

Independent Review of the Australia Public Service

Cancer Council is Australia's peak national non-government cancer control organisation and advises the Australian Government and other bodies on evidence-based practices and policies to help prevent, detect and treat cancer.

Australian Oncology Social Work Inc. (OSWA) is a non-profit, incorporated national organisation dedicated to the enhancement of psychosocial services to people with cancer and their families.

Cancer Council and OSWA welcome the invitation to submit to the Independent Review of the Australian Public Service, specifically to address point 5 of the Terms of Reference:

Improving citizens experience of government and deliver fair outcomes for them.

Cancer Council and OSWA use this opportunity to recommend changes to how people affected by cancer, interface with the welfare system through:

1. Introducing a single point of contact to access all welfare options.
2. Introducing a case management model to assist individuals to navigate the welfare system efficiently and effectively.

Hospitals, community settings and Centrelink provide the infrastructure to enable a case management, central point of contact approach to the provision of information, application and ongoing management of welfare cases to reduce financial hardship for people affected by cancer. The issues and recommendations presented in this submission are equally applicable for people with chronic illnesses other than cancer.

Key welfare issues for people affected by cancer

A change in financial situation is a significant concern for people affected by cancer. Patients are often unaware of their options, such as financial assistance, and hardship arrangements, and have trouble accessing available welfare on their own. This inability to act can place people into financial hardship. Our interest in this matter is centred on the reality that Australian's in the lowest socio-economic quintile are 30% more likely to die from their cancer than those in the highest socio-economic group, even when controlling for type of cancer and stage at diagnosis. Poverty and financial hardship directly impact on whether someone will survive from cancer.

Cancer Council offers a national telephone information and support service (13 11 20) for people affected by cancer to seek practical, emotional and informational support about their disease and managing its physical and social implications. Increasingly, calls to 13 11 20 are received from people with financial concerns, requiring direct financial assistance or financial

counselling to manage unanticipated and often debilitating out of pocket expenses associated with cancer. Issues relating to finance, legal and practical support represent 30% of calls nationally (14,157 calls per annum). Often these calls relate to accessing benefits or negotiating early access to superannuation.

In response to increased demand, Cancer Council established a pilot financial navigation service in one state to conduct rapid needs assessment and link people to an appropriate service, including Centrelink. In the first year of operation, the financial navigation service received 1,804 calls for assistance or guidance. Of these calls, the majority (38%) were related to the need for emergency assistance in the form of bill payments such as car insurance and utilities, or food vouchers due to displacement of funds related to cancer care or inability to attend paid employment for self or a family member. An additional 30% of callers sought to discuss their financial situation and explore their options with a financial professional. A further 20% of calls were made from social workers and health professionals to discuss services and resources available on behalf of their patients.

Many clients are unaware of their eligibility for assistance. Confusion about eligibility can discourage a low-income patient from considering an application for assistance. Alternatively, people who are already receiving unemployment or income support may have their eligibility status change due to illness. Financial counsellors at Cancer Council identify possible options, including Government welfare programs, for their clients.

Inability for people with cancer to easily navigate the welfare system to access disability and unemployment benefits.

People affected by cancer often experience a sudden and immediate change in their ability to generate income, which affects their family and capacity to continue to pay usual bills and financial commitments. This is often compounded by medical expenses, even when fully treated in the public healthcare system. Although their ability to work changes, their usual bills do not and often increase.

Common issues reported by patients related to their experience of Government funded welfare programs (Centrelink, the National Disability Insurance Scheme (NDIS) and My Aged Care) are listed below:

Practical elements related to access of information about available welfare options:

- Highly digital benefit application systems require people to call automated voice systems or have access to a computer. This assumes a degree of computer literacy, numeracy skills and clarity of mind as it also requires recall of personal log in, pin codes and passwords. Telephone access is particularly limiting for patients with communication difficulties such as those resulting from head and neck cancer.
- Visiting the Centrelink office is time consuming and overwhelming for many people, but particularly difficult for people affected by mobility issues due to illness or treatment. People unwell from cancer are least able to tolerate an extended visit to an office. Often people affected by blood based cancers are immune-suppressed and on medical advice, must avoid public settings, at times for months.
- Limited availability of interpreters for people where English is not their first language.

