

Committee Secretariat
Joint Standing Committee on the National Disability Insurance Scheme
ndis.joint@aph.gov.au

6 October 2022

Dear Committee Secretariat,

Re: NDIS General Issues Inquiry

Thank you for the opportunity to provide insights on the impacts of financial hardship experienced by many people living with blood cancer in Australia, and opportunities to alleviate this burden through the NDIS.

The Leukaemia Foundation is the only national organisation that represents all Australians living with blood cancer. We provide practical and emotional support to Australians with a blood cancer, including financial support, thanks to the generosity of the community through our fundraising efforts.

Our supports include accommodation when patients and their families need to travel for treatment; funding and facilitating critical blood cancer research; and advocating for reforms that will improve diagnosis, access to treatment and care.

In performing our role as advocates for the over 135,000 Australians living with a blood cancer, we have developed two important reports over the last four years. At the very heart of these reports is the patient as a recipient of care, as a taxpayer, and as a citizen.

State of the Nation: Blood Cancer in Australia

In September 2019, the Leukaemia Foundation released the *State of the Nation: Blood Cancer in Australia* report, a first of its kind analysis to quantify and articulate the challenges and opportunities that influence survival and quality of life for people living with all blood cancers. To understand real experiences, we undertook a survey of people living with blood cancer and their families, with over 3,200 respondents from across the blood cancer spectrum.

Blood cancer is among the most fatal and most costly conditions affecting Australians today, with survivors facing a long tail of late effects as a result of being exposed to cytotoxic therapies. The effect of a blood cancer extends for a lifetime, impacting adults and children alike, their families, and the wider community.

We know that a blood cancer diagnosis can immediately impact a person's financial circumstances; many people are unable to work due to their illness and treatment, and this can result in a permanent reduction in their capacity to work. This can also extend to their carers, who may also have to take time off work to provide practical support. In the survey of 3,200 people living with blood cancer, we asked about the impacts of blood cancer on their household income. Nearly 60 per cent of respondents needed to take more than six months off work or leave their job

entirely, and 22 per cent of carers needed to do the same to support the person living with blood cancer (Figure 1).

