

# **Support and Rehabilitation**

**Report of the Support and  
Rehabilitation Expert Working Group  
to the Cancer Control Steering Group**

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# Introduction

This document outlines the recommendations of the support and rehabilitation expert working group and provides supporting documentation for these.

## Process

The Support and Rehabilitation Expert Working Group had two face-to-face meetings and two telephone conferences. At its first meeting the group discussed background papers relating to the development of the strategy, including those of overseas initiatives.

Members agreed that the priorities and goals included in the *Canadian Strategy for Cancer Control: Supportive Care/Cancer Rehabilitation Workgroup Final Report* (2002) provided a very strong basis for consideration in the New Zealand context. The group also agreed to adopt the Canadian workgroup definition of supportive care/cancer rehabilitation as: ‘the provision of the necessary services, as determined by those living with or affected by cancer, to meet their physical, social, emotional, nutrition, informational, psychological, spiritual and practical needs throughout the spectrum of the cancer experience’ (Canadian Strategy for Cancer Control 2002).

The group concurred with the Canadian recommendations that:

- high-level acknowledgement is needed of evidence that supportive care is essential at every stage along the cancer care continuum and makes a difference to better coping, lessens distress and increases wellbeing
- leadership at all levels of cancer programmes and services both local and national is essential to engendering cultural and organisational change in order to achieve support and rehabilitation goals
- education of health professionals about the importance of support for all cancer patients is essential
- a supportive care plan for each person diagnosed with cancer is a requirement
- support and rehabilitation must be accessible, appropriate and affordable for all (Canadian Strategy for Cancer Control 2002).

A wide range of groups involved in patient and family support were identified, highlighting the complexity of the area. Included, for example, are family/whānau, neighbours, friends, colleagues, schools, churches, general practitioners, nurses, traditional healers, clergy, chemists, physiotherapists, occupational therapists, dentists, dieticians, home-helpers, counsellors, alternative therapists, social workers, speech language therapists and pain therapists. The group acknowledged that government and non-government agencies have responsibility for support and rehabilitation, thereby requiring collaboration, co-ordination and consistency of services across both sectors.

## **Goal**

**Capitalise on financial investments (health sector, personal, whānau and community) through support and rehabilitation to ensure continuing optimal quality of life and integration into the community.**

## **Objectives**

Proposed objectives to achieve this goal are as follows:

1. Establish integrated programmes of supportive care and rehabilitation with defined leadership.
2. Ensure supportive and appropriate programmes and services are accessible to Māori across the cancer control continuum.
3. Ensure all survivors of childhood cancer receive timely and ongoing support and rehabilitation, including early identification of and intervention in late effects.
4. Ensure all people with cancer and their families are able to access the appropriate support and rehabilitation resources.
5. Improve return to work and quality of life of cancer patients through systematic assessment and appropriate multidisciplinary intervention for their social and vocational needs.
6. Ensure the active involvement of consumer representatives across the spectrum of cancer control activities and services.

# **Objective 1: Establish Integrated Programmes of Supportive Care and Rehabilitation with Defined Leadership**

## **Aim**

Maximise adjustment and adaptation, and reduce distress amongst those receiving, or involved in, cancer care.

## **Background**

All those associated with cancer care potentially contribute to processes and practices of supportive care and rehabilitation. However, some health professionals (cancer nurses and specialists) and disciplines (for example, social work, occupational therapy, psychology, psychiatry and pastoral care) and organisations (for example, Cancer Society and District Health Boards (DHBs)) are more likely to be involved in delivering such services. Across New Zealand cancer centres there is, at present, uneven provision and access to these resources. In some centres such resources are clearly integrated and embedded within routine service delivery. This allows for routine consideration of supportive care and rehabilitation needs at every stage, allowing for early detection of problems, appraisal of risk factors, preventative actions and prompt interventions. Other centres may activate or, where possible, ‘contract in’ such resources only when it is apparent that problems are directly impacting on people’s treatment. In the absence of a national policy regarding supportive care and rehabilitation, cancer care providers have developed in this ad hoc way. It is reasonable to conclude therefore that significant gaps in service provision exist.

Elevated rates of psychiatric and psychosocial morbidity among cancer patients are well documented in many systematic studies and reviews (Holland 2002; Trijsburg et al 1992). There is growing awareness that supportive care and rehabilitation approaches buffer cancer patients and their caregivers from such morbidity and maladjustment (Kornblith 1998). Furthermore, for those who go on to develop intrusive or more severe problems, a range of psychosocial and psychological interventions has been found to be beneficial (Anderson 1992; Fawzy et al 1995). Benefits include improved quality of life and illness adaptation, reduced psychological distress and reduced rates of clinical syndromes. As such, there is a call for guidelines regarding the provision of such services (Schneiderman et al 2001). Internationally it is accepted that supportive care and rehabilitation is desirable at every stage along the continuum of care.

