Guidance for Improving Supportive and Rehabilitative Care for Adults with Cancer in New Zealand
Review Document
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1 Introduction

1.1 How to have your say

This guidance document is a draft only. It is important that it is up-to-the-minute, accurate and reflects the realities of the sector. The guidance will be updated following this review.

There are some key questions we would like you to think about and comment on as you read this draft document. These are outlined in the separate submission booklet.

There are two different ways you can make a submission:

1. Print the submission booklet, write down your comments and post them to:
   Cancer Team
   Supportive Care Submissions
   Ministry of Health
   PO Box 5013
   Wellington

2. Download the submission booklet and email your submission to:
   emma_hindson@moh.govt.nz

All submissions are due by 5 pm, Tuesday 28 October 2008.

1.2 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. The document provides clear objectives based on the best evidence, and suggests best-practice service approaches that will help to ensure that adults with cancer and their families/whānau have access to the essential support and rehabilitative care they need throughout the various stages of cancer, from diagnosis onwards.

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

This document is aimed at both government and non-government organisations (NGOs) involved in the funding, policy provision, planning, development and delivery of cancer support and rehabilitation care services, and in particular at the Ministry of Health, District Health Boards, NGOs, Māori and Pacific providers, primary health organisations, health professionals and other allied professionals.

Finally, the guidance is not a detailed prescription for what specific activities should occur at a local level: needs and resource requirements for supportive care will vary
from region to region. Instead, the recommendations outlined in this document allow for flexibility when implementing the guidance.

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 the recommendations could be applied more broadly across the spectrum of health and wellbeing.

1.3 Definition of supportive and rehabilitative cancer care

The definition adopted by the Expert Advisory Group for Supportive and Rehabilitative Care is adapted from that presented in *The New Zealand Cancer Control Strategy* (Minister of Health 2003) in relation to 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 the physical, social, cultural, emotional, nutritional, informational, psychological, spiritual and practical needs throughout a person’s 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 CSNZ established its own expert supportive care guidance advisory group with a view to:

- reviewing the findings of a literature review, including the NZGG’s comparative review of the United Kingdom-based NICE manual, *Guidance on Cancer Services: Improving supportive and palliative care for adults with cancer* (NICE 2004a) and the New South Wales-based, National Breast Cancer Centre and National Cancer Control Initiative’s *Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer* (2003)
- advising CSNZ on an appropriate needs assessment methodology to gain consumer input into the scoping project
- generally commenting on supportive care needs and current disparities in access to care in New Zealand, based on their expert opinions.

The advisory group’s advice was elicited from one face-to-face meeting held in April 2006 and a teleconference meeting held in June 2006. In its June 2006 report to the Ministry of Health, the CSNZ and NZGG recommended that the NICE evidenced-based guidance on supportive care and rehabilitation were suitable for adaptation for the New
Zealand environment, with appropriate tailoring to suit the needs of New Zealand’s unique population groups.

1.4.2 Formation of the Expert Advisory Group (EAG)

The EAG group overseeing the development of cancer supportive care guidance was established in July 2007. The EAG’s input and the guidance development project as a whole have been funded and the project managed by the Ministry of Health. The EAG’s tasks include:

- defining the scope of the guidance
- reaching agreement on the materials that form the basis of the guidance document
- providing expert input into the content of the guidance
- deciding on an appropriate format for the guidance
- peer-reviewing the guidance
- overseeing the consultation with stakeholders on the guidance document
- endorsing the final guidance document.

A list of the EAG 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) includes a number of support and rehabilitation-related actions. These actions broadly cover:

- promoting leadership in support and rehabilitation care
- developing policy to support the development of support and rehabilitation care
- improving access to supportive and rehabilitative care services
- ensuring information about cancer and related services generally is of high quality, accessible, well co-ordinated, culturally appropriate and patient- and family/whānau-friendly.

This guidance has been developed to progress the areas of action outlined above. Following are some of the other areas of the Ministry of Health’s work programme that will contribute to improving supportive care for adults with cancer.

- The development of a long-term conditions framework which establishes a vision for a health system that meets the needs – physical, emotional, social, cultural and spiritual – of people with long-term conditions, and their family/whānau and carers. The framework aims to sustainably embed effective long-term condition management across the health system over the next 10 years.

- The development of a formal regional cancer network infrastructure to improve the integration of services between primary, secondary and tertiary care providers across geographic areas. The networks’ memberships are based on cross-sectoral, cross-cultural, collaborative relationships drawn from within and across DHBs. The networks’ general purpose is to improve equity of access to cancer services for those affected by cancer, reduce service fragmentation, duplication and gaps, and
generally co-ordinate the planning and delivery of cancer services, including support and rehabilitation services.

- The establishment of a supportive care and rehabilitation expert advisory group (EAG), whose current responsibility is to oversee the development of evidenced-based, New Zealand-specific guidance on the planning and delivering of supportive care and rehabilitation for adults with cancer. The EAG's membership includes planners, providers and consumers of cancer services. (EAG members are listed in Appendix 1 of this consultation guidance document.)

- The establishment of three community cancer service pilots to support Māori and rural communities to better access and navigate the cancer continuum. The pilots are developing and testing new models of care, and utilise a range of supports such as information provision, facilitating contacts with treatment services and social support agencies, work with the wider community, and providing a support network at clinical appointments.

- The development of patient management frameworks which describe the patient’s care pathway, identifying critical points along that pathway and the optimal model of care required. The frameworks are intended to improve patient’s outcomes by providing consistent care based on evidence and best practice across the country. Supportive care underpins the framework and should be considered at all stages across the patient pathway.

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 from all causes. In 2004 cancer was the leading cause of death, and each year around 17,000 people are diagnosed with cancer. A diagnosis of cancer and the treatment regime that follows have the potential to seriously disrupt those affected. The experience brings with it a range of anxieties and emotional and financial stresses and strains for all those directly involved. It is a time when support is most needed from everyone around the patient, including the providers of cancer services. Evidence suggests that when people with cancer receive good social, psychological and cultural support, the quality of their life improves (Cancer Society of New Zealand and the New Zealand Guidelines Group 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.

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
Like all the actions from the Cancer Control Strategy Action Plan 2005–2010 that have been implemented, the guidance that follows 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 help ensure all services and interventions delivered have an equity focus. These tools include the Reducing Inequalities Intervention Framework (Ministry of Health 2002, the Health Equity Assessment Tool: A user’s guide (Signal et al 2008) and the Whānau Ora Health Impact Assessment Tool (Ministry of Health 2007). It is important that these equity assessment tools are used when purchasing, monitoring and evaluating support and rehabilitation 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, its companion Action Plan and subsequent implementation activities indicate that access to support and rehabilitative resources for people directly affected by cancer varies considerably between and within some regions. The 23 cancer implementation projects funded by the Ministry of Health in 2006 encompassed several that focused on patients’ pathway through local cancer services. These studies highlighted a range of issues with regard to patients’ access to support and rehabilitative services, particularly for Māori, Pacific and rurally isolated patients. The issues identified included:

- the changing needs of cancer patients and their carers throughout the diagnosis, treatment and rehabilitation stages, combined with inconsistent access, meant that patients and their carers were not always able to access all the services or resources they needed or were entitled to

- eligibility for disability support services varied cross regions because funding is limited for people who have 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 access to existing transport and accommodation allowances to and from the regional cancer treatment centres is highly variable

- health professionals’ patient assessments routinely are not giving due consideration to the patients and their carers’ personal situation 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.
It was also found that eligibility for long-term support services for people with impairments due to cancer varied nationally due to a funding and service gap in long-term support services for people under the age of 65 with chronic health conditions.

1.7 What do patients and their family/whānau expect of cancer services?

The evidence suggests that in addition to receiving the best possible treatment, patients 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 good symptom control
- exercise choice when given 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 throughout the patient pathway
- 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
- have high-quality communication with health and allied professionals who are sensitive to their physical, emotional, cultural and spiritual needs, and those of their family/whānau.

1.8 What areas need to be addressed?

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

- improve the integration of support and rehabilitation services, 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 that informs cancer patients and their family/whānau about the available services and options open to them
- develop holistic assessment models that include identification of individual patients’ and their family/whānau’s support and rehabilitation needs throughout the cancer service pathway
- provide training for professionals involved in services that will assist them to meet the supportive and rehabilitative needs of cancer patients and their family/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 selfmanage both the short-term and long-term effects of their cancer.

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 journey.

It is likely that the disparities in Māori and non-Māori cancer incidence and mortality rates are due in part to differences in exposure to risk and protective factors for cancer. Barriers to accessing regular screening as well as high-quality, timely treatments also contribute to poorer cancer outcomes for Māori (Robson and Harris 2007).

