

# Financial Impact of Cancer

Community Engagement | March 2025



At **Rare Cancers Australia (RCA)**, our mission is to improve the lives and health outcomes of people affected by rare, less common and complex cancers. We redefine cancer support, so no one is left behind or feels alone. Everyone is given the best possible chance to live beyond cancer.

We do whatever it takes to change the story of a rare cancer diagnosis through limitless support and advocacy. Our commitment extends to driving change in access, affordability, and quality of care, ensuring better outcomes for the patients of today and tomorrow.

We aim to be a beacon of hope, a force for change, and a steadfast ally for people living with rare, less common and complex cancers.



# Executive summary

Through our direct patient support work at Rare Cancers Australia, we've witnessed firsthand the devastating financial impact of rare and less common cancers on the patients and families we serve daily. This report shares the lived experiences of our community members, whose voices illuminate the true cost of cancer beyond medical statistics.

Our national survey confirms what we've long observed in our support programs: the financial toxicity of cancer creates an additional battle for those already fighting for their lives. Community members in our care frequently report **out-of-pocket costs exceeding \$10,000, with one in ten facing extraordinary expenses over \$100,000.**

The people we support often make heartbreaking choices between **life-saving treatments and basic necessities like housing and food.** These impossible decisions are particularly acute for our rare cancer community members, who face additional barriers including limited treatment options, need for interstate travel, and fewer financial support pathways.

Our daily work with patients reveals significant inequities in the cancer journey, particularly for those in regional and remote areas who form a vital part of our community. These insights, gathered through years of direct patient support, underscore the urgent reforms needed to better serve all Australians affected by rare and less common cancers.



## Survey design and participants

A national online survey was conducted between October and December 2024, targeting people diagnosed with cancer and their carers. The survey captured both quantitative and qualitative data on financial impacts, including direct medical costs, indirect expenses, treatment decisions influenced by financial constraints, and financial management strategies. The survey was developed in consultation with Rare Cancers Australia's Patient Advisory Group and distributed via LinkedIn, Facebook, patient advocacy groups, and cancer councils.

## Objectives

The survey was designed to:

- 1 Quantify out-of-pocket expenses**  
across different aspects of cancer care
- 2 Identify financial barriers**  
**which** have impacted treatment decisions
- 3 Examine disparities in funding**  
access between different cancer types
- 4 Understand the various financial coping mechanisms**  
employed by affected individuals and their families
- 5 Provide evidence to support advocacy**  
for system-level changes

“A rare cancer diagnosis is simply the beginning, however that is something you often do not realise at the time. In hindsight you begin the process with optimism and hope, but you quickly realise this can be misguided when your child has been diagnosed with a rare cancer which has not seen quantifiable change in over four decades. The cost was never a consideration for us, we expected a cure and nothing less, and we would stop at nothing to facilitate it. Now I realise we were one of the fortunate families who could, and many if not most cannot do what we were able to do for our son. It is now our life's work to ensure others have the same and more opportunities which exist to assist them in navigating the minefield that exists when a loved one is diagnosed with a rare cancer.”

– carer of a child with osteosarcoma, who spent over \$100,000 in costs, primarily for treatment.

# Introduction

A cancer diagnosis brings profound emotional distress, but its financial toll can be just as devastating. For those diagnosed with rare and less common cancers, this burden is even heavier—limited treatment options, minimal government funding, and steep out-of-pocket costs place life-saving care out of reach for many.

The impact extends far beyond the individual patient. Families are forced into impossible choices: depleting life savings, selling homes, or forgoing treatment altogether. Over one-third of people who contact Rare Cancers Australia report financial distress in their first call, and many require financial assistance at some point during their treatment. With out-of-pocket costs frequently exceeding \$100,000 and 32% of patients forced to stop working entirely, cancer's financial burden creates a cycle of hardship that can persist long after treatment ends.

The phenomenon of "**financial toxicity**" — remains a critical yet underexplored challenge. The effects go beyond medical bills, undermining mental health, family stability, and long-term financial security. For those with rare cancers, these struggles are even more severe. Many face higher costs with fewer support options. In regional and remote areas, where patients must travel hundreds of kilometres for treatment, expenses for travel and accommodation further compound the strain.

