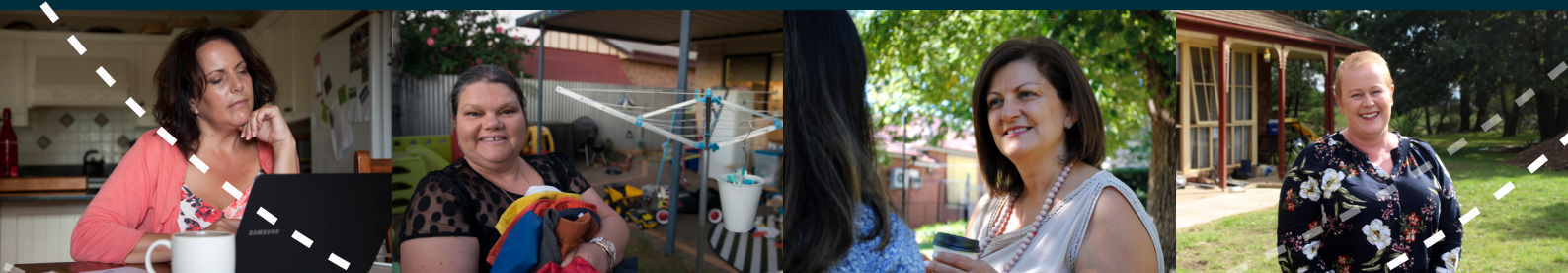


The financial impact of breast cancer



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About Breast Cancer Network Australia

Breast Cancer Network Australia (BCNA) is the peak national organisation for Australians affected by breast cancer, and consists of a network of more than 120,000 individual members and 300 Member Groups. BCNA supports, informs, represents and connects people affected by breast cancer. BCNA works to ensure that Australians affected by breast cancer receive the very best support, information, treatment and care appropriate to their individual needs. BCNA's vision is a better journey for all Australians affected by breast cancer.

bcna.org.au
1800 500 258

Breast
Cancer
Network
Australia



Foreword



Message from BCNA Board Member **Lisa Montgomery**

As a finance professional with more than 30 years' experience, it was only when I was diagnosed with breast cancer in 2012 that I turned my attention to the financial impact of cancer. This report illustrates some of the common financial challenges women face – high out-of-pocket or 'gap' fees for treatment and care, costly travel expenses for those living in a regional or rural area, paying for breast reconstruction, managing the ongoing financial stress of living with metastatic breast cancer, loss of household income when a woman is not able to continue in paid work as a result of her treatment, and the resulting devastating loss of financial independence.

I know from my own experience how life-altering a cancer diagnosis can be. Reducing the financial burden of breast cancer will let women focus on what is most important – their health and their loved ones.

I look forward to working with policy makers in government, health care and the private health insurance industry to minimise the financial impact of breast cancer.



Message from BCNA Chief Executive Officer **Christine Nolan**

A diagnosis of breast cancer should not mean financial hardship but for many Australian women this is unfortunately the case.

For nearly 20 years BCNA has heard stories of the financial impact of breast cancer on Australian families. This report quantifies the out-of-pocket costs as reported by our members and explores the factors that contribute to the financial burden. Our report has found that out-of-pocket costs can reach into the tens of thousands of dollars and add considerably to the stress of cancer. Some of the findings in this report are troubling. Breast cancer pushes many women, and their families, to the financial brink, where they are reliant on financial assistance from family, friends and their communities.

Women with private health insurance typically pay around double the out-of-pocket costs of those who do not hold private health insurance. Women living with metastatic disease face additional challenges due to the uncertain nature of their disease progression.

BCNA is proud to deliver this report, which illuminates the many financial challenges people face when they are diagnosed with breast cancer. The recommendations in this report aim to help alleviate the financial burden. We call on decision makers in government, health care systems and the private health insurance industry to implement them and help improve the journey of Australians affected by breast cancer.

Executive summary

For many years BCNA has heard from its members about out-of-pocket costs they incur for their breast cancer treatment and care. They tell us these costs are a source of stress and can result in financial strain for them and their families. BCNA commissioned Deloitte Access Economics to conduct a survey of its membership about the out-of-pocket costs of their breast cancer treatment and care in the first five years after their cancer diagnosis. Almost 2,000 women completed the survey and the results of the study confirmed that breast cancer can have a significant financial impact on women and their families.

Our survey found that a woman will pay around \$5,000 in out-of-pocket costs in the first five years from diagnosis. Many women will have costs that continue for longer than the first five years after diagnosis, which are not captured in this survey, but contribute to the cost of breast cancer over a woman's lifetime.

A woman without private health insurance pays around \$3,600 in out-of-pocket costs. This figure rises to \$7,000 for a woman who holds private health insurance. Sometimes the out-of-pocket costs are much higher than \$7,000 for privately insured women. In our survey, some had expenses upwards of \$21,000. This financial burden for private health insurance holders comes from higher out-of-pocket costs for direct medical expenses including surgeries, chemotherapy, radiotherapy, breast MRI scans and other diagnostic tests, and specialists' consultations.

Many women receiving breast cancer treatment will need to take some time off work. For some this may mean reduced work hours, but others find they need to give up work altogether for a period. During this time a woman may be able to rely on paid sick leave or income protection insurance to replace her wage. However, if she is one of the 38 per cent of Australians who do not have paid leave entitlements¹, has insufficient paid sick leave to cover her time off work for treatment, or has no or limited income protection insurance, her household income is

likely to drop significantly. Our survey found that the total number of household hours worked dropped by 50 per cent in the first year after a breast cancer diagnosis. It also showed time away from work can continue beyond the first year after diagnosis. In the second year after diagnosis, household hours worked remain 13 per cent lower than before breast cancer. This adds to the financial burden particularly for single women who do not have a partner's income to rely on while their income reduces or stops.

Women living in a rural or regional area face issues such as travelling long distances for treatment, staying away from home, and disruption to family life. All these can affect the household budget.

