwards.

This guidance is specific to adults. It does not include an in-depth focus on palliative care; nor does it cover care for children and adolescents. Guidance for these two areas is currently being developed separately by expert advisory groups with specialist knowledge.

This document is aimed at both government and non-governmental organisations (NGOs) involved in the funding, planning, policy and programme development and delivery of cancer supportive care services, including the Ministry of Health, District Health Boards (DHBs), NGOs, Māori and Pacific service providers, primary health organisations (PHOs) and other health and allied professionals.

This guidance is a living document and will be updated as new evidence emerges. It is not a detailed prescription for what should occur at a local level: needs and resource requirements for supportive care will vary. The areas for action outlined in this document allow for flexibility in implementation.

Details on how this guidance will be implemented with the sector are outlined in section 1.2.

The Ministry of Health wishes to acknowledge that high-quality supportive care is needed by many people with a chronic condition. This guidance is aimed specifically at people affected by cancer. However, a number of this document's recommendations could be applied more broadly across the spectrum of health and wellbeing.

1.2 What will happen next? – implementing the guidance

This document outlines objectives and areas for action to help ensure that adults affected by cancer have access to essential support and rehabilitative care they need throughout the cancer journey. In order to realise the objectives outlined in this guidance document, the Ministry of Health will work with the regional cancer networks, DHBs, the Cancer Society and other NGOs to develop a plan to implement the guidance. The implementation plan will be based on the objectives and areas for action set out in the guidance. Components of the first phase of the work programme are outlined in Figure 1 (section 1.11), and further elaborated in the the following sections.

1.2.1 Stocktake and gap analysis of supportive care services

A stocktake will be undertaken to get a clearer picture of what services and programmes are currently being provided at a regional level and who is accessing those services. The information will then be used to analyse where gaps exist and to develop a sector-wide implementation plan.

This process will also provide an indication of key priorities and resourcing requirements.

The objectives of the stocktake will be to:

- identify current providers of particular supportive care services across the region
- identify the population/s that mainly access the services
- identify gaps or overlaps in service provision (using recommendations in the supportive care guidance as a benchmark for best practice)
- identify where inequalities exist with respect to access and availability of services
- identify and prioritise issues specific to each cancer region
- gather information to further develop the intervention logic, down to the level of activities and outputs.

1.2.2 Implementation planning

On completion of the stocktake and gap analysis, workshops will be held with relevant stakeholders to share the stocktake and gap analysis findings, receive feedback, and to develop a plan for implementing the guidance. The logic model referred to in section 1.5 and 1.11 (see Figure 2) will also be further developed. The implementation plan will identify a specific set of prioritised actions and the agencies responsible for them.

1.2.3 Monitoring and evaluation

Indicators will be developed at a number of levels (process through to outcome) to track progress against the objectives set out in the guidance. This will be done in association with Cancer Control New Zealand.

Evaluation is an essential part of implementation in the context of the implementation plan. These include: building the evidence base to support planning; ensuring interventions align with best practice and achieve their objectives; describing outcomes at an individual and population level; and demonstrating accountability.

An evaluation component should be an integral part of all newly introduced service models and programmes. Appropriate evaluation will determine the effectiveness of particular interventions in improving patient outcomes in different contexts.

1.2.4 Financial implications

Once the stocktake and implementation plan are completed, the Ministry of Health will consider the costs of developing new services and enhancing existing support services where required. These will then be prioritised and form the basis for future budget planning.

1.3 Definition of supportive and rehabilitative cancer care

The definition adopted by the Expert Advisory Group (EAG) for supportive care is adapted from that of *The New Zealand Cancer Control Strategy* (Minister of Health 2003) in its Goal 4:

Improve the quality of life for those with cancer, their family and whānau through support, rehabilitation and palliative care.

In this guidance document, supportive care and rehabilitation services include:

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.

1.4 Approaches used to develop this guidance document

1.4.1 Preliminary scoping and planning phase

In January 2006 the Ministry of Health commissioned the Cancer Society of New Zealand (CSNZ) to scope the development of guidance for supportive care for people affected by cancer, within a six-month timeframe. The project was led by the New Zealand Guidelines Group (NZGG) under a CSNZ subcontract.

The final report in June 2006 recommended that the Ministry of Health should adapt the United Kingdom-based National Institute for Health and Clinical Excellence (NICE) manual, *Guidance on Cancer Services: Improving supportive and palliative care for adults with cancer* (NICE 2004a), taking into account the needs of New Zealand's unique population groups.

1.4.2 Formation of the Expert Advisory Group

In July 2007 the Ministry of Health established an Expert Advisory Group (EAG) to oversee the development of supportive care guidance for adults affected by cancer. The EAG's membership included consumers, service planners and providers (including Māori and Pacific service providers), a general practitioner (GP) with extensive knowledge of complementary and alternative medicines (CAM), a clinical psychologist and representatives from the regional cancer networks.

The EAG's tasks included:

- defining the scope of the guidance
- reaching agreement on the materials to form the basis of the guidance document
- providing expert input into the content of the guidance

- deciding on an appropriate format for the guidance
- overseeing consultation with stakeholders
- peer-reviewing the guidance and the consultation submission analysis
- endorsing the final guidance document.

A list of the EAG's members is provided in Appendix 1.

1.5 This guidance in context

The New Zealand Cancer Control Strategy Action Plan 2005–2010 (Cancer Control Taskforce 2005) broadly covers:

- promoting leadership in supportive care
- developing policy for supportive care
- improving access to supportive care services
- ensuring information about cancer and related services generally is of high quality, accessible, well co-ordinated, culturally appropriate and people, family and whānau-friendly.

This guidance has been developed to progress these areas. A logic model diagram (see Figure 2, section 1.11) shows how the areas for action and objectives outlined in this document link to medium- and longer-term supportive care and overall cancer outcomes.

Other areas of the Ministry of Health's current work programme that will similarly contribute to improving supportive care for adults with cancer include:

- Strengthening the regional cancer network infrastructure to improve the integration of services between primary, secondary and tertiary care providers within and across DHBs. The networks' memberships, which include consumers, are based on cross-sectoral, cross-cultural collaborative relationships. The overall intent of the networks is to improve equity of access to cancer services, reduce service fragmentation, duplication and gaps, and generally co-ordinate the planning, policy development and delivery of cancer services, including supportive care services.
- Funding three community cancer pilots to support Māori and rural communities to better access and navigate cancer services. The pilots are developing and testing new models of care, and utilise a range of support services, including information provision, facilitating contacts with treatment services and social support agencies, working within the wider community and providing support at clinical appointments. Funding for the pilots ends in 2010.
- The development of patient management frameworks that describe a person's care pathway, identifying critical points along that pathway and the optimal model of care required, including the provision of information resources. The frameworks are intended to improve patient outcomes by aiming to provide consistent care based on evidence and best practice across the country. Supportive care underpins the frameworks at all stages.

1.6 Rationale for developing the guidance

1.6.1 The impact of cancer

As in other Western countries, cancer is a significant cause of illness and death in New Zealand, where cancer accounts for 29 percent of deaths. Each year around 19,000 people are diagnosed with cancer. A diagnosis of cancer and the treatment regime that follows have the potential to seriously disrupt lives. The experience brings a range of anxieties, including emotional and financial strain. Support from everyone around the person with cancer, including the providers of cancer services, is crucial. Evidence suggests that when people with cancer receive good social, psychological and cultural support, the quality of their life improves (CSNZ and NZGG 2006).

1.6.2 Reducing cancer inequalities

Longstanding and significant inequalities exist between Māori and non-Māori in terms of the incidence of cancer morbidity and mortality, access to cancer services, the stage at which cancer is first diagnosed and survival rates (Cormack et al 2005; Robson et al 2006). Inequalities are also evident for Pacific peoples and lower socioeconomic groups (Ministry of Health 1999a; Ministry of Health and Ministry of Pacific Affairs 2004).

Reducing health inequalities between population groups is a key principle of all government health strategies and their associated action plans, principally the *New Zealand Health Strategy* (Minister of Health 2000), the *New Zealand Cancer Control Strategy* (Minister of Health 2003) and *He Korowai Oranga: Māori Health Strategy* (Minister of Health and Associate Minister of Health 2002). DHBs have a statutory responsibility under the New Zealand Health and Disability Act 2000 to reduce health inequalities in their regions, including improving outcomes for Māori.

This guidance aims to promote and improve access for groups facing inequitable cancer outcomes. Various assessment tools have been developed to assist planners, funders and service providers to ensure all services and interventions have an equity focus. These tools include the *Reducing Inequalities Intervention Framework* (Ministry of Health 2002b), *The Health Equity Assessment Tool: A user's guide* (Signal et al 2008) and the *Whānau Ora Health Impact Assessment Tool* (Ministry of Health 2007b).

This guidance does not make specific recommendations for different population groups. Rather, it is intended that the guidance be read with an 'equity lens', and that the tools available are used when purchasing, monitoring and evaluating supportive care services for people affected by cancer.

1.6.3 The quality of current service provision

Evidence and general information gathered during the development of the *Cancer Control Strategy* and the *Action Plan* indicate that access to cancer support resources varies considerably between and within regions. Several implementation project studies funded by the Ministry of Health in 2006 focused on people's pathways through local cancer services. These studies highlighted issues regarding access to supportive care services, particularly for Māori, Pacific and geographically isolated people. These issues included the following:

- Changing needs of those affected by cancer throughout the diagnosis, treatment and rehabilitation stages means that people with cancer and their carers are not always able to access all the services or resources they are entitled to.

- Eligibility for disability support services varies across regions. Funding is limited for people with long-term conditions, particularly for those between 18 and 65 years of age.
- Accessing financial support from Work and Income New Zealand can sometimes be complex and difficult.
- Ease of accessing transport to and from regional cancer treatment centres, and accommodation allowances, are variable.
- Health professionals' patient assessments are not giving due consideration to the person affected by cancer and their carers' personal situations outside the hospital setting.
- Integration and co-ordination between primary, secondary and tertiary cancer services, and between cancer services and public and private settings, is often less than optimal.

The implementation studies also found that eligibility for long-term support services for people with impairments due to cancer varied nationally due to a lack of funding for people under the age of 65 with chronic health conditions.

1.7 What do people with cancer, their families and whānau expect of cancer services?

The evidence suggests that in addition to receiving the best possible treatment, people with cancer want and expect to:

- be treated as individuals, with dignity and respect for their culture, lifestyles and beliefs
- know they will only undergo those interventions and procedures for which they have given informed consent
- have their symptoms adequately controlled
- exercise choice as to the range of treatments and services available to them
- receive relevant, timely, culturally sensitive, understandable information about their condition and the various treatments required at all stages
- know which support and rehabilitative service options are available to them through the state-funded health service, other government sectors, NGOs and the voluntary sector
- communicate effectively with health and allied professionals who are sensitive to their physical, emotional, cultural and spiritual needs, and those of their family and whānau.

1.8 What areas need to be addressed?

Recent cancer control activities, including the work that underpins the development of this guidance document, suggest a need to:

- improve the integration of supportive care, co-ordination of care across geographical areas, and cross-sectoral engagement on cancer support and rehabilitation issues at a regional level
- provide consistent access to a range of high-quality consumer-friendly information for all people with cancer, their families and whānau, including those treated in private hospital settings, about available support services
- develop holistic assessment models that include identification of individual's, their family's and whānau's support and rehabilitation needs throughout the cancer service pathway

- provide training for professional service providers that will assist them to meet the supportive needs of people with cancer, their families and whānau
- provide a voice for local people directly affected by cancer in the planning and development of cancer services in their region
- actively promote support group services that help those dealing with cancer to self-manage the short-term and long-term effects of their cancer
- continue to invest in research and evaluation studies that determine the most effective ways of providing support for people with cancer, their families and whānau.

1.8.1 Responsiveness to the support needs of Māori

Cancer is a significant health concern for Māori and has a major and disproportionate impact on Māori communities. Although overall mortality and morbidity rates are improving, Māori are still more likely to be diagnosed with cancer, and even more likely to die of cancer. This is consistent with substantial international evidence of ethnic disparities in cancer incidence and outcomes, and of the disproportionate impact of cancer on indigenous peoples (Robson and Harris 2007). The provision of supportive care for Māori affected by cancer should therefore be an integral part of the cancer service pathway.

It is likely that the disparities in Māori and non-Māori cancer incidence and mortality rates are partly due to differences in exposure to risk and protective factors for cancer. Barriers to accessing regular screening and to high-quality, timely treatments also contribute to poorer cancer outcomes for Māori (Robson and Harris 2007). Fear and cultural and religious belief systems can also lead to a low uptake of cancer screening and prevent or delay early detection of cancer among Māori (Hutt Valley and Wairarapa DHBs 2006).

This document does not provide ‘one-size fits all’ guidance. To ensure that the needs of Māori are met, supportive care services must be accessible, effective and culturally responsive.

Mainstream cancer services, including supportive care services, do not always support a whānau-based approach to cancer care, and some providers have indicated that such services sometimes fail to recognise the important role that whānau play in supporting Māori affected by cancer. Services are not always geared towards providing opportunities for whānau input and participation, facilitating whānau access to appropriate information, or providing whānau with adequate direction and support (Cormack et al 2005).

Te Whare Tapa Wha

The Te Whare Tapa Wha model, as developed by Dr Mason Durie (1994), is a holistic health model that compares health to the four walls of a house, which are all required to ensure strength and balance, each wall representing a distinct dimension: taha wairua (the spiritual side), taha hinengaro (thoughts and emotions), taha tinana (the physical side) and taha whānau (family). Effective support for Māori affected by cancer will involve equal consideration of all four aspects of the Te Whare Tapa Wha health model.

He Korowai Oranga

He Korowai Oranga: Māori Health Strategy (Minister of Health and Associate Minister of Health 2002) sets out a framework for responding to Māori health issues. The overall aim of the strategy is whānau ora: support that provides Māori whānau with the maximum health and wellbeing. Whānau ora seeks to achieve the following outcomes:

- Whānau experience physical, spiritual, mental and emotional good health and have control over their own destinies.
- Whānau members live longer and enjoy a better quality of life.
- Whānau members participate in te ao Māori and wider New Zealand society.