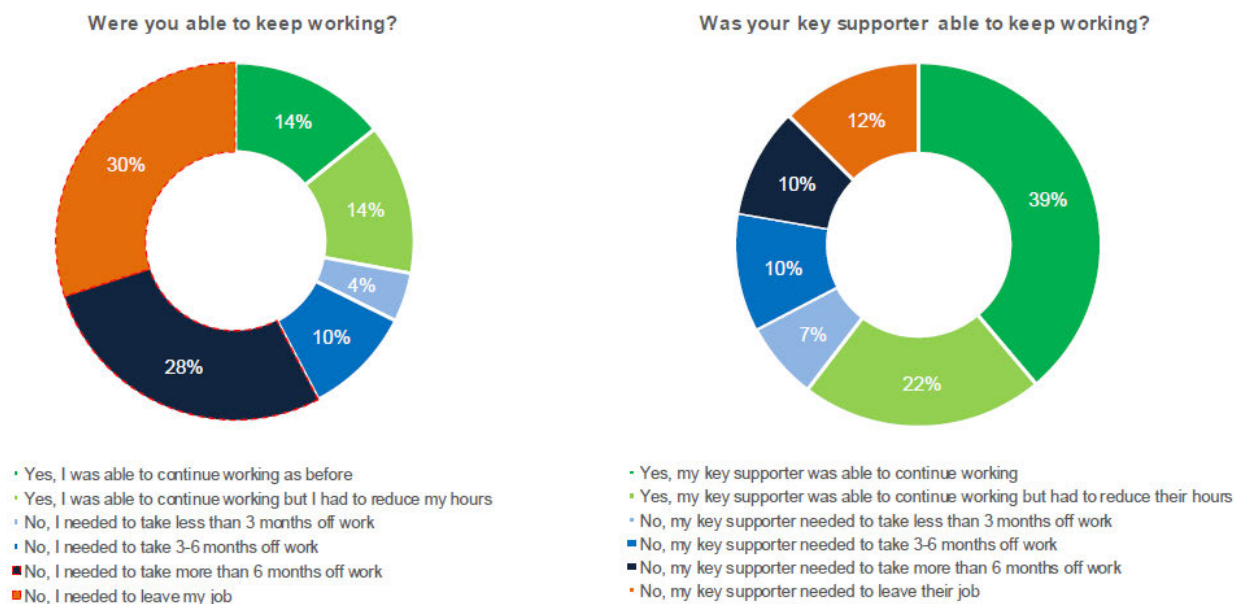


Figure 1: Impacts of blood cancer on household income. Source: Insight Economics, 2019, State of the Nation: Blood Cancer in Australia, p. 24.

Additionally, treatment for blood cancer can result in out-of-pocket costs. The *State of the Nation* survey documented the scale and type of out-of-pocket costs for its respondents: over 30 per cent reported incurring out of pocket costs (Figure 2). While the majority of these costs were up to \$1,000, some respondents reported out-of-pocket costs in excess of \$20,000. Many of these costs are for items that a person might not expect to have to cover out-of-pocket, such as diagnostic tests, treatments, medicines for symptom relief, and re-vaccination following stem cell transplant.

The most frequent source of out-of-pocket cost for people living with blood cancer was travel, with nearly 700 people reporting out-of-pocket transport costs and nearly 500 reporting spending over \$500 on travel. While each state and territory maintains a subsidy service for people needing to travel for medical treatment under various Patient Assisted Travel Schemes (PATS), these schemes are restricted and only offer very limited reimbursement of travel and accommodation expenses. Additionally, PATS payments are not permitted to be used for the reimbursement of travel for involvement in a clinical trial, which is standard of care for many blood cancers.

As noted in the report, approximately 7 per cent of respondents who indicated they incurred costs reported they had spent more than \$5,000 on treatment for their blood cancer, and those with private health insurance were much more likely to report incurring costs in the '\$5,000 to \$20,000' cost band across a range of services.¹

¹ Insight Economics, 2019, *State of the Nation: Blood Cancer in Australia*, p. 74. Available at https://www.leukaemia.org.au/wp-content/uploads/2020/06/State-of-the-Nation-Blood-Cancer-in-Australia_Leukaemia-Foundation.pdf