Some women find that paying for cancer treatment and its associated costs pushes them to the brink. They are forced to rely on government benefits, charity handouts and emergency help from family, friends and community to get by. Even an expense as simple as car parking at the hospital can add a significant burden to the household budget. A Cancer Council Victoria study found that people with cancer spend an estimated \$1,128 on parking in the first year of treatment.²

While there is a range of government benefits that may help a woman when she finds herself in financial difficulty because of a cancer diagnosis, many report that bureaucracy can be a significant barrier to accessing entitlements, for instance Centrelink benefits or superannuation.

People living with metastatic breast cancer carry additional financial burdens because of the unpredictable and ongoing nature of their disease. The incurable nature of metastatic breast cancer means that additional financial burdens include costs of treatment, which may continue for the rest of life, difficulty making financial plans for the future, and not knowing whether a life-extending new drug will be listed on the Pharmaceutical Benefits Scheme (PBS).

Palbociclib (Ibrance), for example, is a new drug treatment for metastatic breast cancer. It was approved for sale in Australia in May 2017 but is not currently listed on the PBS. Australian women who wish to take palbociclib pay around \$5,000 per month to buy it. Not knowing if/when it may be listed on the PBS or for how long the treatment may benefit them makes it almost impossible to budget for the ongoing purchase of this treatment.

I have spent approximately \$100,000 of my superannuation funds on palbociclib but it has been worth every cent. It has given me an extra nine months of feeling perfectly well. – Carolyn, who bought palbociclib from overseas at a cost of around \$10,000 per month before it became available in Australia

This report explores the costs of breast cancer and proposes recommendations to help mitigate them. These recommendations are for private health insurers, government, health service providers and BCNA itself as an advocacy organisation.

By working together we can help make a better journey for all Australians affected by breast cancer.



FARRAH



LYNNE

RECOMMENDATIONS

For private health insurance companies

1. Private health insurance companies increase the number of practitioners with whom they have a 'no gap' arrangement to allow for greater choice in treating doctor and fewer 'gap' payments.
2. Private health insurance companies better promote their lists of 'no gap' providers.
3. A \$5,000 trauma insurance benefit is paid by private health insurance companies to policyholders diagnosed with cancer to help cover out-of-pocket costs. This one-off payment should be in addition to the normal private health fund rebates paid for treatment and care.

For government

4. Centrelink provides specialist chronic illness liaison officers to help people with cancer (and other chronic illnesses) navigate the various entitlements and benefits that are available to assist them.
5. Medicare rebates are increased to better reflect the cost of providing services to reduce the out-of-pocket costs faced by patients. In particular, breast MRI and DXA bone mineral density scans are rebated by Medicare as these are tests commonly used in treatment and care of breast cancer.
6. Changes are implemented to enable radiotherapy services to be covered by private health insurance.
7. State and territory patient assisted travel schemes are updated to reflect the real cost of travelling away from home for cancer treatment and follow-up.
8. Free parking is introduced at hospitals for people with cancer.

9. A metastatic cancer card is introduced to acknowledge the additional financial burden people with metastatic disease face. This card could be similar to the pension or Department of Veterans' Affairs (DVA) card to allow services to be provided at a discounted rate.
10. PBS approval processes for new cancer drugs are reviewed to ensure that Australians can access medications in a timely and affordable way.

For health service providers

11. Health practitioners provide patients having treatment in the private health system with comprehensive written information about all out-of-pocket costs of any proposed procedures prior to those procedures taking place to improve transparency and avoid 'bill shock'.
12. Health practitioners advise patients they are entitled to a second opinion on the costs of treatment quoted to them.

For BCNA

13. People with breast cancer are empowered with information about their rights in the workplace. Employers are made aware of their responsibilities to staff while they are undergoing treatment and afterwards.
14. High-quality and appropriate financial advice is provided to people with breast cancer at the time of diagnosis. This advice should be sensitive to a person's age, acknowledging that young people may not have accumulated resources, and whether a person's breast cancer is early or metastatic. This advice should also explore insurance and superannuation options and involve referral as necessary to services that can help people make their claims.

Introduction

In 2016, BCNA contracted Deloitte Access Economics (Deloitte) to undertake research into the financial impact of a breast cancer diagnosis and treatment on individuals and their families.

For many years BCNA has heard from its members about out-of-pocket costs they incur for their breast cancer treatment and care. They have told us these costs are sometimes significant, particularly for women who choose to have their treatment in the private health system using private health insurance.

A previous study conducted in 2007 by Access Economics for Cancer Council NSW found that the average lifetime financial cost faced by a household of a person with breast cancer was \$28,500.³ These costs were lifetime costs, which means that Access Economics estimated the expected costs from diagnosis to when the person was likely to die. This included lost earnings and superannuation.

Our research aimed to quantify the total out-of-pocket costs and loss in income a person may experience in the first two years after their diagnosis and the overall expenditure of women with breast cancer who were diagnosed in the last five years. The reason for choosing to do this was to keep the focus on actual rather than projected expenditure to gain a clear picture of the real costs of breast cancer as they impact a woman and her family at the stressful time of treatment, diagnosis and return to the 'new normal'.

The last 12-18 months we've struggled harder than we've ever struggled. You know, some fortnights I've gone to bed crying when I sit down and look at what we've got and look at what we have to pay. – Helen

This report provides a summary of the research findings and recommends actions that could be taken to reduce the out-of-pocket costs of Australians diagnosed with breast cancer.

Georgie had been in her job for four months when she was diagnosed with early breast cancer in October 2015. She thought about the financial cost of breast cancer before anything else.

The first thing I actually said to my doctor when he told me that I had breast cancer was 'I can't afford to do this – I've just started a new job. I'm going to end up on the street.' Even before I started thinking about, 'Oh hell, I've got breast cancer,' my first thought was actually, 'Oh my God, I've got no money'. There was not one day that I wasn't stressing about money.

Georgie was single and living in her own home, paying a mortgage. She loved to travel and was planning future trips, but these plans changed when she was diagnosed. Her financial position became very difficult, as she could not work during her treatment because of side effects.