As a baseline, the whānau ora strategic framework outlined in *He Korowai Oranga: Māori Health Strategy* calls for:

- Māori involvement in health decision-making
- direct collaboration with whānau, hapū, iwi and Māori communities
- any service (not just Māori-specific services) to be effective in terms of meeting Māori health needs and reducing health disparities between Māori and non-Māori
- all sectors (not just the health sector) to address Māori health outcomes (Minister of Health and Associate Minister of Health 2002).

Whānau ora services designed to provide support services for Māori affected by cancer might take the form of:

- a ‘for Māori, by Māori’ service, such as the pilot Hunga Cancer Care Service provided by Te Kahui Hauora Trust in Rotorua (see Section 9, ‘Coordination of Support’, for further information)
- a service that integrates Māori expertise and advice with existing mainstream services
- a service like either of the two above that is established within a Māori setting, for example on a marae or tūrangawaewae.

Other Māori-specific services may also incorporate traditional healing practices, such as mirimiri and rongoā as part of an overall cancer service.

Areas for action provided in this guidance should be considered in the context of *He Korowai Oranga: Māori Health Strategy* to improve health outcomes for Māori in relation to cancer.

1.8.2 Responsiveness to the support needs of Pacific peoples

Like Māori, Pacific peoples have a higher cancer incidence and mortality rate than the general population (Ministry of Health and Ministry of Pacific Affairs 2004). Rates are even higher for certain cancers. Socioeconomic determinants play a role in these inequalities through the distribution of risk and protective factors, as well as the failure of the current health system to address Pacific peoples’ health needs.

The diversity of the Pacific population is enormous. There are over 22 Pacific communities in New Zealand, which encompass Pacific Island-born, New Zealand-born and multi-ethnic subgroups (Ministry of Health 2008). Although this diversity is to be celebrated, it offers challenges to the

delivery of services that are accessible, effective and culturally responsive. However, there are also commonalities across Pacific groups, including:

- Christianity
- a shared mythology
- communal land ownership
- a genealogically based identity
- a belief in the accountability of the extended family
- a belief that wellbeing and illness are linked to obligations to extended family being met (Tiatia and Foliaki 2005).

This guidance acknowledges the diversity of Pacific communities in New Zealand when developing and delivering supportive care services.

Pacific views, beliefs, values and practices

Pacific beliefs about health and illness generally differ from those of mainstream New Zealand culture. Pacific peoples share two fundamental beliefs pertaining to health: a holistic notion of health, and a view of health as a family concern rather than an individual matter. Many Pacific peoples' sense of health and wellbeing relates to the quality of their relationships with their families, extended families and community networks, such as that of the church (Counties Manukau DHB 2006). In particular, churches play a key role in empowering communities to improve their health (Ministry of Health 2008). Cultural and religious beliefs may act to deter Pacific peoples from accessing cancer screening services, resulting in delays in diagnosis and treatment (Hutt Valley and Wairarapa DHBs 2006). It is important that cancer support services are delivered in culturally appropriate, community-based settings.

This guidance acknowledges that culture plays an integral role in Pacific peoples' ability to access quality health services. Providing services in appropriate settings, involving Pacific communities in the development and delivery of services and taking multiple approaches will enhance Pacific peoples' experience of supportive care services for cancer (Ministry of Health 2008).

1.8.3 Consumer involvement in developing cancer services

Prior to the release of *The New Zealand Cancer Control Strategy*, the voice of consumers had not been actively sought in assessing, guiding and formulating the requirements for support and rehabilitation services. The strategy and its companion *Action Plan* endeavoured to change this through Goal 5, objective 3, which aimed 'to ensure active involvement of consumer representatives across the spectrum of cancer control services'. The development of regional cancer networks has since provided a formal conduit for active and culturally representative consumer involvement in decision-making with regards to developing cancer support services that are responsive to people with cancer, their family's and whānau's needs. The networks facilitate and support consumer participation in the planning, development and evaluation of cancer support services and resources. The development of this guidance document was overseen by an EAG that included consumer representation.

1.9 Principles underpinning this guidance

The principles underlying this guidance reflect those of *The New Zealand Cancer Control Strategy* in that it aims to:

- work within the framework of the Treaty of Waitangi to address issues for Māori
- reduce health inequalities
- ensure timely and equitable access for all New Zealanders to a comprehensive range of health and disability support services, regardless of a consumer's ability to pay
- be of a high quality
- be sustainable
- reflect a person-centred approach
- actively involve consumers and communities
- recognise and respect cultural diversity
- take a planned, co-ordinated and integrated approach.

Further to the cancer control strategic principles, the following aims specific to this guidance apply:

- that high-quality care and effective services are available from both government and NGOs, regardless of a person's ethnicity, culture, place of residence or geographic area
- that services are co-ordinated and integrated across providers
- that consumers can access services and make informed choices about those services
- that consumers are involved in planning, delivering and evaluating services
- that services are configured to promote access for groups facing inequalities in cancer outcomes
- that CAM and traditional therapies are acknowledged
- that consumers are better able to look after themselves, with the support of their families and whānau, and in partnership with health professionals and community resources.

1.10 Evidenced-based approach

Providing an evidenced-based source of advice that is specific to the planning and delivery of supportive care has underpinned the development of this guidance document. In considering the evidence, this guidance has sought to identify best-practice service approaches for the planning, development and delivery of supportive care for those affected by cancer.

The evidence for this guidance has largely come from government reports, strategies and action plans, and published journal articles. Historical knowledge and professional experience have also been drawn on, particularly in those sections specific to cultural and spiritual models of supportive care. This guidance also draws substantively from the NICE manual, *Guidance on Cancer Services*, and its companion research evidence (NICE 2004a, 2004b).

1.11 Topic areas

This guidance document provides evidence-based best practice advice on the following components of supportive care:

- information resources
- interpersonal communication
- psychological support
- social support
- CAM
- support for living long-term with cancer
- spiritual support
- co-ordination of care and support.

Each of the above topic areas is presented separately in the following guidance for the sake of clarity. However, in practice these components often overlap.

Each section within this document consists of:

- an introduction
- a definition of the service component
- a set of specific objectives
- a context and rationale that incorporates evidence-based, best-practice service models
- suggested enhancements to the current service provision.

General areas for action are also included at the end of each section. A summary of all the areas for action included in the guidance document is provided in Appendix 2 of this report. Appendix 3 of this guidance provides a list of tools to support implementation, while Appendix 4 provides a glossary of key words and concepts used throughout the document.

Figure 1: Implementing the Guidance Flow Diagram

Next steps for developing an implementation plan for the Supportive Care Guidance

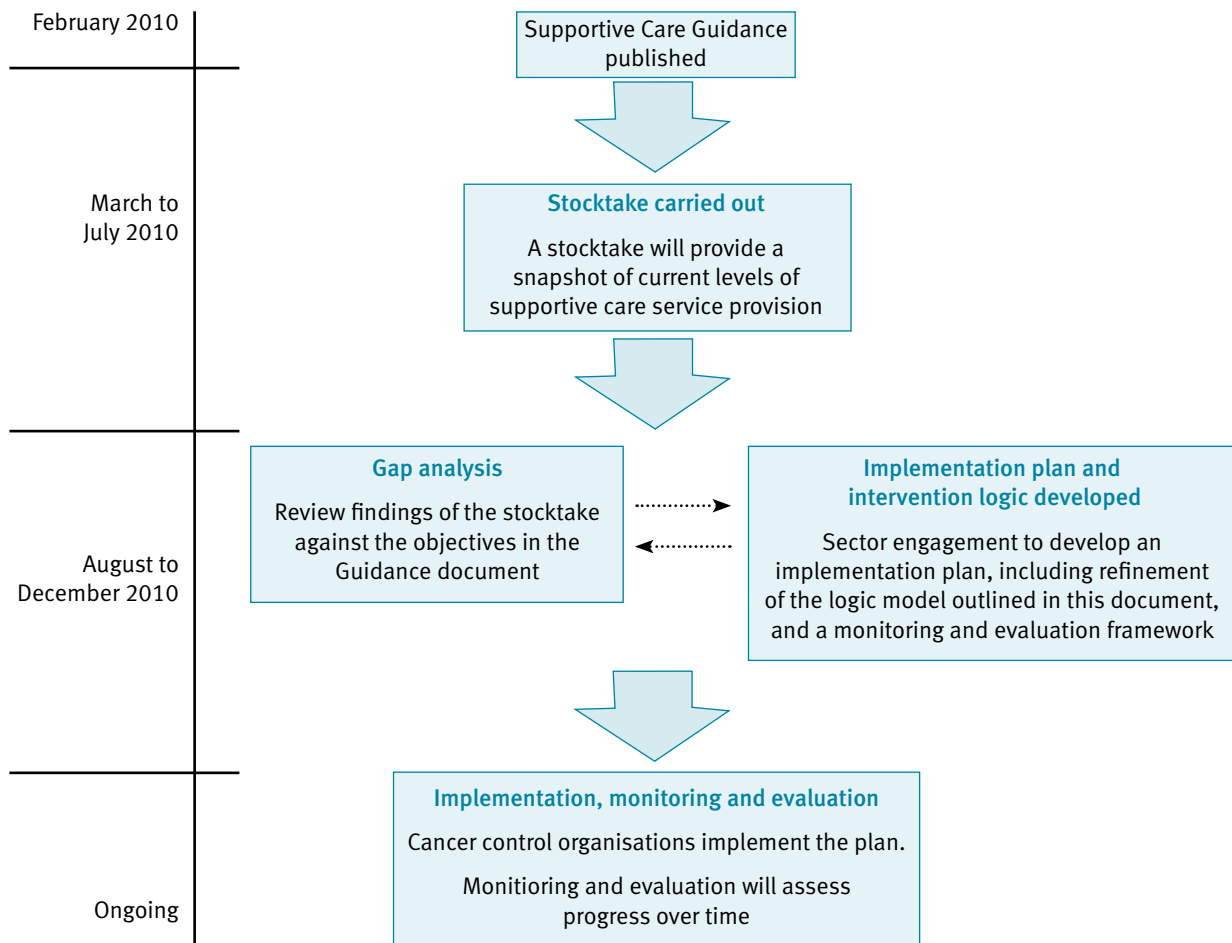
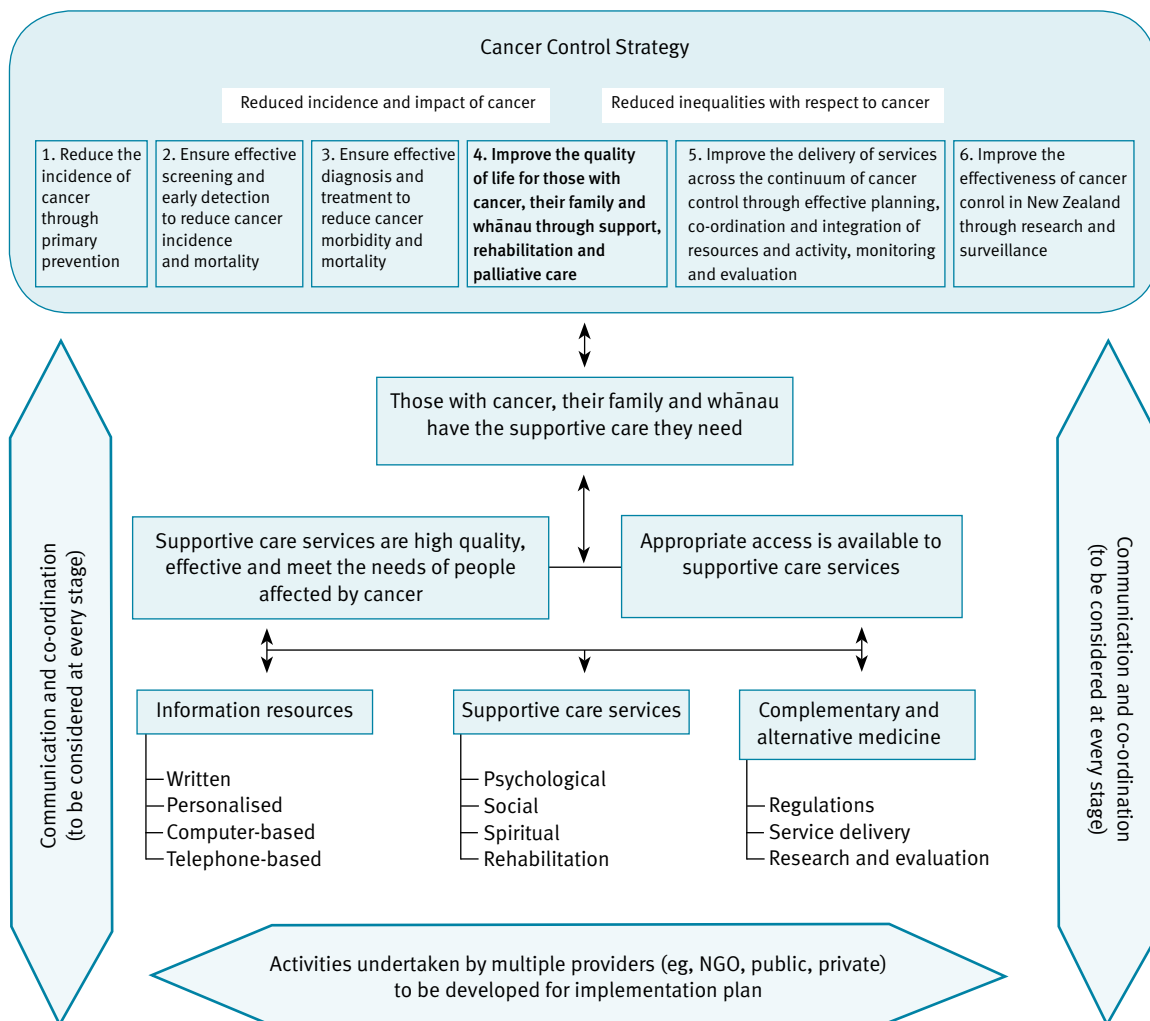


Figure 2: Supportive Care Logic Model

Strategic level intervention logic diagram for Supportive Care in New Zealand



1.12 Research and evaluation

Future research should focus on further improving the quality of support provided to those affected by cancer. Funding of longitudinal studies of people with cancer and their carers' experiences and expectations with regards to their ongoing care and support will be necessary. Specific research and evaluation recommendations are included in some of the sections in this guidance.