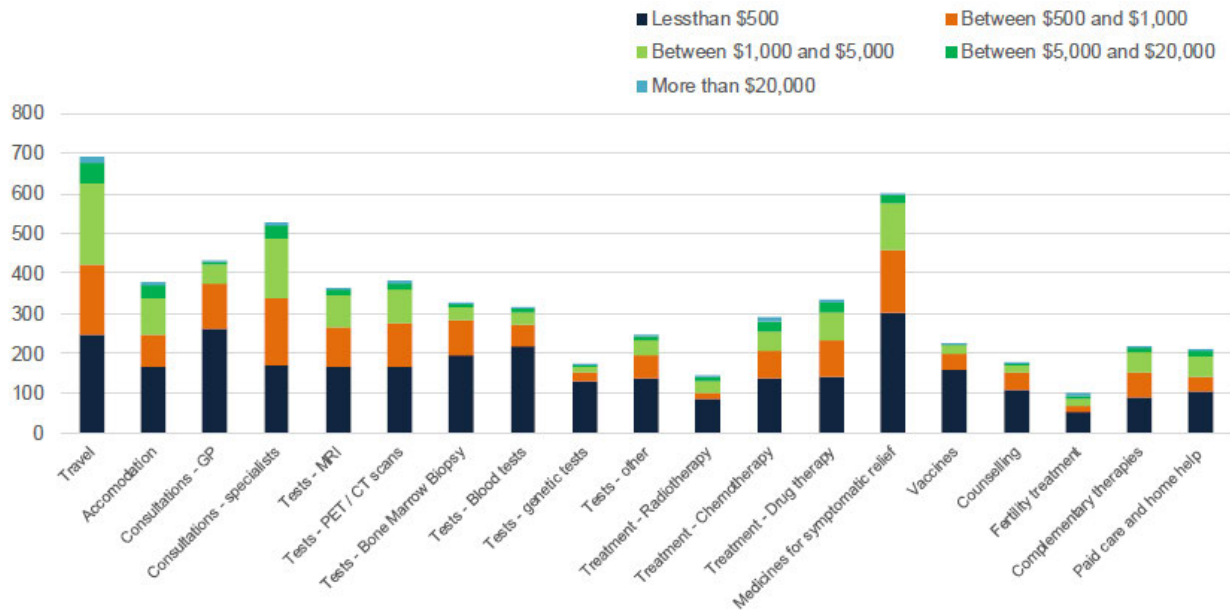


Figure 2: Frequency and magnitude of out-of-pocket costs by category for people living with blood cancer. Source: Insight Economics, 2019, State of the Nation: Blood Cancer in Australia, p. 74.

Of those 3,200 consumers, a full 30% reported that they had to seek financial assistance to cope with the reduction in household income due to their blood cancer diagnosis.

The National Strategic Action Plan for Blood Cancer

The findings of the *State of the Nation* report led the Federal Government to establish the Blood Cancer Taskforce in 2019. The Taskforce, representing the needs of people living with blood cancer, unites 32 of Australia’s leading haematologists, researchers, patients and members of the blood cancer community, and is supported by the Leukaemia Foundation as its Secretariat.

In 2020 the Taskforce released National Strategic Action Plan for Blood Cancer, which is a roadmap to save the lives of thousands of Australians each year living with blood cancer by setting consistent quality standards for diagnosis, treatment, and care. Through collaboration with patients and leaders in the community four major priorities were identified for people living with blood cancer and their families: Empower patients and their families; Achieve best practice; Accelerate research; and Enable access to novel and specialised therapies. These priorities are supported by 21 recommendations, from research, clinical trials, precision medicines, treatment access and reimbursement, through to achieving best practice in diagnosis, treatment and supportive care.

Noting the major impact that financial hardship can have on people living with blood cancer, the National Action Plan made the following specific recommendations:

- **Action 2.7.1:** Consult with all jurisdictions to reform Patient Assisted Travel Schemes (PATS), including advocating for streamlined administrative processes, greater access to the schemes and support for patients to participate in clinical trials.
- **Action 2.7.2:** Review options for the introduction of financial support mechanisms (such as a temporary disability payment) to support people with cancer and other serious illness who require temporary financial support.

Addressing financial hardship for people living with blood cancer

Financial hardship can have negative impacts on health. A meta-analysis led by the Cancer Council of more than 70,000 Australians with cancer found that financial hardship was a frequent consequence of a cancer diagnosis² with average out-of-pocket costs ranging from \$1,000 to over \$11,000 depending on the specific disease. Notably, several demographics were particularly impacted by financial hardship: people under 65, Aboriginal and Torres Strait Islander people, people in rural and/or remote areas, households with low income, those who were unemployed and people with private health insurance.

There are a number of studies demonstrating that people in lower socio-economic areas experience poorer survival outcomes for cancer in Australia³. The Cancer Council and Oncology Social Work Australia's submission to the Independent Review of the Australian Public Service, which detailed issues with Australia's welfare system for people with cancer, noted that:

*"Australians in the lowest socio-economic quintile are 30% more likely to die from their cancer than those in the highest socioeconomic 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."*⁴

The National Disability Insurance Scheme (NDIS) and, separately, the Disability Support Payment (DSP) through Centrelink are payments intended to provide support for people living with a disability. The eligibility requirements for both of these schemes are necessarily restricted to ensure that support reaches those who meet it most. The general eligibility requirements are, broadly, a disability caused by a permanent impairment, which is fully diagnosed, treated and stabilised, and will substantially reduce functional capacity to work, study or take part in social life. The NDIS is additionally restricted to those under the age of 65, and both the schemes have complexities in application.