The superannuation fund that held Georgie's funds had recently stopped providing automatic income protection insurance and Georgie had not arranged a replacement policy before she was diagnosed. This left her with no income protection insurance. As she had only been in her role a short time, Georgie did not have much sick leave available to her. Her colleagues donated a total of six weeks of additional sick leave. Their act of generosity allowed her to have some extra paid leave while having cancer treatment. Unfortunately, this still was not enough to cover all of the time she was unable to work during her treatment.

Because she could not work, Georgie applied for Centrelink sickness benefits. She was shocked to discover this benefit was significantly less than other safety net payments, such as the age and disability pensions. It did not provide enough income for her to meet her daily living expenses.

It made me feel even worse, because it felt like I was being penalised for having cancer. When people are unable to work because they're unwell, it is more likely than not that there will be an extra cost burden, rather than a lesser cost burden, because there'll be medications and treatments. And it just adds insult to injury to only have that [benefit] paid at \$250 a week. I tried – you can't live on that.

At times Georgie felt very low about her situation.

I no longer feel quite as bleak, but at one stage there I was just going 'I may as well have died on the operating table because if this is the rest of my life I don't want it'.

Georgie has now returned to full-time work and is starting to get back to where she was financially before cancer. The lingering worry about money was with her through her cancer journey and was as significant for her as her worries about her health.

The burden of having cancer, treatment and feeling crap was sitting on one shoulder and the, 'Oh, my God, I've got no money, what am I going to do?' burden was sitting on the other one. It just became this pervasive horrible thing that never went away.

GEORGIE



Method

A comprehensive online survey was developed by Deloitte in consultation with clinical specialists from BCNA's Strategic Advisory Group and BCNA staff.

An invitation to participate in the survey was emailed to approximately 13,000 BCNA members who had been diagnosed with breast cancer between one and five years previously. The survey was open from 19 August to 20 September 2016. Almost 2,000 responses were received, with 1,919 responses used in the final analysis. Respondents were asked to report the out-of-pocket costs they incurred since their diagnosis, which was up to five years ago. In addition, respondents were asked to provide information about their own individual income, and the income of their partner, for the 12 months previous to their diagnosis, the 12 months immediately after diagnosis, and the 12 months after that.

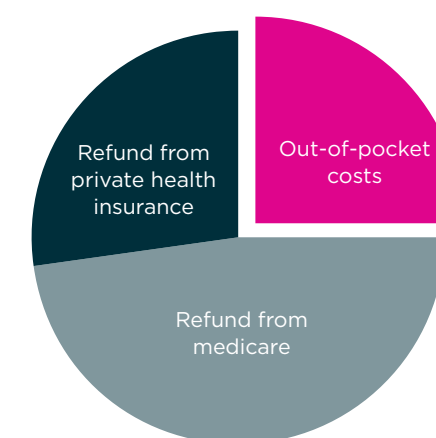
Thirteen men who had been diagnosed with breast cancer completed the survey. Their results have been removed for the purposes of Deloitte's analysis because the clinical treatment pathways used specifically related to women. While men do get breast cancer it is much more common in women. In 2017, 17,586 women and 144 men are expected to be diagnosed with breast cancer. The responses of the 13 men were removed to better represent the typical breast cancer experience.

There were some significant 'outliers' – dollar values significantly higher than the majority of the out-of-pocket costs – in the responses to the survey. To ensure that the data presented here is a reasonable and accurate representation of the typical experience, Deloitte's analysis focuses on the out-of-pocket costs between the 25th and 75th percentiles – the middle 50 per cent of costs incurred. It is important to consider that these outliers have been removed and that there is a small group of people whose reported costs were very much higher than those provided in this report.

Case study interviews were conducted by BCNA staff with 15 survey participants. These interviews were conducted over the phone for between 45 and 90 minutes. Excerpts from the case studies have been included in this report. The full case studies are available at BCNA's website bcna.org.au.

Out-of-pocket costs are defined for this report as any cost that an individual meets either in full or when they share the costs of goods and services with a third party such as Medicare and/or a private health fund. Out-of-pocket costs are the total cost minus any amount received back from Medicare or private health insurance (Figure 1). For example, a woman may pay \$100 for a physiotherapy appointment for shoulder pain post mastectomy. She receives \$35 back from her private health insurance fund. Her out-of-pocket cost for her physiotherapy appointment would be \$65.

Figure 1: Definition of out-of-pocket costs



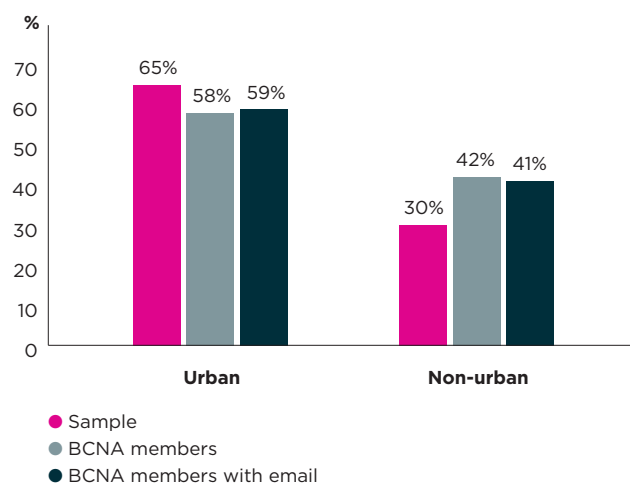
An out-of-pocket cost is the **total cost minus any amount received back** from Medicare and/or private health insurance.

Based on a chart provided by Deloitte Access Economics, *Financial impacts of breast cancer in Australia*, Nov 2016.

Demographics

BCNA's membership at the time of administering the survey was broadly representative of the distribution of people with breast cancer in Australia. Recruitment was limited to people who had had a diagnosis of breast cancer between one and five years ago and had an email address. The responses received closely represented the geographical distribution of people with breast cancer across Australia's states and territories. A slightly higher proportion of urban women completed the survey compared with rural and regional women (Figure 2).