2 Information Support

2.1 Introduction

The information needs of people affected by cancer vary over time. In the initial stages following diagnosis, there is a preference for practical information to support their treatment and care-related decisions, information specific to the type of cancer they have, information on the treatment options open to them and information as to the likely outcomes of those treatments. In the latter part of a person's cancer journey, when their focus turns to their long-term prognosis, additional and more comprehensive information will be required to support their ongoing self-care and rehabilitation. Information should be timely and disseminated in a way that does not overwhelm the recipients.

Coulter and Ellins (2006) suggest that people affected by cancer will need information that enables them to:

- understand what is wrong
- gain a realistic idea of their prognosis
- make the most of consultation
- understand the processes and likely outcomes of possible tests and treatments
- provide or assist with their own self-care
- learn about the services and other sources of help available to them
- help others to understand their condition and needs
- legitimise their help-seeking and concerns
- learn how to minimise the risk of further illness
- find additional supportive care information and self-help groups
- identify the best and most appropriate health care providers.

2.2 Definition

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 treatments, or support and rehabilitation options.

2.3 Objectives

1. All people affected by cancer have access to high-quality information resources when they need them, in a form that is evidenced-based, regularly updated, culturally sensitive and available in various formats and languages.
2. Cancer information resources are relevant to the needs of Māori, Pacific peoples and other ethnic groups resident in New Zealand.
3. Involvement of consumer representatives is actively sought for the design, development and evaluation of cancer information resources.

4. Health professionals familiarise themselves with the information resources available.
5. Health professionals ensure that those affected by cancer understand the information provided, or refer them on to suitably qualified service providers/advisors who can interpret the information for them where necessary.

2.4 Context and rationale

In New Zealand, biomedical, medical and surgical services and interventions cannot be supplied without the consent of the individual concerned. Consent must be given freely following the provision of information that has been tailored to the individual's level of understanding and cultural background. It is vital that people affected by cancer receive information that enables them to make informed decisions along the cancer continuum, ideally in a setting where they feel comfortable and able to ask questions on treatment options such as surgery, radiation and chemotherapy, and the risks and benefits associated with those options, and on complementary and alternative therapies.

Evidence suggests that many people want more information than they currently receive, and health professionals tend to overestimate the amount of information they provide. The NICE research review indicates that information is most effective when it is targeted to the individual (Gysels and Higginson 2004).

Currently many agencies are involved in the development of cancer information resources, including the Ministry of Health, the CSNZ, DHBs and individual service providers. As a result, there is considerable potential for duplication, quality inconsistency and information gaps.

2.4.1 Written information

Evidence suggests that written information, used as an adjunct to professional consultation and advice, improves a person's knowledge and health outcomes (Coulter 1998). In this country leaflets and booklets are one of the more common forms of written cancer information available. The recently completed CSNZ stocktake and review of cancer information resources found very few cancer resources specifically targeted to Māori, other minority cultural groups and people with disability impairments (CSNZ 2006b). One of the cancer pathway implementation project studies found the limited written information available to Māori and Pacific peoples tended to be wordy, with minimal or no visual content (Hutt Valley and Wairarapa DHBs 2006).

A 1993 Ministry of Health report suggested that to effectively reach a Māori audience, health-related information should be conveyed in a manner that is both familiar and acceptable (Ropiha 1993).

The CSNZ review of written resources also found little evidence of consumer involvement in the development and review of resources, despite many of the resources giving an impression of supporting informed decision-making and consumer empowerment (CSNZ 2006b).

2.4.2 Personalised information

Personalised booklets are a particularly effective way of telling readers 'something new' and are more likely to be shared with confidants (Jones et al 2006). Audio and video cassettes, DVDs and CD-ROMs containing recordings or summaries of consultations and patient care records can also be helpful. These personalised forms of information foster improved patient outcomes in terms of enhancing a person's knowledge and recall, symptom management, level of satisfaction, preferences and use of health care services (Gysels and Higginson 2004).

2.4.3 Computer-based information

People affected by cancer increasingly use the internet to find information (Ziebland et al 2004). However, the quality of information on internet sites with regard to health generally and cancer specifically is highly variable (Eysenbach 2003; Ziebland et al 2004). Although the internet can be a convenient way for a person to access cancer information, evidence suggests it can also be a source of confusion for both people with cancer and health professionals (National Breast Cancer Centre and National Cancer Control Initiative 2003). The Ministry of Health and CSNZ websites provide access to nationally available, computer-based cancer information resources. Their websites also provide links to approved international cancer websites.

2.4.4 Telephone-based information

Telephone helplines, such as that provided by the CSNZ, are another useful information source, particularly for people with cancer who live in geographically isolated areas or who have limited or no access to transport.

2.4.5 CAM information sources

The CSNZ's 2006 stocktake and review of cancer information resources found very few resources available from CAM service providers. This was considered a major gap requiring remedial action. Evidence suggests most people learn about CAM cancer information from sources other than their doctor (Kronenberg et al 2005; McHughes and Timmerman 2005). The main sources of CAM information in New Zealand are printed resources, presumably provided by CAM service providers, and information downloaded from the internet (MACCAH 2004).

The information on most CAM websites does not comply with recognised quality standards (Molassiotis et al 2005; Wallji et al 2005). While a few CAM therapies are supported by solid evidence (for example, aromatherapy and massage), most are not (Ernst et al 2007). Some potentially interact antagonistically with conventional cancer treatments, such as chemotherapy. It is essential that health professionals are able to discuss CAM with their patients in a knowledgeable and objective way and provide informed advice when necessary.

2.5 Best-practice service components

2.5.1 Consumer information principles

The following consumer information principles were developed by the advisory committee that informed the CSNZ review and stocktake of cancer information resources.

- Health information has a critical role in reducing cancer inequalities.
- Health information has an important role in health literacy, informed decision-making and empowerment.
- Cancer information must meet the needs of diverse audiences.
- Consumers and service providers should be involved at all stages of the resource development process.
- Cancer information must be easy to follow, be written in everyday language and take account of the culture and literacy levels of the intended audience.

- Health information must be accurate, unbiased, balanced and based on the best available evidence.
- Health information must be regularly reviewed, validated and updated.
- Health information should be free and accessible to all (CSNZ 2006b).

It is important to ensure that people with cancer, their families and whānau have access to high-quality information when they need it. Information in a variety of formats should be:

- developed in different languages and tailored to different ethnic groups, including Māori, Pacific peoples and Asian groups
- designed and developed with input from service providers and consumer representatives, including Māori and Pacific providers and consumers
- distributed to appropriate locations where people with cancer and their family and their whānau can readily access it
- delivered free at all points of access.

2.5.2 Resource design and development process

Anecdotal reports indicate that current processes for developing resources at a national level could be improved. Any replacement process must ensure that a need for the resource has been established; that relevant technical expertise, information service providers, cultural advisors and consumer representatives are involved in the design and development process; that the information presented is evidence-based; and that the overall design and development process is guided by the cancer information principles. Evaluation should be part of the development process. All information resources should be regularly reviewed to maintain currency.

On the basis of the CSNZ's review of cancer information resources, it developed a tool for testing the quality of cancer information resources, against which it evaluated current cancer support resources. It has since established a web-based directory of the evaluated cancer information resources that should be promoted to service providers, appropriately funded and regularly updated. There is a need to establish a national 'clearing house' for reviewing, disseminating and evaluating cancer information resources.

The Ministry of Health, in collaboration with cancer NGOs, regional cancer networks and other relevant agencies, should oversee the commissioning, design, quality assurance and compilation of a comprehensive range of high-quality information materials for people affected by cancer, their families and whānau.

Information service providers should also carry out needs assessments to ensure that suitable information resources about cancer are available for people with hearing, eyesight and other sensory and learning impairments.

To ensure that cancer resources are developed to appropriate quality standards, the Ministry of Health recommends that information providers planning to develop additional cancer resources refer to its 2002 *National Guideline for Health Education Resource Development in New Zealand*, which is available online from the Ministry of Health's website (<http://www.moh.govt.nz>).

Regional social support service directories should be developed for health and social support professionals who advise people with cancer and their carers. The directories should be circulated to all relevant services and agencies, including local libraries and citizens' advice bureaus. The directories could also be posted on DHB, CSNZ and other relevant websites (see <http://www.macmillan.org.uk> for a useful support service website model).

2.5.3 Information dissemination

Cancer NGOs, DHBs and health professionals caring for those affected by cancer need to be able to provide high-quality cancer information resources to those who need them. Resources need to be readily accessible in locations where people with cancer, their families and whānau are most likely to go, such as primary health care services, including Māori whānau ora and Pacific primary health care services, hospitals, cancer-specific NGOs and hospices.

Policies should be developed at the DHB and cancer regional network level to ensure that information is provided in a timely manner that is disease-specific; and that it accords with the person's own cancer service pathway.

Those newly diagnosed with cancer should be provided with a comprehensive resource pack that is timely, pertinent to the type of cancer they have, in an appropriate format and readily comprehensible in terms of language and cultural affiliation. The pack could be supplemented with additional information that helps put the person's own individual experience into context, and refers them to other available support service providers, such as Māori whānau ora services in the case of Māori, Pacific community health services for Pacific peoples and the CSNZ for people with cancer in general. The resource pack might also include a list of recommended cancer-specific websites, including CAM websites. Additional information may be needed for each person over time.

2.5.4 Information delivery

Service providers should ensure that people affected by cancer have ready access to a wide range of high-quality information resources, including leaflets, booklets, audio cassettes, CD-ROMS and DVDs. The resources should be culturally relevant to Māori and other predominant local cultural communities, and to people of different age groups, disability impairments and stages of disease.

Areas should be specifically set aside for displaying information, or dedicated information display shelving should be immediately visible in settings such as primary health care, acute hospital, specialist oncology and regional cancer treatment centres, and in service settings specific to Māori, Pacific peoples and other cultures. Processes should be established to ensure that all information outlets are regularly restocked, and that information is updated as new resources come to hand.

The format, level and type of information required by people with cancer and their family and whānau will vary. Some people actively seek information; others do not. Those who do not articulate their information needs may appear disinterested, but this is rarely the case. Clinicians and service providers should be wary of making assumptions about their patients' information needs. It is imperative that the person's carers and family and whānau are kept informed too. Some people may wish to entrust all the decision-making regarding their treatment and support to their carers or family and whānau members.

Those affected by cancer require information to enable them to make fully informed decisions regarding the treatment and support options open to them. Their information needs and preferences need to be assessed at regular intervals along the cancer service pathway.

Clinicians and other service providers must ensure that when information and advice are being presented, it is in a conducive and private setting, with appropriate support available to help people cope with the emotional impact of the information. Professionals need to make people with cancer and their carers aware of the various support options open to them. These include the cancer helpline, 0800 CANCER (226 237), which is a CSNZ information line managed by experienced oncology nurses with counselling experience; the CSNZ's face-to-face liaison nursing

service; Māori kaupapa and Pacific community health services; and a variety of supportive care education and information groups. Written contact details should be provided where possible.

Given that a sizable proportion of people with cancer use the internet to access information about cancer, health professionals and service providers should familiarise themselves with the best quality cancer information websites, such as those listed on the Ministry of Health's and CSNZ's websites. This will enable them to offer appropriate guidance.

Service providers should maintain a database of approved translators to support the information needs of those people with cancer and their carers for whom English is not a preferred language.

There is a need for service provider organisations and regional cancer networks to collaborate to determine the adequacy of local service cancer information and to ensure it is reviewed regularly.

2.5.5 Workforce development

Cancer service providers should familiarise themselves with the range of information resources available from which they can provide timely, relevant, culturally specific information to people with cancer and their families and whānau. The information should be discussed with the person and their carers in an environment that encourages questions and comments. Health professionals and community workers who are new to cancer services will require information resource training.

2.6 Areas for action

General

1. Ensure people affected by cancer have ready access to a wide range of high-quality resources.
2. Ensure consumer cancer information is culturally appropriate.
3. Ensure consumer representatives are involved throughout the design, development and evaluation phases of information resource production.

Service delivery

4. Ensure staff are familiar with the available consumer cancer information.
5. Establish a national information resource clearing house.

3 Interpersonal Communication

3.1 Introduction

The decision-making process that follows a diagnosis of cancer requires people affected by cancer to absorb a considerable amount of highly technical medical terminology in circumstances where most will be feeling anxious and distressed. It is therefore essential that the health professionals communicating the diagnosis and the treatment and ongoing support options do so effectively and empathetically in a manner that best promotes the person's understanding and comprehension and encourages them to ask questions and generally participate in the decision-making process.

There is a close relationship between effective patient–health professional communication and improved health outcomes for people affected by cancer (Gysels and Higginson 2004). Effective communication between health professionals and people affected by cancer requires a patient-centred communication approach. Health professionals should:

- obtain, understand and verify the perspective of those affected (that is, their concerns, feelings and expectations)
- understand them within the context of their own personal, socio-cultural and socioeconomic circumstances
- reach a shared understanding about the person's particular cancer problem, its treatment and the support required
- empower the person by offering them meaningful involvement in choices relating to their health
- build quality patient–health professional relationships based on mutual trust, respect and commitment.

3.2 Definition

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 (NICE 2004a).

3.3 Objectives

1. Those affected by cancer are enabled throughout the patient pathway to discuss issues and ask questions concerning their cancer, its proposed treatment and potential impacts with knowledgeable professionals who are skilled communicators.
2. Health and social care professionals listen and respond to people in a manner that enables informed decision-making in an atmosphere of genuine collaboration.
3. Emotional distress and anxiety are reduced through the use of effective communication.
4. Health professionals actively seek cultural advisor support where appropriate when communicating with Māori cancer patients and their whānau and those affected by cancer from other cultural groups.

3.4 Context and rationale

Evidence suggests that most people with cancer prefer a consumer-centred communication approach when receiving information immediately following diagnosis, especially when the prognosis is poor. Nowadays, few people favour the traditional, authoritative, doctor-centred communication approach (Dowsett et al 2000).