Complex and confusing application processes:

- Each Government welfare program is administered in isolation of other schemes, requiring individual applications and assessment.
- Difficulty accessing appropriate welfare options despite lodgement of written letters of support from health professionals about the diagnosis and, or the effects of the condition on employment. Terminology used by the doctor is critical to the success of the claim and wrong terminology may mean starting again.
- Time delays in welfare access can be compounded by the need to submit further documentation.
- No transparency of the estimated wait time and/or status of applications within the review process.
- No emergency assistance available to high need applicants during the review process.
- Information about the reason for rejection or the processes for appeal are not routinely provided. People report that advice of an alternative claim option is not provided, which leads them to believe they have no entitlement to income or other support.
- Interaction with multiple Centrelink officers, leading to telling the story over again, and can create high levels of discouragement in the application process and sometimes abandonment.
- Difficulty obtaining an appointment with Centrelink social workers. A claims issue can be solved quickly by a hospital social worker with assistance of a Centrelink Worker or Community Liaison Officer but these resources seem limited.
- Expiration of a medical certificate and discontinuation of payment without warning. This is particularly problematic for people who are unwell, hospitalised for long periods, geographically isolated and away from home, as well as for socially marginalised and vulnerable population.

These issues are stepped out in the way of case examples from people who have contacted Cancer Council (all names have been altered)

Paul, 49, was diagnosed with advanced kidney cancer which had advanced into his brain, spine and both lungs. Due to the diagnosis and advanced nature of illness Paul was unable to continue work. Paul lived with his wife Melanie and their young child. Melanie, as the primary carer for Paul, was forced to reduce her work hours resulting in a sharp decline in their income. Managing mortgage repayments and daily expenses became difficult and led to severe stress. Increased out of pocket expenses related to travelling and accommodation for treatment are making it difficult for them to make ends meet. Cancer Council NSW Financial Assistance Services team assisted the family to address their primary financial concerns and financial counsellors provided them with options and information to better manage their change in financial situation. They informed them about Income Protection and managed mortgage stress. Assistance was provided with payment of car registration and unpaid telephone and water bills through the Emergency Financial Assistance Program. The client was then referred to Pro Bono Financial Planning Service to assist with accessing Income Protection.

Good case management includes reviewing individual circumstances and advising on the options that would benefit the client. In this scenario Paul may have avoided unnecessary application to Centrelink as the Cancer Council linked him with a financial planner who identified that he was ineligible and would benefit from different assistance.

Sophie, 53, from Queensland relays a story about being told she could call and speak to Centrelink Social Workers for assistance with the application process, but when calling the number for the social worker, none of the options on the Centrelink voice message matched to social work. When she chose a different option, the system would not allow the call to progress, and the call ended. This made her feel like she couldn't access social work or support from Centrelink and was left feeling frustrated and anxious, and like she wasn't entitled to receive assistance. Referral to the Cancer Council pro bono financial service linked her to a financial planner who could review her case and guide Sophie to the assistance she was entitled to.

A cancer diagnosis can have implications for low income earners with an existing income assistance arrangement. They may be required to revise arrangements due to illness. However, they are either unaware of the implications or have compromised ability to engage in the process, resulting in stoppage of regular payments. Although this is a system-wide issue, it has a substantial impact on cancer patients who often require immediate assistance after a diagnosis. Recently, an Australian newspaper reported that a man with bowel cancer had his Newstart Allowance removed as he was no longer able to meet the reporting requirements or achieve the minimum job applications conditions of the program while he was undergoing cancer treatmentⁱ. In this example, the patient was too ill to negotiate a change to his arrangements. With the availability of a case manager, this man could have been transitioned to a sickness allowance without delay to regular income support. Improved coordination of a person's needs during different situations would reduce delay in access to financial assistance and exacerbate their experience of financial distress.

'Intent to claim' process for earlier access to support:

We are concerned by the recent changes to the 'intent to claim' processⁱⁱ. Under the 'intent to claim' process people had their payments backdated to the date of first contact with Centrelink. Under the new arrangements, some claimants may no longer be able to commence the application process prior to lodging all the necessary forms and identification documents. People who have difficulty finalising their paperwork due to reasons of illness (and sometimes inability to proceed with their claim altogether), may lose several weeks of benefit payments. This disadvantages people who are acutely unwell, hospitalised for long period, geographically isolated and away from home, as well as those who are socially marginalised and vulnerable, including homeless or transient people.

The impact of current access pathways to financial support in the form of welfare payments on patients and families.

Vulnerable people may cease pursuing their entitlements if they do not have an advocate to assist them. Carers are another vulnerable group who may not pursue an application for support when it becomes difficult.

Myriam and her three sons, unable to speak English, arrived in Australia as refugees from Iraq. She was diagnosed with cancer of the larynx and underwent a laryngectomy with tracheostomy and palliative radiation. She was unable to communicate via phone, only in person due to the impact on her vocal chords. Her youngest son was appointed as power of attorney, and was working shifts at McDonalds around school to support his mother and

brothers. On referral to Cancer Council for financial assistance and help with a will, Myriam was behind on her rent, and at imminent risk of having her utilities cut off. There were also a number of debt demands, with money being prioritised for these over providing food for herself and her family. She was receiving Centrelink benefits, but these were ceased when she became unwell while visiting family overseas, meaning she could not return to Australia within the required timeframe to continue access. Cancer Council was able to work with Myriam and other community organisations to:

- Provide financial counselling about how to reinstate Centrelink and other ongoing supports*
- Put a temporary hold on rent and utility payments via advocacy to her housing manager and the Health Ombudsmen while hardship programs were explored*
- Provide referral to pro bono services for access and support with writing a will*
- Provide food vouchers to the value of \$300 via Cancer Council Financial Assistance Program.*

Cancer Council was a central point of contact in this case. The financial navigation service arranged access to support services as well as being an advocate to institutions to ensure debt could be managed while benefits reinstatement was pursued.