## **Recommendations**

### **Goals**

- Cancer centres adopt a common understanding of the principles and practice of supportive care and rehabilitation, and these are integrated across the continuum of cancer care.
- Those most at risk of developing, or who do develop, significant psychosocial distress and dysfunction are identified early, and provided with appropriate psychosocial/psychological/psychiatric assessments and interventions.
- Oncology-specific education is provided for all supportive care and rehabilitation disciplines, and supportive care/rehabilitation education is available to oncology and oncology-related disciplines.

### **Targets**

- Principles of supportive care and rehabilitation become formal policy at a central government level. As such, the objective needs to be accepted, circulated, and utilised by those involved in cancer care.
- Major providers of cancer care (for example, DHBs, Cancer Society) actively plan and implement integrated services, and these plans are developed in conjunction with recognised leaders in the field and evolving international guidelines (Schneiderman et al 2001).
- Major providers of cancer care and other key stakeholders involved in workforce development (Ministry of Health, Ministry of Education, Clinical Training Agency, DHBs, non-government organisations (NGOs) and so on) actively endorse and support training opportunities in supportive care/psycho-oncology.

### **Actions**

- Guidelines to assess and address the psychosocial needs of all people with cancer are developed.
- Organisations centrally involved in cancer care adopt the framed guidelines.
- These guidelines are distributed to, and endorsed by, key stakeholders.
- Training opportunities in supportive care and psycho-oncology are developed by relevant education providers.

## **Expected outcomes**

The adoption of comprehensive supportive care and rehabilitation programmes should lead to specific processes (for example, those involved in cancer care appraising broader psychological considerations and approaches) and specific outcomes. ‘Processes’ are not easily measured as they form part of a culture of care and reflect attitudinal and philosophical considerations. However, potentially measurable outcomes include the following:

- reduced overall cancer-related distress
- reduced caregiver (family and health professional) burden
- increased psychosocial adjustment and quality of life
- reduced complications from physical and medical interventions, and reduced doctor and hospital visits
- increased patient satisfaction
- reduced staff burnout
- increased ability of staff and caregivers to respond to the psychosocial needs of those with cancer
- increased numbers of cancer care staff completing training in psychosocial aspects of cancer/psycho-oncology.

## **Objective 2: Ensure Supportive and Appropriate Programmes and Services are Accessible to Māori across the Cancer Control Continuum**

### **Aim**

Reduce disparities in access to programmes and services between Māori and non-Māori.

### **Background**

Cancer is a leading cause of morbidity and mortality among Māori. Significant disparities exist between Māori and non-Māori in relation to the incidence of cancer, cancer mortality rates and utilisation of cancer services. Cancer is the leading cause of death for Māori women and the second leading cause of death for Māori men. In 1998 the Māori female death rate was 78% higher than the non-Māori female rate (Ministry of Health 2001).

Under-utilisation of primary and tertiary care services and late presentation of cancer have a profound effect on health outcomes for Māori and contribute to the disparities in health status between Māori and non-Māori. *Hauora: Māori Standards of Health III* (Pōmare et al 1995) notes that a number of barriers to accessing services need to be overcome in order to improve Māori health outcomes. These barriers are: cost; location of services, particularly in relation to travelling distances; acceptability of the service in terms of legal, ethical, physical and cultural safety; and attitudes towards services, including reluctance to attend general practice clinics, and whakamā (embarrassment). Barriers to access tend to be multi-dimensional and closely interrelated, so they need to be addressed as a whole, rather than as a number of separate issues.

Differential access to health services is therefore an important issue. Further, the predominantly mono-cultural mode of ‘one fits all’ is inadequate. For example, kaumātua services to Māori are limited and often not recognised. There are some indications that access to hospice services is improving for Māori.

Māori approaches to health are primarily based on the view that hauora, or holistic health, is the product of wellbeing at the physical, spiritual, psychological and social levels. There are many Māori models of health in use that encompass this approach, including Te Whare Tapa Whā, or the four corner posts of health (Pōmare et al 1995), Te Pae Mahutonga, or the Southern Cross (Durie 1999), and Te Wheke, the Octopus (Pōmare et al 1995), to name just a few. Services being delivered to Māori need to reflect an understanding of hauora Māori and approaches that appropriately address Māori health needs.

Kaupapa Māori, or ‘by-Māori, for-Māori’, services are being increasingly integrated into the mix of health and disability services in New Zealand. Kaupapa Māori health services are those that are planned and delivered by Māori health workers and professionals using cultural concepts and values. While the target audience for these services is Māori and their whānau, they are usually also accessible by other members of the community.

