



Cancer Council Australia and Clinical Oncological Society of Australia Submission to Productivity Commission Inquiry into National Disability Care and Support

Cancer Council Australia is the nation's peak non-government cancer control organisation. Cancer Council Australia advises the Australian Government and other bodies on practices and policies to help prevent, detect and treat cancer and also advocates for the rights of cancer patients for best treatment and supportive care.

The Clinical Oncological Society of Australia is the peak multidisciplinary society for health professionals working in cancer research or the treatment, rehabilitation or palliation of cancer patients.

Introduction

Cancer Council Australia and the Clinical Oncological Society of Australia (COSA) welcome the opportunity to provide comments in relation to the Productivity Commission's inquiry into new national disability care and support arrangements for Australia. The focus of our comments is on ensuring that cancer patients who suffer a disability as a result of their cancer or its treatment, together with their carers, are appropriately covered by any new disability care and support arrangements recommended by the Commission rather than on the specific design of these arrangements.

Overview

To ensure equity, it is essential that any new disability care and support scheme must be based on meeting the needs of those who are disabled, regardless of the cause of their disability. Therefore people who acquire a disability through diseases such as cancer must be covered under any new scheme, in addition to those who are born with disability or acquire disability as a result of accidental injury.

Cancer Council Australia and COSA strongly support the introduction of a national disability insurance scheme as the central element of new disability care and support arrangements. This scheme should provide funding for essential care, support, therapy, aids, equipment, home modifications, respite care and access to the community, education and training for people with severe or profound disability. People with more moderate disabilities and those experiencing short-term disability (7-12 months) should also be eligible for some assistance based on their needs.

Adequate income support must also be a critical element in any new disability care and support arrangements, whether this is provided through a disability insurance scheme or separately through the social welfare system. In either case it is important that income

support arrangements make appropriate allowance for people who are in financial distress as a result of an acute or terminal illness such as cancer.

In addition consideration should be given to developing a new category of income support payment for people with acute or terminal illness who are experiencing financial distress, but who may not be eligible for income support under disability care and support arrangements.

Cancer in Australia

Around 105,000 new cases of cancer are diagnosed in Australia each year. Incidence rates are expected to increase at over 30% per decade until population aging peaks in the middle of the century. (1)

The survival rate for many common cancers is also increasing and has improved by more than 30 per cent in the past two decades. More than 60% of cancer patients will now survive more than five years after diagnosis.(2) Consequently, cancer is increasingly being viewed as a chronic disease.

There are currently about 300,000 people living with a diagnosis of cancer (based on 5-year prevalence data for 2004)(2) and this number is expected to increase substantially as cancer incidence and survival rates increase.

Cancer and Disability

Cancer is a significant cause of disability in Australia.

A cancer diagnosis is a devastating and often life-changing experience. People diagnosed with cancer face a range of psychological, emotional, social, financial, practical and other issues as a result of their cancer and its treatment. (3)

Treatment for cancer can be severely disabling and can last for extended periods, with an uncertain prognosis. While some cancer survivors can resume a relatively normal life once their treatment is completed, others may face longer-term or permanent physical and emotional effects as a result of their cancer or its treatment. These effects can range from mild to very severe, depending on the type of cancer and the treatment received. While research in this area is limited, it appears that overall 20-30% of cancer survivors are likely to be at risk of ongoing poor health as a result of their cancer.(4)

In 2003 there were 62,400 people in Australia who were disabled due to cancer, of whom 22,500 had a severe or profound disability. The most common cancers reported as the main underlying cause of disability were breast, prostate and colon cancers, which are the three most common cancers in Australia, and brain cancers.(5) Together these cancers accounted for nearly 40% of new cancer cases in Australia in 2006.(6)

The most common impairments associated with cancer as reported to the Australian Bureau of Statistics' Survey of Disability Ageing and Carers, include receiving treatment or medication, chronic or recurrent pain or discomfort, restriction in physical activities or in doing physical work, and shortness of breath or breathing difficulties.(7) Major issues faced by people with cancer are also outlined in clinical practice guidelines for the psychosocial care of adults with cancer (3) and are summarised in the table below.