Most people are reportedly satisfied with the services provided by their clinicians and other health professionals throughout their treatment for cancer. Where there is dissatisfaction, it is largely the result of communication failure on the health professional's part as opposed to dissatisfaction with the actual care provided.

People's preferences for involvement in decision-making, especially decisions related to treatment options, differ. Some actively seek highly detailed and complex information. Some require only what will enable them to make the decisions required. Others may make little or no effort to elicit information over and above that required for informed consent purposes. However, generally, most want as much information as they can get (Jones et al 2006). Information needs assessments should be routinely and regularly carried out throughout the patient pathway, irrespective of whether the person appears interested or disinterested.

People with cancer face many practical, emotional and psychological demands in addition to those of their physical treatment. The evidence suggests that psychological needs are significantly and frequently not met (Epstein and Street 2007). A 2006 report suggests that a high level of fear of cancer, and of hospitalisation generally, is a major barrier to Māori and Pacific people seeking information (CSNZ and NZGG 2006). Good communication that enables the person with cancer and their family and whānau to access the information and treatment they need can alleviate fear and distress.

3.4.1 Clinician–patient communication

Effective communication between people with cancer and their clinicians positively influences a person's rate of recovery, pain management and control, adherence to treatment regimes and psychological wellbeing (Fellowes et al 2004). Poorly communicated information may lead people to feel anxious, uncertain and dissatisfied, and to decline commencing or continuing their treatment or care. People affected by cancer appreciate health and social service professional providers who can engage with them on a one-to-one level, clearly communicate what they want to know, listen carefully, encourage questions and generally convey a caring and sympathetic attitude (NICE 2004a).

Face-to-face (kanohi-ki-te-kanohi) communication, as opposed to written information, is of particular importance to Māori and Pacific people (Hutt Valley and Wairarapa DHBs 2006). The information provider or messenger is equally – if not more – important than the actual message when presenting information to Māori (Ropiha 1993).

Ministry of Health-commissioned patient pathway study projects strongly support actions that aim to improve the quality of interpersonal communication between people with cancer and cancer service providers, particularly where Māori and Pacific people are concerned. Strong interpersonal communication between clinicians and people with cancer and their family and whānau in cancer service settings is central to improving Māori and Pacific peoples' access to and engagement with these services. Ineffective communication between clinicians and those affected by cancer has been linked to a lack of job satisfaction and emotional burnout among health professionals (Fellowes et al 2004).

3.4.2 Communication skills training

Communicating information about a life-threatening disease requires a particular skill on a health professional's part. In some countries mandatory communication modules are a prerequisite for postgraduate training programmes for health care professionals working with people with cancer. These vary in intensity and length, ranging from 2 to 15 days (Fellowes et al 2004). One-off training programmes and workshops are also an option.

A Cochrane review of communication skill development programmes for health care professionals working with people affected by life-threatening diseases, such as cancer, shows that the demand for these types of programmes has increased in line with the advancement of the idea that communication skills can be learnt and maintained. The evidence also suggests that more labour-intensive communication training programmes are effective in improving attitudes and communication behaviour among trained health care professionals, particularly those working at more senior levels.

Such programmes focus largely on the communication that occurs between clinicians and patients during formal assessment procedures. The programmes vary in terms of content and design, but in general:

- are learner-centred
- are provided in a 'safe' learning environment that enables participants to develop and practise skills
- involve face-to-face training led by trained facilitators who are conversant with the clinical cancer setting
- cover the cognitive, behavioural and emotional aspects of communication, with a focus on the acquisition of skills and strategies for dealing with specific situations
- use learning techniques such as role playing with 'simulated patients, group work and discussions'
- develop and practise skills, reflection and self-awareness
- assess measurable core competencies
- provide constructive feedback to participants.

3.4.3 Other communication improvement techniques

A range of techniques and methods has been developed to improve face-to-face communication between health care providers and patients that supports patient participation in decision-making (Gysels and Higginson 2004). (For further information, see the preceding section.) The following communication-enhancing techniques have proven beneficial for those working with people affected by cancer:

- written or taped recordings of consultations for people with cancer and their carers
- individualised patient education sessions
- use of decision aids for treatment options
- the provision of relevant information and opportunities to meet other health care professionals prior to significant consultations.

Comprehensive relationship building and communication skills training programmes that highlight culturally appropriate practices and procedures for frontline cancer service providers are essential for improving the experiences of Māori and Pacific people and their family and whānau coping with cancer.

3.5 Best-practice service components

3.5.1 Overview

It is important that clinical supervision is provided to health professionals involved in caring for people with cancer to help them explore emotions and reactions with their patients and to help avoid blocking techniques.

When seeking a person's informed consent, health care professionals should ensure that the person and their carers genuinely understand the nature, benefits and risks of the treatment options and procedures open to them. They should ensure that people with cancer and their carers have sufficient information to adequately inform their decision-making.

People affected by cancer's preferences regarding their treatment, support and rehabilitation options should be assessed on an ongoing basis. Preferences should be documented in the person's individual medical file and in the records of other providers.

Cultural support advisors, trained patient advocates and interpreters must be available within mainstream hospital-based cancer services to support Māori and Pacific peoples and their carers and those from other cultural groups whose first language is not English. Communication skills training programmes that include inter-cultural communication skills training should be available to all frontline staff working with people affected by cancer.

3.5.2 Service delivery

Understanding the particular cultural and spiritual sensitivities of various ethnic groups with regard to cancer treatment is essential. The use of appropriate communication techniques for Māori, such as waiata and karakia, should also be considered. In all patient consultations health professionals should allow time to discuss a person's particular cancer condition, its treatment and support options, and any related problems and issues.

Health care professionals need to be aware of their own personal limitations when communicating face to face with patients and their carers. In situations where there is a clear need for a more experienced person to deliver the necessary information, assistance should be sought without delay. Professionals conveying a diagnosis should do so in an honest, timely and culturally appropriate way and in the presence of a member of the nursing staff. The setting in which the diagnosis and associated information are delivered should be both comfortable and private.

The communication of significant or distressing news should always be delivered by a senior member of the interdisciplinary oncology team who has received training in advanced communication skills. In those situations where the consultant does not have the desired specialised skills, they should be supported by someone who is suitably skilled. People should have the time and opportunity to arrange for support people to be with them. Health professionals should seek the support of appropriate cultural advisors in communicating with Māori or Pacific peoples and their carers.

Key outcomes emerging during the course of significant consultations should be documented in patients' notes. Services to assist people who have hearing, sight or other impairments should be readily available.

3.6 Areas for action

General

6. Incorporate communication skills training, including inter-cultural communication skills, into all health professionals' training curricula and ongoing professional development training programmes.

Service delivery

7. Ensure that people with cancer and their carers understand the nature, benefits and risks of the treatment options and procedures open to them.
8. Ensure that cultural advisors, trained patient advocates and interpreters are available to Māori and other cultural groups.
9. Ensure that health professionals are sufficiently skilled and supported to effectively communicate with all those affected by cancer, including Māori, Pacific peoples and those from other ethnic minorities.

4 Psychological Support

4.1 Introduction

Emotional distress is common among people affected by cancer. It is an understandable and natural response to a life-threatening situation. People with cancer may be distressed at any stage, not just at the point of diagnosis, during treatment or when learning of a relapse. Most distress takes the form of a time-limited adjustment reaction, rather than a psychiatric or mental disorder. Most distress resolves on its own and in the context of routine clinical care (Coyne et al 2006).

Nonetheless, distress falls along a continuum, ranging from normal feelings of vulnerability, sadness and fear, to disabling anxiety, depression or other maladjustment symptoms, to that of significant clinical problems such as major depression or an anxiety disorder (Carlson and Bultz 2003). Other problems that can arise in people with cancer include psychosexual difficulties or disorders, neuropsychological syndromes, exacerbation of substance-related disorders, body image disturbance and the effects of chronic pain.

Although studies vary in their estimation of the rates of such problems, there is a modest consensus that up to a third of people living with cancer experience clinically significant and intrusive psychological distress or disturbance. This rate increases slightly for those who have a poorer expected outcome, greater disease burden or specific types of cancer (Zabora et al 2001). In general, the number of those presenting with mood and anxiety disorders will be higher than the number expected in the population without cancer.

4.2 Definitions

At the broadest level, psychological services involve those services concerned with attending to how people think, act, react and interact. Simply supportively talking with a person affected by cancer could fall under this umbrella. All staff directly responsible for clinical care can offer general emotional support based on skilled communication, effective provision of information, courtesy and respect. At the more advanced level, formal psychological assessments and interventions (including psychological therapies) are the more structured and evidence-based professional services provided by trained health practitioners with relevant qualifications and vocational scopes.

Psychologists and psychiatrists are the professionals appropriately consulted for more advanced psychological problems because they have training in causes and therapies for a range of emotional, health and psychiatric conditions and disorders presenting in people affected by cancer. However, in New Zealand a range of primary health care practitioners, including counsellors, are often the first port of call because psychologists and psychiatrists are in short supply.

Health professionals use a range of psychological assessment and treatment approaches. Documents such as evidence-based best practice guidelines for the *Identification of Common Mental Disorders and Management of Depression in Primary Care: An evidence-based best practice guideline* (NZGG 2008) provides careful appraisal of the available research evidence (see <http://www.nzgg.org.nz>). These guidelines advocate a stepped care approach to management options for depression in primary health care, from simple advice and monitoring to intensive multidisciplinary intervention.

4.3 Objectives

1. The mental health and wellbeing of people with cancer and their carers is considered at all stages of the cancer pathway.
2. Those affected by cancer have access to mental health services appropriate to their needs. Those experiencing significant distress or disturbance are referred to health practitioners with the requisite specialist skills.
3. The work-related mental health needs of staff caring for such people are acknowledged and managed.

4.4 Context and rationale

At any one time, 10 percent of people with cancer experience severe levels of psychological distress and are likely to benefit from specialised psychological or psychiatric intervention (NICE 2004a). The presence or severity of psychopathology in haematopoietic stem cell transplant recipients has been associated with poorer treatment compliance (Rodrigue et al 1999), poorer adjustment and increased impact of side effects (Molassiotis 1999).

As in non-cancer populations, psychological problems experienced by people with cancer is generally under-detected and under-treated. A number of social and structural factors are likely to be responsible for this, including stigma, failure of clinicians to ask about psychological problems and lack of services.

In managing psychological distress and associated mental health issues that do not reach the clinical threshold for diagnostic disorders, people with cancer may prefer to access support from those immediately providing cancer treatment and support rather than being referred to mental health professionals (Coyne et al 2006).

4.5 Best-practice service components

4.5.1 Overview

A range of mental health and psychological support and services should be available from a range of providers, such as PHOs, specialist mental health services (which should provide access to mental health practitioners such as clinical psychologists) and the voluntary and NGO sector. This last sector is an important part of the continuum of care through services such as telephone helplines (for example, Lifeline) and self-help and support groups.

All larger cancer centres must incorporate psychological services as part of their service provision. Local service directories on supportive care should include information on the range of available primary mental health services, community and NGO mental health and support services, specialist mental health services and psychological support services. Where psychological services exist, they should be set up in a way that is proven to improve outcomes for such people.

For the most part, psychological interventions offered to people with cancer should be the same as those that have proven successful in people without cancer. Empirically supported treatments should be the front line of interventions. These may include psychological treatments for mild to moderate anxiety/depression or a combination of psychological and pharmacological treatments for moderate to severe anxiety/depression. (Note that pharmacological treatments are not covered in this guidance but are discussed in *Identification of Common Mental Disorders and Management of Depression in Primary Care*).

One strategy in approaching the under-detection of mental health issues and/or psychological distress is routine screening for psychological distress and disturbance in people with cancer. A variety of short screening measures to facilitate this are often referred to in the cancer literature. However, such an approach has been found to be only modestly effective in detecting significant psychiatric or psychological disorders (Mitchell 2007). Routine screening of all people with cancer using common screening measures is likely to result in over-referral of ‘false positives’, while missing approximately 20 percent of true cases. Such screening instruments are slightly better at detecting clinical depression, but much less effective at screening for anxiety. In general, their ‘rule in’ ability is poorer than their ‘rule out’ ability. For these reasons they are only moderately helpful and should not be singularly relied on to triage referrals or prompt referral to mental health services. In short, a number of factors should influence referral and resource prioritisation.

People with cancer and carers who are found (or suspected) to have significant levels of psychological distress should be offered prompt referral to services able to provide specialist psychological or psychiatric assessment and treatment. There are specific circumstances when a formal psychological assessment should form part of treatment preparation decisions, for example, people being considered for haematopoietic stem cell transplant (Reznik et al 2006).

People who have completed active treatment should be informed about the range of psychological support services available and how to access them. Need for psychological support services can develop a considerable time after treatment has stopped. The usual mental health services should be available in and out of normal working hours, and for mental health problems both related and unrelated to cancer.

4.5.2 Service delivery

Services could be made available as part of an integrated cancer service, liaison teams attached to hospital services, PHOs or part of the mental health services. The first option is preferable and would enable the establishment of expertise and facilitate uniform national service provision.

Professionals offering different levels and types of mental health assessments and interventions should develop mechanisms to co-ordinate their service provision. A triage and tiered model of mental health service provision should be developed and implemented in each cancer centre (see *Identification of Common Mental Disorders and Management of Depression in Primary Care*, NZGG 2008). Such a model should offer outreach advice and support to smaller centres.

General support for emotional distress in people with cancer should be the responsibility of all staff working in cancer services. Such staff should be able to:

- communicate honestly and compassionately with those affected by cancer
- treat people with kindness, dignity and respect
- establish and maintain supportive relationships
- inform people and their carers about the wide range of emotional and support services available to them
- undertake preliminary enquiries or screening for significant problems where suspected
- make referrals to relevant health professionals at the next level.

At the next level, a range of health and social care practitioners could provide more specialised support and counselling, and, where necessary, screen for more serious mental health problems and make referrals. Finally, for those experiencing psychological distress or difficulties, assessment and treatment services should be delivered by specialist mental health professionals. Clear pathways to access such services should be presented.