Figure 2: Location of respondents

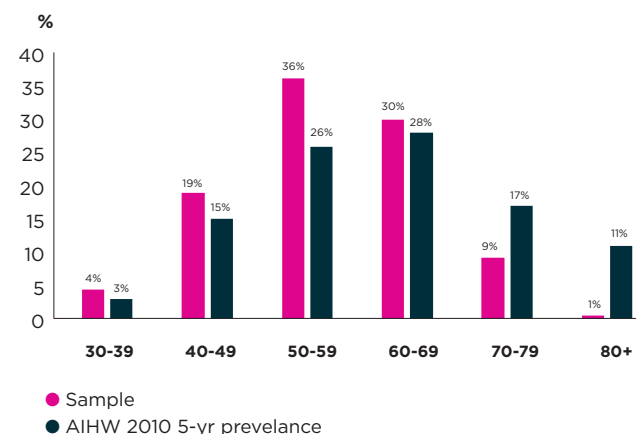


Sample does not equal 100% due to 5% not providing a response.

Based on a graph provided by Deloitte Access Economics, *Financial impacts of breast cancer in Australia*, Nov 2016.

The highest proportion of respondents to the survey were in the 50–59-year-old age group (Figure 3). Responses in the 70–79 and 80+ age group were lower than expected whereas responses in the 30–39, 40–49 and 60–69 year age groups were higher than expected.

Figure 3: Age of respondents



The number of cases in the <30 age group were minimal so have not been included. Sample is equal to 99% due to 1% rounding error.

Based on a graph provided by Deloitte Access Economics, *Financial impacts of breast cancer in Australia*, Nov 2016.

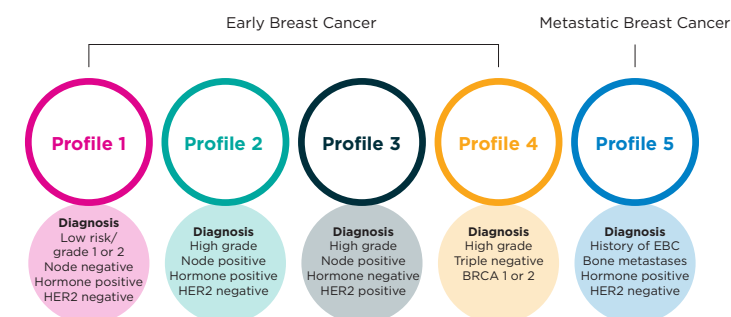
Profiles

Breast cancer is not one disease, but many. Treatment recommended is dependent on the following factors:

- size and grade of the tumour
- molecular subtype of the tumour
- patient factors, including treatment preferences.

Recognising that different diagnoses may mean different treatment pathways, Deloitte and members of BCNA's Strategic Advisory Group developed five key breast cancer 'profiles' with the aim of determining the average costs for each profile (Figure 4). The profiles differed on disease characteristics such as cancer stage, grade, involvement of lymph nodes and molecular subtype (HER2 and hormone receptors).

Figure 4: Cancer characteristics of the five survey profiles



Based on an image provided by Deloitte Access Economics, *Financial impacts of breast cancer in Australia*, Nov 2016.

While we had expected to find some consistency in out-of-pocket costs within each individual treatment profile, this was not the case. Results within each profile were highly variable and so this report has instead focused on the out-of-pocket costs for the whole sample and considered a range of other factors that influence the financial impact of breast cancer.

Limitations



There are limitations to this study.

As discussed on page 8, the demographics of the sample are skewed towards younger age groups. This may be due to the online format of the survey.

The survey was administered only to women who had a diagnosis of breast cancer in the last one to five years and only collected data about a woman's most recent breast cancer diagnosis. While this decision was made to allow for more accurate recall of costs and a valid comparison to today's costings, it nonetheless limits this study in that costs incurred prior to 2011 are not captured. A woman's lifetime cost will be greater than is captured here, especially if she had more than one diagnosis of breast cancer. This survey found that the bulk of the costs of breast cancer treatment usually occur in the first two years after diagnosis, which means that the results of this survey may not be capturing the additional expense years for survey respondents who have recurrent breast cancer or metastatic breast cancer.

Further, only 68 women with metastatic breast cancer completed the survey and met the criteria for Profile 5 (metastatic breast cancer in the bone) on which the results in the report for metastatic breast cancer are based. There were additional women who have metastatic breast cancer in other sites (e.g. liver, lung, brain) in the larger sample, not included in the results for Profile 5. The low response for those with bone metastases may be due to the time commitment required to complete the survey and/or that women with metastatic disease may not have kept detailed records of their expenses given the ongoing nature of their disease.

Another consideration when reviewing this data is that there were some significant 'outliers' – dollar values significantly higher than the majority of the out-of-pocket costs reported. To ensure that the data presented here is a reasonable and accurate representation of the typical experience, Deloitte's analysis focuses on the out-of-pocket costs between the 25th and 75th percentiles – the middle 50 per cent of costs incurred. It is important to consider that these outliers have been removed and that there is a small group of people whose reported costs were very much higher than those provided in this report.

This study has also not considered projected wage or superannuation losses. Therefore, the long-term changes to earning potential and/or superannuation as a result of a breast cancer diagnosis were not addressed in this survey.

Results

The results of the survey showed that women within each of the five cancer profiles experienced a wide range of out-of-pocket costs and that the range of costs for the five profiles overlapped, suggesting there were a number of factors that contributed to increased costs and not just cancer characteristics (Figure 5).

Figure 5: Out-of-pocket costs of respondents by the five profiles and total sample



Costs are the median out-of-pocket costs incurred, with whisker bars marking the 25th and 75th percentiles.

Based on a graph provided by Deloitte Access Economics, *Financial impacts of breast cancer in Australia*, Nov 2016.

Because of the extensive overlap of out-of-pocket costs experienced by people with different types of breast cancer (the five different profiles), this report focuses on exploring the key factors that contribute to the financial impact of breast cancer for women and their families.

You can read about the breakdown of costs for each cancer profile in the Deloitte report available on BCNA's website bcna.org.au.