Issues faced by people with cancer

Challenges of cancer	Specific issues
Emotional and social	Lack of support from family and friends, stress in partners, stress in children, social impairment
Psychological	Self-concept, body image, sexuality, interpersonal problems, post-diagnosis relationships, stress and adjustment reactions, severe emotional distress, anxiety, depression, suicidal thoughts, post-traumatic stress disorder
Physical	Nausea and vomiting, pain, fatigue, fertility (male and female), pregnancy, lymphoedema, disfigurement, body odour, incontinence, bowel problems, cognitive problems, communication difficulties, nutritional deficiencies, lack of appetite, oral symptoms, swallowing difficulties, respiratory symptoms, general health
Practical and financial	Costs, reconstructive surgery, lymphoedema, travel and accommodation, loss of income, child care, domestic, business difficulties, legal issues at the end of life, access to prostheses
Towards the end of life	Physical, psychological, social, existential and spiritual, effects on the family, effects on caregivers
Survival	Physical symptoms, sexuality, emotional concerns, concern about recurrence, concerns of familial cancers

Source: *Clinical practice guidelines for the psychosocial care of adults with cancer*. Camperdown, NSW: National Breast Cancer Centre (National Breast Cancer Centre & National Cancer Control Initiative 2003)

A significant proportion of new cancer cases occur in those aged less than 65 years. Of the nearly 105,000 new cancer cases in 2006, 43%, or over 45,000 occurred in those aged less than 65 years. (6)

As cancer incidence and survival rates rise, the number of people living with cancer and associated disabilities in the future is also expected to increase significantly. Consequently, it is important that the needs of those who are affected by cancer are adequately considered when reviewing disability care and support services.

Disability Insurance Scheme

To ensure equity, Cancer Council Australia considers that it is essential that any new disability care and support scheme is based on meeting the needs of those who are disabled, regardless of the cause of their disability. Therefore people who acquire a disability through diseases such as cancer must be covered under any new scheme, in addition to those who are born with disability or acquire disability as a result of accidental injury.

Cancer Council Australia strongly supports the introduction of a national disability insurance scheme as the central element of new disability care and support arrangements. This scheme should provide funding based on need for essential care, support, therapy, aids, equipment, prosthetics, home modifications, respite care and access to the community, education and training for people with severe or profound disability, regardless of the cause of their disability. People with more moderate disabilities and those experiencing short-term disability (7-12 months) should also be eligible for some assistance based on their needs.

It is important that policy and program settings and service delivery under any new scheme take into consideration the particular needs and sensitivities of people facing a life-threatening illness of uncertain prognosis or those whose illness is likely to be terminal. For example an important issue for cancer patients and their carers is the need for specialised equipment to be immediately available. Equipment to assist carers in their tasks of lifting and carrying out personal care is essential for maintaining the carers' own physical health during

the caring period. People who are in the last stage of their illness being put on waiting lists to receive necessary equipment is untenable for both patient and carer.

Recommendation:

That any new disability care and support arrangements and/or insurance scheme be based on meeting the needs of those who are disabled, regardless of the cause of their disability, including those who acquire a disability through diseases such as cancer.

That policy and program settings and service delivery arrangements under any new disability care and support arrangements make appropriate allowance for the needs of people suffering from acute or terminal illnesses such as cancer.

Income support

In addition to the physical and psychological challenges faced by people diagnosed with cancer, a diagnosis of cancer can have major financial implications for individuals and their households in the form of both reduced income and increased out-of-pocket expenses.

During treatment a patient may not be able to work, leading to a significant loss of income. Long-term employment prospects may also be affected. In addition, loss of income can be compounded when a partner or other family member needs to take time off work in order to care for the person with cancer. Cancer may also affect an individual's capacity to undertake unpaid work such as housekeeping and caring for children or elderly parents.

