



CANCER COUNCIL NSW

# **Priorities for NSW Budget 2022-23.**

**Cancer Council NSW** is the leading cancer charity in NSW dedicated to reducing the impact of cancer, and ensuring programs and services reach communities throughout NSW. We are the only organisation in Australia that works across every area of every cancer, including research, prevention, support, and advocacy.

Cancer Council NSW is a committed key stakeholder in delivering the NSW Cancer Plan and improving the quality of life for people with cancer. In the 2016-2021 NSW Cancer Plan, Cancer Council NSW is a lead organisation responsible for:

- Facilitating access to psychosocial support for people affected by cancer
- Providing accessible information and support for people affected by cancer
- Implementing strategies and disseminating tools and resources that support people affected by cancer to appropriately self-manage.

# Foreword from the CEO.

Professor Sarah Hosking

In 2022, more than 51,000 people in NSW are expected to be diagnosed with cancer – and almost 16,000 people will die from cancer. Cancer is the biggest burden of disease in NSW – more than stroke and heart disease combined.

While NSW has some of the best survival outcomes in the world, cancer continues to have an enormous impact on the lives of people affected by it, their families and the health system. Many people require support to help them navigate and manage the immense emotional, financial and practical pressures that accompany a cancer diagnosis.

For people in regional and rural NSW, the pressures can be even greater where access to care can be limited, local support services often do not exist, and out-of-pocket costs can be enormous.

Often when a person with cancer cannot access support locally or within the health system – or are feeling uncertain, fearful and anxious – they turn to Cancer Council NSW for support.

The COVID-19 pandemic has created a perfect storm for people with cancer, exposing gaps in services and amplifying the pressures on a person's emotional and financial wellbeing. Over the past two years, Cancer Council NSW has seen heightened levels of financial toxicity, emotional distress and poor mental health among those who contact us for support. There has been unprecedented demand for our services and many people in need don't reach out for help and are slipping through the cracks.

In this submission, we call on the NSW Government to improve access to care for those in rural and regional NSW and work with us to support the emotional and financial wellbeing of people with cancer across the state.

The next NSW Cancer Plan recognises that cancer is not just a health issue and requires collaboration across the entire sector and including community-based organisations. Cancer Council NSW is on the frontline supporting people with cancer every day and is in a unique position to reach more people at a time when need has never been greater.

The four initiatives outlined in this document are not an exhaustive list of the issues that need attention. They are however issues that must be addressed in the upcoming Budget and will result in immediate benefits for people with cancer, their families, and the entire health system.



# SUMMARY OF RECOMMENDATIONS

**Goal 1:** Support mental health and financial wellbeing of people with cancer



## RECOMMENDATION 1

Provide funding to increase access to cancer-specific counsellors



## RECOMMENDATION 2

Provide funding to increase access to financial counsellors for people with cancer

**Goal 2:** Make it easier for people in regional NSW to access care



## RECOMMENDATION 3

Increase IPTAAS subsidies



## RECOMMENDATION 4

Expand IPTAAS eligibility criteria and include people with cancer travelling for clinical trials

# GOAL 1.

## Support mental health and financial wellbeing of people with cancer

### RECOMMENDATIONS

1. Provide funding to increase access to cancer-specific counsellors
2. Provide funding to increase access to financial counsellors for people with cancer

The emotional and financial impact of the COVID-19 pandemic on people with cancer, their families, and carers has been severe [1, 2, 3]. The pandemic has not only exposed existing gaps in the care and support services available to people affected by cancer, it has widened them. Research shows that service models and funding for care and support services for people affected by cancer, including financial and mental health support, were stretched well before COVID-19 [4].

Investment is needed to ensure that NSW is prepared to address cancer survivors' increasing supportive care needs [4] and avoid a second crisis of trauma following the pandemic. Addressing the economic and mental health impacts of public health emergencies are key elements of an effective recovery response [5].

COVID-19 has heightened distress for people with cancer. The pandemic has taken an enormous toll on the mental health and emotional wellbeing of people affected by cancer [1,6]. The risk of COVID-19 for people affected by cancer is leaving many feeling uncertain, fearful and anxious. Strategies like social distancing, quarantine, travel restrictions and visitor limitations provide important protections while also limiting opportunities for practical and emotional support, and social connection. It is no wonder that 85% of healthcare professionals report being concerned about the increased pressure COVID-19 has placed on patient's mental health and wellbeing [6].