The true scale of financial toxicity is likely far worse than current data suggests. Many patients, too ashamed or overwhelmed, never report their financial struggles. Others, consumed by the immediate challenges of treatment, may not fully grasp the long-term financial toll until years later. Existing research captures only those who seek help or participate in surveys—countless others suffer in silence, having already exhausted every available support option.

A systematic review published in Cancer Research found that 28–48% of cancer patients experience some form of financial toxicity when measured by monetary indicators.[1] Yet the burden extends far beyond direct medical costs, and the long-term financial consequences remain poorly understood. For rare cancer patients, the knowledge gap is particularly acute—small patient populations and limited research funding mean critical questions remain unanswered.

[1] Gordon, L.G., Merollini, K.M.D., Lowe, A. et al. A Systematic Review of Financial Toxicity Among Cancer Survivors: We Can't Pay the Co-Pay. *Patient10*, 295–309 (2017). <https://doi.org/10.1007/s40271-016-0204-x>



# Findings

## Demographics

The survey received responses from 182 eligible participants: 133 (73%) were cancer patients, and 49 (27%) were carers. Using the AIHW classifications of rarity, 100 respondents (55%) had a rare cancer, 16 (9%) had less common cancers, and 66 (36%) had common cancers (**See Figure 1**).

It is important to note that the AIHW classification does not account for rare subtypes of common cancers and calculates incidence based on the affected population rather than the total population (e.g., ovarian cancer per 100,000 females). As a result, some cancers classified as common may still be rare in practice.

Figure 1. Rarity of cancer diagnosed (by AIHW classification)

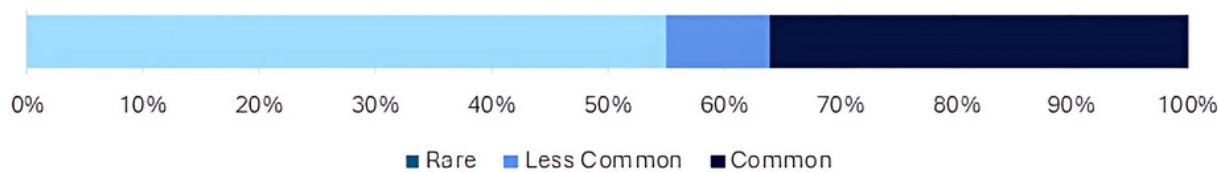
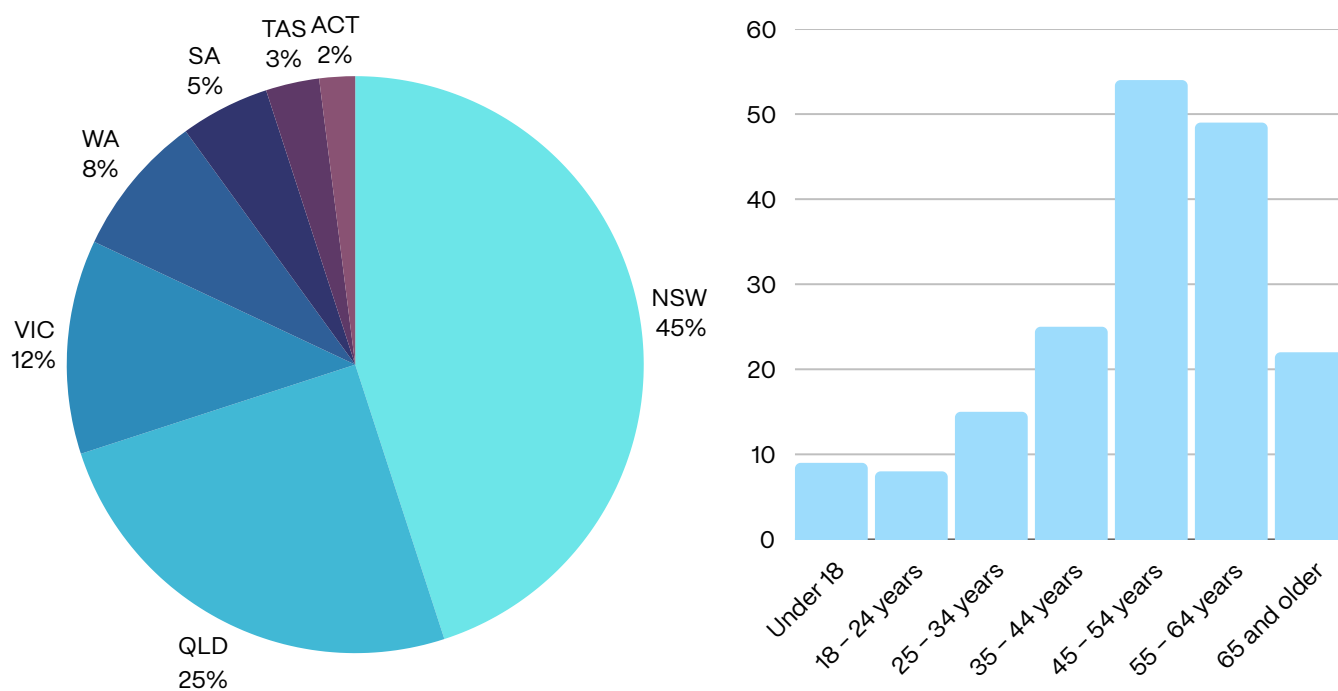


