



**HEALTH SURVEY**  
*Everyday*

**Financial burden of cancer treatment for patients**





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## 1.0 Executive summary

Cancer Council Queensland’s latest Everyday Health Survey sought to understand the financial impact of a cancer diagnosis and how the associated challenges influenced treatment decisions.

Over 27,000 Queenslanders are diagnosed with cancer each year and over 8700 will die from the devastating disease. Although healthcare in Queensland is primarily publicly funded, most cancer patients are burdened with out-of-pocket costs, even in the public system.

**Almost two-thirds (63%) of those surveyed had been impacted by out-of-pocket costs, a quarter (26%) of these at a very high level.**

Impact of the disease can be further exacerbated by reduced or lost employment and subsequent loss of income, as reported by participants. Those travelling more than 50km for treatment experienced a greater impact. Auxiliary costs, specifically travel and parking expenses, were frequently noted by respondents when describing the impact of out-of-pocket costs.

**Alarming, one in three participants report that the out-of-pocket costs associated with a cancer diagnosis would deter them from seeking treatment.**

These results provide insight into the cost of a cancer diagnosis for Queensland patients and their families. Australia has a good health system by international standards, yet too many people are at risk of experiencing inequities associated with their capacity to afford adequate care. We are calling for more targeted financial assistance and promotion of support services. Government assistance should be targeted to those with the greatest need to help ensure that a positive cancer outcome is not a function of individual wealth.





## 2.0 Project overview

**Queensland cancer patients and their families experience significant financial burden as a result of their diagnosis. To date, the actual cost to cancer patients in Queensland is largely unknown.**

The Everyday Health Survey: Financial burden of cancer treatment for patients investigated the financial impact of a cancer diagnosis and treatment and strived to understand how this impacted the financial position of patients and their families as well as how this influenced treatment decisions, and psychological health and wellbeing.

The survey was the third in a series of surveys designed to give Queenslanders a voice and engage them in a conversation about the health issues that affect all members of the community. It was launched in April 2017 and was open for six weeks. Recruitment was conducted via social media and email promotion to members of Cancer Council Queensland databases and other health professional contact lists.

### Respondents

The survey attracted 560 responses all of whom were either patients or carers.

The respondents can be described as:

- Patients (55%)
- Female (71%)
- 30 years and older (86.5%)
- Married or in a de facto relationship (60%)
- In households with dependents (54%)
- Living in major cities (53%)
- From low and middle socioeconomic backgrounds (65%)

- Aboriginal and Torres Strait Islander (2%)
- Distribution of respondents for gender, age, remoteness, and socioeconomic status is generalisable to the Queensland cancer cohort.



## 3.0 Findings

### 3.1 Health system costs

#### 3.1.1 Out of pocket costs

Almost two thirds (63%)\* of those surveyed have been impacted by out-of-pocket costs. One quarter (26%) reported very high levels of impact. A third (35%) of participants reported that out-of-pocket costs deter them from seeking medical treatment. Alarming, the majority (62%) of respondents were not fully aware of the out-of-pocket costs associated with a cancer diagnosis and treatment prior to accessing the service.

*"I was surprised how much the financial gap was."*

*"I am a self-funded retiree (who works a little part time) and after having FULL private health insurance for around 40 years, did NOT expect to be so far out-of-pocket for my radical prostatectomy."*

Participants from outer regional areas reported a median weekly out-of-pocket cost of \$600, more than double that of respondents from inner regional areas and major cities. Specifically, those living in Mackay reported an average of \$900 of out-of-pocket costs per week.

Patients diagnosed with prostate cancer faced the highest financial burden of all cancers reported at approximately \$900. This creates cause for concern as prostate cancer is the most commonly diagnosed cancer and the second most likely to cause death in Queensland men.

\*This percentage is based on the total number of respondents (n=560). This can underestimate the strength of associations.

#### 3.1.2 Personal situation

##### Aboriginal and Torres Strait Islander status

Among respondents who identified as Aboriginal or Torres Strait Islander (2%), 70% reported a significant impact of out-of-pocket costs, compared to only 15%

of non-indigenous respondents.

##### Carer and family situation

Just under half (44%) of patients had a carer to help them through their diagnosis and treatment. 'Having a family to assist with care might have provided practical and emotional support, but it did not reduce the financial burden of a cancer diagnosis.

*"Husband took 3 months off work to be with me, cost \$20,000 loss of income."*

*"We have had no income for 10 months as my husband is on leave without pay to care for me."*

*"Daughter (aged 17 years) had to pay for medication."*

Impact was exacerbated for respondents who had one or more dependents (54%). Those with dependents were twice as likely to experience significant impact from out-of-pocket costs and half as likely to not be impacted at all.