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

Kaupapa Māori approaches

Mainstream cancer services, including supportive care services, do not always support a whānau-based approach to cancer care, and some providers have indicated that there is low recognition by mainstream cancer services of the important role of whānau. Services are not always seen to be geared towards providing opportunities for whānau input and participation, facilitating whānau access to appropriate information, or providing adequate support for whānau (Cormack et al 2005).

It is important that services are specifically designed to meet the needs of Māori affected by cancer. This may include integrating Māori expertise and advice within mainstream services, locating services in Māori settings and incorporating Te Reo Māori. Other Māori-specific cancer interventions include incorporating traditional healing practices, such as mirimiri and rongoā, as part of an overall cancer service.

He Korowai Oranga

He Korowai Oranga: Māori Health Strategy (Ministry of Health and Associate Minister of Health 2002) sets out a framework for responding to Māori health issues. The overall aim of this strategy is whānau ora: Māori families are supported to achieve their maximum health and wellbeing. The vision of whānau ora seeks to achieve the following outcomes:

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

A good example of how the principles of He Korowai Oranga are put into practice in a service setting is the Hunga Manaaki Community Cancer Service. This service is outlined in greater detail in section 9, Co-ordination of Cancer Support.

Recommendations provided in this guidance should be considered in the context of He Korowai Oranga 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. Rates are even higher for specific cancers. Socioeconomic determinants play a role in these inequalities through the different distribution of risk and protective factors, as well as a 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, and within these groups there are differences depending on whether people are Pacific Island-born, New Zealand-born or multi-ethnic (Ministry of Health 2008). Although this diversity is to be celebrated, it offers up challenges to deliver services that are accessible, effective and culturally responsive. However, there are commonalities across Pacific groups, including:

- belief in Christianity
- mythology
- commemal land ownership
- genealogically based identity
- extended family accountability
- beliefs that wellbeing and illness are linked to obligations to extended family being met or not 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 culture and beliefs about health and illness generally differ from those of mainstream New Zealand culture. Pacific peoples share two health fundamentals: a holistic notion of health and 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 church (Counties Manukau DHB 2006). In particular, churches have been increasingly
identified as playing a key role in empowering communities to improve their health (Ministry of Health 2008). For Pacific peoples it is important that supportive care services are delivered in 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).

1.9 Principles underpinning this guidance

The principles underlying this guidance reflect those of the New Zealand Cancer Control Strategy in that the suggested approaches:

- 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 ability to pay
- are of a high quality
- are sustainable
- reflect a person-centred approach
- actively involve consumers and communities
- recognise and respect cultural diversity
- are undertaken within the context of a planned, co-ordinated and integrated approach.

Further to the cancer control strategic principles, the following principles specific to this guidance development project have been identified. These principles aim to ensure 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
- services are co-ordinated and integrated across providers
- consumers are empowered to access services and make choices about those services
- consumers are involved in planning, delivering and evaluating services
- services are configured to promote access for groups facing inequalities in cancer outcomes
- complementary, alternative and traditional therapies are acknowledged.
1.10 Evidenced-based approach

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

The evidence was largely derived from government reports, strategies and action plans, and published journal articles. Historical knowledge and professional experience have also been drawn on to inform the best-practice approaches, particularly in those sections and subsections of the report specific to cultural and spiritual models of supportive and rehabilitative care.

The following guidance also draws substantively from the National Institute for Clinical Excellence (NICE) manual, *Guidance on Cancer Services*, and from the manual’s companion research evidence (NICE 2004a, 2004b). Both documents were reviewed by the Supportive Care Guidance Group, established by the Cancer Society of New Zealand in association with the New Zealand Guidelines Group, and assessed as providing a suitable base document, with appropriate modification, for informing the development of the following guidance.

1.11 Topic areas

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

- information resources
- interpersonal communication
- psychological support
- social support
- complementary and alternative medicines
- 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, it is important to recognise that in practice these components often overlap. Each section 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
- processes to enhance current service provision.
Recommendations are also included, some of which are specific to the Ministry of Health, some to DHBs and their service providers, some to NGO service providers, and some directed towards research agencies such as the Health Research Council of New Zealand and the research arm of the Cancer Society of New Zealand (CSNZ). References specific to each of section are listed at the end of each section.

Appendix 2 of this guidance provides a list of tools to support the implementation of this guidance for support for people affected by cancer.

1.12 Next steps

This draft guidance document will be updated following the wider sector review. For ease of reference, a summary document outlining the key objectives and recommendations will be produced to accompany the guidance document. Priority recommendations will also be identified, and these will be the focus for immediate implementation.

Following the release of the final document, the Ministry of Health and the regional cancer networks will work with key stakeholders to develop district, regional and national implementation plans. This process will be facilitated by:

- promoting and educating people about the new supportive care guidance and assisting with its adoption
- identifying current providers of supportive care services across the region and the services they provide
- identifying where there are gaps or overlaps in service provision
- identifying areas where inequalities exist in relation to access and the availability of services
- facilitating a regional and a national view of the current situation
- promoting best practice.

1.13 References


NICE. 2004b. *Improving Supportive and Palliative Care for Adults with Cancer: Research evidence.* London: National Institute for Clinical Excellence.


2 Information

2.1 Introduction
The information needs of people affected by cancer vary as they progress through the cancer service pathway. In the initial stages following diagnosis, there is a preference for practical information to support their treatment and care-related decisions, information that is specific to the type of cancer they have, the treatment options open to them and the likely outcomes of those treatments. In the latter part of the cancer journey, when the patient's 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 both timely and staged 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 available to them, and the sources of help
- help others to understand their condition and needs
- legitimise their help-seeking and concerns
- learn how to minimise the risk of further illness
- identify additional information and self-help groups
- identify the best health care providers.

2.2 Definition
Information resources are those produced and provided in any medium or form for the benefit of patients and those caring for them. The content of the information may be specific to the disease state itself, a particular manifestation or stage of the disease, the various cancer treatments, or to support and rehabilitation options open to them.

2.3 Objectives
1. All people affected by cancer have access to high-quality information resources when they need them, and in a format that is appropriate to their level of understanding.
2. Cancer information resources are relevant to the needs of Māori and other ethnic groups resident in New Zealand.
3. Health professionals familiarise themselves with the information resource options available.

4. Health professionals ensure that those affected by cancer understand the information provided, or refer them on to appropriate interpreters should this be 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 ethnicity. It is therefore vital that people affected by cancer are given information that enables them to make informed decisions at appropriate times along the cancer continuum, ideally in a setting where they feel comfortable and able to ask questions to seek clarification on treatment options such as surgery, radiation, chemotherapy, and complementary and alternative therapies.

Evidence suggests that many patients want more information than they currently receive, while 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, 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, helps to improve patients’ 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 cultural groups and people with disability impairments (CSNZ 2006). One of the cancer pathway implementation project studies found the limited written information that is available to Māori and Pacific peoples tends to be wordy, with minimal or no visual content that is pertinent to either group (Hutt Valley DHB and Wairarapa DHB 2006).

A 1994 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 1994). 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 the impression of supporting informed decision-making and consumer empowerment (CSNZ 2006).
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 have also proven helpful. These personalised forms of information show improved patient outcomes in terms of enhancing the person with cancer’s knowledge and recall, symptom management, level of satisfaction, preferences, and health care utilisation (Gysels and Higginson 2004).

2.4.3 Computer-based information
The internet is an increasingly used information access point for people affected by cancer (Ziebland et al 2004). However, the quality and reliability of information on internet sites with regard to health generally and cancer specifically has been found to be highly variable (Eysenbach et al 2004; Ziebland et al 2004). Although the internet can be a convenient way for patients to access cancer information, evidence suggests it can be a potential source of confusion for both patients and health professionals (NH&MRC 2003).

2.4.4 Telephone-based information
Telephone helplines, such as that provided by the CSNZ, are another useful information source.

2.4.5 Complementary alternative medicine (CAM) information sources
The CSNZ’s 2006 stocktake and review of cancer information resources elicited very few CAM resources from requests put to CAM service providers. This was considered a major gap requiring remedial action. Evidence suggests most patients 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).

Most CAM websites do not comply with quality standards with respect to the information provided (Molassiotis et al 2005; Wallji et al 2005). While a few CAM therapies are supported by solid evidence (mainly aromatherapy and massage), most are not (Ernst et al 2007). Some have potentially antagonistic interactions with conventional cancer treatments, such as chemotherapy. It is essential that health professionals are able to discuss CAM with their patients in an authoritative and objective way and provide informed advice when and where 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, informing 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, 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 (Cancer Society of New Zealand 2006).