Figure 2A & 2B. Area of residency and distribution of age at diagnosis





# Meet Natalie

Natalie is a 35-year-old from Byron Bay. Just one year ago, she was diagnosed with an extremely rare form of cancer and was told she **might not survive the night**. Today, she is using her experience to advocate for change, sharing the stark realities of navigating a fragmented healthcare system as a rare cancer patient.

Natalie was diagnosed with **adrenocortical cancer**—a rare and aggressive disease. Living in a regional town, they faced delays in diagnosis, limited access to specialists, and financial hardship.

Despite seeing three doctors, Natalie's concerns were dismissed until she insisted on further investigation. A scan revealed a 17cm tumour millimetres from her heart. Unsure of her options, she turned to a friend at a cancer centre, who helped her access **genomic testing**—a turning point in her treatment.

She was matched to Pembrolizumab (Keytruda), an immunotherapy drug that offered hope. However, while Keytruda is listed on the Pharmaceutical Benefits Scheme (PBS) for 13 other cancers, **it is not covered for Natalie's rare cancer**.

With no government support, Natalie had to access her superannuation early, while her mother sold 200 head of cattle to help cover treatment costs. **Her estimated costs have now exceeded \$200,000**. Natalie also had to move back home, facing the financial and emotional toll of her diagnosis.

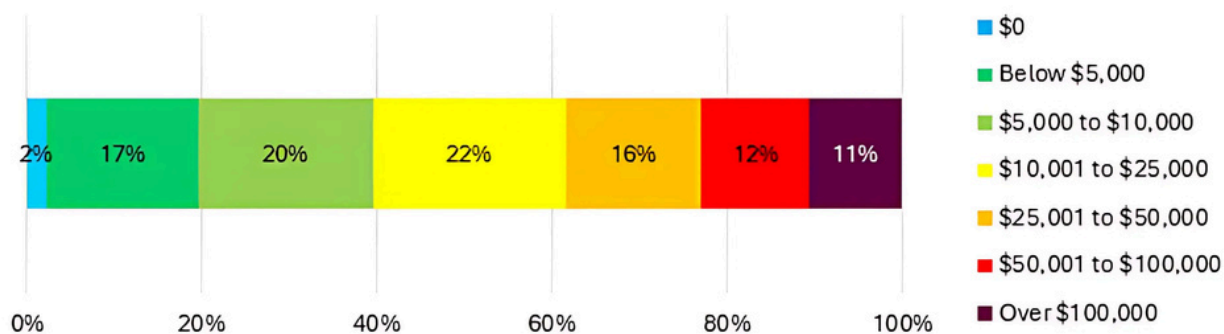
**I need one round of the immunotherapy every six weeks, each costing \$8,000 and requiring me to commute between Byron and Brisbane... In the land of the fair go, this 'cancer lottery' is unacceptable. Every person diagnosed with cancer in Australia should have the best chance to survive and live well, no matter their cancer type, income, or where they live.**