In addition to services specifically developed within a Māori cultural framework, there is a need to ensure that all services delivered to Māori demonstrate a level of cultural competency. Durie's report, *Cultural Competence and Medical Practice in New Zealand* (2001), notes the need to ensure that treatment and service delivery in New Zealand are based on the 'cultural competence or capacity of health workers to improve health status by integrating culture into the clinical context'.

*Whakatātaka: Māori Health Action Plan 2002–2005* (Minister of Health and Associate Minister of Health 2002b) is the implementation plan for *He Korowai Oranga*, and provides a framework and specific priority action areas to improve Māori health outcomes. There are four pathways that need to be addressed:

- development of whānau, iwi and Māori communities
- active participation by Māori at all levels of the health and disability sector
- effective health and disability services – timely, high-quality, effective and culturally-appropriate services to improve health and reduce inequalities
- intersectoral – with the health and disability sector taking a leadership role across government sectors and government agencies to achieve whānau ora by addressing the broader determinants of health.

Full implementation of *Whakatātaka* has the potential to address many of the issues faced by the health and other sectors that impact on Māori health status generally. However, this will require commitment from all sectors involved in cancer control.

## Recommendations

### Goal

Increase Māori access to cancer services through the four pathways of *Whakatātaka*.

### Target

Ensure cancer control programmes and services are accessible to Māori.

### Actions

- Implement the four pathways as outlined in *Whakatātaka* (Minister of Health and Associate Minister of Health 2002b).
- Ensure that treatment services have policies in place that recognise the specific needs of Māori.
- Develop culturally-appropriate practices and procedures as an integral requirement in the purchase and provision of support and rehabilitation services for Māori.
- Ensure that palliative care services have policies in place that are specific to addressing the needs of Māori, and that these policies are implemented and monitored.

- Improve linkages between palliative care providers and Māori development organisations to assist in meeting the specific needs of Māori.
- Further develop and maintain Māori health providers, and improve the accountability of mainstream providers for Māori health outcomes.

#### **Expected outcome**

An improvement in the cultural appropriateness of cancer services to Māori.

# **Objective 3: Ensure all Survivors of Childhood Cancer Receive Timely and Ongoing Support and Rehabilitation, including Early Identification of and Intervention in Late Effects**

## **Aim**

Establishment of comprehensive, nationally-consistent support and rehabilitation services, including late-effects programmes for survivors of childhood cancer.

## **Background**

It has been estimated that by the year 2000, 1 in every 900 young adults would be a survivor of childhood cancer (DeLaat and Lampkin 1992). Although remarkable survival rates in malignancies of childhood have been achieved over the last 30 years, there is emerging evidence of major physical and psychological sequelae which, if not identified early and addressed by intervention strategies, can result in serious loss of quality of life. The impact of such 'late effects' of the disease or its treatment will be evidenced by escalating utilisation of other social services in New Zealand, such as education, employment and welfare.

### **Late effects**

Many types of childhood cancer are now considered curable, but the lifesaving treatments may produce lasting damage to developing organs and structures. The growing child may be susceptible to the effects of the various treatment modalities of cancer on normal tissues – effects that may not become apparent until the child matures. Late effects can range in severity and are highly dependent on the specific cancer, the treatment received and the age of the child during therapy. For example, young children treated for brain tumours are at an increased risk for problems with growth and cognitive abilities, whereas adolescents undergoing surgery and chemotherapy for osteogenic sarcoma may have reproductive dysfunction or problems with body image and self-esteem.

#### *Intellectual, educational and behavioural sequelae*

Cranial radiation has often been implicated as the agent most responsible for long-term neurocognitive and academic deficits among survivors of leukaemia and brain tumours. However, recent studies show that intrathecal and high-dose systemic chemotherapy can also be linked with specific deficits (DeLaat and Lampkin 1992; Silber et al 1992; Auger et al 2000; Kramer and Moore 1989).

Reports in the literature indicate that the changes that seem to be most important to remembering and learning are (brain) changes, which appear late, usually two to five years following completion of therapy, and which do not disappear with time (Mulhern and Copeland 1997). The negative effects of treatment of childhood cancer appear greatest for those treated in infancy and early childhood, and would seem to be dose related (Moore et al 2000).

The use of prophylactic central nervous system chemotherapy in acute lymphoblastic leukaemia has significantly contributed to disease-free survival, but there is some evidence suggesting that there may be detrimental effects to children's cognitive abilities which may subsequently manifest in declined intellectual and academic skills (Auger et al 2000). Declines in these areas could negatively affect the child's future education and economic opportunities.

#### *Educational needs*

Most survivors of an adult form of cancer have already completed the education process and, having usually experienced some sort of vocational training, are in employment. Conversely, children with cancer are at either preschool or at an early stage of their formal education when diagnosed. Unless there is recognition of possible learning difficulties and a strategy in place to provide remedial assistance, they can be hugely disadvantaged (Hays et al 1997). Moore et al (2000) indicate that 'improving or maintaining pre-treatment academic ability in children who receive central nervous system (CNS) treatment is an important health care priority that may have long-term implications on the child's quality of life and ability to survive independently'.