Psychological and financial support services provide essential support for people with cancer to live well [7]. However, in NSW there are simply not enough cancer-trained counsellors. Many cancer-related mental health services have prohibitively long wait times or rely heavily on out-of-pocket payments that many cannot afford. At a time when average distress levels of callers to our information and support line has doubled compared to pre-pandemic levels [1], some people report unacceptably long waiting times to see a publicly funded psychologist.

***“We are hearing of six weeks to three month wait times for psychologists as a normal thing. The advantage of our service is we generally book a counselling session in for our clients within a week of our initial counselling assessment call”.***

– Felicity Hale, Supportive Care Specialist, Cancer Council NSW

When people with cancer need help, they simply cannot wait three months. Even for those who are lucky to access an appointment with a psychologist, some cannot afford the out-of-pocket costs, which are often more than \$100 per session. Compounding these challenges is the loss of the usual social and peer-support networks, a consequence of pandemic control measures [1]. These factors are leading many to turn to unreliable sources for information and support needs [8].

## RECOMMENDATION 1.

### Provide funding to increase access to cancer-specific counsellors

#### ANNE'S STORY

In 2012, Anne was diagnosed with ovarian cancer and underwent surgery and chemotherapy. After receiving the all clear, and just over six years later, Anne's cancer returned. Since then, Anne has undergone numerous rounds of chemotherapy, radiation and blood transfusions – many of which have required her to travel from her home in Dubbo to Sydney.

Cancer Council NSW has supported Anne through her cancer diagnosis. Anne was connected with a counsellor who she speaks to over the phone once a fortnight. Sessions with the counsellor have helped Anne navigate the emotional journey of a recurrence in her cancer and the need for more chemotherapy. Anne was also linked in with a fortnightly telephone support group to talk with other people with cancer and provided taxi vouchers to assist with the cost of getting to hospital.



Our suite of emotional and financial support services helps thousands of people every year whose needs are not being met through the public health system. With funding from the NSW Government, Cancer Council NSW can expand its proven effective counselling program and reach more people with cancer.

The Clinical Oncology Society of Australia recognise community services as one of the pillars of survivorship care [9] and best practice cancer care recommends that each of the more than 50,000 people diagnosed with cancer each year in NSW be notified of the support services offered by Cancer Council [10].

## Specialised and quality cancer support

Cancer Council NSW currently employs 2.5FTE cancer-trained counsellors. Unlike other generalist services, our qualified counsellors have completed professionally recognised training and are accredited with the following recognised professional organisations:

- Australian Counselling Association, or
- Professional Association of Psychotherapy and Counselling, or
- Accredited Social Workers.

Cancer Council NSW counsellors are also members of the Cancer Counselling Professionals Network, a forum where cancer support specialists can share their experiences and expertise. As members of the Network, our counsellors keep up-to-date on the best available support and developments to ensure they can give the best available support for people affected by cancer.

In addition to our qualified team providing specialist support for people affected by cancer, we uniquely offer a fully subsidised service for those who are in financial distress. Our service offers an initial six consecutive sessions, includes family and friends, and clients are case managed by the one Supportive Care Specialist to ensure a consistent and quality service. Limited resources prevent us from widely promoting our cancer specialist support service. Referrals mostly come via our 13 11 20 Information and Support line, social workers and clinicians located in cancer treatment centres or psychologists who are not able to cater for the specialist needs of people affected by cancer or when patients can't afford the out-of-pocket costs. We don't publicly promote this service as we don't want to create expectations for services that we are not able to meet and risk creating excessively long wait times. Each year we pay over \$100,000 to an external provider to care for those who exceed our capacity.

***“We’re pretty burnt out right now. Our team is working at capacity. We know more people need specialist support and it would be great to have the additional resources to address the unmet demand that we know is out there”.***

– CCNSW counsellor

## Cancer Council NSW support services

 Cancer Connect	 Telephone Support Services	 Online Community	 Support Group Leaders	 Cancer Counselling
One-on-one	Groups	Forums	Community delivered groups	Professional counselling
Telephone	Telephone	Online	Face-to-face	Phone or in-person
Newly diagnosed, treatment, survivorship	Advanced, poor prognosis, carers and bereaved	Everyone affected by cancer	Training, ongoing support and resources	Counsellors with extensive experience with cancer issues
All cancers	Advanced and poor prognosis, cancers, carers and bereaved	All cancers, survivors and family, friends, carers	All cancers and carers	All cancers, survivors, friends, carers

**People affected by cancer have been doubly hit by the costs of cancer and the financial impacts of the pandemic.**

*“A self-employed photographer diagnosed with cancer was recently referred to us. He was not able to earn an income for an extended period of time but being self-employed, he had no sick leave to fall back on. We were able to provide him emotional support and financial assistance to get him through the immediate crisis. We also supported him with financial counselling to re-organise his finances and help him beyond the immediate crisis”.*

– Felicity Hale, Supportive Care Specialist, Cancer Council NSW

People affected by cancer often experience significant out-of-pocket costs for their treatment and care. The myriad of costs that accompany a cancer diagnosis can include transport, medication, diagnostics and allied health. The COVID-19 pandemic has worsened the financial burden of a cancer diagnosis. For many, these costs could not come at a worse time because people with cancer – and in many cases the family members caring for them – are often unable to work or are even forced into early retirement [11]. During 2020, we saw a 20% increase in referrals to our financial assistance program compared to 2019.