### Out-of-pocket costs

The financial burden of cancer treatment extends far beyond hospital bills, with most patients facing substantial out-of-pocket expenses throughout their cancer journey. Over 60% of participants reported spending more than \$10,000 on cancer-related expenses, with 10% incurring costs exceeding \$100,000 (See Figure 3). These expenses span across treatments, diagnostic tests, travel, accommodation, and various support services essential for cancer care.

Figure 3. Total approximate out of pocket costs for all expenses




**Travel and accommodation costs** emerge as a major financial burden, particularly affecting rural and regional patients. Many individuals must travel hundreds of kilometres for essential care, with some forced to temporarily relocate to access treatment. While support programs like the Patient Transport Assistance Scheme exist, they often fall short of covering actual costs. One patient reported: *"I had to travel 80km round trip for treatment. I did this daily for radiotherapy... I also spent \$12,000 on a car for myself to get to treatments as we were a one car family."*

“Once first line treatment is exhausted, the road to accessing experimental therapies can be fraught with delays and inequity for all those living with this cancer. There is nothing more cruel than to have a potential therapeutic match, and not have the funds to pay for it. Despite there being some very solid viable options for fundraising, the fact remains not everyone can do this, and therefore the equity is often not present across the board. Most people going into a cancer diagnosis believe all costs are covered by our health system, however whilst our health system is one of the best in the world, costs are not all covered, and the impact can be enormous and far reaching. The fact is a number of families simply never recover emotionally or financially from a cancer diagnosis.

– carer of a child diagnosed with osteosarcoma.





**Hidden costs** add significantly to the financial burden. Patients face ongoing expenses for hospital parking (often exceeding \$30 per visit), childcare during treatment sessions, and specialised items such as compression garments, wigs, and medical-grade skin care products. These expenses are rarely covered by insurance or Medicare, creating an additional strain during an already challenging time. As one participant shared: *"Cannot believe all the extras; dressings post-surgery, meds, petrol, parking, take away when too unwell to cook for my family..."*

*"Trying to get things done quickly when living regionally is difficult unless you travel to a major city and go private – this is very expensive."*

– NSW patient living in Central Coast diagnosed with dedifferentiated endometroid adeno carcinoma.

**Rehabilitation and ongoing care costs** extend the financial impact well beyond initial treatment. Many patients require long-term physiotherapy, mental health support, and specialised medical equipment. One osteosarcoma patient detailed: *"All rehabilitation had to be privately funded and has been ongoing for two years... \$180 per hour for physio (3 times per week initially, private health cap maxed within a month)."*

The cumulative effect of these expenses forces many families to make impossible choices between basic living costs and necessary medical care. Some patients report spending **upwards of \$30,000 per month** on life-saving medications unavailable through the PBS, driving some to seek more affordable alternatives overseas. Others deplete their savings and superannuation, creating long-term financial vulnerability that persists well beyond the active treatment phase.

The situation is particularly acute for those with rare cancers, who face both higher costs and fewer support options. As one carer explained: *"Most people going into a cancer diagnosis believe all costs are covered by our health system, however whilst our health system is one of the best in the world, costs are not all covered, and the impact can be enormous and far reaching."*