It is essential that health and social care professionals empower and equip people to manage their own psychological needs. Support from friends, family or support groups can form an important component of self-management. Primary care and specialist physicians also have an important role in the psychological care of people with cancer and their carers. Pharmacological treatment may be an option (see NZGG 2008).

Appropriate facilities should be available for undertaking mental health/psychological assessments and interventions, reflecting the needs of people with cancer and their carers for privacy and comfort. Where people are unfit to travel, specialist psychological or psychiatric interventions should be provided through domiciliary visits. Subject to confidentiality and Privacy Act 1993 considerations, psychological services should have agreed processes for transferring information within their service and with other services, teams and practitioners. Findings from such assessments, proposed treatment plans and the outcomes of treatment should be available to those concerned.

4.5.3 Workforce development

Staff providing mental health, primary care and psychological services should be adequately trained, and should work within the scope and competencies of their respective disciplines (see, for example, the Health Practitioners Competence Assurance Act 2003). Presently there are insufficient numbers of registered health practitioners qualified to offer the more specialised forms of assessment and treatment required for those with significant psychological disturbance. Such staff should be actively recruited into cancer care. Course work and training in psycho-oncology for psychological health providers and the cancer workforce generally should be promoted and supported.

4.5.4 Research and development

High-quality evaluative research is urgently needed to determine the efficacy and effectiveness of psychological service provision for people with cancer. The development of psychological services should be accompanied by systematic evaluation to test the extent to which such services improve psychological outcomes for people with cancer.

4.6 Areas for action

Service delivery

10. Ensure that psychological support and services are available as part of an integrated cancer service.
11. Offer prompt referral for psychological assessment to people affected by cancer who have significant levels of psychological distress to determine the need for treatment and management.

Workforce development

12. Ensure that staff providing mental health services are qualified to do so, and work within the scope and competencies of their respective disciplines.

Research and evaluation

13. Determine the efficacy and effectiveness of psychological support for those affected by cancer.
14. Accompany the development of psychological services with systematic evaluation.

5 Social Support

5.1 Introduction

Diagnosis and treatment of cancer can seriously disrupt and impair people's lives. Many will need some form of support to help them cope with emotional, social and economic upheaval. People with cancer and their carers' social support needs should be routinely, regularly and systematically assessed. Information should be provided about the range of support service options open to them, and the means by which these services can be accessed. It is therefore essential to have health care professionals specifically charged with the responsibility of ensuring that social support needs assessments are carried out and addressed accordingly.

Some people affected by cancer may be reluctant to ask for help, preferring instead to remain independent. Some may find it difficult to articulate their concerns, or lack knowledge about the support services available or the skills to access them. Others may not even recognise their needs at all. Consequently health professionals need to thoughtfully and carefully assess and elicit people with cancer and their carers' thinking on their social support needs and ensure they get the information and support they require.

The term 'social support' encompasses a range of elements, including:

- practical assistance with domestic and home maintenance tasks
- assistance with personal hygiene or physical care
- support with the continuance and enhancement of social networks
- practical equipment aids (refer to Section 7, 'Support for Living Long-term with Cancer')
- residential support
- emotional support
- income and/or financial support
- employment and workplace support
- legal and welfare advocacy
- childcare support
- cultural support
- spiritual care (refer to Section 8, 'Spiritual Support')
- travel and accommodation assistance
- provision of information and resources (see Section 2, 'Information Support')
- home safety support
- provision of relief and respite support for the principal carers
- advocacy and liaison with the treatment team at the hospital
- family support
- support with relationship and communication issues
- support with adjustments to lifestyle changes.

5.2 Definition

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. Social support is largely focused on the home environment. In addition to the clinical team, support providers will include the person's immediate and wider family and whānau, friends and other social networks (such as the workplace) and external government and non-government agencies, for instance the CSNZ, Māori and Pacific health service providers and Work and Income New Zealand.

5.3 Objectives

1. The social support needs of those affected by cancer are routinely assessed and addressed by relevant health and social support agencies working collaboratively with people with cancer, their families and whānau and health professionals.
2. Timely and acceptable practical and financial support are available to those affected by cancer.
3. People with cancer and their carers experience an integrated and co-ordinated system of continued social support, overseen by trained health professionals, to ease the social consequences arising from their experience with cancer and enhance their quality of life.

5.4 Context and rationale

Historically, there has been a lack of strategic oversight in this country with regards to the provision of social support services for people affected by cancer. This has led to:

- an absence of regular comprehensive social support needs assessments for people affected by cancer
- variable interpretations of eligibility criteria for health and disability support within and across regions
- an absence of regionally consistent support service models
- fragmentation of support and rehabilitative services
- regional inconsistencies in the provision and availability of support services
- a lack of identification of national workforce and research requirements
- a lack of cancer-specific Māori and Pacific services
- poor access to support services for those living in geographically and rurally isolated areas.

The interface between hospital-based treatment and the myriad of community-based support services is complex. Support services pathways are difficult to navigate in the absence of any organised effort towards integration. Recent studies commissioned by the Ministry of Health into people's cancer journeys suggest this situation has been frustrating for cancer patients and their carers, who have largely had to negotiate their own way through support services (Noble et al 2006, Waitemata DHB Health Gain Team 2006, Hutt Valley and Wairarapa DHBs 2006).

5.4.1 Geographical access barriers to social support services

One of the cancer journey studies (Noble et al 2006) found people living with cancer in the geographically isolated West Coast of the South Island had particular difficulties in accessing the support they needed because:

- systematic needs assessments had not been carried out to determine their own and their carer's needs; nor did they receive any information about their support entitlements
- social support services, especially home care support and peer support groups, in rurally isolated areas are few and far between
- there is a lack of local after-hours care.

Financial anxiety was a relatively common feature among people with cancer, their families and whānau on the West Coast. Cancer inevitably has an impact on occupational, home and childcare commitments. The need to self-fund frequent long-distance travel was a sore point for many who did not qualify for travel and accommodation assistance. Slow processing of claims for reimbursement of travel costs for those who did qualify was also a concern.

5.4.2 Access barriers to social support services for Māori

Research shows that Māori are less likely to access support services. Suggested approaches to remedy this include:

- developing community-based outreach whānau ora cancer support services
- establishing 'patient navigators' to assist Māori cancer patients and their whānau through the cancer service pathway
- improving the cancer workforce's responsiveness to Māori affected by cancer within both mainstream and Māori-specific services (Cormack et al 2005; Hutt Valley and Wairarapa DHBs 2006).

5.4.3 Access barriers to income support

The economic impact of cancer can be considerable, largely due to the inability of the person experiencing cancer to work and the subsequent loss of employment income. This situation may be compounded when a partner has to stop work to become a full-time carer. While there is a range of financial support entitlements available from Work and Income New Zealand for those affected by long-term conditions such as cancer, these are often significantly less than their former employment income. Furthermore, people with cancer and their carers may be reluctant to ask for financial support because they feel embarrassed, wish to maintain their independence from the state-provided support system, or consider professional efforts to determine financial support needs to be intrusive. While acknowledging these concerns, it is important that those immediately affected by cancer are made aware of the financial support available.

5.4.4 Access entitlements to health and disability support

The Ministry of Health and DHBs fund a number of health and disability support services that assist people with long-term conditions and their carers in their day-to-day lives. Although these services do not provide direct financial assistance, they can improve the quality of life of those with a chronic health condition and alleviate pressures faced by carers.

People with cancer and its associated long-term functional impairments and disabilities do not always meet the access criteria for Ministry of Health-funded disability support services or DHB-funded long-term support services. Funding is currently allocated to an interim pool, which provides funding for people under the age of 65 with chronic health conditions who are expected to have a high need for support services for six months or longer. People with cancer who meet these criteria could be eligible. Funded services include home-based support such as personal care and household management, carer support, equipment and modification services, and residential care.

Anecdotal evidence suggests that many people who receive treatment within private hospitals do not realise that the availability of supportive care may be different in a privately funded hospital. It is important that these people are informed about the support services available to them (for example, CSNZ services).

5.4.5 Current actions under way to improve access to social support services

Recent and current projects under way that aim to improve access, quality and consistent delivery within supportive care services include:

- the establishment of the regional cancer networks
- the establishment of ‘patient navigator’ roles in some DHBs
- three community cancer support service pilots, funded by the Ministry of Health, to address barriers and access inequalities experienced by Māori and rural residents
- the development of *Guidance for Improving Supportive Care for Adults with Cancer in New Zealand*.

5.5 Best-practice service components

5.5.1 Overview

The body of research evidence concerning the role and effectiveness of social support provision for people affected by cancer is small. Of the more robust studies carried out, most have focused on support provision for people with cancer and their carers in palliative care settings (NICE 2004a). The few available studies that are specifically applicable to people living with cancer suggest the following.

- Assigning a ‘key worker’ (for instance, a social worker, a case manager or a patient navigator) as a point of contact between hospitals and community-based health and social care professionals has proven an effective way of transferring patients’ and their carers’ support needs information and ensuring that needs are met (NICE 2004a; Payne et al 2002). Positive improvements in people’s emotional wellbeing and quality of life are the result. Research here indicates this type of approach could be an effective way of improving overall access, quality and consistency within cancer care and support services (Waitemata DHB Health Gain Team 2006).
- Touch-screen computer-based support needs assessment systems have proven effective in providing people with breast cancer with information and access to social support (Gustafson et al 2001). This type of self-reported needs assessment tool is of particular value where service providers face time and staffing resource constraints.

5.5.2 Service delivery

The main components of a quality social support service model at the regional or local level vary, as do the needs of individual persons and their carers. However, ideally the essential components of high quality social support care are:

- systematic assessment of social support needs, including those of principal carers and other immediate family and whānau members
- development and maintenance of up-to-date local social service directories
- access to health professionals and community service providers who have up-to-date knowledge of local support services and are able to assist people with cancer and their carers to complete application forms for income support or other welfare assistance
- established integration between treatment and community support agencies and also between the various community services
- practical support in the domestic setting, including personal care
- provision of equipment and home modification support to help a person maintain an independent life (refer to Section 7, ‘Support for Living Long-term with Cancer’)
- support in maintaining employment status
- day care and other respite care support
- psychosocial counselling and peer group support (refer to Section 4, ‘Psychological Support’)
- culturally appropriate support in both hospital and community settings
- well co-ordinated care within an integrated system (refer to Section 9, ‘Co-ordination of Support’).

The establishment of patient navigators and case management models, the use of telemedicine (such as audio conferences between cancer specialists and local medical services), providing after-hours services and reviewing the process of travel reimbursement claims are all ways to improve the quality of cancer services in rurally isolated areas and improve access for people with cancer and their carers.

Hospitals and cancer treatment centres’ multidisciplinary teams should develop, establish and routinely use social support needs assessment tools and procedures for all people with cancer and their carers at each critical stage along the cancer service pathway. Assessment tools should cover personal care, social support relationships and networks, the domestic environment (for example, assistance required with housework chores), childcare, employment, transportation to and from cancer-related appointments, and income-related costs.

Hospital-based multidisciplinary teams should establish relationships with other internally based and external community-based support services (for example, primary health care providers, including Māori and Pacific support service providers, the CSNZ and Work and Income). Service providers should reach agreement on responsibilities for agency-specific assessments, referral procedures and information sharing.

Appropriately knowledgeable social workers or other assigned key health workers should be available to people affected by cancer to help them apply for financial support. Service providers should ensure that people are aware of the support services and financial support entitlements open to them, and have access to good quality information about these options. Information should be available in various culturally appropriate formats and in the preferred language of patients and their carers.

A stocktake of regional cancer support services, overseen by the Ministry of Health, DHBs and regional cancer networks, will be undertaken to identify existing resources, gaps in service provision and possible access inequalities. The stocktake should be used to inform an update of service directories for use by social support service providers, which could be posted on DHB, CSNZ and other relevant websites. Any activities of this nature should build on the Ministry of Health-commissioned 2006 national stocktake of psychosocial services (Surgenor et al 2006).

Regional cancer networks are currently best placed to promote the use of this guidance to all relevant cancer service providers and to assist, where practicable, in its implementation.

5.5.3 Workforce development

Cancer service support providers generally should ensure that staff are trained to undertake social needs assessments and are familiar with standard procedures in relation to carrying out specialist social support assessments and helping people access available support services. There may be a need to develop specific social support assessment schedules. The internationally validated InterRAI Suite used in palliative care has been suggested as one possible model. The Ministry of Health and DHBs are currently funding needs assessment and service co-ordination services (NASCs) to assess and co-ordinate support services for their patient groups.

DHBs and community social support providers should establish systems to assess the training needs of hospital and community-based professionals, including Māori and Pacific service providers, with regard to providing high-quality social support for people affected by cancer. They should also consider the training needs of unregulated support workers.

5.5.4 Research and evaluation

Further research and systematic evaluation of existing and new social support service initiatives, including those that seek to improve the co-ordination of social support services, is needed to determine effectiveness and possible areas for improvement.

5.6 Areas for action

General

15. Continue to improve equitable access to social support services.
16. Develop and disseminate regional social support service directories.

Service delivery

17. Develop and use social support needs assessment tools.
18. Build a seamless interface between hospital and community-based social support services.
19. Ensure people affected by cancer are able to access financial and social support entitlements.

Workforce development

20. Establish systems to assess the training needs of hospital and community-based service providers.

Research and evaluation

21. Determine the effectiveness of social support services for those affected by cancer.

6 Complementary and Alternative Medicine

6.1 Introduction

Evidence suggests that many cancer people with cancer use CAM in addition to the mainstream, biomedical treatments and modalities prescribed by their medical practitioners and physicians. While some seek advice from their doctors about whether CAM is appropriate in their case, many do not. Some CAM treatments are supported by relatively sound or at least encouraging evidence, although more research is needed (Ernst et al 2007). Anecdotally, mainstream health providers in general practice, hospital and hospice settings are increasingly incorporating CAM therapies into the range of services they offer to people with cancer. Given the current scale of CAM usage among cancer people with cancer and biomedical practitioners, it is essential that all parties concerned are fully informed about potential benefits and risks.