The survey found that the financial burden of breast cancer treatment and care is unequally shared – with some women reporting no out-of-pocket costs and others reporting costs in the tens of thousands of dollars in the first five years after diagnosis. Twelve per cent of women reported no out-of-pocket costs but the vast majority – 88 per cent – reported some cost. The cost was around \$5,000 across the total sample, which included women with private health insurance and women without. The cost for privately insured women was higher at around \$7,000. For uninsured women it was around \$3,600.

While a cost of around \$5,000 may not seem significant to some people, recent research into financial resilience in Australia shows that almost 65 per cent of Australians are facing some level of financial stress and vulnerability. Half have limited savings (two months or less of their usual wage) and 10 per cent have no savings at all.⁴ Given this high level of financial vulnerability among the Australian population, the true impact of a diagnosis of breast cancer on the financial health of many Australians becomes clear.

Many women have costs that continue for longer than the first five years after diagnosis, which were not captured in this survey, but contribute to the cost of breast cancer over a woman's lifetime. These may include paying for hormone therapy drugs such as tamoxifen, letrozole and anastrozole (generally taken for between five and 10 years) and paying for follow-up care including follow-up mammograms, scans and specialists' fees, lymphoedema treatment, physiotherapy and counselling.

Differences between early and metastatic breast cancer

The results of this survey found that women with early breast cancer and women with metastatic breast cancer faced similar costs over the first five years since diagnosis. Women with metastatic breast cancer incurred around \$5,600 in out-of-pocket costs, compared with around \$5,000 for the whole survey sample. However, the way that those costs were experienced by women with metastatic breast cancer differ greatly from those experienced by women with early breast cancer.

Treatment costs for those with early breast cancer usually have an 'end point' and treatment follows a more predictable pathway. On the other hand, treatment for metastatic breast cancer continues for the rest of a woman's life and is likely to involve constant monitoring, testing, appointments and treatment. The nature of metastatic breast cancer also means that women with this diagnosis are more likely to face an unpredictable treatment pathway. It is harder for women with metastatic breast cancer to plan for what treatment may be next and what their future out-of-pocket expenses may be.

Because of this difference in the way that costs are experienced, this report is structured in two sections – the first on the financial impact for women with early breast cancer and the second on costs for women with metastatic breast cancer. There is some overlap between the two groups. For example, the challenges of living in a rural or remote area are similar for women with early and metastatic breast cancer. However, the experiences of women with metastatic breast cancer and their specific financial impacts are highlighted in this report to show that this particular diagnosis presents additional challenges.

Early breast cancer



Early breast cancer is cancer that is contained within the breast and lymph nodes in the breast or armpit. The aim of treatment is to cure the cancer and to prevent it coming back.

Introduction

Funding the cost of treatment and care for early breast cancer can stretch people's budgets to breaking point. Australia's health care system through Medicare covers about half of all services for people with breast cancer. However, most people – 88 per cent – will have some out-of-pocket cost for their treatment and care. Breast reconstruction surgery, radiotherapy treatment, breast MRI scans, genomic tests such as Oncotype DX, and genetic testing are some of the biggest expenses.

The cost for a woman who has private health insurance is typically around \$7,000, but can be more than \$21,000 for some privately insured women.

The cost for a woman without private health insurance is usually around \$3,600. Overall, the typical cost for all respondents with early breast cancer – including women with and without private health insurance – was around \$5,000 over the five-year period for which this survey collected data, with the majority of those costs incurred within the first two years from diagnosis.

Work disruption

Treatment for breast cancer can be arduous and may result in women reducing the number of hours worked in the paid workforce or giving up paid work altogether for a period. Partners may also reduce work hours to attend appointments and provide care for their loved one.

Our survey found that the total number of household hours worked dropped by 50 per cent in the first year after a breast cancer diagnosis. It also showed time away from work can continue beyond the first year after diagnosis. In the second year after diagnosis, household hours worked remain 13 per cent lower than before breast cancer. Lingering side effects from treatment, such as fatigue and 'chemo brain', can affect a woman's ability to return to a previous role or work at her previous level. Career goals may no longer be possible because of long-term side effects of breast cancer and its treatment and the way organisations approach these physical limitations.

Some people are able to mitigate this disruption to their income by taking sick leave or using income protection insurance to cover this period. Others, however, do not have this option and instead resort to using savings, borrowing from family and friends or relying on the support of donations from their community.



KYLIE

Sick leave

Some people are able to use paid sick leave, income protection insurance or other types of insurance to cover this period. When these supports are not available, taking time off work for treatment impacts the household’s income. Not having paid sick leave is an issue that affects many people. The Australian Bureau of Statistics (ABS) reports 38 per cent of Australian employees do not have paid sick leave benefits.⁵ People who are self-employed also face challenges around income reduction. The survey found a small proportion of women – around 7 per cent – was forced to return to work earlier than they expected to meet their medical costs.

Kylie’s career development has been impacted by a workplace culture that does not easily accommodate the need to maintain a healthy and balanced lifestyle, limit exposure to stressful environments, and step back when fatigued. This limits the roles in which she can perform.

My workplace has been fantastic in managing my return to work, however whether I will be considered for future promotion with the limitations I now have will remain to be seen. I was recently overlooked for a promotional opportunity despite being one of the most senior and experienced people to apply. In fact, I was not even considered for interview.

Using savings and borrowing from family and friends

Our survey found that around two thirds of women – 67 per cent – paid for their breast cancer treatment by using household savings. Many used their ‘nest egg’ – money that was being saved for something particular such as a house deposit, retirement, travel or another significant goal – to support themselves and their families during treatment. Using this money to fund cancer treatment changes people’s plans. Years of careful saving are lost.

Dannette and her family had sold a business in the last five years and planned to use the proceeds for a deposit on a new home. However, this money had to be used to cover the cost of her cancer treatment and to top up the family’s reduced income.

Our house got postponed. We were about to start the building process when I was diagnosed and so everything got put on the backburner.

The family of four continues to live in their two bedroom unit.



DANETTE

For those who did not have sufficient savings to help them through this period, borrowing money, often from family, was an alternative source of income. Eleven per cent of survey respondents said they borrowed or were given money by family, friends or community fundraising. Borrowing from family and friends can add to the emotional burden, and it contributes to ongoing financial burden if or when these loans need to be repaid.