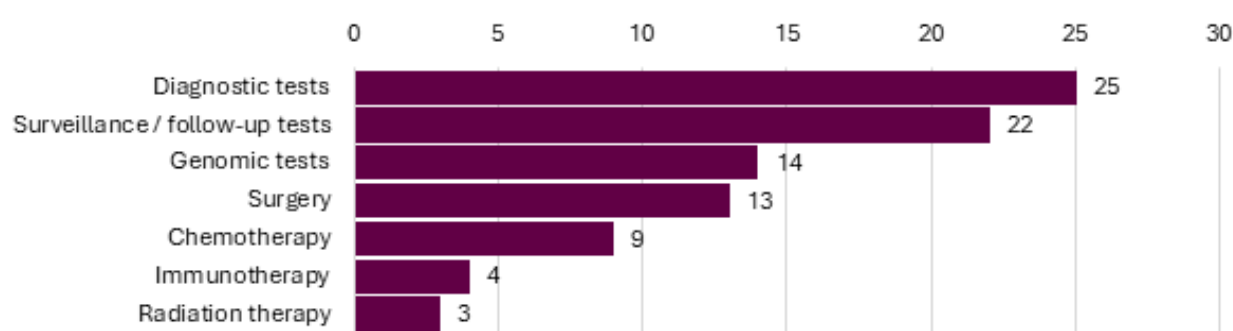
### ***Declining or delaying tests or treatment***

Participants were asked if they had ever said no to having a test or treatment or delayed them because of cost. **One-third of patients said they had**, with diagnostic tests being the most common deferral, followed by surveillance and follow-up tests (See Figure 4).

*A nearly \$3,000 Medicare safety net is so high when you are a single income household. You have to make cuts in food, in lifestyle, and have to consider what is critical care and what can be delayed. With cost-of-living increases, I'd already made cuts in insurances both directly and on my super and this diagnosis just added a level of financial stress. And I'm "lucky" because I had a savings fund.*

– patient diagnosed with an extra-gastrointestinal stromal tumour (E-GIST).

Figure 4. Types of tests or treatments declined due to cost



Many patients delay or refuse recommended tests due to high costs, even when those tests could offer more precise monitoring or better treatment options. These include genomic tests, circulating tumour DNA (ctDNA) tests for surveillance, and even specialised pathology. Some have forgone expert consultations due to the high cost of out-of-pocket expenses, while others have been forced to choose slower, less comprehensive tests that fit their budget.

*I got the social worker to advocate on my son's behalf to waive gap fees that he would have been charged – they would have been significant at approximately \$400 per scan – and he had many scans of all types... Later, after the incorrect advice from the Centrelink/ Medicare office we figured out that he could get a low-income healthcare card which would usually eliminate or at least minimise fees, but that was many scans into diagnosis and treatment... It would be helpful for hospitals to be very aware of these funding options and for them to be very proactive in advising adolescents with serious illnesses like cancer about the early in the diagnosis or at least at the start of treatment. Centrelink/Medicare staff should be better trained about the healthcare supports that exist for Australians and let patients know about the options when they go in for advice.*

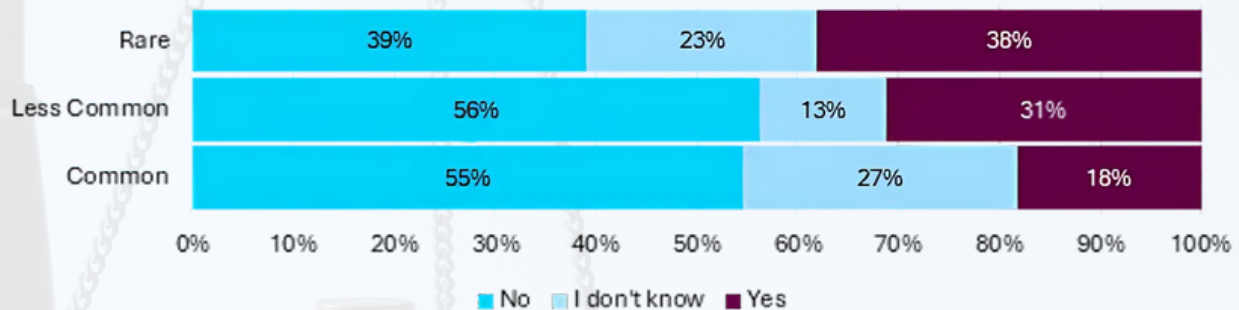
– carer of a child with Ewing Sarcoma.