2.5.2 Resource development co-ordination
A number of steps should be taken to ensure that patients and their family/whānau have access to high-quality information when they need it. Information in a variety of formats should be:

- developed in languages and tailored to different ethnic groups, including Māori, Pacific peoples and Asian groups
- distributed to appropriate locations where patients and their family/whānau can readily access it
- delivered free at the first point of access.

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 patients affected by cancer.

On the basis of its review of cancer information resources, CSNZ is now nationally co-ordinating cancer information. A national clearing house has been established to review, disseminate and evaluate cancer information resources. CSNZ further recommended that organisations and agencies developing cancer information send their information to CSNZ for inclusion in the national clearing-house database.
Provider organisations 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 the quality standards desired, it is recommended that information providers planning to develop additional cancer resources refer to the Ministry of Health’s 2002 *National Guideline for Health Education Resource Development in New Zealand* for guidance, which is available online in PDF format from the Ministry of Health’s website.

Regional social support service directories should be developed for use by those health and social support professionals who advise cancer patients 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 ensure that high-quality cancer information resources are available to those who need them. This will require resources to be readily accessible in locations where patients and their family/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 establish what information should be available at particular points along the patient’s cancer pathway. It is also recommended that processes be put in place to ensure high-quality cancer consumer information is peer-reviewed by consumers, relevant health professionals and appropriate cultural advisors. Resources should also be regularly reviewed.

Information should be routinely offered at the various contact points along the patient cancer pathway. For example, newly diagnosed people should be provided with a comprehensive resource pack that is timely, pertinent to the type of cancer they have and readily comprehensible in terms of format, language and cultural sensitivity. The pack could be supplemented with additional information that helps put the patient’s own individual experience into context, and includes information or referrals to other available support service providers, such as Māori whānau ora services and CSNZ. The pack might also include a list of recommended internet cancer-specific websites, including CAM websites.
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 tapes, CD-ROMS and DVDs. The resources should include those that are 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 Māori, Pacific and other culturally specific services. Processes should be established to ensure that all information outlets are regularly restocked, and information is updated and replaced as new resources come to hand.

The format, level and type of information required by cancer patients and their family/whānau will vary. Some people actively seek information; others do not. Those who do not articulate their information needs may be viewed as not interested, but this is rarely the case, and clinicians and service providers should be wary of making assumptions about what their patients’ information needs are. People 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 also need to be assessed at regular intervals and points 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 if required to help patients cope with the emotional impact of the information. Professionals need to make patients and their carers aware of the various support options open to them, such as the Cancer helpline, 0800 CANCER (226 237), which is a CSNZ information line managed by experienced oncology nurses with counselling experience; CSNZ’s face-to-face liaison nursing service and community workers; and a variety of supportive care education and information groups. Written contact details should be provided where possible.

Given that a sizable proportion of cancer patients use the internet to access information about cancer, health professionals and service providers are advised to 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 to those patients indicating an interest in this information source.

Service providers should maintain a database of approved translators to support those patients and carers’ information needs for whom English is not their preferred or first language. Special consideration should be given to identifying the cancer information needs of their clients and the most effective ways of meeting those requirements. There is also a need for service provider organisations and cancer networks to work collaboratively to ensure 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 various cancer information resources available to enable them to provide timely, relevant resources to their patients and family/whānau at particular points along the patients’ cancer treatment and support pathway.

2.6 Recommendations

These recommendations summarise the key best-practice service components outlined in this section.

<table>
<thead>
<tr>
<th>General recommendations</th>
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<tbody>
<tr>
<td>1. <strong>Ensure people affected by cancer have ready access to a wide range of high-quality resources.</strong> Information and cancer consumer resources need to be of a high quality, evidenced-based, guided by the cancer information development principles, and freely available and accessible to people affected by cancer throughout the various stages of their cancer pathway.</td>
</tr>
<tr>
<td>2. <strong>Ensure consumer cancer information is culturally appropriate.</strong> Information needs to be culturally appropriate and in languages and a format that is easily understood by people regardless of their reading ability.</td>
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<thead>
<tr>
<th>Service delivery recommendations</th>
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<tr>
<td>3. <strong>Ensure staff are familiar with the available consumer cancer information.</strong> Health professionals should be aware of and familiar with the range of information and available resources, and present these in an environment that encourages questions and comments.</td>
</tr>
<tr>
<td>4. <strong>Establish a national information clearing-house.</strong> A national clearing-house for cancer resources should be established and approved by the Ministry of Health to ensure that all cancer information resources are nationally co-ordinated, reviewed, evaluated and updated.</td>
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2.7 References


3 Interpersonal Communication

3.1 Introduction

The decision-making process that follows a diagnosis of cancer requires patients and their carers 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 delivering the diagnosis, treatment and ongoing support options have the ability to communicate effectively and empathetically in a manner that best promotes the patient’s understanding and comprehension, and encourages them to ask questions and generally participate in the decision-making process throughout the patient pathway.

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. The approach calls for health professionals working with people experiencing cancer to:

- obtain, understand and verify the perspective of those affected (eg, their concerns, feelings and expectations)
- understand them within the context of their own personal, socio-cultural and socioeconomic circumstances
- reach a shared understanding about their particular cancer problem and its treatment
- share power with the patient 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 patients and their carers are helped to explore issues and arrive at decisions in discussion with health and social care professionals. It is most effective when there is mutual understanding, respect and awareness of the individual’s roles and functions (NICE 2004).

3.3 Objectives

1. All those affected by cancer are enabled throughout the patient pathway to discuss issues and ask questions concerning their cancer, proposed treatment, and the impact of cancer or its treatment, with professionals who are knowledgeable and skilled communicators.

2. Health and social care professionals listen and respond to patients 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.
3.4 Context and rationale

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

Most patients are reportedly satisfied with the services provided by their clinicians and other health professionals throughout their treatment for cancer. Where there is dissatisfaction, this largely results from communication failure on the health professional’s part as opposed to dissatisfaction with the actual care provided.

Patients’ 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 patient appears interested or uninterested.

People with cancer face many practical, emotional and psychological demands, in addition to their physical treatment. The evidence suggests that these psychological needs are significantly and frequently unmet (Epstein and Street 2007). Recent reporting suggests that a high level of fear of cancer, and of hospitalisation generally, is a major barrier to Māori and Pacific people seeking information (Cancer Society of New Zealand and New Zealand Guidelines Group 2006). Good communication can help alleviate fear and distress, and enable the patient and their family/whānau to access the information and treatment that they need.

3.4.1 Clinician–patient communication

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

Face-to-face (kanoho-ki-te-kanohi) communication, as opposed to written information, is of particular importance to Māori and Pacific people (Hutt Valley DHB and Wairarapa DHB 2006). The information provider or messenger is equally – if not more – important than the actual message when presenting information to Māori (Ropiha 2004).
Ministry of Health-commissioned patient pathway projects strongly support actions that aim to improve the quality of interpersonal communication between patients and cancer service providers, particularly those with Māori and Pacific patients. Actions designed to strengthen interpersonal communication between clinicians and patients, their family/whānau in cancer service settings are considered central to improving access and engagement with Māori and Pacific peoples. 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

As we have seen, most complaints from those affected by cancer arise from communication breakdowns between patients and the health professionals caring for them. Communicating information about a life-threatening disease is recognised as requiring particular skills on the health professional’s part. In some countries mandatory communication modules have been introduced as a prerequisite for postgraduate training programmes for health care professionals working with cancer patients. The courses or modules tend to vary in intensity and length, ranging from 2 to 15 days (Fellowes et al 2004). One-off training programmes and workshops have also proved popular.

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 communications skills can be learnt and maintained. The evidence also suggests that the more labour-intensive communication training programmes are effective in improving attitudes and communication behaviour among trained health care professionals, particularly those working at the more senior levels.

These programmes focus largely on the communications that occur between clinicians and patients during formal assessment procedures. The programmes vary in terms of content and design, but in general tend to:

- be learner-centred
- be provided in a ‘safe’ learning environment that enables the participants to develop and practise skills
- involve face-to-face training led by trained facilitators who are conversant with the clinical cancer setting
- include 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’
- facilitate the developing and practising of skills, reflection and self-awareness
- have definable and measurable core competencies
- provide constructive feedback to participants.
3.4.3 Other communication improvement techniques

A range of techniques and methods have been developed to help improve face-to-face communication between health care providers and patients to support patient participation in their decision-making. (For further information, see the preceding information section). Following is an outline of communication-enhancing techniques that have proven beneficial for people affected by cancer:

- written or taped recordings of consultations for patients and their carers who indicate an interest in taking up the offer of such recordings
- individualised patient education sessions
- use of decision aids for treatment options
- providing information and opportunities to meet other health care professionals prior to significant consultations.

