

Dept of Families, Housing, Community Services and Indigenous Affairs' pension review – submission from Cancer Council Australia

Cancer Council Australia is the nation's largest non-government cancer control organisation, representing the national interests of its eight state and territory members.

Responsibility for the content of this submission is taken by Cancer Council Australia Chief Executive Officer, Professor Ian Olver. Contact for further information is Paul Grogan, Director, Advocacy, c/o paul.grogan@cancer.org.au or (02) 8063 4155. This submission consists of an overview and specific comment against the questions in ACIP's discussion paper.

Recommendations in summary

- Increase levels of financial support for carers of cancer patients experiencing financial hardship
- Ensure easier criteria and clearer policy guidelines for access to Social Security payments for cancer patients and carers
- Ensure automatic provision of a Health Care Card for people with cancer.
- Double the liquid asset cut-offs to \$5000 for singles and \$10,000 per couple for households with a member diagnosed with cancer
- Expand Centrelink outreach services which allow people to send in their claims with accompanying medical information if too ill to attend in person.
- Provide privacy and easier queuing systems for cancer patients and carers attending a Centrelink office.

Introduction

A diagnosis of cancer can have major financial implications for individuals and their households in the form of both reduced income and increased expenses leading many cancer patients and their carers to seek income support from the government.

As cancer incidence and survival rates rise, the number of people living with cancer is expected to increase significantly. As a result, there is also likely to be an increase in the number of people affected by cancer who will require financial support from the Australian Government and in the length of time for which financial support may be required. It is therefore important that the needs of those affected by cancer are adequately considered when reviewing income support and pension arrangements.

Increasing numbers of people living with cancer

An estimated 106,000 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. In addition, the increasing prevalence of obesity, which is an important risk factor in a number of cancers, is likely to lead to further increases in overall cancer incidence.

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. 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 five-year prevalence data for 2004) and this number is expected to increase substantially as cancer incidence and survival rates increase.

Costs of cancer

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 expenses.

Treatment for cancer can be severely disabling and can last for extended periods, during which time the 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.

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.

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. Costs are generally higher for males than for females (due largely to differences in expected lifetime earnings) and for children than for older people.

In the context of this pension review, the age groups of particular relevance are people of working age and pensioners. 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. Over 40,000 new cancer cases or 42.4% of new cancer cases occur in this age group.

For people aged 65 years and over, the average lifetime costs of cancer decreases to an average of \$13,400 for males and \$10,600 for females, with costs less than \$20,000 even for the most expensive cancers. However, this represents a significant proportion of income for those who are retired or on fixed incomes. Over 56,000 new cases of cancer or about 57% of new cases occur in this age group.

Although these amounts represent the lifetime financial costs including loss of income, it is expected that 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 modifications.

Recommendation: Increase levels of financial support available through Centrelink for cancer patients experiencing financial hardship

Carers

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

Research indicates that cancer survivors rely strongly on their partners and families for emotional support, rather than psychologists or other healthcare providers. Carers are often working while providing many hours of care each week, with some carers needing to take periods of leave to maintain the role. As a result of caring commitments some carers are unable to work, or have to work fewer hours or in a lower paid job with financial consequences.

The Centre for Health Research and Psycho-oncology (a behavioural research centre jointly funded by the Cancer Council NSW and The University of Newcastle) is conducting a research study into the needs of partners and carers of cancer survivors over the first five years from the cancer diagnosis.

Preliminary results from the study 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.

Almost half of the study group was currently employed (full-time, part-time, casual, self-employed) and a similar proportion had taken leave or had changed their work situation because of their caring role. Particular issues arose for carers who were self-employed: they were unable to apply for new contracts if unwell or if they had to look after their partner and some had to sell their business.

The study also found that approximately three-quarters of carers reported having significant out-of-pocket costs associated with caring:

- Almost half of carers paid for costs when the cancer survivor visited health care professionals. Average cost \$1700, ranging up to \$14,000.
- Almost half of carers paid for prescription medication for the cancer survivor, and/or over-the-counter medication for the cancer survivor.
- A third of carers paid for travel costs when the cancer survivor visited healthcare professionals. Average cost was \$415, ranging from \$20 to \$5000.
- The majority of carers reported costs paid for these from income, savings and loans.

Care-giving imposes a financial burden in terms of lost income as well as extra expenses, hence increased levels of financial support for carers are needed.

Recommendation: Increase levels of financial support for carers of cancer patients experiencing financial hardship

Social security payments

Cancer patients of working age who are under financial stress may be eligible to receive assistance through Centrelink under a range of payments.