6.2 Definition

The definition of CAM adopted by MACCAH is:

Complementary and alternative medicine (CAM) is a broad domain of healing resources that encompasses all health systems, modalities and practices and their accompanying theories and beliefs, other than those intrinsic to the politically dominant health system of a particular society or culture in a given historical period. CAM includes all such practices and ideas self-defined by their users as preventing or treating illness or promoting health and wellbeing.

Apart from the few extreme alternative approaches that could be considered to replace and therefore contravene orthodox cancer treatments, the more commonly used CAM, such as massage or mirimiri (massage as practised by Māori) and other relaxation techniques (for example, aromatherapy and reflexology), by and large can complement orthodox cancer therapies when practised by suitably qualified practitioners. These techniques are generally aimed at improving people with cancer's quality of life rather than seeking to cure or treat cancer. Further definitions are provided in the box below.

Alternative medical systems involve complete systems of theories and practices that have evolved independently of biomedical systems. More commonly used examples in this country include rongoā Māori, Pacific traditional healing, Chinese herbal medicines, acupuncture, homoeopathy and naturopathy.

Mind/body/spirit interventions comprise techniques administered to facilitate healing, such as hypnotherapy, spiritual healing and Māori traditional healing approaches such as karakia and waiata.

Biological-based therapies involve naturally and biologically based practices, interventions and products, including dietary products such as Chinese herbal medicines.

Manipulative and body-based therapies involve manipulation and movement of body parts, for example chiropractic, osteopathy and massage (therapeutic and remedial).

Energy therapies, such as reiki, 'touch for health' and bioelectricmagnetic-based therapies, focus on energy fields emanating from the body (biofields) or other sources (electromagnetic fields).

Source: Based on a prototype developed by the National Center for Complementary and Alternative Medicine (www.nccam.nih.gov/)

6.3 Objectives

1. People affected by cancer are empowered to make their own decisions about complementary therapies and therapists through the provision of high-quality information.
2. Health professionals working with people affected by cancer have access to high-quality information about CAM.
3. Those involved in providing support for people affected by cancer, their families and whānau are informed about the benefits and risks of CAM.
4. Complementary therapies are provided safely by appropriately trained practitioners who are sufficiently knowledgeable about the clinical problems and psychosocial and spiritual issues with which a person can present.

6.4 Context and rationale

Currently there are no national prevalence data specific to CAM usage among people living with cancer in New Zealand. The most recent New Zealand national health survey showed that around a quarter (23.4 percent) of the survey population had visited a CAM health practitioner in the preceding 12-month period. A self-administered regional survey of 200 cancer patients attending one or other of two MidCentral region hospital oncology outpatients' clinics found that just on half (49 percent) had used some form of CAM modality (Chrystal et al 2003). People affected by cancer who use CAM therapies are more likely to be highly educated, female (Kronenberg et al 2005; Molassiotis et al 2005), of younger age (Begbie et al 1996; Chrystal et al 2003; Molassiotis et al 2005) and in receipt of multiple forms of cancer treatment (Kronenberg et al 2005).

Having a disability or a long-term chronic condition such as cancer is one of the most common reasons for visiting a CAM practitioner (Ministry of Health 2004). People affected by cancer use CAM because they believe it is non-toxic and holistic (NICE 2004a), may boost their immune systems, may help relieve pain and reduce the side effects of their cancer and cancer treatments and will help to improve their quality of life (Chrystal et al 2003; NICE 2004a).

The evidence base for CAM as a means of supportive care is actively researched. Some treatments are now supported by sound, or at least encouraging, evidence, but more research is undoubtedly required (Ernst et al 2007). In particular, music therapy, massage and hypnosis may have a positive effect on anxiety, and both acupuncture and massage have a therapeutic role in cancer fatigue. Acupuncture and selected botanical treatments may reduce chemotherapy-induced nausea and emesis, and hypnosis and guided imagery may be beneficial in anticipatory nausea and vomiting (refer to Section 7, 'Support for Living Long-term with Cancer', for information about other more conventional pharmaceutical approaches to relieving pain and nausea). Transcendental meditation and mindfulness-based stress reduction can play a role in the management of a depressed mood and feelings of anxiety (Mansky and Wallerstedt 2006).

In terms of safety, acupuncture is generally well tolerated. The most frequent side effects include minimal local bleeding or bruising and mild pain. Acupuncture, manipulative therapies and deep tissue massage are not advisable in people with thrombocytopenia, bleeding disorders or aplasia. Neither should osteopathy and chiropractic therapies using forceful manoeuvres be used to manage new pain, because such pain may be due to bone metastases. CAM mind–body therapies are generally considered safe as long as they are administered by properly trained and experienced practitioners. A number of botanical and dietary supplements have potential drug interactions and need to be used with caution (Mansky and Wallerstedt 2006).

The New Zealand Health Survey conducted in 2002/03 found that massage therapists, chiropractors, osteopaths, homoeopaths and naturopaths were the most commonly visited CAM practitioners (Ministry of Health 2004). Acupuncture, chiropractic and hypnosis therapies were the most frequently reported CAM therapies used by Wanganui general practice patients, and aromatherapy and rongoā Māori traditional therapies were among those lesser used (Taylor 2003). Other studies suggest that vitamins or megavitamins, faith and spiritual healing, relaxation techniques and alternative dietary regimes are also popular CAM choices among people with cancer (Begbie et al 1996; Chrystal et al 2003; Molassiotis et al 2005).

The NICE guidance manual and its companion evidence manual suggest that the attitudes of doctors, nurses and allied health professionals have shifted considerably over the past decade, from a position of some scepticism and antagonism to a willingness to coexist productively. The limited research available in New Zealand suggests this country's GPs play a relatively minor part in providing information about CAM to their patients and making referrals to CAM practitioners (Chrystal et al 2003; Ministry of Health 2004). However, one Wanganui-based study suggests that GPs may feel more inclined than they used to refer patients with cancer to CAM, with 92 percent of the 25 doctors surveyed having made such referrals (Taylor 2003).

CAM service provision is not formally integrated into New Zealand's state-funded health system. However, the Ministry of Health does fund some rongoā Māori services. People with a cancer diagnosis are eligible for subsidies from the Accident Compensation Corporation (ACC) in the case of injuries. In some situations Work and Income New Zealand will cover the cost of vitamins, dietary supplements, herbal remedies and minerals for those receiving a disability allowance (MACCAH 2004).

A high proportion of people with cancer do not inform their 'biomedical' practitioners about their use of CAM (Chrystal et al 2003; Taylor 2003). Reasons for not doing so include difficulties talking to their doctor, assumptions their doctor will not be interested, fear of disapproval or ridicule, and concern they may compromise their future care within the health service (Taylor 2003).

Investigations as to the prevalence of CAM usage by people affected by cancer internationally and here in New Zealand have been largely limited to descriptive, non-randomised regional or settings-based studies. Many studies have considerable methodological limitations, rendering their conclusions unreliable.

6.4.1 Legislation, regulations and standards governing CAM

In New Zealand there is no one specific legislative act regulating the training, practice and products of CAM practitioners. Statutory regulation and modality-specific self-regulation are the two main regulatory forms currently operating to protect health services consumers.

Like other Western countries, New Zealand has generally taken a risk-based approach to the statutory regulation of health practitioners (MACCAH 2004). With respect to CAM practitioners, only chiropractic and osteopathic practitioners are currently regulated under the Health Practitioners Competence Assurance (HPCA) Act 2003. Acupuncture and medical herbalism have been approved by the Minister of Health for statutory regulation, and will come under the HPCA Act within the next 12 to 18 months. These professions have been chosen because of the inherent risks of their particular modalities, which require more intensive training to ensure their safe practice. There are, however, a number of legislative provisions that indirectly govern CAM practices and products and serve to protect CAM consumers, including the Consumer Guarantees Act 1993; the Fair Trading Act 1986; the Food Act 1981; the New Zealand (Australia New Zealand Food Standards Code) Food Standards 2002 and the Disability Commissioner Act 1994 and associated Code of Health and Disability Consumers' Rights.

In addition to statutory regulation, biomedical practitioners are self-governed by the individual statutes of their own professional organisations, such as the Medical Council of New Zealand (MCNZ). Organisational bodies such as the MCNZ generally control their practitioners' training, registration and continuing professional development requirements, and their disciplinary regimes. CAM practitioners are similarly governed by the codes of their particular modality's professional bodies, although membership is largely voluntary. Some CAM practitioners (for example, homoeopaths and naturopaths) operate under the umbrella of the New Zealand Charter of Health Practitioners (MACCAH 2003).

A recent attempt by the Australian and New Zealand governments to establish a jointly regulated authority to control the quality of therapeutic products, including CAM products, was suspended by the New Zealand Government in 2007 because it lacked the numbers in Parliament to support the proposed legislation. Nevertheless, collaborative efforts between the two countries with regard to CAM are expected to continue.

The 1999 national standards of Māori traditional health developed by the Ministry of Health in consultation with the Ngā Ringa Whakahaere o te Iwi Māori (the national body of traditional Māori healers) outline the role of rongoā Māori in the health sector and specify standards for use by those developing and providing existing whare oranga services (Ministry of Health 1999b). The rongoā Māori development plan – Taonga Tuku Iho – has also recently been implemented under the auspices of the Ministry of Health.

There is a need to fully engage CAM agencies and practitioners in research and evaluation to examine and determine the efficacy and impact of the various CAM modalities, including rongoā Māori, and the effectiveness of CAM-related information resources for people affected by cancer (see Section 2, 'Information Support', for further detail about CAM education resources).

6.5 Best-practice components

6.5.1 Service delivery

Medical practitioners should consult the MCNZ's 2005 advice statement with regard to CAM (see subsection 6.4.1 above). This advice is based on the premise that every doctor requires some basic understanding of CAM therapies, irrespective of whether they intend using them or recommending their use to their patients (MCNZ 2005). It is generally acknowledged that issues relating to the training, qualifications and competence of biomedical and CAM practitioners should be addressed at the national level in the interest of patient safety.

It is imperative that health professionals caring for and supporting people affected by cancer know which CAM therapies they are using, given that some therapies and products are known to adversely affect conventional cancer treatments. To counter possible reluctance on a person's part to discuss CAM with their doctors, the MCNZ advises biomedical practitioners to ask their patients in a respectful way if they are currently using any particular CAM therapies and to be mindful that some CAM therapies are practised within a specific cultural context.

The benefits and risks of many of the more commonly used CAM therapies are outlined in the MACCAH advice to the Minister of Health (MACCAH 2004). This report should be used as a starting point for any future policy work with regard to CAM.

Service providers should ensure that people with cancer who express interest in using a CAM modality or product have access to a suitably qualified individual who can authoritatively and

objectively discuss their choices. They should also be able to provide the person with high-quality information resources. If the person indicates an interest in using the internet to access information about CAM, then the health practitioner should become conversant with those websites that are considered reliable.

People affected by cancer can access CAM services from a variety of sources, either from private CAM practitioners or from general medical practitioners who practise CAM therapies. The CSNZ also provides some complementary therapies, such as relaxation and massage services. It also provides a useful, user-friendly information sheet on its website, entitled *Complementary and Alternative Medicine* (CSNZ 2006a). The resource provides: information about commonly used CAM therapies, ways in which these differ from evidenced-based medical treatment, advice to those thinking of using CAM, a number of questions to consider when making CAM treatment-related decisions and references to reputable cancer-specific sites with regards to CAM.

An overarching CAM advisory group that included CAM service provider representation could usefully be established with a view to developing:

- policies to ensure safe CAM practice
- appropriate CAM therapy support service components within an integrative care context
- an infrastructure to promote robust CAM-specific research (for further information see MACCAH 2004).

6.5.2 Research and evaluation

Research and evaluation should be conducted to examine the usage, cost-effectiveness and safety of commonly used CAM therapies in cancer care, including acupuncture, osteopathy and rongoā Māori. It has been suggested the latter be examined across whānau, hapū and iwi boundaries and undertaken by researchers approved by all concerned parties.

Other research areas that could be covered include:

- perceptions, preferences and expectations relating to the use of CAM by people affected by cancer
- health professionals' knowledge of, and attitudes towards, CAM
- perceived benefits and risks of the various CAM modalities for people with cancer.

Evaluative research is also required to determine the best ways to provide consumers with information about CAM therapies.

6.6 Areas for action

General

22. Develop policy and service specifications to ensure the informed and safe delivery of CAM to people affected by cancer.
23. Provide access to high-quality CAM information within cancer services.

Research and evaluation

24. Evaluate the usage, cost-effectiveness and safety of some of the more common forms of CAM therapies used to support people affected by cancer, including acupuncture, osteopathy and rongoā Māori.

7 Support for Living Long-term with Cancer

7.1 Introduction

Advances in the early detection and treatment of cancer over recent decades have seen increasing numbers of people surviving cancer, and many cancers once considered fatal are now treatable. However, improved survival times have given rise to a variety of new challenges for those who either experience a long-term remission or survive cancer long-term.

Many of those affected by cancer require very little rehabilitative support after treatment and will largely pick up their lives from where they left off. Others, whose cancer treatment has resulted in physical impairment, may require short-term rehabilitative support to assist them in re-establishing their pre-cancer lifestyle. Where treatment has entailed amputation or removal of body parts, longer term support may be required. Whatever the scale of effects and impairments, the overall aim of post-treatment support is ‘to maximise dignity and reduce the extent to which the cancer interferes with an individual’s physical, psychosocial and economic functioning’ (NICE 2004a).

Post-treatment care and support requirements vary, and may require the services of a number of health and allied professionals and support workers. Some people may need:

- equipment and prostheses
- physiotherapy
- stoma and continence therapies
- lymphoedema therapy
- personal health care
- oral and dental health care
- dietary and nutritional support
- speech and language therapy
- psychological counselling (for example, dealing with effects on sexuality and sexual functioning)
- genetic counselling and support
- fertility counselling and support
- pharmaceutical support to manage ongoing nausea and pain
- occupational therapy
- support with workplace and employment issues
- support in adopting and maintaining behavioural lifestyle changes, such as improving nutrition, physical activity and quitting smoking
- support with household tasks
- family support (for example, respite care).