Comprehensive relationship building and communications skills training programmes that highlight culturally appropriate practices and procedures for frontline cancer service providers are considered essential for improving the resilience of Māori and Pacific patients and their family/whānau throughout the course of their cancer service pathway.

3.5 Best-practice service components

3.5.1 Overview

Health care professionals should ensure that patients and their carers have genuinely understood the nature, benefits and risks of the treatment options and procedures open to them when seeking patients’ informed consent. Patients and their carers should also be asked if they have been given sufficient information to adequately inform their decision-making.

Patients’ and their family’s/whānau preferences regarding their treatment, support and rehabilitation options should be assessed on an ongoing basis throughout the patient pathway. These preferences should be documented in the patients’ individual medical records.

Cultural support advisors, trained patient advocates and translators must be available in mainstream hospital-based cancer services to support Māori and Pacific patients 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.
3.5.3 Service delivery

Understanding the particular cultural and spiritual sensitivities of various ethnic groups with regard to cancer treatment is essential. The use of appropriate communications for Māori, such as waiata and karakia, should also be considered. Time should be allowed in all patient consultations to discuss their 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 those situations where they sense a clear need for a more experienced person to deliver the necessary information, appropriately skilled 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 specialist oncology nurse where one is available. 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 communications skills. In those situations where the consultant does not have the desired specialised skills, they should be supported by someone who is suitably skilled. The person with cancer should have the time and opportunity to arrange for support people to be with them.

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

3.6 Recommendations

These recommendations summarise the key best practice service components outlined in this section.

<table>
<thead>
<tr>
<th>General recommendations</th>
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<tr>
<td>5. Incorporate communication skills training, including inter-cultural communication skills, into all health professionals’ training curricula and ongoing professional development training programmes.</td>
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<tr>
<th>Recommendations for service providers</th>
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<tr>
<td>6. Ensure that cancer patients and their carers understand the nature, benefits and risks of the treatment options and procedures open to them.</td>
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<tr>
<td>7. Ensure that cultural advisors, trained patient advocates and translators are available to Māori and other groups, where required.</td>
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<tr>
<td>8. 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.</td>
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3.7 References


4 Psychological Support

4.1 Introduction

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

Such 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 a clinical diagnosis of, for example, major depression or an anxiety disorder (Carlson and Bultz 2003). Other problems that can arise 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 psychological distress or disturbance. This rate increases slightly for those with a poorer prognosis, greater disease burden, or specific types of cancer (Zabora et al 2001). The point prevalence rates for mood and anxiety disorders are higher than those expected in a population without cancer (see DSM-IV).

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 patient 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 commonly understood as the more structured and evidence-based professional services provided by trained health practitioners with the relevant qualifications and vocational scopes to deliver such services.

Psychologists and psychiatrists are the professionals appropriately consulted for more advanced psychological problems because they have training in the causes and therapies for a range of emotional, health and psychiatric conditions and disorders presenting in people affected by cancer. However, in New Zealand primary health care practitioners are usually the first port of call because psychologists and psychiatrists are generally in short supply.
A range of psychological assessment and treatment approaches are used by such health professionals. New (July 2008) evidence-based best practice guidelines for the Identification of Common Mental Disorders and Management of Depression in Primary Care (New Zealand Guidelines Group 2008) provides careful appraisal of the available research evidence (see 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, with those experiencing significant distress or disturbance being referred to health practitioners with the requisite specialist skills.
3. The work-related mental health needs of staff caring for such patients 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 2004). 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 morbidity in 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 the unavailability 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 supports and services should be available from a range of providers, such as primary health organisations (PHOs), specialist mental health services, NGOs and the volunteer sector. The voluntary and NGO sector is an important part of the continuum of care through services such as telephone helplines (eg, Lifeline) and self-help and support groups. The more specialised services should include access to mental health practitioners such as clinical psychologists.
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, community and NGO mental health and support services, specialist mental health services, and psychological support services. Where psychological services exist, these should be set up in such a way that there is evidence that the service improves patients’ outcomes.

For the most part, psychological interventions offered to people with cancer should be the same as those that have proven efficacious in managing the same clinical disorders in non-cancer patients. Accordingly, empirically supported treatments should be the front-line of interventions, and this 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 covered in guidelines for the Identification of Common Mental Health Disorders and Management of Depression in Primary Care (New Zealand Guidelines Group 2008).

When considering how to tackle the under-detection of mental health issues and/or psychological distress, routine screening for psychological distress and disturbance in people with cancer has some initial appeal, and a variety of short screening measures are often referred to in the cancer literature (eg, the Distress Thermometer). However, such an approach has been found to be only modestly effective at screening for significant psychiatric or psychological disorders (Mitchell 2007). Routine screening of all cancer patients using these 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 relied on to triage referrals or prompt referrals to mental health services.

Patients and carers 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 if indicated. There are specific circumstances when a formal psychological assessment should form part of treatment preparation decisions (eg, patients being considered for haematopoietic stem cell transplant, Reznik et al 2006).

Patients who have completed active treatment should be informed about the range of psychological support services available and how to access these directly. It should be recognised that such needs can develop a considerable time after treatment has stopped. The usual mental health services should also remain available for those requiring such services in and out of normal working hours, and for mental health problems that are unrelated to cancer.
4.5.2 Service delivery

Services could be made available as part of an integrated cancer service, part of liaison teams attached to hospital services, PHO primary mental health services or part of the mental health services. The former 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 Health Disorders and Management of Depression in Primary Care (New Zealand Guidelines Group 2008). This resource should offer outreach advice and support to smaller centres.

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

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

At the second 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. At the third level, involving more serious concerns such as psychological distress or difficulties, assessment and treatment services should be delivered by specialist mental health professionals with the relevant scope and competencies to do so. Clear pathways to access such services should be presented.

It is also essential that health and social care professionals empower and equip patients 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 patients and carers, which may include, where indicated, the use of pharmacological options. (See guidelines for Identification of Common Mental Health Disorders and Management of Depression in Primary Care (New Zealand Guidelines Group 2008).)
Appropriate facilities should be available for undertaking mental health/psychological assessments and interventions, reflecting the needs of patients and carers for privacy and comfort. Where patients are unfit to travel, specialist psychological or psychiatric interventions could be provided through domiciliary visits. Subject to confidentiality and Privacy Act considerations, psychological services should have agreed processes for transferring information within their service and with other services, teams, and practitioners working with individual patients. Information should include the findings from such assessments, proposed treatment plans and the outcomes of treatment.

4.5.3 Workforce development

Staff providing mental health, primary care and psychological services should be adequately trained to do so, and should work within the scope and competencies of their respective discipline (see, for example, 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 should be promoted and supported for psychological health providers and the cancer workforce generally.

4.5.4 Research and development

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

4.6 Recommendations

These recommendations summarise the key best practice service components outlined in this section.

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<th>Service delivery recommendations</th>
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<tr>
<td>9. Psychological support and services should be available as part of an integrated cancer service.</td>
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<tr>
<td>10. People affected by cancer who have significant levels of psychological distress should be offered prompt referral for psychological assessment to determine the need for treatment and management.</td>
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<th>Workforce development recommendations</th>
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<tr>
<td>11. Staff providing mental health services should be qualified to do so, and should work within the scope and competencies of their respective disciplines.</td>
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</tbody>
</table>
Research and evaluation recommendations

12. The efficacy and effectiveness of psychological support should be determined for those affected by cancer.

13. Development of psychological services should be accompanied by systematic evaluation.

4.7 References


5 Social Support

5.1 Introduction

Diagnosis and treatment of cancer can seriously disrupt the lives of those directly affected, both emotionally and at a personal and family/whānau level. Most people will need support in some form or other to help them cope with the emotional, social and economic upheaval arising from the diagnosis and its treatment. Regular assessments of the family/whānau’s support needs and the provision of quality information about the support options available to them are required at each of the critical stages throughout the patient pathway. It is therefore essential to have health care professionals charged with the specific responsibility of ensuring that support is there when required.