##### Employment and income

A cancer diagnosis and subsequent treatment resulted in a substantial decline in employment. Full time employment decreased from 36% at time of diagnosis, to just 8% during treatment. At 12 month's post treatment, full time employment remained low at 14%. Similar trends were seen for part time and casual workers. Unemployment was consistently associated with high levels of financial impact throughout the entire cancer journey. In addition 13% of retirees had to come out of retirement and 63% of students had to stop studying.

As is expected with a decline in employment, weekly income also decreased. The number of respondents earning over \$800 per week was

## Findings (cont.)

halved between diagnosis and treatment. Those who reported no income more than doubled from 8.2% at diagnosis to 18% during treatment.

*"Loss of one income over [a] long period of time has put significant financial pressure on the family."*

*"Loss of income when unable to work in the first 12 months and during ongoing treatment."*

Having income protection did not eliminate the financial impact of a cancer diagnosis. Dissatisfaction with coverage and the application process was a common theme.

*"75% of wage is not enough to live on when you have your normal household bills plus house payments then medication and travel on top."*

*"Too much red tape to persevere with an application. It was all too difficult. I eventually tapped into my savings and our lifestyle was very much impacted."*

### 3.1.3 Use of public and private health system

Almost half (49%) of respondents had private health insurance at the time of cancer diagnosis. Of these, 75% used their coverage for treatment. Private health insurance reduced the impact of out-of-pocket costs. Of those with coverage, only 10% reported a significant impact compared to 26% who did not have insurance.

There was a correlation between satisfaction with health insurance and impact. Those with higher levels of satisfaction experienced lower levels of impact, however only 44% of people rated their private health insurance as good or excellent. Dissatisfied respondents expressed confusion

about unmet expectations and reported large out-of-pocket hospital costs.

*"I was under the belief I would be covered for that sort of diagnosis. I feel cancer should be covered on all levels of health insurance. My insurance provider was not empathetic at all to my circumstances."*

*"Gap between fees and rebate were extensive at times. Still spent several thousand dollars even though in private health insurance."*

More than half (51%) of patients with private health insurance were unaware of the option to access cancer treatment in both the public and private system. Given the option, 17% of patients would have opted for public treatment, mainly to reduce financial burden.

*"If I'd known the surgeon would charge \$3000 over scheduled fee, and I'd been advised I could see a surgeon through the public system asap I would definitely have gone through [the] public system."*

*"Would have been a lot less expensive. I can't believe I pay over \$6k per year for private health insurance and am still out-of-pocket."*

### 3.1.4 Accessing treatment and support services

A positive correlation exists between distance travelled to treatment and impact of out-of-pocket costs. Just over a quarter (28%) of respondents travelled greater than 50km to treatment, most commonly by personal vehicle (67%). Auxiliary costs, specifically travel and parking expenses, were frequently referred to by respondents when describing the impact of out-of-pocket costs.

*"Paying for parking when you have no choice and need lifesaving treatment seems grossly unfair."*

*"I had to live 350kms away from my family, the cost of living away plus the cost to support children at home was huge."*

*"I was back and forth between Brisbane and Gladstone a lot, so car hire, flights and parking came into the costs, and when I had my car in Brisbane, the fuel costs, parking and any tolls also added to that cost."*

About a third (36%) of respondents who were eligible for the Patient Travel Subsidy Scheme (PTSS) did not access the service, likely due to a lack of awareness of the service, or difficulties in application processing. One respondent suggested it was 'emotionally exhausting fighting for the PTSS'.

Three quarters (76%) of those surveyed accessed support services. The most frequently accessed service was Cancer Council's 13 11 20 (42%), Centrelink (39%) and a social or welfare worker (28%). Least accessed services included Cancer Council's Pro Bono service (1%), financial counselling services (4%) and emergency money or food (6%). Over half (55%) of people would have accessed support services had they known about them, suggesting lack of awareness is a major barrier to service provision. Alarming, 43% of Centrelink applications took longer than two months to be actioned and respondents frequently referred to difficulties accessing support.

*"I found Centrelink one of the most stressful components during my treatment. Despite being eligible for sickness benefits, Centrelink kept changing my payments to Newstart Allowance and then suspending them for failure to respond to interviews."*

*"Centrelink mucked us around ... they would only give us support when the doctor wrote terminal on the Centrelink forms ... which was sad and gave my husband no hope ... I find Centrelink a heartless organisation."*





## 4.0 The need for action

The full impact of a cancer diagnosis and treatment cannot be expressed by numbers alone. Below, everyday Queenslanders share their experiences, revealing the emotional and wellbeing cost of coping with the financial impact of cancer diagnosis and treatment.