Many of these forms of support are provided outside hospitals. Consequently it is important that all frontline health professionals and other hospital-based support staff (such as Māori cultural advisors) who work in or with cancer treatment services:

- are aware of the benefits that post-treatment rehabilitative support can provide
- establish ongoing relationships with relevant rehabilitative support service providers

- assess and identify each person’s rehabilitative and ongoing surveillance needs in a formal ongoing support and care plan, prior to their discharge from treatment services
- make the necessary referrals for ongoing support and surveillance and ensure that the person affected by cancer and their carers know how to access relevant services.

7.2 Definitions

Rehabilitative support following the treatment of cancer attempts to maximise the ability of those who have been treated for cancer to function as normally and 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.

7.3 Objectives

1. All people living with cancer long-term have their continued care and support needs routinely assessed at each critical point throughout their cancer service pathway.
2. All people living with cancer long-term receive a planned approach to their continued care and support that includes needs assessment, goal setting, an ongoing care plan, regular evaluation and referral to appropriate specialist support and care services.
3. Continued care and support services are readily accessible, and provided in a timely and acceptable manner.
4. Health professionals and support workers working with people affected by cancer receive culturally appropriate education and training that enables them to assess the person’s continued care and support needs and to make appropriate referrals to specialist services.

7.4 Context and rationale

Recent evidence from the United States suggests that close to two-thirds of those newly diagnosed with cancer can expect to survive five or more years post-diagnosis (Demark-Wahnefried et al 2006). Research from the United States also suggests that some cancers, such as Hodgkin’s disease and acute childhood leukaemia, which at one time were considered fatal are now treatable and frequently curable. Survival rates in that country for some of the more common cancers have also improved (Ganz 2006; Oeffinger and McCabe 2006). A recent analysis of survivorship in New Zealand likewise shows considerable improvements in both short- and long-term survival rates for some of the more common cancer groups, namely colorectal, lung, breast and prostate cancer (New Zealand Health Information Service (NZHIS) 2007).

Following treatment, some people can face life-long health risks and challenges as a result of their cancer, exposure to cancer treatments, co-morbid health conditions, fertility and genetic issues and changes to lifestyle behaviours (Oeffinger and McCabe 2006). Others living with cancer may experience mobility, physical and psychological functioning limitations that seriously affect their daily lives, which in turn can compromise their wellbeing and feelings of self-worth (NICE 2004a).

In the United States most people return to work after completing their cancer treatment. However, close to 20 percent report limitations in their ability to work for between one and five years following treatment, while one in ten find themselves unable to work at all (Short and Vargo 2006).

There is increasing recognition in the United Kingdom that rehabilitative support services have an important part to play in improving the quality of people's lives following treatment for cancer (NICE 2004a). However, specialised rehabilitation services are reportedly few and far between and tend to be compartmentalised. The situation here in New Zealand appears to be similar. The Support and Rehabilitation Expert Working Group, in its report to the Cancer Control Steering Group (2003), reported:

- there was variable availability of access to rehabilitative support services and resources between and within regions
- access appeared to be largely dependent on the 'local knowledge' of some health professionals
- Māori and Pacific cancer patients were most likely to experience access difficulties to rehabilitative support services.

Currently there is no in-depth knowledge of what rehabilitative support services are available regionally for people with cancer, and whether they face any workforce issues. This situation suggests a need for a stocktake and service gap analyses at a regional level.

7.5 Best-practice service components

7.5.1 Service delivery

The short-term continued support needs of adults receiving treatment for cancer should be routinely assessed throughout the treatment period, and their long-term rehabilitative support requirements, together with their ongoing cancer monitoring needs, require explicit identification in what Earle (2006) has described as 'a survivorship care plan'.

Formal protocols and assessment tools are required to ensure that the continued care and support needs of people affected by cancer are regularly assessed through the treatment phase and at the point of discharge. These protocols should incorporate specifications for long-term follow-up by primary health care providers.

The duration of continuing surveillance following treatment for cancer varies. For instance, in the United States specialised care is largely limited to the first six months after discharge from treatment, unless specific guidelines state otherwise. Thereafter, primary health care providers generally become the key gatekeepers in terms of monitoring the health and wellbeing of long-term cancer survivors. Evidence suggests that formal transition from specialist cancer treatment services to primary health care services is infrequent (Oeffinger and McCabe 2006). In New Zealand, specialists often follow up for two years and beyond, although some GPs are now supervising patients within the first 6 to 12 months. Referral to primary care follow-up is generally in the form of a discharge letter from a specialist to a person's GP.

In recent years the 'shared care model' has increasingly become the standard for managing a person's ongoing care and support needs. This term refers to care shared between two or more clinicians working within different specialities or systems. Evidence suggests that the shared care model improves patient outcomes and enhances the management of chronic disease conditions such as diabetes. The 'cornerstone of shared care is communication and periodic transfer of information between physicians and primary health care practitioners' (Oeffinger and McCabe 2006). This approach is considered applicable to cancer given its potential for monitoring cancer-related morbidity, increasing the likelihood, for example, of the early detection of late effects of cancer treatment, which leads to more effective treatment.

The NICE (2004a) guidance for support for adults with cancer indicates that the need for continued care and support among some cancer groups has long been recognised (for instance, in the

treatment of head, neck and bone tumours). However, approaches are still evolving for those adults whose condition progressively deteriorates or for those who experience late effects following cancers that have required aggressive treatment interventions.

Prime ‘teachable moments’ are the time of diagnosis, during treatment and on discharge from cancer treatment services; at these stages health professionals can most effectively encourage cancer survivors to make long-term healthy lifestyle changes (Demark-Wahnefried et al 2006). Physicians are considered ‘among the most powerful catalysts’ for encouraging people to make healthy lifestyle behavioural changes. However, the evidence suggests that just 20 percent of oncologists make use of this motivational potential (Demark-Wahnefried et al 2006).

The Ministry of Health and DHBs, with the support of the regional cancer networks, will undertake a regional stocktake to identify available support services, gaps in service provision, service delivery and workforce issues and possible access inequalities.

7.5.2 Workforce development

Evidence suggests that providing training for frontline interdisciplinary oncology service professionals is an effective way of increasing recognition of the continued care and support needs of people affected by cancer (NICE 2004a).

Regional systems should be established to assess the training needs of cancer treatment support team members regarding the provision of continued care and support and the monitoring and surveillance of people following cancer treatments.

7.5.3 Research and evaluation

Continued care and support services and efforts to establish effective co-ordination of social support services should be accompanied by systematic evaluation.

7.6 Areas for action

General

25. Enable people affected by cancer to have greater control in looking after themselves.
26. Improve equitable access to continued care and support for people living long term with cancer.
27. Develop and distribute regional continued care and support directories.

Service delivery

28. Develop and use continued care and support assessment protocols and tools.
29. Ensure a seamless interface between hospital and community-based continued care and support services.

Workforce development

30. Establish systems to assess ongoing care and support training needs for hospital and community-based service providers.

Research and evaluation

31. Determine the efficacy and effectiveness of continued care and social support for people affected by cancer.

8 Spiritual Support

8.1 Introduction

Surviving the challenges following the diagnosis and treatment of cancer can take its toll on the spirit as well as the body. Many struggle during this time with unsettling existential, ‘meaning of life’ questions such as ‘Why me?’, ‘What have I done to deserve this?’ and ‘How will I cope?’ Questions of this nature tend to re-emerge or become more focused at certain points along the cancer pathway; for instance, when:

- cancer is first diagnosed
- new symptoms appear and/or there is a recurrence of cancer
- the side effects of a cancer treatment become particularly upsetting
- those affected have to adjust their lives to accommodate the physical changes brought on by their cancer condition
- changes affect their relationships with their significant others
- treatment for the cancer is no longer an option, or the person is deemed ‘palliative’.

It is natural for those grappling with the impact of cancer to look for guidance and strength to help them through their cancer pathway. Some may seek spiritual support by:

- drawing on their religious or philosophical beliefs
- reaffirming a faith they have let lapse
- reconnecting with family, friends and whānau
- participating in a religious or spiritual community
- embracing life with a reinvigorated purpose.

8.2 Definitions

Spirituality means different things to different people. For the purposes of this document, spirituality includes beliefs, values, a sense of meaning and purpose, identity and, for some people, religion (Egan 2007).

8.3 Objectives

1. Those affected by cancer are offered spiritual support, at any time they need it, to enable them to make sense of and cope with the difficulties cancer presents for them and their family and whānau, and to foster hope and promote wellbeing.
2. Health professionals are able to acknowledge the religious, spiritual and existential issues facing those coping with cancer in a flexible, non-judgemental, non-imposing and culturally safe manner and attend to those needs by making appropriate referrals.
3. Health professionals have respect for and understanding of the culturally unique spiritual needs of Māori coping with cancer and are suitably informed to make referrals to appropriate Māori service providers.

8.4 Context and rationale

The NICE (2004a) support and rehabilitation guidance manual suggests that the spiritual needs of people receiving treatment and care in cancer services are often not met. For instance:

- people have insufficient sources available to them upon which they can call when they need spiritual support, or may be unaware of the various options open to them
- health professionals may lack awareness of how to access professionals who provide spiritual support services, such as hospital chaplains or specialist counsellors
- there may be reluctance on health professionals' parts to call on these spiritual support services, or they may feel awkward talking about spiritual matters with their patients.

Evidence from the United States suggests that health professionals in that country receive little or no education about the possible relationship between religious/spiritual factors and health outcomes (Thoresen and Harris 2002). The situation is similar here in New Zealand. Some health professionals are reluctant to ask questions about a person's religion or spiritual views because they consider these matters a private concern. Others may feel uncomfortable, or consider they lack the competence to discuss spiritual matters (Dein 2006).

Nurses caring for people receiving treatment and support for cancer, given their close and regular proximity to patients, are often best placed to pick up on a person's spiritual needs and make referrals to hospital chaplains, counsellors, or other appropriate people (Gysels and Higginson 2004). However, all members of multidisciplinary teams caring for those affected by cancer should be able to respond to their patients' expressed spiritual needs.

Over the past 20 years research examining the relationship between religious and spiritual beliefs and health outcomes has increased dramatically. Some studies have found positive evidence in terms of risk of disease, survival times, coping with bereavement (NICE 2004a) and a reduction in all-cause mortality (Thoresen and Harris 2002). Thoresen and Harris' review suggests a need to strengthen future research methodologies and clarify conceptualisations of religious and spiritual factors.

A review undertaken by Ramondetta and Sills (2003) suggests that seriously ill people expect and appreciate their physicians asking them about spiritual issues as part of their medical assessments.

8.4.1 Culture and spirituality

Cultural traditions, ethnicity, family background, socioeconomic status and gender underpin and shape people's religious and spiritual values (Ramondetta and Sills 2003; Dein 2006). In this country the involvement of the wider whānau or fono throughout a person's cancer journey has been found to be a spiritually sustaining coping strategy for both Māori and Pacific peoples (Waitemata DHB Health Gain Team 2006). Spirituality is one of the four essential dimensions identified in the Te Whare Tapa Wha (four walls of the house) health model, as developed by Durie (1994).

Traditional medicine and healers play an important role in both Māori and Pacific cultures because their assessments and therapeutic practices encompass a highly valued spiritual dimension, and are delivered in a culturally appropriate manner (Durie 1994; Ministry of Health 2008).

8.5 Best-practice service components

8.5.1 Overview

All service providers should be aware of the spiritual needs of people coping with cancer and have the ability to handle those needs in a culturally sensitive way. The provision of religious or spiritual care for people affected by cancer should be an integral component of all cancer treatment and support services.

Health professionals working in cancer treatment and support services should:

- have access to and be familiar with their workplace's religious/spiritual assessment procedures
- have access to, and establish working relationships with, suitably qualified and recognised spiritual leaders and counsellors
- be familiar with, and know how and where to access, spiritual information resources
- be trained to have a basic understanding of the spiritual needs of people affected by cancer, including being aware of and sensitive to the relationship between culture, ethnicity and spiritual beliefs, especially those relating to Māori and Pacific peoples
- establish a meaningful and sustainable relationship with iwi and mana whenua in their locality to ensure that appropriate spiritual support and guidance are available to Māori cancer patients and their whānau
- develop memoranda of understanding and service agreements with regards to providing spiritual support services for Māori.

An assessment of spiritual requirements needs not be formally structured. Suitable questions can be included in general medical assessment instruments. The questions asked will vary to suit the person's culture, their 'stage of cancer' and other circumstances. At the broadest level, questioning should identify whether there is any particular person(s) a patient might want to speak to about spiritual matters.

It is desirable that the spiritual needs assessments of Māori patients and their whānau are conducted by culturally competent staff.

Systems should be established to ensure that those directly affected by cancer give their consent for information about their spiritual needs to be passed on to the hospital chaplaincy services or other appropriate services (for example, Māori and Pacific health services). Spiritual support should include the provision of suitably furnished 'spiritual enhancing' spaces in inpatient and day care facilities in which spiritual activities can be privately practised.

8.5.2 Workforce development

It is essential that all staff working in cancer treatment services have a basic understanding of the spiritual needs of people with cancer, possess the skills to assess those needs and know how to go about contacting spiritual caregivers when required. Training specific to the cultural and spiritual needs of Māori is essential.

8.6 Areas for action

General

32. Provide access to spiritual support services for people affected by cancer.

Service delivery

33. Ensure all staff are familiar with standard spiritual assessment arrangements and referral procedures.
34. Ensure the spiritual needs of Māori patients and their whānau are assessed by culturally competent staff.

Workforce development

35. Raise the professional awareness and competency of health professionals through training specific to the spiritual needs of people with cancer, their families and whānau.

9 Co-ordination of Support

9.1 Introduction

People affected by cancer may require supportive care at various points along the cancer service pathway. In this country these support services tend to be delivered by a range of government and non-government service providers, in multiple settings. The pathway is further complicated by the fact that many people affected by cancer have to travel considerable distances for lengthy periods of time, in order to access specialist services. As a consequence, many people – especially those who currently face inequalities in cancer outcomes – find the cancer service pathway difficult to navigate.