### ***Inequity of experience***

Participants were asked if they had ever been told that a test or treatment was funded for other cancers, but not for their type of cancer. One-third (30%) had said yes, nearly half (46%) said no, and a quarter (24%) were unsure. This was much more common for people with rare cancers (**see Figure 5**).

Figure 5. Told test or treatment was funded for other cancers but not for their type, by rarity



*After chemotherapy failed the first time, we were advised that the only option we had left was Pembrolizumab (Keytruda). A form of immunotherapy that is covered for some cancers considered more common, such as breast cancer, however not for Thymic Carcinoma as it is too rare and there aren't enough studies to prove that it is an effective treatment... Having to prioritise money – for example, 'do we pay for treatment not covered under the PBS or do we put food on the table?' it's an awful and heartbreaking situation as it is without the added stress.*

– patient diagnosed with Thymic Carcinoma.

While the public health system offers some support, significant gaps remain in areas like genomic testing, access to innovative therapies, and support for ongoing side effects. Individuals report covering costs for vital diagnostic scans, genomic sequencing, and consultations with international experts—all critical for rare cancer treatment yet not uniformly supported. Private insurance, while beneficial for some, still fails to cover essential treatment-related expenses such as follow-up therapies and gap fees for specialists. This inconsistency in support, combined with the complex navigation of insurance policies, leads many patients to fall through the cracks.

### ***Accessing funds***

Participants were asked if they had to take any of the following actions because of the cost associated with their cancer care:

- Accessing superannuation early
- Accessing life insurance
- Selling a house or another significant asset
- Taking out a personal loan
- Using credit cards
- Borrowing or being gifted money from family or friends
- Moving in with family or friends
- Starting a crowdfunding campaign



Over one third of participants borrowed or were gifted money from their family or friends. Withdrawing from superannuation, at times heavily taxed, has been a financial necessity for some, particularly those who face restrictions on accessing other support like Centrelink payments due to eligibility rules that don't align with their circumstances. For retirees, the financial strain is even more challenging, affecting their ability to support children or maintain an expected quality of life.



“The cost of living has become so high and being a single, one-income worker, I no longer qualify to be accepted in rentals as I don't earn enough money. Centrelink offers no assistance as I'm currently on income protection, yet I'm earning \$900 less a fortnight. Finances are definitely my number one reason for concern and stress... To me, that is crazy, given I'm dealing with an incurable cancer and I am more stressed over finances.

– patient diagnosed with an extra-gastrointestinal stromal tumour (E-GIST).

Families report taking personal loans, relying on family support, or even community fundraising to cover costs of scans, accommodation for out-of-town surgeries, and basic living expenses. For those lacking family support or savings, meeting these costs is especially challenging, adding significant stress.

### Impact on income

The financial impact of cancer on employment and income is devastating, creating a "perfect storm" of economic hardship for patients and their families. One-third (32%) of respondents were forced to stop working entirely due to their diagnosis, with treatment side effects and illness making continued employment impossible (See **Figure 6**). While 14% maintained some form of employment, many did so out of financial necessity rather than readiness to work.

Figure 6. Impact on employment and income



The "double financial hit" phenomenon emerges as a critical challenge – patients face rapidly increasing expenses for treatment, medications, and care precisely when their income drops dramatically. This financial pressure often persists long after active treatment ends, as ongoing fatigue, cognitive difficulties, and physical limitations continue to impact work capacity. As one respondent noted: ***"It's the intangible costs of not being able to work that truly add up in addition to the costs of treatments and testing themselves."***

Those who remained employed often depleted their leave entitlements trying to manage treatment schedules. One-sixth (16%) exhausted their sick leave and annual leave, while 15% were forced to take unpaid leave. This short-term solution frequently led to longer-term vulnerability once leave balances were exhausted. As one participant shared: ***"We both used up every holiday and long service. The children had to be removed from school and go to family to be looked after. Treatment was not in our town."***