Social support encompasses a range of possible support needs, including:
- continuance and enhancement of social networks
- practical assistance in the home with domestic and home maintenance tasks
- assistance with individual personal hygiene or physical care
- 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
- childcare support
- cultural support
- spiritual care
- travel and accommodation assistance
- provision of information and resources
- home safety support
- provision of relief care
- advocacy, liaison with the treating team at the hospital, family meetings and problem solving
- family support, and addressing personal and family crises
- helping with relationship and communication issues
- assisting with adjusting to lifestyle changes
- legal and welfare advocacy.
5.2 Definition
Social support describes those services that enable people affected by cancer to adjust to and cope with the personal, domestic and financial challenges to their everyday lives resulting from cancer. Social support is largely focused on supporting those affected by cancer in their home environment. That support can be provided by other family/whānau members, friends, other social networks (such as workplace colleagues), and government and non-government agencies.

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 the client, family/whānau and health professionals.
2. Timely and acceptable practical and financial support are available to those affected by cancer.
3. Patients and 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
In New Zealand there has been a lack of strategic oversight in the provision of social support services for people affected by cancer. These services have traditionally been provided by various government and non-government organisations, with the latter comprising a large voluntary workforce of support workers. Some NGOs providing support services receive little to no government funding for the services they provide.

This lack of strategic direction has led to:
- variable interpretation of eligibility criteria for disability and health-related needs support within and across regions
- an absence of regionally consistent support service models
- fragmentation of support and rehabilitative services
- an inability to identify national workforce and research requirements
- an absence of regular and comprehensive needs assessments of patients and their family/whānau support needs
- regional inconsistencies in the provision and availability of support services
- lack of cancer-specific Māori and Pacific services
- Some populations face additional barriers to accessing social support services. For example, those living in rural settings often have to travel great distances to access services, which in turn has considerable financial complications. The Ministry of Health introduced the National Travel Assistance Scheme in 2006 to provide national consistency for travel and fuel reimbursements and to allow for quicker processing of claims, and this has gone some way towards improving the situation.
Other issues faced by rural communities include various other financial concerns (rural populations are generally less well off than urban populations), the absence of support needs assessment and after-hours support services, multiple interfaces between services, and the lack of key workers to act as navigators to ensure patients and their family/whānau have access to support services when they need them (Noble et al 2006).

For Māori, cancer support providers have noted a lack of specific kaupapa Māori services and mainstream services that do not always practise a whānau-based approach to cancer care and support.

5.4.1 Access to income support

The financial and economic impacts of cancer can be considerable due to the inability of the person experiencing cancer to work and the subsequent loss of employment income, a situation that may be compounded if a partner has had 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 employment income. Furthermore, patients and carers may be reluctant to ask for financial support because they feel embarrassed, may wish to maintain their independence from the social security system, or may consider professional efforts to determine financial support needs to be intrusive. These concerns aside, it is important that those immediately affected by cancer are made aware of the financial support available to them.

5.4.2 Access to health and disability support

The Ministry of Health and DHBs fund a number of health and disability support services. These services assist people with long-term conditions, and their carers, to function better 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 the pressures of those caring for people with a chronic condition such as cancer.

People with cancer and its associated long-term functional impairments can experience difficulty accessing long-term support services because they do not meet the access criteria for either Ministry of Health-funded disability support services or DHB-funded long-term support services. Funding has been allocated to an interim funding 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 for support services funded by the interim funding pool. These include home-based support such as personal care and household management, carer support, equipment and modification services, and residential care.
5.4.3 The essential components of a social support service model

The main components of a social support service model available at the regional or local level are likely to vary, as will the needs of individual patients and their carers. However, ideally the components of care available should include:

- an assessment of needs, including those of the principal carers and other immediate family/whānau members
- access to individuals with appropriate knowledge to assist patients and their carers to complete application forms for income support or other welfare assistance requirements
- practical support in the domestic setting, including personal care for patients
- equipment and home modification support to maintain independent living (refer to section 7, Support for Living Long-term with Cancer, for further information)
- support to maintain employment status
- day care and other respite care support
- psychosocial counselling and peer group support
- culturally appropriate support in both hospital and community settings
- linking with appropriate community agencies.

A stocktake of regional cancer support services needs to be carried out to identify gaps in service provision and possible access inequalities, as well as to inform the development of regularly updated service directories for use by social support service providers. The directories could also be posted on DHB, CSNZ and other relevant websites. These activities should build on the national stocktake of psychosocial services undertaken for the Ministry of Health in 2006 (Surgenor et al 2006).

Cancer service support providers generally should ensure that relevant staff are familiar with the standard social support assessment requirements and procedures in relation to obtaining specialist social support assessments and access to a full range of the support services available. The Ministry of Health and DHBs currently fund needs assessment and service co-ordination services (NASCs) to assess and co-ordinate support services for their respective client groups.

5.4.4 Current remedial actions under way

Recent and current projects under way that aim to improve the quality and consistent delivery of supportive care 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 inequities experienced by Māori and rural residents
- the development of this cancer support guidance.

1 See http://www.macmillan.org.uk for a useful support service website model.
5.4.5 The evidence

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

- Assigning a ‘key worker’ (for instance, a social worker 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 identified needs are met (NICE 2004; Payne et al 2002). The research also suggests this approach is an effective way of improving the overall quality, consistency and access to care and support for cancer patients (Waitemata DHB Health Gain Team 2006). Positive improvements in patients’ emotional wellbeing and quality of life have been observed as a result of this approach.

- Group therapy, education and unstructured psychosocial counselling sessions and cognitive behavioural therapeutic approaches show considerable promise in providing medium- and long-term emotional support for patients with cancer (Newell et al 2002).

- Touch-screen computer-based support needs assessment systems have proven effective in providing breast cancer patients with information and access to social support (Gustafson et al 2001). This type of self-reported needs assessment tool is of particular value in those situations where service providers face time and staffing resource constraints.

5.5 Recommendations

<table>
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<tr>
<td>14. <strong>Continue to improve equitable access to social support services for people affected by cancer.</strong></td>
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<td>15. <strong>Undertake a stocktake of regional social support services.</strong> A regional stocktake of support services should be carried out to identify available cancer support services (including those providing support equipment), service gaps and possible access inequalities. These activities should build on the national stocktake of psychosocial services undertaken for the Ministry of Health in 2006 (Surgenor et al 2006).</td>
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<td>16. <strong>Develop and disseminate regional social support service directories.</strong></td>
</tr>
<tr>
<td>17. <strong>Promote the use of this guidance.</strong> Regional cancer network representatives should promote the use of this guidance to all relevant cancer service providers and assist with the implementation of the recommended best-practice service models where practicable.</td>
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<tr>
<td>18. <strong>Develop a consistent supportive care service model.</strong></td>
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**Service delivery recommendations**
19. **Develop and utilise social support needs assessment tools.** Hospitals and cancer treatment centres’ multidisciplinary teams should ensure that social support needs assessment tools and procedures are developed, established and routinely used to assess all patients and their carers’ social support needs at each critical stage along the cancer service pathway. The assessment tools should cover the domains of personal care, social support relationships and networks, domestic environment support needs (eg, assistance required with housework chores), childcare, employment, transportation to and from cancer-related appointments, and income-related costs.

20. **Ensure a seamless interface between hospital and community-based social support service settings.** Key workers (eg, social workers, patient navigators, kaimahi hauora / Māori health and Pacific health advisors) should be assigned in all hospital-based cancer services to co-ordinate a seamless interface between hospital and community support service settings for all cancer patients and their families/whānau. Hospital-based multidisciplinary teams should endeavour to establish relationships and co-ordination mechanisms with relevant support services (eg, kaimahi hauora / Māori health hospital services, PHOs, primary health care providers, including Māori and Pacific service providers, CCNZ and Work and Income New Zealand). Agreement should be reached on establishing responsibilities for agency-specific assessments, referral procedures and information sharing.

21. **Ensure patients and their carers have access to financial and social support entitlements.** Patients and their carers should be offered assistance by appropriately knowledgeable social workers or other assigned key health workers to help them apply for the financial support they may be eligible for. Service providers should ensure that all patients and their carers are aware of the support services and financial support entitlements open to them, and have access to good-quality information about the support services they might need. The information should be available in various culturally appropriate formats and in the preferred language of the patients and their carers, where possible.

**Workforce development service recommendations**

22. **Establish systems to assess the training needs of hospital-based and community-based service providers.** DHBs and community social support providers should establish systems to assess the training needs of the relevant hospital- and community-based professionals, including Māori and Pacific service providers, with regard to providing high-quality social support for people affected by cancer. It is also important to consider the training needs of unregulated support workers to enable the delivery of safe, high-quality support services, irrespective of who delivers them.