Some children appear to display a general decline in IQ resulting in lowered intellectual function; others show deficits in special skills, including attention, concentration and mathematical reasoning (Mulhern 1994). Other deficits described in the literature include poor eye-hand co-ordination, decreased speed in processing information and impairment of short-term memory. Children with CNS disease treated with high doses of cranial irradiation are at considerable risk in terms of compromised educational outcomes, with some work indicating that 50% have special education needs (Hill et al 1998).

Those needs of children impacted by consequences of cancer are clearly identified in the literature. However, in this country they are largely unmet on a consistent and equitable basis. Paediatric oncologists are constantly attempting to modify protocols to reduce the risk of educational problems, while achieving the best possible outcomes in terms of survival. It is important that other services support these efforts by providing the means to reduce the impact of cancer and its treatment on learning and school performance.

To be able to measure the effects of the disease or its treatment on cognitive function a neuropsychologist or educational psychologist who is experienced in working with children should perform a baseline evaluation. This should be carried out at the earliest opportunity after diagnosis, then at intervals. Without a baseline evaluation it is difficult to make objective analysis of acquired damage and thus plan remedial therapy. Recent research by psychologists suggests that cognitive remediation may be helpful in minimising these problems to focus on improving memory, attention, and maths skills (Butler and Rizzi 1995).

#### *Endocrine consequences*

Endocrine complications of cancer treatment may include ovarian or testicular dysfunction resulting in infertility or abnormal pubertal progression, impaired growth, hypothyroidism and pan-pituitarism (DeLaat and Lampkin 1992). The impact of combination cytotoxic

chemotherapy upon gonadal function depends on the sex and age of the child undergoing treatment and the nature and dosage of the drug(s). The risk of gonadal irradiation damage is related to the dose delivered and the age at treatment, and both testes and ovaries are vulnerable to radiation damage (Shalet et al 1985; Waring and Wallace 2000). These problems will be identified along with other possible late effects during clinical follow up. However, strategies and resources to provide rehabilitation or the means to lead a positive quality of life are not found within the existing health services.

#### *Employment and financial difficulties*

Stable employment is described as one measure of security and social independence. Mostow et al (1991) in an analysis of 40 non-CNS adolescent cancer survivors reported a significant risk (more than twice that of controls) of permanent unemployment. Furthermore there was evidence of discrimination based on their medical history (Li et al 1984; Yebby et al 1989). This is consistent with other reports and can cause huge loss of self esteem, psychological problems and poor quality of life. As a result of these difficulties survivors of childhood cancer are at risk of discrimination not only in the workplace but also experience difficulty in obtaining health, travel, house and life insurances and mortgage finance. Such denial of insurance coverage because of a history of past health problems in childhood (but with a long disease-free period at time of application) impacts very negatively upon their efforts to become productive members of society.

## Recommendations

### Goals

- Routine assessment of cognitive function of all children who may be at risk of developing problems by a neuropsychologist as soon as possible after diagnosis and at intervals.
- The establishment of late-effects clinics in tertiary centres staffed by a multidisciplinary team which provide high-quality surveillance and identification of problems in survivors of childhood cancer.
- Recognition of the rights of children to receive education as stated in the Human Rights Act 1993, and the United Nations Convention on the Rights of the Child through active intervention and provision of remedial educational programmes on a nationally-consistent basis.
- Access to psychological support, career counselling, and so on.
- Recognition of possible fertility problems and access to funded consultation and treatment at fertility clinics.
- Enabling and encouragement of the parents of children with cancer to participate in planning and decision-making about their child's special education.
- Emphasis and promotion of a healthy lifestyle, with a focus on modifiable risk factors such as smoking cessation programmes and dietary advice.

- Advocacy and public awareness/educational strategies to ensure there is no discrimination of survivors of childhood cancer by prospective employers, financial institutions, insurance companies, and so on.

### Targets

- The Ministries of Health and of Education will recognise the inequity of access to appropriate services for children with cancer and survivors of childhood cancer.
- The Ministries of Health and Education will work co-operatively to develop guidelines to address the health and educational needs of children with cancer.
- District Health Boards and appropriate educational services will implement the guidelines developed by the Ministries of Health and Education.

### Actions

- The Ministries of Health and Education, in collaboration with the Paediatric Oncology Steering Group, will work co-operatively to oversee the development of national guidelines for the support and rehabilitation of children and adolescents with cancer.
- District Health Boards and appropriate educational and non-government services will implement the guidelines developed by the Ministries of Health and Education.
- The Ministries of Health and Education, in collaboration with the Paediatric Oncology Steering Group, will work co-operatively to establish a comprehensive late-effects programme for survivors of childhood cancer.
- District Health Boards and appropriate educational services will implement the programme.