Blood cancers are complex set of diseases. The Leukaemia Foundation uses the term 'people living with blood cancer' rather than 'patients' as we recognise that despite treatment for some blood cancers being curative, blood cancers are typically lifelong conditions with lifelong effects.

There are over 100 different types and sub-types of blood cancer, ranging from acute, rapid onset cancers to chronic or slow-growing cancers; from cancers that can be (relatively speaking) benign to cancers which are aggressive and generally have poor outcomes. Many blood cancers can relapse, sometimes multiple times; patients can become refractory to their treatment, requiring a shift in regimen; some blood cancers can even develop secondary to treatment of other cancers. Regardless of whether their disease is acute or chronic, all people living with blood cancer can

² Bygrave A et al, 2021, Australian Experiences of Out-of-Pocket Costs and Financial Burden Following a Cancer Diagnosis: A Systematic Review, *International Journal of Environmental Research and Public Health* 18: 2442, <https://doi.org/10.3390/ijerph18052422>

³ Such as Afshar N, et al, 2020, Differences in cancer survival by area-level socio-economic disadvantage: A population-based study using cancer registry data, *PLOS ONE*, <https://doi.org/10.1371/journal.pone.0228551>; Tervonen HE et al, 2017, Cancer survival disparities worsening by socio-economic disadvantage over the last 3 decades in new South Wales, Australia, *BMC Public Health* 17, 691, <https://doi.org/10.1186/s12889-017-4692-y>

⁴ Cancer Council and Oncology Social Work Australia, 2018, Submission to the *Independent Review of the Australian Public Service*, <https://www.apsreview.gov.au/file/300/fil03861cde4c8c1c91faac3.pdf?token=D5Gge793>

experience long term side effects that can result in significant impairment, temporarily or permanently.

The eligibility criteria for the DSP and NDIS, and the nature of blood cancers, mean that people living with blood cancer are effectively excluded from either of these schemes. For people requiring external financial assistance, their only other option is JobSeeker.

The Cancer Council and Oncology Social Work Australia, in their 2021 joint submission to the *Inquiry on the purpose, intent and adequacy of the Disability Support Pension*, summarised this state of affairs (which is also applicable to the NDIS):

The DSP eligibility criteria, assessment and determination processes are too complex for people with cancer and their health care team to understand and apply, and do not adequately consider the realities for people with chronic illness such as cancer. Many people will be diagnosed with and survive cancer however treatment and recovery can be lengthy and uncertain, with long-term side effects often keeping people out of work. Prognosis can be uncertain early in someone's cancer experience and people commonly switch treatments over time depending on their progress. Consequently, people affected by cancer must rely on JobSeeker, rather than the more programmatically appropriate DSP.

The current medical rules to qualify for the DSP coupled with changes to the eligibility criteria over the last two years means that people with cancer are usually allocated to income support payments through JobSeeker, despite it being a program intended to provide financial support to the short term unemployed while they actively seek work. In the case of JobSeeker, failure to submit a new medical certificate to continue an exemption to mutual obligations can interrupt payments and affect continuity of financial support. It would be much more appropriate if eligibility criteria and medical evidence requirements for the DSP was adjusted to support people with cancer to receive the DSP instead of JobSeeker. At the present time, people with cancer fall between the cracks of the DSP and Jobseeker programs.⁵

JobSeeker is a short-term supplement payment for people who are actively seeking employment. It is not intended as a 'safety net' payment, with its quantum set at an amount well below the poverty line, and below other 'safety net' payments like the age pension or DSP (income and assets tests apply, but the full aged pension is \$987.60 a fortnight, as is the DSP; JobSeeker is \$642 a fortnight). JobSeeker fundamentally does not cover basic living needs for those who are able to work, let alone those who are unable to work as a result of a cancer diagnosis, by design. Recognising this, the Leukaemia Foundation has recently become a signatory to the *Raise the Rate* campaign.