Combined with the uncertainties of cancer treatment and its effects, financial hardship can lead to further distress, worry and anxiety in an already difficult time [12]. We know that many people experiencing the financial side effects of cancer struggle to afford basic necessities and often skip treatment due to costs [13]. This leads many to experience poorer cancer outcomes, higher levels of psychological distress, and overall reduced quality of life [12]. Recent data show out of pocket expenses had increased by 70% from 2011 to 2015 [14].

The financial impact of a cancer diagnosis is even worse for people in low-income households and people living in regional and remote areas, who experience significant costs travelling to treatment.

Without access to information and specialised support, many patients often do not know where to start when faced with the financial challenges and unforeseen costs of cancer. Financial counselling is an important tool to limit the impact of financial hardship however existing financial counselling services are stretched. This is a major concern as delays in access to financial counselling reduces people’s chances of having financial stresses resolved [17].

There will likely be over 51,000 people with a new cancer diagnosis next year [5]. As cancer survival continues to improve, our population continues to grow and age, so too will the economic and mental health burden of cancer.



## FINANCIAL PRESSURES DURING COVID-19

Due to COVID-19, people affected by cancer faced additional financial hardship.



# 20%

increase in referrals to our Financial assistance program in March and April 2020, compared to 2019.



# 297,161

total debts waived for cancer patients and carers, resulting from negotiations with creditors.



# \$25,000

we helped waive one patients credit card debt of \$25,000.

## RECOMMENDATION 2.

**Provide funding to increase access to financial counsellors for people affected by cancer.**

### ANGELINE'S STORY

Since February 2018, Angeline has worked as a financial counsellor at Cancer Council NSW helping people affected by cancer on the NSW Central Coast and Hunter regions. Since then, she has helped more than 200 clients and their families with cancer and has worked with creditors to waive \$233,846 worth of debt. Angeline's clients report that her work has reduced their financial stress, which has enabled to better cope and focus on getting through their cancer diagnosis.



NSW Government funding can help Cancer Council NSW to expand our financial counselling service and prevent more people with cancer and their families from experiencing financial hardship. Each year, Cancer Council assists hundreds of people affected by cancer to lessen the financial impact of their diagnosis – and we know this is the tip of the iceberg.

Early access to financial counselling can help prevent unnecessary hardship on people affected by cancer who are experiencing financial stress [15]. Financial counsellors provide practical advice and support to people who have debts and may be struggling.

As well as being skilled counsellors, they are also experts in consumer rights, bankruptcy, and social security law, help with budget planning and to navigate hardship schemes as well as assist with debt clearing where appropriate.

Research shows that financial counselling contributes to improved health outcomes. A survey from Swinburne University found 69% of people felt more positive about the future and 63% of people felt their mental wellbeing had improved as a result of financial counselling [15].

Cancer Council NSW provides a free and well recognised financial counselling service to help people manage debt and budgets, credit negotiations and consumer rights. What sets us apart from other financial counselling services is a deep understanding of financial implications of cancer and our ability to refer across our range of services to ensure truly integrated, person centred care. This is highly important considering the scale and scope of cancer burden in NSW. Unfortunately, our service is already functioning at maximum capacity and struggles to meet the heightened demand.

## **Benefits to NSW**

There will likely be over 51,000 people with a new cancer diagnosis next year [16]. Anxiety, depression and financial hardship are highly prevalent among cancer survivors, resulting in not only lower quality of life and increased risk of suicide, but also increased health service use [17]. As cancer survival continues to improve, our population continues to grow and age, so too will the economic and mental health pressure of cancer on the public health system [14].