Disability Support Pension	For people unable to work 15 or more hours per week for at least two years due to illness, injury or disability. This has an income/assets test requirement. Recipients must have a physical impairment that has a rating of at least 20 points under the statutory Impairment Tables, which are used to assess ability to work.
Sickness Allowance	For people temporarily unable to work due to temporary illness, injury or disability who have a job or study to return to.
Newstart Allowance	For unemployed people aged over 21 who are looking for work. An exemption to activity requirements is available for people who are temporarily unable to work due to illness, injury or disability and principal carers (of a child under 16).
Carer Payment/ Carer Allowance	Carer Payment is for people who provide constant care for a disabled person (adult or child) at home. The Carer Allowance is a fortnightly payment of \$100 which can be paid in addition to Carer Payment or on its own.

A number of concerns have been raised by patients regarding the application of these payments.

Confusion regarding eligibility

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. The uncertainty 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.

For example, there have been many reports regarding the confusion that arises in relation to cancer patients whose illness is neither temporary nor expected to last for over two years, and who hence appear ineligible for either Sickness Allowance or the Disability Support Pension. For many people with cancer the duration of illness is actually difficult to ascertain, even by medical experts. Several people with cancer have told the Cancer Council that they were initially denied the Disability Support Pension because Centrelink claimed that cancer was 'a temporary illness.' After repeated visits to Centrelink, some of these claimants eventually received the Newstart allowance, whilst others were granted the Disability Support Pension. In most cases, although payments were finally granted, it demonstrated

confusion on the part of Centrelink staff as to correct criteria, and cancer patients and their carers had to make unnecessary visits to the Centrelink office during a time of illness.

Recommendations: Ensure easier criteria and clearer policy guidelines for access to Social Security payments for cancer patients and carers.

Ensure automatic provision of a Health Care Card for people with cancer.

Concern regarding waiting periods

The waiting periods that apply to payment of income support by Centrelink 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.

Where a person with cancer receives annual leave, sick leave, long service leave or redundancy pay at the time they leave their job, this money is counted as income for the length of time covered by these entitlements thereby reducing or delaying social security payments for some time. The income maintenance period can be reduced, but only if a person can prove that they are in financial hardship, and meet a very strict test. The 'Income Maintenance Period' applies to many payments, including Sickness Allowance, Newstart Allowance and Disability Support Pension.

The waiting period for people applying for Sickness Allowance and Newstart Allowance may be further extended under the Liquid Assets Waiting Period, which can delay payments for up to a further 13 weeks. 'Liquid assets' are funds available at short notice (i.e. within 28 days), such as bank deposits and shares. A person who has liquid assets above \$2500 (as a single person) or \$5000 (for a couple or a single person with a child) will face an extra waiting period of one week for each \$1000 over the limit, up to a maximum of 13 weeks.

The liquid assets cut-offs are very low for households facing the high costs of cancer as estimated by Access Economics. It is counterproductive to force people with significant illnesses to essentially use all of their savings at the same time that they are facing an uncertain future, with an unclear prognosis about how their illness may progress. These waiting periods strip often very sick people of usually modest levels of savings at the very time that they may be facing higher medical expenses and transport costs as a direct result of their illness. Money put aside for home modifications, or to purchase care services, is eaten away by these unfair and harsh waiting periods. The exempt amount of \$5,000 for a couple is hardly enough to cover the costs of an even basic funeral if a member of a couple succumbs to their illness. In families with young children, the implications for their future financial security can be particularly severe.

Recommendation: Double the liquid asset cut-offs to \$5000 for singles and \$10,000 for couple for households with a member diagnosed with cancer

Other concerns

Other Centrelink issues include the lack of privacy for claimants whilst attending a Centrelink office (Centrelink does not generally provide private offices for people to discuss their medical issues); and, at some offices, being forced to queue up for several hours without a

chair to sit on. In theory, if people are very ill they are allowed to fax in their medical forms rather than attend an office in person; however, this practice is discouraged by Centrelink, causing people who are ill and their carers undue hardship in having to attend the office in person at a time of great difficulty.

Centrelink outreach services that allow people to send in their claims with accompanying medical information if too ill to attend in person should be expanded. Adequate privacy and easier queuing systems for cancer patients and carers attending a Centrelink office is needed.

Recommendation: Expand Centrelink outreach services which allow people to send in their claims with accompanying medical information if too ill to attend in person. Provide privacy and easier queuing systems for cancer patients and carers attending a Centrelink office.