### Expected outcome

All survivors of childhood cancer will receive timely and ongoing support and rehabilitation, including early identification of and intervention in late effects.

## **Objective 4: Ensure all People with Cancer and Their Families are Able to Access the Appropriate Support and Rehabilitation Resources they Need**

### **Background**

An informal review of the resource provisions in four regions (Auckland, Wellington, Greymouth, Christchurch) indicated that access to necessary support and rehabilitation resources from both the government and non-government sectors varies according to local arrangements and the age at which cancer is diagnosed. In some situations, even within the same region, the availability of assistance is dependent upon the 'local knowledge' of some health professionals. This clearly creates inequity of access to support and rehabilitation.

It is reported that the variable interpretation of existing eligibility criteria for both disability and health-related needs has allowed resources to be available to some cancer patients and their families and not to others. One such example is the provision of equipment, personal care and funding that allows patients to remain in their own familiar environments when they might otherwise be in hospital. There are indications that the interpretation of existing policies is becoming increasingly restricted as funders look to more effectively manage their budgets.

It is clear that the difficulties relating to access of resources by Māori and Pacific patients and their families are often unacknowledged. As a consequence some needs may be largely unmet. The current lack of an integrated approach to access to support and rehabilitation services may well result in financial disadvantage for families and unnecessarily prolonged use of public hospital beds when other solutions are available.

There also appears to be variability in access to residential care in private hospital or hospices for patients who are unable to be cared for safely in their own homes. Income support and special benefits are available to cancer patients and their carers. These are means tested and may not meet the real costs associated with appropriate home care for patients.

### **Recommendations**

#### **Goals**

- All people with cancer and their families irrespective of age, location, or ethnicity to have equity of access to appropriate support and rehabilitation resources.
- Irrespective of age, appropriate residential care to be provided for those people with cancer unable to be cared for safely in their homes.
- Equity of access to be ensured for patients requiring residential, hospital or hospice care.

## Targets

- All people with cancer to be assessed at regular intervals to identify their resource needs by District Health Board staff and appropriate agencies to determine what action is required to address those resource needs.
- An integrated support and rehabilitation service for those with cancer and their families will be provided by the government and non-government sectors.

## Actions

- Assess current issues relating to access to support and rehabilitation resources. This would include:
  - defining the population groups
  - identifying current services being accessed and from what sources
  - identifying gaps and those groups which are most disadvantaged
  - defining the likely services needed over time
  - identifying the differences between resources available to those with cancer and those available for other conditions, illnesses and disabilities.
- Identify the process by which the above issues will be addressed.
- Identify the responsibilities of the government and non-government sectors in this process.

## Expected outcomes

- The resource needs of people with cancer and their families will be identified.
- National equity of access to appropriate resources including residential care for all people with cancer will be developed.
- Adequate funding for these resources will be provided.
- Collaboration, co-operation and communication between agencies currently providing resources to ensure effective care and effective use of resources will be achieved.

# **Objective 5: Improve Return to Work and Quality of Life of Cancer Patients through Systematic Assessment and Appropriate Multidisciplinary Intervention for their Social and Vocational Needs**

## **Background**

- Over 50 percent of people with cancer will be long-term survivors – many of them will be of working age (Berry and Catanzaro 1992). Many will want to pursue a career or job for economic reasons or for personal satisfaction.
- Many will carry over residual effects of malignancy, or of the treatment, or both, that may affect them at work. These may be physical effects, or indirect psychological or social effects, thus contributing to discrimination, a latent sequel of chronic disease (Corner 2000).
- Cancer patients may encounter outright or subtle discrimination in the workplace, and may encounter other workplace or physical barriers to the return to work.
- Many of these damaging effects could be avoided or minimised if they were addressed in a timely manner as an integral part of an individual treatment plan.
- Currently, cancer patients are defined as having ‘personal health needs’ as opposed to having a disability. If (instead of developing cancer) a patient had suffered a serious back injury at work, they would find themselves in a totally different treatment rehabilitation paradigm (ACC) with an ACC case manager to co-ordinate all appropriate measures with a positive goal of returning the patient to work (Injury Prevention, Rehabilitation, and Compensation Act 2001).
- The effects of malignancy vary widely according to the cancer site and its severity. The long-term prognosis varies extensively according to the cancer site, each with a different life expectancy and vocational outcome (Bottomly 1997).
- The psychosocial effects of cancer are just as potentially damaging to quality of life, and influential as to whether the patient returns to work, thus compounding the above issues (Goldberg and Habeck 1982; Little and Jordens 1998).
- Medical insurance is a special concern for cancer patients, with many having difficulty obtaining adequate coverage due to their past or present condition. They are classified as high risks, and a policy handling this category can be expensive and limited in coverage (Rothstein 1998).
- Despite the increasing numbers of people now living with cancer, the financial services industry remains cautious about doing business with them for life assurance and travel insurance (Schimmel 1999).