**Research and evaluation recommendations**

23. **Determine the efficacy and effectiveness of social support services for those affected by cancer.** Social support services and efforts to establish effective co-ordination of social support services should be accompanied by systematic evaluation.
5.6 References


Noble FD, McKinlay E, Cormack D. 2006. *The Journey of Treatment and Care for People with Cancer on the West Coast*. West Coast District Health Board and the Wellington School of Medicine and Health Sciences, Otago University.


6 Complementary and Alternative Medicine

6.1 Introduction
Evidence suggests that many cancer patients use complementary and alternative medicine (CAM) in addition to the mainstream (biomedical) treatments and modalities prescribed by their general practitioners, physicians and surgeons. While some patients seek advice from their doctors about whether or not using 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 reported to be increasingly incorporating CAM therapies into the range of services they offer to cancer patients. Given the scale of CAM usage among cancer patients and biomedical practitioners, it is essential that all parties concerned be fully informed about the potential benefits and risks of the various CAM modalities to enable patients to make informed choices.

6.2 Definition
The definition of CAM adopted by the Ministerial Advisory Committee on Complementary and Alternative Health (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 (aromatherapy and reflexology), by and large can complement orthodox cancer therapies when practised by suitably qualified CAM practitioners. These types of techniques are generally aimed at helping to improve cancer patients’ 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 Māori rongoā, Pacific traditional healing, Chinese herbal medicines, acupuncture, homoeopathy and naturopathy.

Mind/body/spirit interventions comprise techniques administered to facilitate healing, such as hypnotherapy and spiritual healing.

Biological-based therapies involve naturally and biologically based practices, interventions and products, including dietary products.

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

Energy therapies, such as reike, ‘touch for health’ and bioelectric magnetic-based therapies, focus on energy fields emanating from the body (biofields) or other sources (electromagnetic fields).

Source: Based on a prototype developed by the United States Center for Complementary and Alternative Medicine.

6.3 Objectives

The primary aim of the guidance in relation to CAM is to provide policy makers, service planners, providers of cancer services and the regional cancer networks with essential background information about CAM that will help them to:

- empower people affected by cancer to make their own decisions about complementary therapies and therapists through the provision of high-quality information
- ensure that health professionals working with people affected by cancer have access to high-quality information about CAM
- inform those involved in providing support for people affected by cancer and their families/whānau about the benefits and risks of CAM
- ensure that complementary therapies are provided safely by appropriately trained practitioners who are sufficiently aware of clinical problems and psychosocial and spiritual issues with which patients 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 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 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 (Kronenburg 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 (Kronenburg 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). Those affected by cancer use CAM because they believe that: it is non-toxic and holistic (NICE 2004), it may boost their immune systems, it may help relieve pain and reduce the side effects of their cancer and cancer treatments, and it will generally improve their quality of life (Chrystal et al 2003; NICE 2004).

The evidence base for CAM with regard to supportive care is an actively researched area. 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 botanicals may reduce chemotherapy-induced nausea and emesis, and hypnosis and guided imagery may be beneficial in anticipatory nausea and vomiting. Transcendental meditation and mindfulness-based stress reduction can play a role in the management of a depressed mood and feelings of anxiety (Mansky et al 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 patients with thrombocytopenia, bleeding disorders or aplasia. 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 et al 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 the lesser used CAM therapeutic interventions (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 cancer patients (Molassiotis et al 2005; Chrystal et al 2003; Begbie et al 1996).

People affected by cancer can access CAM therapy services from a variety of sources, mostly from private CAM practitioners and general medical practitioners who practise CAM therapies. The Cancer Society of New Zealand provides some complementary therapies such as relaxation and massage services, and information about CAM that people may wish to consider when making decisions about the usefulness of CAM.
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 productive coexistence. The limited research base available here 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 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 (although the Ministry does fund some rongoā services). People with a diagnosis of cancer are eligible for subsidies from the Accident Compensation Corporation (ACC) in the case of injuries. However, 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 cancer patients reportedly 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). It is imperative that health professionals caring for and supporting patients affected by cancer know which CAM therapies patients are using, given that some therapies and products are known to adversely affect and interfere or interact with conventional cancer treatments. To counter possible reluctance on patients’ part to discuss CAM with their doctors, the Medical Council of New Zealand 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.

If a patient with cancer expresses interest in using a particular CAM modality or product, then service providers should ensure that the patient has access to a suitably qualified individual who can authoritatively and objectively discuss CAM therapies with them. The health service provider should also provide the patient with high-quality information resources, where these are available. If the patient 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.

Prevalence studies 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, making it difficult to draw definite conclusions.
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 used by 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. With respect to CAM practitioners, only chiropractic and osteopathic practitioners are currently regulated under the umbrella of the Health Practitioners Competence Assurance (HPCA) Act 2003. Acupuncture and Western herbal medicine 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 these particular modalities, which require more intensive training to ensure their safe practice. There are, however, a number of legislative acts that indirectly govern CAM practices and products that serve to protect CAM consumers, including the Consumer Guarantees Act 1993; Fair Trading Act 1986; Food Act 1981; 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 and monitor 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 modalities (eg, homoeopaths and naturopaths) operate under the umbrella of the New Zealand Charter of Health Practitioners (MACCAH 2003).

The MCNZ’s 2005 advice statement to its members with regard to CAM 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 (Medical Council of New Zealand 2005). It is generally acknowledged, however, that issues relating to the training, qualifications and competence of biomedical and CAM practitioners should be addressed at the national level to ensure the safety of patients.

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 Whaka Haere ō 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 1999).

There is a need to fully engage CAM umbrella agencies and practitioners in research looking at the efficacy and impact of the various CAM modalities and the effectiveness of information resources on the supportive and rehabilitative care for people affected by cancer (see section 2, Information, for further detail about CAM education resources).

6.5 Recommendations

**General recommendations**

24. **Develop policy and service specifications to ensure the informed and safe delivery of CAM to people affected by cancer.** The Ministry of Health should establish a CAM expert advisory group that includes CAM service provider representation with a view to developing:
   - policies to ensure safe CAM practice
   - appropriate CAM therapy supportive and rehabilitation service components within an integrative care context
   - an infrastructure to promote robust CAM-specific research (for further information see MACCAH 2004).

25. **Provide access to high-quality CAM cancer information.** Service providers should ensure that those affected by cancer have access to high-quality CAM information and services, where these are available.

**Research and evaluation recommendations**

26. **Evaluative research is required to determine the safety and cost effectiveness of the various CAM therapy modalities in relation to providing support to people affected by cancer.** Robust research is also needed to establish:
   - the perceptions, preferences, expectations and use of CAM by people affected by cancer
   - health professionals’ knowledge of, and attitudes to, CAM,
   - the perceived benefits and risks of the various CAM modalities for cancer patients
   - who is currently practising CAM therapies and their CAM training sources.

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


7 Support for Living Long-term with Cancer

7.1 Introduction

Supportive care is no longer limited to the treatment phase of cancer. 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 in some instances given rise to a variety of new challenges for those who either experience a long-term remission or survive cancer long-term. Some of those affected by cancer require very little continued care and support and will simply pick up their lives from where they left off prior to their cancer diagnosis and treatment. Others may be left with physical or psychological effects resulting from the treatment of their cancer, which may require ongoing support to help them to live independently and resume their pre-cancer activities and interests.

Arrangements for ongoing monitoring and surveillance of those affected will also be required in case a person’s cancer condition relapses, to check for subsequent comorbid conditions that may arise, and to keep a watch out for any late effects that may result from their cancer treatment and may require specialised assistance and support.

The post-treatment and sometimes long-term continued care and support requirements of survivors of cancer can take a range of forms and require the support of various health and allied professionals and support workers. For instance, they may require ongoing assistance with:

- equipment and prostheses
- physiotherapy
- stoma and continence therapies
- lymphoedema therapy
- dietary and nutritional support
- speech and language therapy
- psychological counselling (eg, regarding sexuality, sexual functioning, adjustment, reduced quality of life, fear of recurrence, and post-traumatic stress following a diagnosis of cancer)
- oral and dental health care
- genetic and fertility counselling
- self-management support techniques, including self-support groups
- occupational therapy
- workplace and employment issues
- changing and maintaining behavioural lifestyle changes, such as improved nutrition and physical activity, quitting smoking and the management of fatigue
- household tasks
- child care
- family support (eg, respite care)
- accessing mutual support and education groups.
Some forms of support call for the input of professional services beyond the workplace ambit of health professionals. It is therefore important that those frontline professionals working in cancer treatment services:

- are aware of the benefits that post-treatment continued care and support can provide for people following cancer treatment
- establish ongoing relationships with relevant service support providers
- assess and identify each cancer patient’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
- ensure that the person affected by cancer and their carers know how to access the support services.