Out-of-pocket expenses faced by households affected by cancer include treatment and medications, childcare and housekeeping, transport and accommodation costs where travel is required to receive treatment, household modifications, specialist clothing and mobility devices, prostheses, respite care, counselling and support programs and, if the patient succumbs to their disease, funeral costs.(8)

Access Economics has estimated that the average lifetime financial cost of cancer to a household is \$47,200 per person, although this cost varies substantially by age and gender and by cancer type, ranging up to \$103,000 for leukaemia and nearly \$150,000 for brain cancer. Costs are generally higher for males than for females (due largely to differences in expected lifetime earnings) and for children than for older people. For people of working age (aged 15-64) the average lifetime cost of cancer is \$137,400 for males and \$51,500 for females, but this cost can range to up to nearly \$300,000 for males with brain cancer.(8)

Although these amounts represent lifetime financial costs including loss of income, the bulk of the out-of-pocket costs are incurred in the first year of diagnosis and treatment. As well as lost income, a person with cancer can expect to pay an average of \$9,900 in health care costs (medical gap payments, pharmaceutical products etc.) and in other out-of-pocket expenses such as transport, communication, equipment, specialised clothing, respite care and home modification.(8)

Consequently access to adequate income support is of great importance for people with cancer experiencing financial distress.

Under current arrangements cancer patients of working age who are under financial stress may be eligible to receive assistance through Centrelink under a range of payments, including the Disability Support Pension (DSP), Sickness Allowance, Newstart Allowance or Youth Allowance, while their carers may be eligible for Carer Payment/Carer Allowance. However, a number of concerns have been raised by patients regarding the application of these payments.

Firstly the eligibility of cancer patients for any particular payment is not always clear cut and this can lead to protracted negotiations with Centrelink staff regarding eligibility. For example confusion can arise regarding cancer patients' eligibility for the Disability Support Pension or Sickness Allowance because their illness is neither temporary nor expected to last for over two years, or the duration of their illness is difficult to ascertain even by medical experts. As a result they appear ineligible for either payment. In response to these issues, changes to Disability Support Pension assessment processes have recently been introduced to fast-track more claimants with cancer, although the effectiveness of these changes is as yet unclear.

Secondly, waiting periods and liquid assets cut-offs which apply for access to some income support payments can aggravate financial hardship for cancer patients. These requirements can exhaust the financial resources of households affected by cancer at a time when they face an uncertain future with an unclear prognosis for how their disease may progress, increased costs as a direct result of their illness, and loss of income, both in the short term and in terms of their potential future earning capacity.

The uncertainty and difficulties created when these situations arise can place significant additional emotional and financial stress on the household of the cancer patient, especially if they are the main source of income, at a time when stress levels are already high as a result of the cancer diagnosis.

Consequently it is important that eligibility criteria and policy guidelines for access to disability related income support arrangements whether provided through a disability insurance scheme or separately through the welfare system, take into account the particular needs of cancer patients and their carers who are experiencing financial hardship.

In addition, as recommended by the Commonwealth Ombudsman in a recent review of the assessment of claims for disability support pension from people with acute or terminal illness,⁽⁹⁾ consideration should be given to developing a new category of income support payment. This payment should be available to people experiencing an illness that requires a lengthy period of treatment or recovery, or requires additional investigation to identify a more conclusive prognosis, but who would not otherwise be eligible for income support under disability care and support arrangements. A recipient of this payment could be placed on an appropriate medical review cycle (possibly six or 12 monthly). Consideration should be given to creating a list of conditions (including the stage or severity of illness where appropriate) that would automatically qualify a customer for the new payment.

The Ombudsman also recommended that if a new payment could not be developed, policy and administrative arrangements for Newstart Allowance and Youth Allowance should be amended for people experiencing an illness that requires a lengthy period of treatment or recovery to allow Centrelink to grant affected people lengthier periods of exemption from the

activity test and income reporting requirements. Cancer Council and COSA also support this recommendation.

Case Study

Louise was diagnosed with leukaemia at age 18 and was on the DSP for over 2 years. She went into remission but her treating doctor's report stated that she would continue to be affected by fatigue, vagueness, poor memory and anxiety for a further 3-24 months. The report stated that the long-term effects on Louise and her risk of relapse were uncertain. As Louise's doctors wanted to create 'hope' for her, they did not tick a box on her pension review form stating that she could not go back to work within 2 years. Six weeks later, a Centrelink job capacity assessor decided that Louise was fit to go back to work and put her onto the Newstart Allowance, requiring her to 'job seek' every fortnight and go into the Centrelink office to report her job seeking status. Louise was also required to go to a job seeking office and have staff there assist with her job seeking. For 11 months, until the Social Security Appeals Tribunal set aside Centrelink's decision to put Louise on Newstart Allowance rather than the DSP, inadequate allowance was made for Louise's rehabilitation.