## **Recommendations**

### **Goals**

- Recognition of human rights for people disabled by any means, on the same basis as for those who are non-disabled.
- Screening model to include vocational rehabilitation within its scope, triggered at initial presentation.
- Effective referral of the cancer patient to all appropriate health care/counselling/vocational/therapy providers, and provision of appropriate information and resources, contextualised to the New Zealand health care environment.
- Advocacy and public education campaign on the role of cancer survivors in the workplace, aimed at patients, employers, healthcare professionals, insurance and financial institutions.

### **Targets**

- Human rights provisions will be articulated by central government, with a focus on the vocational, independent living and other quality-of-life outcomes for people with cancer.
- All cancer treatment centres and other providers will incorporate vocational rehabilitation considerations into treatment guidelines.
- Return-to-work plans (based on those developed for ACC clients) will provide a guide for cancer patients with the potential for vocational rehabilitation.
- Consumer outreach materials will alert cancer patients (employers, industry organisations and others) to issues/barriers and solutions/strategies regarding vocational, financial and insurance issues.

### **Actions**

- Develop materials on provisions of the New Zealand Public Health and Disability Act 2000, and Human Rights legislation with a focus on people with cancer.
- Work with the New Zealand Cancer Control Trust to develop initial screening tool with ‘triggers’ to assess vocational rehabilitation needs of cancer patients.
- Develop a vocational plan that includes realistic goals, timelines and outcomes for all participants.
- Undertake a campaign of public education and disseminate information materials to include the following points:
  - people diagnosed with cancer have a high chance of long-term survival and quality of life
  - it is normal for cancer survivors to want to return to the workforce/career
  - employees who have survived cancer tend to have an average rate of turnover, a satisfactory attendance and adequate work performance when compared to non-cancer employees

- cancer survivors may need (and are legally entitled to) ‘reasonable accommodation’ in the work setting to assist them to return to a normal work and general life environment after undergoing what is usually a traumatic life event.

### **Expected outcomes**

- Greater awareness of vocational needs as an integral part of the supportive care and rehabilitation of cancer patients.
- Appropriate treatment, resulting in better outcome and improved quality of life.
- Overall, a greater public awareness of the impact of cancer.

# **Objective 6: Ensure the Active Involvement of Consumer Representatives Across the Spectrum of Cancer Control Activities and Services**

## **Background**

The adoption of this priority will ensure that cancer control initiatives and activities are in line with government policy and in keeping with obligations to Māori outlined in the Treaty of Waitangi.

*The New Zealand Health Strategy* identifies the active involvement of consumers and communities at all levels as one of the seven fundamental principles that should be reflected across the health sector. The strategy states that any new strategies or developments that are carried out should relate to these seven principles (Minister of Health 2000).

Other national strategies also identify the importance of addressing consumer needs by consulting with consumers and communities. These include:

- *He Korowai Oranga: Māori Health Strategy Discussion Document* (Minister of Health 2001a)
- *The Pacific Health and Disability Action Plan* (Minister of Health 2002)
- *the New Zealand Disability Strategy* (Minister for Disability Issues 2000)
- *the New Zealand Primary Health Care Strategy* (Minister of Health 2001b)
- *Health of Older People Strategy* (Associate Minister of Health 2002)
- *the New Zealand Palliative Care Strategy* (Minister of Health 2001c)
- *Safe Systems Supporting Safe Care* (National Health Committee 2002)
- *The Child Health Strategy* (Minister of Health 1998)
- *The Youth Health Strategy* (work in progress)
- *New Zealand Health Sector Quality Improvement Strategy* (work in progress, completion due early 2003).

The focus on participation is seen as an essential way to provide a voice to consumers generally as well as specifically to Māori and also to Pacific peoples to address inequalities that impact on health and wellbeing.

## **Benefits of consumer participation and involvement**

The active involvement of consumers using a collaborative partnership approach will have the following benefits. The benefits outlined are based on those already identified in existing publications (FWHC 1992a, 1992b; Women's Health Action 2000a; Minister of Health 2000).

- Inclusion of Māori consumers will help ensure bicultural values are acknowledged and reflected.