Community-based organisations such as Cancer Council NSW can help address many of the unmet care-navigation, psychosocial and information needs of people affected by cancer. Boosting community capacity to support patients manage the financial and emotional side effects of cancer can:

- Equip people with the skills to self-manage. This will limit the need for more intensive and expensive interventions later,
- Reduce demand on public hospital psychologists and social workers,
- Address anxiety and depression to reduce overall health service use and associated costs [18],
- Enhance access to psychological and financial care for people living in regional areas through our virtual models of care.
- Synergise with other NSW pandemic relief initiatives to help ameliorate the economic and financial impacts of COVID-19

## DELIVERING NSW STATE OUTCOMES AND PRIORITIES

Keeping people healthy and out of hospital through improved psychological and financial supports also aligns with several key NSW priorities:

- Health budget outcomes to protect, maintain and improve the health and wellbeing of residents of NSW, specifically supporting healthy and resilient communities and mentally healthy communities
- Keeping people out of hospital to ensure COVID-19 surge capacity
- NSW Cancer Plan, Priority 3 includes a major focus on supportive care services such as psychosocial care, allied health care and financial planning advice
- Premiers Priority of towards zero suicides and improving outpatient and community care
- NSW Health Strategic Priorities to keep people healthy and deliver truly integrated care
- Optimising referral pathways to community support organisation is a key recommendation of the Australian Optimal Care Pathways

### Costing and implementation

Recurrent investment of \$650,000 per year would enable two extra financial counsellors and 2.5 extra cancer-trained counsellors to immediately address critical gaps in the support and wellbeing of people affected by cancer in NSW. In the long-term, this will help reduce cancer-related distress and anxiety, financial toxicity, and improve health and wellbeing for people affected by cancer.

SERVICE	EXPECTED BENEFITS	COST P.A.
<b>3.5 FTE specialist cancer counsellors</b>	<ul style="list-style-type: none"> <li>• An extra 275 people will have access to specialist cancer counselling each year</li> <li>• Almost 3000 counselling sessions for the people of NSW at no cost</li> </ul>	\$400,000
<b>2 FTE financial counsellors</b>	<ul style="list-style-type: none"> <li>• Up to 200 more people will be able to access financial counselling</li> <li>• Professional negotiations with more than 100 creditors on behalf of people affected by cancer</li> <li>• Almost \$400,000 worth of debt waivers</li> </ul>	\$250,000



The medical, practical and emotional aspects of cancer necessitate the specialised care and support for which Cancer Council NSW is known [18].

Cancer Council NSW provides an extensive range of services and support for people affected by cancer including trusted information and services that provide emotional and financial support for people affected by cancer. These services are provided by trained and experienced professionals that can easily be scaled up to meet increased demand.

Cancer Council NSW has a significant footprint of 11 regional offices across the state, referral connections with over 400 health professionals state-wide, our role within the Clinical Oncology Society of Australia Working Groups, and our close working connections with other major organisations across the health sector, to help reach those in need. By early 2022 we will also have eight Cancer Liaisons working within cancer treatment centres across the state whose role is to link people in need of support with the right services at the right time. Our award-winning marketing team are positioned to improve awareness of support services.

Our well recognised 13 11 20 Information and Support line provides an easily accessible channel through which people are referred to Cancer Council NSW and triaged. In 2022, Cancer Council NSW is committing \$750,000 toward a campaign to promote and increase awareness of our information and support services, which will likely see demand for counselling grow. Our financial and emotional counselling services also sit within a suite of supportive care services so cross-referrals can easily be made (e.g. emotional support, legal support, accommodation hardship support, emergency financial assistance) and vice-versa.

The 2022-26 NSW Cancer Plan makes it clear that partnerships with non-government organisations are key to achieving its goal of lessening the impact of cancer. Its upcoming release is a timely opportunity for NSW Government to support Cancer Council NSW to provide more people with cancer in NSW essential supportive care.

# GOAL 2.

## Make it easier for people with cancer in regional NSW to access care

### RECOMMENDATIONS

3. Increase IPTAAS subsidy rates

4. Expand IPTAAS eligibility criteria and include people with cancer travelling for clinical trials

### People with cancer in regional NSW struggle to access care

Everyone in NSW should be able to access cancer care when and where they need it. However, people with cancer living in regional NSW are often faced with having to travel long distances and away from their homes to access the care they need. A recent study found that on average people in regional NSW were required to travel more than 4,600km over the course of a treatment.

Travelling while unwell and spending time away from home, family and support networks adds significant financial and emotional burden to people and families who are already undergoing an immensely stressful time.

For some, the financial cost of travelling and being away from home can be so much that it stops people accessing care. We know that a cancer diagnosis costs a household at least \$43,000 and one-in-five people with cancer living in regional NSW skip care because of out-of-pocket expenses [13,19].

### Isolated Patient Transport and Accommodation Scheme

The Isolated Patient Transport and Accommodation Assistance Scheme offers people with cancer in regional NSW a financial subsidy to offset the cost of travelling to treatment. While IPTAAS helps thousands of people each year, it does not go far enough to ensure people with cancer can access care and can do so affordably and without significant stress.