Lisa had income protection insurance, but the policy had not been updated for 10 years. This meant the amount she received from her insurer did not adequately reflect her income at the time of her diagnosis. This put Lisa’s family in a situation where they were ‘absolutely struggling’ and had to rely on Lisa’s parents for financial help.

We reached flat broke and that’s when my parents financially supported us. I just felt bad having to constantly ask my gorgeous parents for financial help. I thought ‘All their hard-earned savings are going on our electricity bill’. The medical tests, surgeries and reconstructions were very expensive and there, again, my parents covered the outgoings on those things.

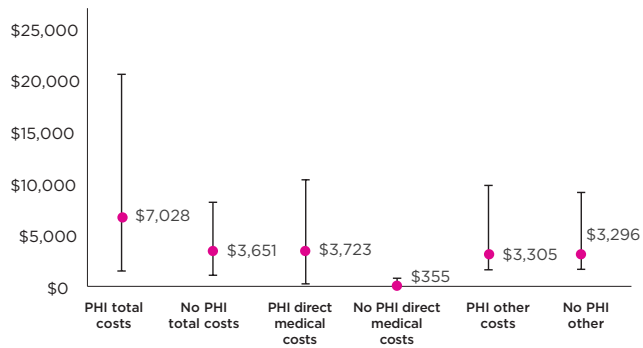
Other strategies for meeting costs of treatment included accessing superannuation, selling investments, re-mortgaging assets, or a partner increasing working hours.

Private health insurance

The majority of women (74 per cent) who responded to our survey held private health insurance at the time of their diagnosis. The results show that women with private health insurance can pay more than twice as much in out-of-pocket costs for their breast cancer treatment and care than women without private health insurance – approximately \$7,000 for insured women compared with approximately \$3,600 for uninsured women.

However, as Figure 6 shows, there is large variability in total out-of-pocket costs paid by women with private health insurance – ranging from in the hundreds to more than \$21,000.

Figure 6: Out-of-pockets costs of respondents by use of private health insurance by direct medical and other costs



Number of respondents: PHU – 1419, No PHU – 500. Costs are the median out-of-pocket costs, with whisker bars marking the 25th and 75th percentiles.

Based on a graph provided by Deloitte Access Economics, Financial impacts of breast cancer in Australia, Nov 2016.

When out-of-pocket costs are further explored, the results show that it is direct medical costs (i.e. treatment-related costs) that are the biggest contributor to this variability in costs experienced by women with private health insurance. These women paid approximately 10 times as much in out-of-pocket costs as women without private health insurance for their direct medical costs – \$3,723 compared with \$355 respectively.

This shows that the greater financial burden for women with private health insurance does not come from accessing extra supportive care items or choosing more expensive products – for instance a \$2,000 wig as opposed to a \$400 wig. Rather, it comes from higher out-of-pocket costs for direct medical expenses including surgery, chemotherapy, radiotherapy, breast MRI and other diagnostic tests, and specialist consultations.

Women treated in the private system may find that their doctors recommend additional tests or treatments that do not have a Medicare or private health insurance rebate, for example molecular testing or breast MRI as part of pre-surgical assessment. Doctors and other medical professionals operating in the private system are free to set their own fees and some charge significantly more than the Medicare Benefits Schedule (MBS) fee for their services. While some health funds have ‘no gap’ arrangements with particular providers, these may not be the providers to whom the woman has been referred.

Further, some people may not be aware that they can choose to have some of their treatment in the private health system and some in the public system – for example chemotherapy and surgery in a private hospital where it is covered by private health insurance and radiotherapy in a public hospital as this treatment is not covered by private health insurance. They may also not be aware that they are able to ‘shop around’ to compare fees and choose a specialist who will provide the treatment at a lower cost.

The high ‘gaps’ and upfront out-of-pocket costs in the private system often come as a shock to women. Women with private health insurance most often nominated out-of-pocket or ‘gap’ payments as their greatest source of financial difficulty (44 per cent) followed by loss of income (36 per cent).

While she is very happy with the results of her surgery, Susan would like to see people in her situation offered more information about their treatment options and the costs associated with them so they can make the choice that is right for them.

Before we went to see the plastic surgeon I would have liked to have known how much it was going to cost. It'd be nice to know the average price range of this operation with or without private health.



Breast reconstruction

Not everyone who has breast cancer will choose to have a breast reconstruction. However, for those who do, breast reconstruction surgery is the most expensive aspect of breast cancer treatment. Research shows around 18 per cent of women in Australia have a breast reconstruction after a mastectomy.⁶ Reconstruction rates are higher for younger women, those with private health insurance and those living in an urban area.⁷ Having the option to have a breast reconstruction if they so choose is a critical aspect of breast cancer care, with demonstrated benefits for quality of life and psychological recovery.⁸

People who choose to have breast reconstruction surgery in the private health system may find they have a large out-of-pocket ‘gap’ payment. While publicly funded breast reconstruction is available in the public health system for women who have had a mastectomy, there may be lengthy wait times, particularly for women living outside metropolitan centres. BCNA has recently been making representations on behalf of women in Cairns who had been advised by medical staff there was a significant waiting list for breast reconstruction at the local public hospital.

Jill had opted to have a breast reconstruction at the same time as her mastectomy and sourced quotes from three plastic surgeons. She was very surprised at the high out-of-pocket cost for this surgery – \$5,000. Aware that she would be facing this high cost, Jill spoke with her plastic surgeon, who suggested she pay for her reconstruction on a payment plan.



Treatment costs

Costs for some breast cancer treatments can also be high. For people receiving treatment in the public system, costs can include co-payments that some state and territory public hospitals charge for chemotherapy treatment. Monthly script fees for hormone therapy drugs (taken for between five and 10 years) and follow-up GP appointments to get scripts renewed are an expense that can continue for many years beyond initial treatment. If a woman develops lymphoedema – a condition that can occur as a result of some breast cancer treatments – treatment for this condition with specialist physiotherapy and massage can be another long-term-expense, particularly in areas where no publicly funded services are available and a woman’s only option for treatment is in the private system. In our survey, the out-of-pocket cost for breast cancer treatment for someone without private insurance and receiving treatment in the public system was around \$3,600.