Employer responses varied dramatically. Some workplaces demonstrated exceptional understanding, offering flexible arrangements and support throughout treatment and recovery. Others showed little accommodation, with respondents reporting discrimination, lack of support, and even wrongful termination. One participant noted: ***"My employer at the time of diagnosis decided to unlawfully terminate my employment – which left me in significant financial distress."***

### ***The Psychological Toll and Family Impacts***

Cancer's toll extends beyond the patient, profoundly affecting family dynamics and relationships. Families often have to restructure roles, with one partner sometimes leaving employment to provide caregiving. This shift not only impacts family income but also creates power imbalances within households, with some patients expressing feelings of dependency or control due to financial reliance on their partner.

Moreover, costs related to mental health support are typically not covered or are insufficient under chronic health plans, leaving families struggling to find affordable, long-term psychological care.

***"Life was difficult as I could not go back to work... I had a teenager and if it was not for good friends and family I would be out on the street. Cancer cost me a lot, plus my marriage."***

– patient diagnosed with Osteosarcoma.

Patients recount being unable to work, leading to significant income reduction or complete financial dependence on partners or family members. For many, the impact extends to their children and other relatives, who often have to rearrange their own work schedules, take on additional jobs, or even suspend their education to support the patient.

***"My husband had to carry the entire financial burden of my illness."***

– patient diagnosed with Essential Thrombocythemia, Vulvar Cancer, SCC & BCC

This disruption not only strains financial resources but also affects mental health, contributing to feelings of guilt, stress, and helplessness.

***"Cancer sucks. We are retirees and our life has basically ended. We worked hard all our lives, paid taxes, and now we can't even afford to help our daughter to complete her uni studies. As a carer, I am unwell and daily life is a struggle... our adult daughter has had to have a break from completely her Masters in Psychology to help at home and she cannot afford and we can't afford to fund her HECS"***

– carer of a patient diagnosed with urothelial cancer.



# Conclusion

1

**Hidden costs:** Patients face numerous indirect expenses including parking, travel, accommodation, childcare, and specialised items (compression garments, wigs, etc.). These costs are often unexpected and not covered by insurance or Medicare.

2

**Income loss impact:** Many patients and their caregivers must reduce work hours or stop working entirely, creating a "double financial hit" of increased expenses and decreased income. This can persist long after treatment ends due to ongoing fatigue and side effects.

3

**Inequitable access to treatments:** There are significant disparities in PBS coverage between different types of cancers. Rare cancers often have less coverage than more common ones, forcing patients to pay out of pocket for effective treatments.

4

**Regional/Rural inequities:** Patients in regional areas face additional financial strain due to travel costs, accommodation needs, and limited access to specialists and clinical trials in their local area.

5

**Medicare gap issues:** Many essential scans and tests are only partially covered by Medicare or not covered at all, leading to significant out-of-pocket expenses. This particularly affects ongoing surveillance scans and specialised testing.

6

**Superannuation access challenges:** While some patients can access their superannuation early, the process is often complicated and may have tax implications. This can deplete retirement savings, creating long-term financial vulnerability.

7

**Centrelink barriers:** Many patients struggle to access Centrelink support due to strict eligibility criteria, complex application processes, and partner income tests that don't account for the full financial impact of cancer treatment.

8

**Private health insurance limitations:** Even with private health insurance, patients face significant gap payments for specialists, surgeries, and treatments. Some treatments may not be covered if provided by certain specialists.

9

**Long-term financial impact:** The financial effects of cancer treatment often extend well beyond the active treatment phase, affecting career progression, retirement planning, and overall financial security.

10

**Family support reliance:** Many patients must rely on family members for financial support, creating intergenerational financial stress and potentially straining relationships.



## Contact us

**Inquiries about this report and RCA's advocacy:**

[policy@rarecancers.org.au](mailto:policy@rarecancers.org.au)

(02) 4862 2768

**Support for patients and their families:**

[support@rarecancers.org.au](mailto:support@rarecancers.org.au)

1800 257 600

**Send a letter:**

Rare Cancers Australia

PO Box 440

Bowral NSW 2578