Recent research of people using IPTAAS has found that the current subsidy rates do not reflect the rising costs of accommodation and are not enough to prevent people from experiencing financial hardship.



### RYAN'S STORY

In November 2019, as the state's bushfire crisis started, Ryan Channells, a father of two and a Rural Fire Service Volunteer on the Mid North Coast, was diagnosed with Stage IV melanoma. At the time, Ryan's cancer was inoperable and so widespread he was given only a year to live.

His oncologist recommended he take part in a leading-edge immunotherapy clinical trial. However, being unable to access IPTAAS, the cost of travelling to Sydney for treatment and the financial stress this would place on his family became, for Ryan, a greater source of worry than the thought of dying itself.

Cancer Council NSW provided Ryan with financial assistance in order for him to travel to Sydney to receive treatment. The clinical trial has worked to shrink his cancer and Ryan has since had the tumour and cancerous lymph nodes removed. Recent scans give Ryan and his family hope for the future.

The nature of cancer treatments means that many people with cancer will require long stays away from home and sometimes for years at a time. When the average cost of modest hotel accommodation in metropolitan Sydney is above \$200 per night, an average course of chemotherapy can be financially crippling for someone who's had to travel from regional NSW.

IPTAAS eligibility criteria can also prevent some people in need from accessing care. A strict eligibility criteria that relies on distance travelled can prevent some people who suffer from transport disadvantage from being eligible.

Despite the lifesaving potential of clinical trials, people who need to travel for clinical trials are excluded from accessing IPTAAS. Financial assistance offered by charities is the only way many people in regional NSW are able to afford to travel to access clinical trials.

### RECOMMENDATION 3.

#### Increase IPTAAS subsidy rates

To ensure that people affected by cancer living in regional NSW can access the care they need, Cancer Council NSW recommends reviewing the Isolated Patient Transport and Accommodation Assistance Scheme and making the following changes:

- Increase the reimbursement rate for accommodation to a level that prevents people from experiencing financial hardship
- Abolish the single occupancy room rate
- Increase the private travel subsidy rate from \$0.22/km

IPTAAS accommodation and private travel subsidy rates have not changed since 2015 and are well below what is required to prevent hardship. With an accommodation rate as low as \$43 per night in some instances, a week-long course of radiation for someone in regional NSW can result in out-of-pocket accommodation costs in the thousands. Covering a minimum proportion of a person's reasonable actual accommodation costs would provide a level of reassurance and a safety net that would prevent people with cancer from experiencing runaway costs.

#### PAUL'S STORY

Paul has been undergoing chemotherapy to treat his cancer since he was diagnosed in 2018. Paul lives in Western NSW and because the treatment he requires is not available at his local hospital he must travel to Sydney. His most recent treatment required him to stay in a serviced apartment for eight weeks.

After Cancer Council NSW informed Paul of IPTAAS, he received \$6,000 in subsidies for accommodation. However, this has still left Paul out of pocket more than \$7,000 for accommodation alone.



**RECOMMENDATION 4.****Expand IPTAAS eligibility criteria and include people with cancer travelling for clinical trials**

- Amend the eligibility criteria to allow people with cancer to access clinical trials
- Improve the administration of IPTAAS

A recent study found that access to financial assistance influenced the decision of a person with cancer, living in regional NSW to take part in clinical trials. For some people, participation in a clinical trial can be lifesaving.

There is significant disparity in access to clinical trials depending on where a person lives. Sydney LHDs has a clinical trial enrolment rate of 14 enrolments per 100 cases of cancer while Western NSW LHD, Central Coast LHD, Nepean Blue Mountains LHD and Southern NSW LHD all report enrolments of one or less per 100 cases [20].

**2.3. Benefits to NSW**

Improving support for people with cancer when trying to access care is an important step towards reducing the disparity in outcomes between those in regional and metropolitan NSW. It is already well documented that travelling long distances, loss of incomes and out-of-pocket costs affect the treatment choices of people with cancer [21]. Improving access to optimal cancer care has the potential to reduce overall health system costs.

Improved access to cancer care for people in regional NSW by expanding IPTAAS eligibility and lifting rates would help achieve objectives in a number of state health strategies, including:

- NSW State Health Plan
- NSW Rural Health Plan
- NSW Cancer Plan 2022-2026
- Aboriginal Health Plan 2013-2023
- NSW State Outcomes in Health; specifically mentally healthy communities, healthy, resilient communities, world class research and innovation; continuously improving healthcare.



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