Even though Farrah had her treatment in the public health system, she was surprised by how much cancer costs.

If someone had said to me ‘When you get cancer it costs money’, it wouldn’t have occurred to me what that meant until now.

Women who have their breast cancer treatment in the private health system often face much higher treatment costs. In our survey, the out-of-pocket cost for a woman receiving treatment in the private health system was about \$7,000. This rises to around \$21,000 for women whose private health insurance does not offer comprehensive coverage.

Women who have radiotherapy treatment in the private health system find that their private health insurance does not cover radiotherapy (as it is an outpatient procedure). This often comes as a surprise to them and can add significantly to the total amount they pay. Other expenses for private patients can include out-of-pocket or 'gap' payments for their breast surgeon and anaesthetist, and charges for staying in hospital.

Penny was surprised at the high out-of-pocket costs for her breast surgeon and the anaesthetist. These costs increased when she needed a second surgery soon after the first to ensure all the cancer was removed.

You're sort of overwhelmed by the diagnosis and you want to get the treatment. It was a lot of money we weren't expecting to have to pay.



Other costs

Many of the hidden costs of breast cancer are for non-medical but important items. Women – both privately insured and uninsured – spent around \$3,200 on 'other' costs. These included counselling, accommodation if travelling for treatment, higher energy bills for heating and cooling a house to make it comfortable for someone having cancer treatment, buying new clothes to suit a new body shape after a mastectomy or weight changes as a result of treatment, and extra wear and tear on a car from driving to and from repeated radiotherapy appointments. A study by Cancer Council Victoria in 2016 estimated that the average cancer patient in Victoria would spend \$1,128 on parking alone in their first year after a cancer diagnosis.⁹ All of these expenses add up and can often overstretch an already tight household budget.

Helen lives on the Central Coast of New South Wales and had to drive a long way for her daily radiotherapy treatment in Gosford. This travel took its toll on the family car, which broke down and was unable to be repaired.

We had to go for a bank loan to buy a car to get me to treatments. We could not be without transport.

The costs started to become too much for their budget and she and her husband sought help from community organisations for food and bills.

We've spent all our money on transport this week – we now have nothing to pay our telephone bill or our food bill. We made a lot of visits to our neighbourhood centre to get some help with food vouchers.

Other non-medical items that are important for helping a person cope psychologically with cancer also cost money at a time when budgets are under strain. These include wigs and turbans, complementary therapies for wellness such as meditation and yoga, and exercise classes such as water aerobics.

Georgie found that things that would have made her feel better physically and emotionally during her treatment – exercising at the gym, going for a coffee, visiting the osteopath or going out for dinner with friends – cost more than she could afford. One friend bought Georgie a wig, as she was finding it difficult to deal with losing her hair as a result of chemotherapy treatment.

A girlfriend paid for a wig for me, which was really lovely. I wouldn't have been able to get through it without a wig. Bald woman equals cancer. When my hair fell out, it was the first time I really had to acknowledge to myself and the world that I had cancer, so the wig was really important – it let me pretend I was normal.

Other friends gave Georgie grocery vouchers, paid for appointments and paid her utility bills and rates.



Tests not covered by Medicare

Making the best possible treatment decisions is important for many women when they are newly diagnosed with breast cancer. To help make decisions, doctors will sometimes suggest tests that are not covered by Medicare. These may have high out-of-pocket costs. Breast MRI can cost hundreds of dollars (\$450–\$1,500) and the Oncotype DX test (to help determine whether or not chemotherapy treatment may be beneficial) costs around \$5,000,¹⁰ with no Medicare rebate. Many people reflect on the importance of these tests in helping them make good treatment decisions with their doctor. However, the high costs add to the financial burden of breast cancer.

The \$4,500 that Lynne spent to have Oncotype DX testing was not covered by Medicare or by her health fund. Lynne and her husband feel it was a good decision to have the test done as the result indicated little benefit in chemotherapy treatment and meant Lynne could avoid having chemotherapy. They were in a financial position to afford the test, but they know others are not.

We had superannuation put away. We did not bat an eyelid in getting that money out. I feel so sorry for men and women, with young families, who don't have a lot of money and who just can't afford to do that.

LYNNE

Younger women

A woman who is diagnosed with breast cancer at a younger age (before she has started menopause) may face additional financial pressures. Younger women may not have accumulated assets. They may not have superannuation or other money put away on which they can draw to fund their treatment and care. They may be just starting to build their financial foundation.

Women with dependent children use psychological services at a greater rate than women without dependent children. Around 75 per cent of women with dependent children sought mental health help compared with around 50 per cent of women who did not have dependent children. This might be because a diagnosis while a woman's children are still young may be more difficult to come to terms with and worries about the future may be more overwhelming. If a woman's GP sets up a Mental Health Treatment Plan for her, she can be eligible for up to 10 sessions per calendar year of Medicare-rebated visits to a psychologist or psychiatrist.

Younger women are more likely to choose to have breast reconstruction. The majority – 86 per cent – of women surveyed who chose breast reconstruction were under 60 years of age. Breast reconstruction is the most expensive aspect of breast cancer treatment, which further drives up costs for younger women.

If a young woman hasn't started or completed her family she may choose to use IVF services to freeze eggs, or take additional medications such as goserelin (Zoladex) to protect her fertility during chemotherapy. Both IVF and goserelin have an out-of-pocket cost.

Another consideration for younger women is how their breast cancer diagnosis may affect their ability to apply for life and other insurances. Their breast cancer diagnosis will need to be listed as a pre-existing condition and may mean that a woman will have to pay higher premiums for insurance products for the rest of her life.



FARRAH

Younger women with young children may need to pay for additional childcare during treatment. Our survey showed the typical cost of childcare needed because of breast cancer is around \$770 over the five-year period from diagnosis.

Childcare was a problem for Farrah. Having on-site childcare at the hospital would have helped.