### 7.2 Definitions

**Rehabilitation** following the treatment of cancer attempts to maximise the ability of those directly affected to function as normally and fully as possible in their everyday life activities; promote independence, dignity and quality of life; and generally assist them to adapt to living with cancer long-term.

**Long-term effects** refer to adverse effects occurring during treatment for cancer and persisting beyond the end of treatment. In contrast, late effects are the consequence of treatment or sequelae that appear many months or years following treatment.

**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. 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. People living with cancer long-term receive a planned approach to their continued care and support needs that includes needs assessment, goal setting, an ongoing care plan, regular evaluation, and referral to appropriate specialist support and care services as required.
3. Continued care and support services are readily accessible, and provided in a timely and acceptable manner to those living with cancer long-term.
4. Health professionals and support workers working with people affected by cancer receive culturally appropriate education and training that enable them to assess people’s continued care and support needs and to make appropriate referrals to specialist services.
7.4 Context and rationale

Recent evidence from the US 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 US 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 similarly 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 (NZHIS 2007).

Survivors of cancer can face life-long health risks and challenges as a result of exposure to cancer treatments; for instance, comorbid health conditions, subsequent fertility and genetic issues, and changes to lifestyle behaviours (Oeffinger and McCabe 2006). Some survivors of cancer may experience mobility, physical and psychological functioning limitations that may seriously affect their daily activities and lives, which in turn can compromise their wellbeing and feelings of self-worth (NICE 2004).

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

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

- there was variable availability of access to rehabilitative 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 considered most likely to experience access problems to these types of services.

Currently we lack any in-depth knowledge of what rehabilitation services are available regionally for people with cancer and what, if any, the workforce issues are. This suggests a need for a stocktake and gap analyses to be undertaken at a regional level.
7.4.1 Managed long-term surveillance

The short-term continued support needs of adults receiving treatment for cancer should be routinely assessed throughout the treatment period, while 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’.

The duration of continuing surveillance following treatment for cancer tends to vary. For instance, in the US 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 to a person’s GP.

In recent years the ‘shared care model’ has increasingly become the standard for managing patients with ongoing care and support needs. Shared care refers to the care of a person with cancer that is shared between two or more clinicians of 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, including the early detection of (and therefore more treatable) late effects of cancer treatment.

The NICE (2004) 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, for head, neck and bone tumours. However, approaches are reportedly 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’ have been identified as being at the time of diagnosis, during treatment and on discharge from cancer treatment services; this is when 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 promoting patients 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).
7.4.2 Training to identify continued care and support needs

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 (Cole et al 2000, cited in NICE 2004).

7.5 Recommendations

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<th>Service provider recommendations</th>
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<td>30. Develop and utilise continued care and support assessment protocols and tools. Formal protocols and assessment tools are required to ensure that the continued care and support needs of people affected by cancer are routinely and regularly assessed through the cancer treatment phase and at the point of discharge. The protocols should incorporate specifications for long-term follow-up by primary health care providers.</td>
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<td>31. Ensure a seamless interface between hospital and community-based continued care and support services. Key workers (eg, social workers, patient navigators, kaimahi hauora / Māori health 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 support service settings for all cancer patients and their families/whānau. Hospital-based multidisciplinary teams should endeavour to establish relationships and co-ordination mechanisms with relevant support services (eg, kaimahi hauora / Māori health hospital services, PHOs, primary health care providers, including Māori and Pacific service providers, CCNZ and Work and Income New Zealand). Agreement should be reached on establishing responsibilities for agency-specific assessments, referral procedures and information sharing.</td>
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<th>Workforce development recommendations</th>
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<tr>
<td>32. Establish systems to assess ongoing care and support training needs for hospital and community-based service providers. Regional systems should be established to assess the training needs of cancer treatment support team members regarding the provision of continued care and support needs and the monitoring and surveillance of potential late effects following cancer treatments, where warranted.</td>
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</table>
Research and evaluation recommendations

33. **Determine the efficacy and effectiveness of continued care and social support for people affected by cancer.** Continued care and support services and efforts to establish effective co-ordination of social support services should be accompanied by systematic evaluation.

7.6 References


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 even more focused at critical 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 particular 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 patient is deemed ‘palliative’.

Many of those grappling with the impact of cancer look for guidance and strength to help them through their cancer pathway. Some may seek spiritual support and search for meaning to their lives and within their illness from:

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

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

8.3 Objectives
1. As part of an integrated support approach, those affected by cancer are offered spiritual support, if and when they need it at any time during the cancer journey/pathway, to enable them to make sense of and cope with the difficulties cancer presents for them and their family/whānau, and to foster hope and promote wellbeing.

2. Health professionals are able to acknowledge the religious, spiritual and existential issues and needs of those coping with cancer in a flexible, non-judgemental, non-imposing and culturally safe manner and attend to those needs by making appropriate referrals.
8.4 Context and rationale

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

- people have insufficient choices for whom they can call on 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 the health professional’s part to call on these spiritual support services, or they may feel awkward talking about spiritual matters with their patients.

Evidence from the US suggests that health professionals in that country receive little or no education about the possible relationship between religious/spirituality factors and health outcomes (Thoresen and Harris 2002). The situation is reported to be similar here in New Zealand. Some health professionals may be reluctant to ask questions about a person’s religion or spiritual views because they consider these matters to be private. Others may feel uncomfortable or consider themselves lacking 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 considered best placed to pick up on patients’ spiritual needs and make referrals to hospital chaplains or counsellors, or other appropriate people where a need is expressed (Gysels and Higginson 2004). However, all members of multidisciplinary teams caring for those affected by cancer should be able to respond appropriately 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 health outcome relationships in terms of risk of disease, survival times, coping with bereavement (NICE 2004) and a reduction in all-cause mortality (Thoresen and Harris 2002). However, the latter review suggests a need to strengthen future research methodologies and clarify conceptualisations of religious and spiritual factors.

A review undertaken by Ramondetta and Sills (2004) suggests that religion and spirituality are an important quality of life measure, especially for people receiving palliative care. This same review found that most seriously ill patients 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 2004; Dein 2006). In this country the involvement of the wider whānau and fono throughout the cancer journey has been found to be a key coping and spiritually sustaining strategy for both Māori and Pacific peoples (Waitemata DHB Health Gain Team 2006). The spiritual dimension of the Māori Te Whare Tapa Whā (four walls of the house) health model, as developed by Durie (1994), is considered an essential but interacting requirement for health. In Pacific cultures the underlying cause of illness is believed to be religious, spiritual or psychological, as opposed to solely physiological (Waitemata DHB Health Gain Team 2006). The recently developed New Zealand-specific Fonofale Model of Health encompasses all the various Pacific cultural groups that reside in this country, and like Te Whare Tapa Whā incorporates culturally specific world views and beliefs about health (Ministry of Health 2008).

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 because they are delivered in a manner that is culturally appropriate (Ministry of Health 2008; Durie 1994).

8.5 Best-practice service components

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 and spiritual care for people affected by cancer should be an integral and core component of all cancer treatment and support services.

Health professionals working in cancer treatment and support services should:

- have access to, and establish working relationships with, suitably qualified, recognised spiritual leaders and counsellors who can act as a resource for people affected by cancer and staff caring for those people
- be familiar with, and know how and where to access, spiritual information resources, hospital chaplains and other spiritual leaders
- be trained to have a basic understanding of the spiritual needs of patients and their carers, including being aware of and sensitive to the relationship between culture, ethnicity and spiritual beliefs, especially those relating to Māori and Pacific peoples
- have access to and be familiar with their workplace’s religious/spiritual assessment procedures.

An assessment of spiritual needs need not be formally structured. Suitable questions can be included in general medical assessment instruments. The questions asked will need to vary to suit the various ‘stages of cancer’ and other possible intervening circumstances. At the broadest level, questioning should identify whether there is any particular person(s) they might want to speak to about spiritual matters.
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 (e.g., 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.