- An informed and collaborative approach to decision-making is more likely with increased opportunities for consumer organisations to participate.
- Consumer participation will ensure there is a consumer focus.
- There will be increased recognition of the value of consumer input.
- Consumer input is less likely to be marginalised if it becomes commonplace.
- Consumers value a holistic approach where the whole person is considered: their whānau, beliefs and circumstances including social, physical, emotional, spiritual and psychological needs.
- There is likely to be a greater emphasis on self-help, wellness and ease rather than disease when consumer perspectives are included.
- Consumer input will also help a range of viewpoints to be taken into account and decision-making is more likely to reflect community values.
- The involvement of consumers will facilitate increased community access to information about cancer control as well as enhancing the community's understanding of the significance of the Cancer Control Strategy.
- There would be a greater sense of community ownership of cancer control activities.
- Decisions are more likely to be made **with** users of services rather than for them.
- Involving consumers is an effective way to balance an overly professional and academic approach.
- Consumers can make sure the impact of decisions are taken into account.
- The focus is less likely to be on people as 'numbers and statistics'.
- Consumers value information that is understandable and publicly available as well as the allocation of resources to services and treatments of demonstrated benefit.
- Reports, written work and material presented in other formats is more likely to use simple, clear language suitable for any audience and avoid confusing jargon.
- Consumer input can help ensure any jargon and terms used will be widely understood.
- There is more likely to be an opportunity to reach a shared understanding when consumers are involved.
- The outcomes/outputs are more likely to be acceptable to consumers.
- Input from consumers will help to identify ways to improve access for consumers to the most appropriate services and treatments.
- Consumer representatives have a role in highlighting the right of consumers to have sufficient information to make informed decisions and choices.

### **Current status**

Although the importance of consumer involvement and the role of consumer representatives have become quite widely recognised in New Zealand, particularly since the release of the Cartwright Report (1988) the implementation of consumer input has been piecemeal and ad hoc. This priority action provides an opportunity for a systematic

approach to the use of consumer representatives in cancer control activities. Countries such as Australia and the United Kingdom have well resourced initiatives in place that facilitate consumer participation and provide opportunities for consumer representatives to be involved in a systematic way (Oliver 1995; Department of Health 1993; Consumer Focus Collaboration 2000a, 2000b, 2000c, 2000d, 2000e; Commonwealth Department of Health and Aged Care 2001; Breast Cancer Network 2001). These provide working examples of what can be achieved with appropriate training, support and sufficient funding.

The situation in New Zealand at present is as follows.

- There are a minimal number of consumers involved as representatives in cancer control activities, although this is only in some activities and only at some levels.
- Consumer voices and concerns are not actively sought in many areas, for instance, in the assessing, guiding and formulation of the requirements for support and rehabilitation services.
- There is no organised approach to make sure that people most represented in the health statistics have a say on an ongoing basis in what the key issues are and what strategies would be appropriate. For example, the overall incidence of cancer is higher in Māori compared with non-Māori. Cancer incidence and mortality is also high in Pacific peoples. Women suffer from a number of cancers of the reproductive tract and men in manual and unskilled occupations are over-represented in the statistics.
- Health professionals and academics are able to participate in working groups, seminars, conferences and consultation processes as part of their paid employment and as an extension of their work. The situation is very different for consumers who either have to take time off from their usual jobs or make arrangements for childcare. Consumer groups don't usually have the funds to provide the financial support needed for their representatives. Guidelines have been produced to assist those interested in working with consumers to help overcome these obstacles (Women's Health Action 1999a).

## Objectives

- All cancer control groups and related activities will have informed consumer representatives who are knowledgeable about cancer control and linked to a consumer organisation or network.
- All potential and aspiring consumer representatives will be able to access appropriate training so they are well prepared to be effective and knowledgeable representatives.
- Guidelines developed by consumers to provide practical advice and guidance on consumer participation and representation will be utilised (FWHC 1992a, Women's Health Action 1999b, 2000, Te Puni Kokiri 1993, Ministry of Pacific Island Affairs 2001).

## **Recommendations**

### **Goals**

- All cancer control groups and activities will have a policy and/or terms of reference that include the active involvement of consumer representatives.
- The consumer participation policy and terms of reference reflect consumer guidelines on consumer representation.
- All permanent groups, working groups, advisory groups and other groups involved with cancer control and related work will have at least one consumer representative included in the group's membership.
- All permanent groups, working groups, advisory groups and other groups involved with cancer control and related work will have at least one representative able to provide a Māori consumer perspective included in the group's membership.
- All permanent groups, working groups, advisory groups and other groups involved with cancer control and related work will have at least one representative able to provide a Pacific peoples' consumer perspective included in the group's membership.
- All consumer representatives involved with cancer control groups and related activities will have the appropriate experience and/or training so they are well prepared to be effective and knowledgeable representatives.

### **Targets**

- All cancer control groups will be able to demonstrate they have a policy and/or terms of reference that include the active involvement of consumer representatives (to be achieved by May 2003).
- The groups will be familiar with and utilising guidelines developed by consumers that provide practical advice and guidance on consumer representation (to be achieved by May 2003).
- All permanent groups, working groups, advisory groups and other groups involved with cancer control and related work will be able to demonstrate that they have at least one consumer representative included in the group's membership (to be achieved by September 2003).
- All potential and aspiring consumer representatives will have the appropriate experience or have had appropriate training so they are well prepared to be effective and knowledgeable representatives (to be achieve by August 2003).