There are also practical issues with JobSeeker, as highlighted above: beyond the complexity of application process in general, the requirement to regularly submit medical certificates to support a person's exemption from mutual obligations can result in people having to complete onerous paperwork, while undergoing intensive treatment, in a hospital bed.

⁵ Cancer Council and Oncology Social Work Australia, 2021, Submission 65 to *Inquiry into the purpose, intent and adequacy of the Disability Support Pension*. Available at https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/DisabilitySupportPensio/Submissions

Other than financial assistance from governments, people with blood cancer undergoing financial hardship can access funds from superannuation, life or income protection insurance, loans or other avenues. The Leukaemia Foundation also provides limited financial support, totalling \$164,000 in the 2020-21 financial year and with grants averaging \$274, including reimbursements for groceries, transport petrol and utility bills on top of our accommodation services. As a philanthropic organisation, which is almost entirely dependent on community donations, our ability to do much more beyond this is limited.

Ultimately, as the JobSeeker payment is not a suitable fit to provide support to people living with blood cancer, and they are largely ineligible for the NDIS and the DSP, many suffer financial hardship. The costs of cancer go beyond diagnosis and treatment of the disease itself and can include the temporary or permanent reduction in capacity to work, supportive care such as long-term physiotherapy, dieticians, psychosocial support, palliative care or other complex care needs that may be ongoing for the remainder of the person's life.

The current eligibility requirements for the NDIS and the DSP are unnecessarily exclusionary of people with cancer, and especially blood cancer with the nuances of its specific diseases. For the DSP, for person's cancer to be "fully diagnosed, treated and stabilised" can often depend on how a patient's diagnosis and treatment pathway is considered. It excludes people who are in active treatment, even if that treatment is long-term, and even if that patient is acutely unwell pursuant to either their treatment or their disease. For example, in chronic myeloid leukaemia (CML) which accounts for approximately 15 per cent of all leukaemias, the majority of patients need to take a tyrosine kinase inhibitor daily for the rest of their lives to keep their disease suppressed. While their disease may be "fully diagnosed", it is not "fully treated" or "fully stabilised": for approximately 5 per cent of people with CML, their disease will 'progress' in spite of treatment to an accelerated form called blast phase CML, resembling more acute forms of leukaemia.

For the NDIS, the impairment resulting from a cancer diagnosis or treatment may not meet the specific thresholds defined for eligibility which is not flexible enough to consider refractory, relapsed or secondary cancers, or long-term debilitating conditions as a result of cancer treatment. Graft versus host disease (GvHD) is one such lifelong complication arising from bone marrow or stem cell transplant (a common treatment for blood cancers) and can result in significant morbidity or death. GvHD can affect anyone who has undergone a bone marrow/stem cell transplant, although typically the better the match between donor and recipient, the less severe the effects. While there are novel therapies available and in development to treat GvHD, those with the condition will usually need to take corticosteroids for much of their remaining lives.

An additional complicating factor in considering financial hardship is that many blood cancers are more common in people over the age of 65, resulting in significant impairment, for which they are ineligible to receive support through the NDIS due to their age. Their support needs may be above and beyond what is provided through the age pension and age care packages.

The Senate Standing Committee on Community Affairs' final report for the *Inquiry into the purpose, intent and adequacy of Disability Support Pension* identified this issue of eligibility, and recommended that "the Australian Government investigates how the requirement that a condition be 'fully diagnosed, treated and stabilised' is preventing people with conditions that are complex, fluctuating, or deteriorate over time, from accessing the Disability Support Pension, and could be modified to ensure people get the support they need."

The Leukaemia Foundation concurs with this recommendation and suggests the NDIS eligibility criteria could similarly be refined to ensure that people living with blood cancer are not left to slip through financial cracks through reliance on the inappropriate JobSeeker payment.

Sincerely,


Chris Tanti
Chief Executive Officer