### Psychological impact

*"Attempted suicide during my cancer treatment."*

*"Financial concerns take a patients focus away from their real battle and the stresses of this have adverse impacts on all aspects of a patient's life."*

*"Financial strain on family affects overall happiness ... can't afford social outings of the past."*

### Budget constraints

*"Still struggling to keep the roof over me and my kid's heads"*

*"Trying to maintain one household at home and provide another household while treatment is occurring"*

*"Not having enough money left over for kids as it was Christmas time so they missed out on things you normally do at that time of year."*

### Financial hardship

*"After 6 months of treatment with our son we are now well over \$12,000 dollars in debt."*

*"My husband has since passed away at 43 years old. During his treatment we had to access quite a bit of credit to enable us to cover medication for him and had to refuse some treatments due to the exhaustive costs. My husband has gone and I continue to try and pay down this debt."*

*"It is extremely hard to manage on a pension for any extras at all."*

*"As pensioners, any out-of-pocket expenses generally affect our way of life."*

### Reliance on others

*"The worry and stress of having to rely on distant family members for accommodation, emotional support, food [and] transport."*

*"Had to sell our house as could not afford repayment. Mum had to quit her job to look after myself and my 3 children so my husband could still work."*

*"Daughter (17 years) had to pay for medication."*

*"Patient had little income. All costs covered by two children who also had their own mortgage and bills."*

### Income pressures

*"We went on one wage suddenly and it put a financial strain on our household. Horrible to stress over money when you are already enduring enough stress and anxiety as it is."*

*"As a full time carer, I had to take unpaid leave for 8 months. These costs were crippling with no income."*

*"I was more frightened of the bills than I was of the cancer. I had to rush back to work because I had no money and was scared I would lose my house."*

### Loss of savings

*"We had to access all of our life savings during treatment."*

*"We withdrew superannuation to pay mortgage and school fess, car loans etc. As a full time carer I was unable to continue working and two of our older adult children reduced hours for three months to help care for their father."*

### I can't afford care

*"Always broke."*

*"Could not fill partner's prescription...could not pay things like telephone, electricity, behind in rent, personal grooming e.g. haircuts"*



## 5.0 Recommendations

Results from the Everyday Health Survey: Financial burden of cancer treatment for patients highlight the need for greater action to reduce the financial burden of a cancer diagnosis for patients and carers.

### Cancer Council Queensland calls on the Queensland state government to:

1. Increase funding for the Patient Travel Subsidy Scheme, to provide more remote, rural and regional Queenslanders with the financial support that better enables them to choose treatment options that are best for their health and not constrained by their economic circumstances.
2. Provide funding to Cancer Council Queensland for refurbishment of aging accommodation lodges. Whilst there are six lodges across the state, the lodges in Toowoomba, Townsville and Herston need upgrading due to their age and usual “wear and tear”. The lodges provide accommodation at minimal cost combined with information and support for patients and carers to enable them to access lifesaving treatment; reducing the cost burden, informing and counselling; and helping to navigate complex treatment pathways.
3. Provide funding for extension of the Cancer Council Queensland newly implemented Transport to Treatment scheme to include new services across the state to lessen the financial burden for patients and carers and reduce the complexity of getting to treatment centres.
4. Provide funding support for the Cancer Council 13 11 20 and Cancer Counselling Service. While the 13Health COACH program provides free phone coaching for coronary heart disease, diabetes and COPD, Cancer Council Queensland fills the gap in providing advice,

information and support for the state’s major chronic disease.

5. To follow through on previous commitments in relation to the provision of parking concessions for cancer patients who are frequent visitors and those suffering financial hardship.
6. Promote systems within hospitals and HHS’s that enable patients and carers to have a better understanding of treatment options (public and private) and to determine the out of pocket costs associated with each option.
7. Encourage health professional, patient and carer referral to Cancer Council Queensland via 13 11 20.

### Cancer Council Queensland calls for broader community support i.e.:

1. Centrelink to provide specialist roles dedicated to assisting people with cancer (and other chronic diseases) to simplify application processes and address long waiting periods for patients and carers seeking allowances and benefits related to their illness and absence from the workforce.
2. Workplaces to implement policies and procedures that support cancer patients and carers during treatment and recovery in recognition of the benefits from increased staff loyalty and becoming an “employer of choice” with associated community recognition.
3. Private health insurance companies to increase the number of practitioners with whom they have a ‘no gap’ arrangement to reduce gap payments for patients.

4. More research into the costs associated with a cancer diagnosis and treatment to supplement this preliminary study with stronger evidence and further explanation.

*Cancer Council Queensland sincerely thanks all survey respondents including those who took the time to share their story and personal experiences. Your contributions have helped shine light on the true costs of a cancer diagnosis. For support and information please call 13 11 20. All Queenslanders, all cancers.*



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