### **Actions**

The Cancer Control Secretariat will:

- advise and assist groups working within the cancer control umbrella to make sure they have a policy and/or terms of reference that will adequately address consumer representation

- ensure that it has established formal links with relevant consumer organisations that have an interest in cancer control
- investigate progress on planned New Zealand consumer training initiatives and liaise with the organisations involved to establish whether the proposed training is likely to meet the needs of those planning to work as consumer representatives in a cancer control area
- in conjunction with the relevant consumer organisations, review existing guidelines developed by consumers to provide practical advice and guidance on consumer representation to ensure all necessary areas are covered
- will provide advice as well as practical assistance to groups needing to find appropriate consumer representatives.

### **Feasibility of implementation**

As the action plan identifies the Cancer Control Secretariat as being most appropriate for oversight of the implementation work of this priority action, a review of the existing workforce capacity will need to be carried out. It is expected that the current workforce capacity of the Secretariat is already at its limit and not in a position to take on additional work until this is addressed.

Assuming the workforce issues are addressed as a matter of urgency, changes to policies and terms of reference should be straightforward and relatively easy to achieve. Incorporating existing consumer guidelines should also be straightforward although the need for some additional information may be identified. A collaborative approach with consumer organisations will enable changes/additions to be easily carried out.

Although formal links have already been established with relevant consumer organisations, this is likely to be an ongoing process. The ongoing links and liaison with consumer organisations will enable the Secretariat to provide advice and suggestions to groups needing to locate consumer representatives.

It is preferable (in the interests of time and resources) that existing or planned consumer training be accessed if it is appropriate, although a training programme specifically for consumers involved with cancer control groups and activities may need to be established.

### **Expected outcome**

Cancer Control decision-making, policy development, advice, planning, purchasing and service provision all incorporate consumer participation strategies and reflect consumer and whānau/family needs and values.

### **Priority ranking**

This priority action should have a top priority ranking with all Expert Working Groups as it is consistent with Government policy and is required to meet Cancer Control Strategy objectives.

## **Appendix One: Support and Rehabilitation Expert Working Group Members**

Associate Professor Chris Atkinson (Chair)	Chair Oncology, Haematology, Palliative Care, Christchurch Hospital
Betsy Marshall (Co-ordinator)	Project Manager, New Zealand Cancer Control Trust
Marilyn Barclay	Consumer, Auckland
Janet Bernard	Nurse, Paediatric Oncology Department, Children's Pavilion, Dunedin Hospital
Kay Morris	Executive Director, Child Cancer Foundation, Auckland
Fiona Pearson	Assistant Divisional Manager, Cancer Society of New Zealand, Wellington Division
Dr Tony Ruakere	General Practitioner, New Plymouth
Doug Sexton	Social Worker, Christchurch Hospital
Dr Lois Surgenor	Senior Clinical Psychologist, Canterbury District Health Board

The Support and Rehabilitation Expert Working Group would like to thank Judi Strid, consumer representative, Women's Health Action, for her assistance in developing the objective in the report on consumer representation.

## **Appendix Two: What is Meant by Community and Consumer?**

### **Who to involve?**

In general there are a number of categories to consider for potential consumer input (Minister of Health 2000, Women's Health Action 2000; Bastian 1996; Breast Cancer Network 2001). It will depend on the situation as to which category or categories is appropriate:

- members of Māori communities
- Pacific peoples
- patients/consumers/users of health and disability services
- caregivers and family/whānau members
- representatives from organised community groups
- other members of the public.

Factors such as age, health condition, disability, culture, rural issues and a gendered approach also need to be taken into account.

### **Consumer representation**

There are particular benefits in involving consumer representatives (those who are linked to a consumer group or are part of a network of consumers) rather than consumers as individuals. Consumer representatives are selected for their particular skills and expertise as well as the ability to represent consumer issues and to advocate on behalf of the consumers they represent. An individual provides their own perspective and is not accountable to anyone. They are often in a vulnerable position with only personal systems of support. They may not understand obscure medical jargon and may be easily intimidated. An individual may not be up-to-date with how the health system works and what the current consumer concerns are.

Consumer representatives should:

- be actively involved in community-based work on health issues with links and connections to a consumer group/s or a network of consumers
- have a mandate to represent consumer views
- be accountable to the consumer groups or networks they represent
- have the responsibility and mandate to report back
- be trained to: be an effective member of a committee; be involved in structures and processes; present arguments rationally and convincingly; negotiate on issues to achieve the best acceptable outcome; and analyse an issue and judge its effects on consumers and different sectors of the community.

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