Delay in receiving benefits:

The time taken to process claims can leave people without an income for a significant period. Where illness is the reason for a Centrelink application, the loss of income has usually been sudden and unanticipated. During this time patients must maintain upkeep of basic living expenses which can be increased by additional costs associated with attending treatment centres and paying for medical treatment and tests. Patients who relocate from rural or regional areas before their claim has been assessed can be particularly disadvantaged due to a need to resolve claim issues remotely. Change in financial situation may result in people delaying investigations to confirm a cancer diagnosis, making sub-optimal treatment choices based on ineligibility for income support or being unable to pay for support services. This may contribute to a compromised ability to adhere to treatment recommendations due to financial burden. The decision to forego recommended treatment is likely to contribute to the 30% higher aged-standardised cancer mortality experienced by disadvantaged peopleⁱⁱⁱ. A poorly navigable welfare system can worsen survivorship and wellness prospects for people diagnosed with cancer.

Recommendations for improving the experience of welfare in the public system.

Below is a list of recommendations to be considered by the panel.

- 1. Implement a coordinated case management approach to welfare across all Government programs to support provision of individualised information, application assistance, and ongoing management of access to welfare, for people affected by cancer.*

A welfare case manager would be assigned to each client who currently accesses Government assistance, and representatives would be available in hospitals to discuss welfare options with newly diagnosed, low income patients.

For low income earners, not currently accessing benefits, this model would enable:

- Increased service provision to reduce waiting times and improve ease of access.

- Improved access to welfare options for people who are on the border of being eligible.
- A streamlined system allowing health professionals access to Centrelink personnel to confirm or update client information.
- Clearer direction toward available options for younger people.

Additional recommendation for existing welfare recipients:

- Relaxing the reporting requirements for low income earners on welfare undergoing cancer treatment, with a simplified mechanism for confirming treatment arrangements and duration without interruption to payments.

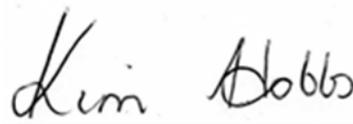
This may require employment of additional Community Engagement Officers by Centrelink to enable personnel to visit patients in hospital or at home to facilitate their claim process.

2. *Fast track claims for people in minority populations or people at risk high of financial hardship, based on immediate or urgent need.*
3. *Provision of services, such as improved access to interpreters, to support culturally and linguistically diverse access to services.*
4. *Re-introduce 'Intent of Claim' scheme to enable earlier commencement of applications, and payment of entitlements from when the situation changed.*
5. *Undertake a full review of Centrelink processes and protocols, including:*
 - Ensuring accessibility to these programs for vulnerable populations, experiencing the greatest need.
 - Classification of cancer as a chronic and debilitating disease, creating long term financial implications.
 - Gaps in access for people who are borderline eligible.
 - Emergency assistance for high need clients.
 - Transport allowance or subsidy for people receiving an income payment undergoing chemotherapy or radiation therapy.
 - Increase in, and equitable access to, social workers across the health system who are resourced to provide more comprehensive support to people affected by cancer.

We would welcome further discussion about this submission to reduce the burden faced by people affected by cancer. We believe the skills and services offered by our organisations can be of direct relevance to an improved Centrelink service and greater levels of engagement between our organisations.



Professor Sanchia Aranda
CEO, Cancer Council Australia



Ms Kim Hobbs
Clinical Specialist Social Worker
Westmead Hospital, Sydney

Contact:

Kate Whittaker, Manager, Cancer Care Policy, Cancer Council Australia 02 8063 4161

Kim Hobbs, Clinical Specialist Social Worker, and member of OSWA Executive 02 9845 6699

ⁱ Pro Bono Australia *Man battling cancer and Centrelink raises social media storm*, published 10th July 2018, accessible via <https://probonoaustralia.com.au/news/2018/07/man-battling-cancer-centrelink-raises-social-media-storm/>

ⁱⁱ Department of Human Services. *Intent to claim is stopping on 1 July 2018* published 5 June 2018, Commonwealth Government. Accessible via <https://www.humanservices.gov.au/individuals/news/intent-claim-stopping-1-july-2018>

ⁱⁱⁱ Australian Institute of Health and Welfare 2017. *Cancer in Australia 2017*. Cancer series no.101. Cat. no. CAN 100. Canberra: AIHW.