Providing a seamless progression of care and support for those affected by cancer requires:

- good communication between support service providers, the person affected by cancer and their carers
- a single point of contact, such as a specifically trained patient navigator, to support people to access the services they need
- linking Māori, Pacific and other cultural groups to culturally specific cancer support services
- a flexibility on the part of health care professionals in their responses to the changing needs of people with cancer and their carers
- establishing information transfer systems to ensure that relevant information follows the person within and between cancer services.

9.2 Definition

Care and support co-ordination 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.

A *key worker* is a health care provider who, with the consent of the person affected by cancer, takes a key role in co-ordinating their care, promoting continuity and ensuring that they and their carers know who to go to for information and advice (NICE 2004a).

9.3 Objectives

1. All people affected by cancer, their family and whānau have access to care and support services.
2. Service providers deliver timely and seamless support to those affected by cancer.
3. Services are of the highest possible quality and are appropriate to the needs of those affected by cancer, including their cultural needs.

9.4 Context and rationale

Co-ordination of cancer services has improved considerably over the last few years. A key driver of this has been the establishment of the regional cancer networks. The networks provide leadership in facilitating:

- improved co-ordination of care and support for cancer patient groups across geographic areas and between primary, secondary and tertiary providers
- collaboration within and across DHBs
- improved equity of access to cancer services
- reduced gaps and duplication of cancer services
- better co-ordination, planning and development of cancer care and support services.

Primary health care, as envisioned by the Primary Health Care Strategy (Minister of Health 2001), aims to provide integrated and co-ordinated service delivery and managed care and consequently has a key role in the delivery of supportive care for people with cancer in community settings.

The 2006 Ministry of Health-funded patient pathway studies identified a need to develop and implement specific inpatient and community-based cancer co-ordinating service models to improve continuity of care and support and information sharing among cancer service providers (Noble et al 2006; Waitemata DHB 2006; Waitemata DHB Health Gain Team 2006; Hutt Valley and Wairarapa DHBs 2006). The findings of these studies added weight to the recommendations of earlier research conducted by Cormack et al (2005), which called for the establishment of Māori kaupapa, community-based cancer support services. These services would have the potential to reduce some of the traditional barriers Māori have experienced with regard to accessing mainstream cancer services, which have resulted in significant and persistent cancer outcome inequalities between Māori and non-Māori.

The cancer journey mapping studies also identified a need to develop culturally specific cancer support services in appropriate settings for Pacific peoples who, like Māori, have poorer cancer health outcomes, high health needs and a 'vulnerability to disengaging from health services' (Waitemata DHB Health Gain Team 2006).

9.4.1 Cancer support service co-ordinating approaches

It is important that care co-ordination takes place at a systems level as well as at the individual level of the person affected by cancer. Several approaches are outlined below.

The clinical care co-ordination approach

This approach is driven by members of a multidisciplinary team within a clinical treatment service setting. It aims to co-ordinate the different aspects of cancer care by means of regular multidisciplinary meetings, clinical treatment and the provision of follow-up care, psychosocial patient and carer needs assessments, information provision, systematic referral practices, data collection and the development of common protocols. A person's GP is considered a member of the multidisciplinary team. Although care co-ordination does not tend to specifically support people and their families through the non-clinical aspects of the patient's cancer service pathway, the multidisciplinary team's social worker member may often take on some aspects of non-clinical support. This model of care is known to operate throughout this country in various forms.

The Ministry of Health is currently working with regional cancer networks to develop an optimal care co-ordination matrix and patient management frameworks for each of the major tumour streams, similar to those developed by the State Government of Victoria's Department of Human Services in Australia.

BreastScreen New Zealand

BreastScreen New Zealand is a clinically driven service model that supports and co-ordinates follow-up activities for women treated for breast cancer three to four years post-operatively. The support is driven by specialist nurses who provide people affected by cancer with information, educational advice and support, psychosocially and physically. These nurses are also involved in patient advocacy, meeting and liaising with the multidisciplinary team and managing the BreastScreen New Zealand database.

The patient navigator prototype

Patient navigation refers to individualised, non-clinical, but specifically trained assistance offered to people, their carers and families to help them overcome systemic health service barriers and facilitate timely access to quality medical and psychosocial care (Epstein and Street 2007). Cancer patient navigator programmes are now well established in some Canadian provinces, where the concept appears to have developed. In recent years the model has gathered momentum in some parts of the United States. Evaluation results from the Canadian-based patient navigator programmes show that patient navigators have successfully:

- improved the overall co-ordination, quality and consistency of care and support
- provided more timely referrals
- increased patient and carer awareness and use of community support services
- increased earlier referrals to cancer support services, including home and palliative care
- gained widespread support for their role from health professionals, patients, families and administrators
- increased people's knowledge about their cancer
- helped co-ordinate appointments, arrange referrals to community support services, assist with the logistics of getting a person to cancer treatment centres and locate sources of financial support for people with cancer and their families.

In this country, a number of DHBs have established patient navigator positions. Others have implemented hospital-based clinical nurse care co-ordinators who endeavour to make the necessary connections with primary health care providers and other community-based services to make certain that people affected by cancer receive the care they need.

Co-ordinated cancer support pilot programmes

The Ministry of Health currently funds three community cancer service pilots that are based on the ‘patient navigator’ model.

The West Coast PHO service is delivered solely by community workers. The team comprises one co-ordinator and three community workers. One of these is a Māori-specific role. Most of the referrals to the service are from the community and from primary care.

Te Kahui Hauora Trust delivers a Hunga Manaaki service through the Rotorua Hospital to provide support, care and advocacy for Māori patients. The cancer service pilot is an extension of this service. Referrals come through the hospital; nurses work with people and transfer them to a community worker once they are out of hospital.

Tamaki Healthcare provides an urban-focused service for the Auckland DHB catchment area. The service is provided by a mix of nurse and community workers, and receives referrals from a number of sources.

All three Ministry of Health-funded pilots are accompanied by a comprehensive evaluation programme. The evaluation results from these services will serve to inform the general development of cancer care and support service co-ordinating models.

9.5 Best-practice components

9.5.1 Overview

Evidence and feedback from the 2006 Ministry of Health-funded patient pathways studies indicates that delivery of timely and seamless care and support to those affected by cancer requires the following:

- **quality planning and service provision** based on comprehensive service mapping, needs assessments, workforce stocktakes and support service directories
- **development and provision of high-quality information** about the support service options open to those affected by cancer, including information that ensures people with cancer and their carers know how to access the support services they need
- development and implementation of **patient and carer support needs assessments tools**
- **cultural advisors, guides and specifically trained patient navigators** to support those affected by cancer and to facilitate their access to support services
- **timely referrals** and transfer of relevant patient information to service providers delivering care and support
- **co-ordination within multidisciplinary teams** in which all team members discuss the support needs of individual people at team meetings, record the outcomes and communicate with patients and their carers (with the consent of the person), undertaking periodic reviews of the dynamic processes within the team to ensure continuity of effective support
- **co-ordination between teams** – in some instances, people may access support services away from their home base (for example, at a regional or specialist treatment centre), in which case mechanisms need to be established to ensure comprehensive and timely information is transferred to the person’s local care and support team.

The Ministry of Health is currently working with regional cancer networks on developing care co-ordination matrixes and cancer patient management frameworks along the lines of those developed in Victoria, Australia. These models take a systems approach to care co-ordination.

On completion of the cancer support services stocktakes, social service directories should be developed that will be available to cancer support and other relevant service providers, people with cancer, their families and whānau. These directories should be regularly reviewed.

DHBs and regional cancer networks will need to work with local iwi and Māori cancer service providers and consumers of cancer services to identify whānau ora-type cancer care co-ordinating service models. A similar approach is required for developing support services for Pacific people.

Co-ordinating key worker roles are pivotal to achieving continuity of care and ongoing support for those affected by cancer. Key workers (for example, cancer nurse specialists, social workers, patient navigators, kaimahi hauora/Māori and Pacific health advisors) should be assigned in all hospital-based cancer services to co-ordinate a seamless interface between hospital and community-based continued care and social support services for all people with cancer and their families and whānau. Hospital-based multidisciplinary teams should endeavour to establish relationships with relevant community support services (for example, kaimahi hauora/Māori health hospital services, PHOs, primary health care providers, including Māori and Pacific service providers, the CCNZ and Work and Income New Zealand). Agreement should be reached on establishing responsibilities for agency-specific assessments, referral procedures and information sharing.

9.5.2 Workforce development

Existing and newly introduced co-ordinating service models should be accompanied by training that takes a systems approach to care and support co-ordination.

9.5.3 Research and evaluation

The limited international evidence on the effectiveness of the patient navigation and clinical nurse care co-ordinating service models suggests a need for independent evaluations to accompany all newly established co-ordinating cancer care and support service models to ensure their effectiveness from the perspective of people with cancer, carers, family and whānau, service funders, planners and providers.

9.6 Areas for action

Service delivery

36. Develop co-ordinating cancer care and support service models to ensure a seamless interface between hospital and community-based support service settings for people affected by cancer.
37. Develop culturally appropriate co-ordinating cancer care and support models to improve access to support services for Māori and Pacific peoples affected by cancer.

Workforce development

38. Provide appropriate systems-focused training for staff to ensure a seamless interface between hospital and community-based support services for people with cancer and their carers.

Research and evaluation

39. Ensure all co-ordinating cancer care and support models are accompanied by independent evaluations.

Appendix 1: Expert Advisory Group Membership

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Appendix 2:

Areas for Action

Information support

1. Ensure people affected by cancer have ready access to a wide range of high-quality resources.
2. Ensure consumer cancer information is culturally appropriate.
3. Ensure consumer representatives are involved throughout the design, development and evaluation phases of information resource production.
4. Ensure staff are familiar with the available consumer cancer information.
5. Establish a national information resource clearing house.

Interpersonal communication

6. Incorporate communication skills training, including inter-cultural communication skills, into all health professionals' training curricula and ongoing professional development training programmes.
7. Ensure that people with cancer and their carers understand the nature, benefits and risks of the treatment options and procedures open to them.
8. Ensure that cultural advisors, trained patient advocates and interpreters are available to Māori and other cultural groups.
9. Ensure that health professionals are sufficiently skilled and supported to effectively communicate with all those affected by cancer, including Māori, Pacific peoples and those from other ethnic minorities.

Psychological support

10. Ensure that psychological support and services are available as part of an integrated cancer service.
11. Offer prompt referral for psychological assessment to people affected by cancer who have significant levels of psychological distress to determine the need for treatment and management.
12. Ensure that staff providing mental health services are qualified to do so, and work within the scope and competencies of their respective disciplines.
13. Determine the efficacy and effectiveness of psychological support for those affected by cancer.
14. Accompany the development of psychological services with systematic evaluation.

Social support services

15. Continue to improve equitable access to social support services.
16. Develop and disseminate regional social support service directories.
17. Develop and use social support needs assessment tools.
18. Build a seamless interface between hospital and community-based social support services.
19. Ensure people affected by cancer are able to access financial and social support entitlements.

20. Establish systems to assess the training needs of hospital and community-based service providers.
21. Determine the effectiveness of social support services for those affected by cancer.

Complementary and alternative medicine

22. Develop policy and service specifications to ensure the informed and safe delivery of CAM to people affected by cancer.
23. Provide access to high-quality CAM information within cancer services.
24. Evaluate the usage, cost-effectiveness and safety of some of the more common forms of CAM therapies used to support people affected by cancer, including acupuncture, osteopathy and rongoā Māori.

Support for living long-term with cancer

25. Enable people affected by cancer to have greater control in looking after themselves.
26. Improve equitable access to continued care and support for people living long term with cancer.
27. Develop and distribute regional continued care and support directories.
28. Develop and use continued care and support assessment protocols and tools.
29. Ensure a seamless interface between hospital and community-based continued care and support services.
30. Establish systems to assess ongoing care and support training needs for hospital and community-based service providers.
31. Determine the efficacy and effectiveness of continued care and social support for people affected by cancer.

Spiritual support

32. Provide access to spiritual support services for people affected by cancer.
33. Ensure all staff are familiar with standard spiritual assessment arrangements and referral procedures.
34. Ensure the spiritual needs of Māori patients and their whānau are assessed by culturally competent staff.
35. Raise the professional awareness and competency of health professionals through training specific to the spiritual needs of people with cancer, their families and whānau.

Co-ordination of support

36. Develop co-ordinating cancer care and support service models to ensure a seamless interface between hospital and community-based support service settings for people affected by cancer.
37. Develop culturally appropriate co-ordinating cancer care and support service models to improve access to support services for Māori and Pacific peoples affected by cancer.
38. Provide appropriate systems-focused training for staff to ensure a seamless interface between hospital and community-based support services for people with cancer and their carers.
39. Ensure that all co-ordinating cancer care and support models are accompanied by independent evaluations.

Appendix 3:

Useful References for Tools to Help Implement this Guidance

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Appendix 4: Glossary

Best practice	May be either evidenced-based or a way of doing something where the evidence is minimal. Best practice may also refer to a consensus view that recognises an effective method or approach, fitting with the circumstances of a situation
Cancer journey	The individual and personal experience of a person with cancer throughout the course of their illness
Cancer service pathway	The cumulative cancer-specific services that a person with cancer uses during the course of their experience with cancer
Consumer	User of services
Hapū	Clan; sub-tribe
Iwi	Nation; tribe; people
Karakia	Incantation; spell; prayer; worship
Late effects	Consequences of treatment or sequelae that appear many months or years following some treatments for cancer
Local	Pertaining to the local district of a DHB
Long-term effects	Effects that occur during treatment for cancer and persist beyond the end of treatment
Mana whenua	Power associated with the possession of lands; the term is also associated with the ability of the land to produce the bounties of nature
Mirimiri	A traditional form of massage practised by Māori
Patient navigator	An appropriately trained person who provides support and guidance through a cancer journey for people affected by cancer
Region	An area under the responsibility of multiple DHBs
Rongoā	The Māori term for medicines that are produced from native plants in New Zealand
Te ao	The Māori world
Tūrangawaewae	Home place; spiritual home
Waiata	Sing; song
Whānau	Extended family and whānau. The whānau is recognised as the foundation of Māori society

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