8.6 Recommendations

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<tr>
<td>34. Provide access to spiritual support services for people affected by cancer.</td>
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<th>Service delivery recommendations</th>
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<td>35. Ensure all staff are familiar with standard spiritual assessment arrangements and referral procedures.</td>
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<th>Workforce development recommendations</th>
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<td>36. Raise professional awareness of the spiritual needs of those affected by cancer.</td>
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8.7 References


9 Co-ordination of Cancer Support

9.1 Introduction
People affected by cancer may require supportive care at various points along the cancer pathway. In this country these support services tend to be delivered by a range of government and non-government service providers, from multiple and sometimes widely dispersed settings. The complexity of the pathway is further complicated by the fact that many patients and their carers have to travel considerable distances, for lengthy periods of time, in order to access the specialist services required to treat cancer. As a consequence, many people – especially those who already face inequalities in cancer outcomes – find the cancer pathway complicated and 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 patient navigator, to help guide and support patients to access the services they need throughout their cancer journey
- linking Māori, Pacific and other cultural groups of patients and carers to culturally specific cancer support services, where these are available
- an ability on the part of health care professionals to be flexible in their responses to the changing needs of patients and their carers as they journey along the cancer pathway
- establishing information transfer systems to ensure that timely and relevant information follows the patient within the cancer treatment centre or hospital, and between this and their external care and support providers, mainly the patient’s primary health service provider.

9.2 Definition
Care and support co-ordination is a comprehensive approach that seeks to achieve continuity of care and support for patients, their family/whānau and carers. The approach aims to ensure that all care and support are delivered in a responsive, integrated and timely manner in order to meet the care and support needs of those affected by cancer.

9.3 Objectives
1. People affected by cancer have ready access to support services if, when and where they need them.
2. Service providers deliver the support in a way that is perceived by those affected by cancer as timely and seamless.
3. The services provided are of the highest possible quality and are appropriate to the support and cultural needs of those affected by cancer.
9.4 Context and rationale

Evidence and feedback from the 2006 Ministry of Health-funded patient pathways studies indicate that to deliver care and support that is perceived by those affected by cancer as both timely and seamless requires the following essential service components and arrangements:

- **quality planning and service provision** based on comprehensive service mapping, needs assessments, workforce stocktakes, and the development of support service directories

- **development and provision of high-quality support service information** for those affected by cancer about the support options open to them

- development and implementation of **patient and carer support needs assessments tools**

- **timely referrals** and transfer of relevant patient information to service providers delivering care and support

- **provision of cultural advisors, guides or patient navigators** to support those affected by cancer and to facilitate their access to care and support services

- **co-ordination within multidisciplinary teams**, which requires the team to discuss the needs of individual patients at team meetings, record the outcomes of those discussions and communicate these to the patient and their carer (with the consent of the patient), and periodic reviews of the dynamic processes within the team and with other teams to ensure continuity of effectiveness

- **co-ordination between teams** – in some instances, care and support services may have been organised and accessed by patients and their carers away from their home base (eg, while receiving treatment from a regional or specialist treatment centre), in which case mechanisms need to be established to ensure comprehensive and timely information is transferred to the patient’s locally based care and support team.

The regional cancer control networks have been established to provide leadership and oversight to facilitate:

- improved co-ordination of care and support for cancer patient groups across geographic areas and between primary, secondary and tertiary providers

- the development of collaborative links 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, now has an increased focus on integrated and co-ordinated service delivery and managed care and will likely be a key player in the future delivery of supportive care in community settings.
9.4.1 Co-ordinating access to support services across the cancer pathway

As noted earlier, in 2006 the Ministry of Health funded a number of projects that sought to:

- map the treatment, care and support journeys of individuals affected by cancer from various population groups, particularly Māori, non-Māori, Pacific people and those living in geographically isolated areas
- identify service improvement opportunities from the perspective of the person affected by cancer and their carers (Noble et al 2006; Waitemata DHB 2006; Waitemata DHB Health Gain Team 2006; Hutt Valley and Wairarapa DHBs 2006).

The studies indicated a need to develop and implement specific inpatient and community-based co-ordinating cancer service models to help improve care and support co-ordination and information sharing among cancer service providers. The studies’ findings also added additional weight to recommendations emanating from earlier research (Cormack et al 2005), including a call to develop Māori kaupapa, community-based cancer support services. These types of services are seen to have considerable potential to help address the barriers many Māori experience in accessing mainstream cancer services that have resulted in significant and persistent cancer outcome inequalities between Māori and non-Māori.

The cancer pathway mapping studies also identified a similar need to develop culturally specific cancer support services in appropriate settings for Pacific peoples, based on these populations’ poorer cancer health outcomes, their generally high health needs, and their ‘vulnerability to disengaging from health services’ (Waitemata DHB Health Gain Team 2006).

In response to these studies, the Ministry of Health funded three pilot community cancer support services on the West Coast of the South Island, Rotorua and Auckland. Evidence suggests that this type of community service may be effective in supporting Māori and rural communities to better access and navigate the cancer service continuum community. A number of DHBs have also established local ‘patient navigator’ positions.

9.5 Cancer support service co-ordinating approaches

There are a number of cancer service co-ordinating service models currently operating here in this country.

9.5.1 The care co-ordination approach

The care co-ordination approach is largely driven by the various members of a multidisciplinary team from within a clinical treatment service setting. This type of cancer care co-ordination encompasses the various aspects of cancer care, including regular multidisciplinary meetings, clinical treatment and the provision of care, psychosocial patient and carer needs assessments, information provision, systematic referral practices, data collection, and the development of common protocols. The patient’s GP is also regarded as a member of the multidisciplinary team. Although care co-ordination does not tend to specifically include supporting patients and their
family/whānau through the non-medical aspects of the cancer journey, the social worker member of the multidisciplinary team may often take on some of the support responsibilities as well.

9.5.2 BreastScreen New Zealand

BreastScreen New Zealand is a clinically driven model that supports and co-ordinates follow-up activities 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 for both their psychosocial and physical needs. The role also calls for patient advocacy, meeting and liaising with the multidisciplinary team, and the management of a BreastScreen New Zealand database.

9.5.3 Patient navigator programmes

Patient navigation refers to individualised non-clinical assistance offered to patients, their families and care givers to help them overcome systemic health care barriers and facilitate timely access to quality medical and psychosocial care throughout the cancer service continuum (Epstein and Street 2007). Cancer patient navigator programmes are now well established in some Canadian provinces, and the concept has recently been gathering momentum in the US. An evaluation of the Canadian patient navigator programmes found them to have:

- improved the overall co-ordination, quality and consistency of care and support
- provided timelier referrals
- increased patient and carer awareness and utilisation of community supports
- increased earlier referrals to cancer support services, including home and palliative care
- gained widespread support for their role by health professionals, patients, families and administrators alike
- increased patients’ knowledge about their cancer
- helped co-ordinate appointments, arrange referrals to community support services, assist with the logistics of getting patients to cancer treatment centres, and locate sources of financial support for patients and their families.

9.5.4 An example of a co-ordinated care approach in a New Zealand context

The Hunga Manaaki hospital-based cancer support pilot programme was established at the end of 2007 and is funded by the Ministry of Health. The service aims to reduce cancer inequalities faced by Māori in the Rotorua district by increasing this population’s uptake of cancer treatment services. The pilot extends an existing Te Kahui Trust hospital-based Māori health service. The primary focus of the cancer care pilot is to provide support for patients and their whānau post-diagnosis by way of:
• hospital-based workers, whose role it is to support the Rotorua hospital’s cancer ward’s patients and their whānau throughout the hospital stay
• a linked community-based team of community workers, whose responsibilities include supporting those affected by cancer, advocating on their behalf and providing health promotion following the patient’s discharge from hospital.

In addition to the above cancer support co-ordinating programmes, the Ministry of Health has also funded two PHO-led community-based patient navigator cancer support services. Both services aim to reduce cancer health inequalities. One is rurally based and caters to people living on the West Coast who are affected by cancer; the other is located in Auckland and specifically aims to improve cancer service uptake among Māori.

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

The limited international evidence available on the outcomes and effectiveness of the patient navigation and care co-ordinating service models indicates a need for independent evaluations to ensure they achieve the desired improvements from the perspective of both those affected by cancer and the service funders, planners and providers.

9.6 Recommendations

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<tr>
<td>37. Develop culturally appropriate co-ordinating cancer care and support service models to improve access to support services for all people affected by cancer. Service providers need to deliver care and support in a way that is perceived by people affected by cancer as timely and seamless.</td>
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<tr>
<td>38. The development of co-ordinating cancer care and support models should be accompanied by systematic evaluations.</td>
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9.7 References


Noble FD, McKinlay E, Cormack D. 2006. *The Journey of Treatment and Care for People with Cancer on the West Coast*. West Coast District Health Board and the Wellington School of Medicine and Health Sciences, Otago University.


Appendix 1: Expert Advisory Group Membership

Jo Anson
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Ministry officials (for all or some of the project)
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Velma McClellan (Contractor)
Appendix 2: Useful References for Tools to Help Implement this Guidance