Recommendations

That appropriate income support arrangements are available for cancer patients and their carers who are experiencing financial hardship.

That eligibility criteria and policy guidelines for access to income support under disability care and support arrangements take into account the needs of cancer patients and their carers who are experiencing financial hardship.

That consideration be given to developing a new category of income support payment for people with acute or terminal illness who are experiencing financial distress, but who may not be eligible for income support under the disability care and support arrangements.

That if a new payment is not developed policy and administrative arrangements for Newstart Allowance and Youth Allowance be amended for people with acute or terminal illness to allow Centrelink to grant affected people lengthier periods of exemption from the activity test and income reporting requirements.

Impact on Carers

Cancer is one of the 10 most common health conditions in receipt of informal care giving in Australia.(10)

Caring affects the physical, financial and emotional wellbeing of carers.

Care-giving imposes a financial burden in terms of lost income as well as extra expenses. As a result of caring many carers are unable to work, or have to work fewer hours or in a lower paid job to be able to meet their caring commitments. Preliminary results from a research study into the needs of partners and carers of cancer survivors over the first five years from the cancer diagnosis found that a third to a half of carers reported a net household income of

less than \$500 per week and many carers received a government pension or benefit. The study also found that approximately three-quarters of carers reported having significant out-of-pocket costs associated with caring including medical costs, medications and travel costs, often met through savings or loans.¹ In another study, the extra costs to carers associated with illness and disability were estimated to account for more than one quarter of weekly household expenditure in 1997.(10)

Carers can also experience difficulties in returning to the workforce, especially after long periods of caring and can suffer longer term financial consequences such as reduced superannuation and retirement savings.(10)

Carers also experience adverse health effects such as depression and physical injury sustained while providing care. Care giving has been associated with poorer levels of overall health compared to the general population,(11;12) and with a higher risk of injury, stress, tiredness, burnout, and high blood pressure.(13) Reduced opportunities for social and physical activities also reduce the emotional wellbeing of carers.(10) Access to adequate respite and other support services has been identified as an important service gap by carers and support organisations.(10)

Consequently, improved support for carers should be a key component of new disability care and support arrangements. These arrangements should include improved financial assistance for carers, better access to support services, specialized equipment and respite care, greater availability of in-home help and assistance with maintaining or returning to employment.

Recommendations: *That increased levels of financial support are provided for carers of cancer patients experiencing financial hardship.*

That improved support is provided for carers of cancer patients including improved access to support services, specialised equipment and respite care and assistance in maintaining or returning to employment.

¹ The Centre for Health Research and Psycho-oncology (CHeRP). The Partners and Caregivers Study

Summary of recommendations

That any new disability care and support arrangements and/or insurance scheme be based on meeting the needs of those who are disabled, regardless of the cause of their disability, including those who acquire a disability through diseases such as cancer.

That policy and program settings and service delivery arrangements under any new disability care and support arrangements make appropriate allowance for the needs of people suffering from acute or terminal illnesses such as cancer.

That appropriate income support arrangements are available for cancer patients and their carers who are experiencing financial hardship.

That eligibility criteria and policy guidelines for access to income support under disability care and support arrangements take into account the needs of cancer patients and their carers who are experiencing financial hardship.

That consideration be given to developing a new category of income support payment for people with acute or terminal illness who are experiencing financial distress, but who may not be eligible for income support under the disability care and support arrangements.

That if a new payment is not developed policy and administrative arrangements for Newstart Allowance and Youth Allowance be amended for people with acute or terminal illness to allow Centrelink to grant affected people lengthier periods of exemption from the activity test and income reporting requirements.

That increased levels of financial support are provided for carers of cancer patients experiencing financial hardship.

That improved support is provided for carers of cancer patients including better access to support services, specialised equipment and respite care and assistance in maintaining or returning to employment.

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