It makes complete sense to me that there should be a creche for young mothers who have cancer, so you can put your baby somewhere while you have an appointment.

Friends, family and her community donated to help Farrah, and Cancer Council Western Australia helped her with bills.

I've been very lucky that I've had donations given to me ... that money has been essential in so many ways, just being able to pay car registration or my extra heating bill.

The support has made a big difference for Farrah and her young family.

Rural and regional women

Women in rural and regional areas incur about the same out-of-pocket costs as women in metropolitan areas, but they receive fewer treatments and services for that money. Women in rural and regional areas had fewer medical consultations and tests, and were less likely to undergo radiotherapy treatment and breast reconstruction than women in urban areas. They also used fewer allied health services.

As household incomes in rural and regional areas are generally lower than those in metropolitan areas – \$1,050 per week for rural people compared to \$1,250 for metropolitan people (Figure 7) – money spent on breast cancer treatment and care for women in this group is a larger proportion of the average household income.

Household hours worked also decrease more dramatically for women in rural and regional areas – a 70 per cent decrease compared to a 50 per cent decrease for metropolitan households (Figure 8). This means that rural and regional women have a greater financial burden – they receive fewer treatments and services for the money they spend, and they spend a bigger percentage of their household budget on cancer treatment and care.

Having to travel long distances to and from treatment can also mean time away from family, friends and normal life. This disruption can increase financial pressure. While all Australian states and territories offer patient assisted travel schemes (PATS), these schemes do not fully cover the costs of travelling for treatment. Regional and rural women pay more for travel even after reimbursement schemes – around \$560 compared to around \$370 for women in metropolitan areas.

When Ruth was diagnosed with breast cancer she was 38 weeks pregnant with her first baby. This challenging situation was made more difficult by her location – Ruth and her husband lived in Kalgoorlie, where they both worked as high school teachers. Ruth's treatment was in Perth, almost 600 km away. While Ruth found PATS helpful, especially during her chemotherapy treatment, she still had out-of-pocket costs to meet because the PATS payments did not cover the complete cost of travel and accommodation.

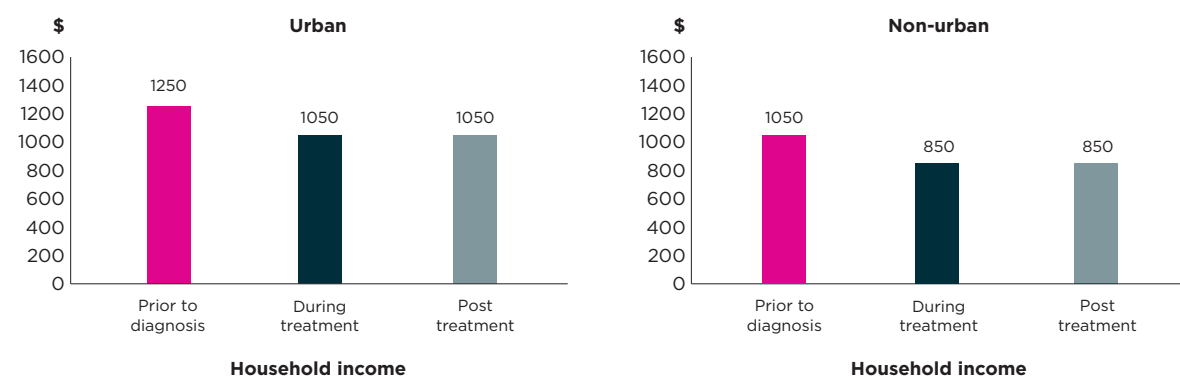
PATS flew me to Perth to do my chemotherapy, so that was really fantastic. But the costs it didn't meet were taxi fares from the airport to the hospital and back again.

When it came time for her daily radiotherapy treatment, Ruth relocated to Perth with her newborn son. Being away from her husband, who had to stay in Kalgoorlie for work, was hard.

RUTH



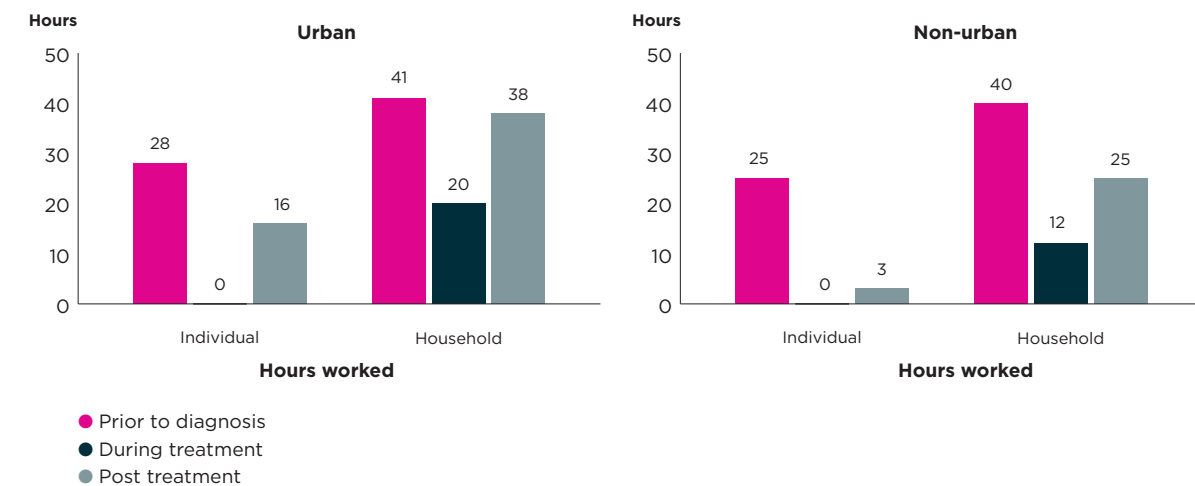
Figure 7: Household income by time since diagnosis by residential location



Median weekly income reported.

Based on a graph provided by Deloitte Access Economics, *Financial impacts of breast cancer in Australia*, Nov 2016.

Figure 8: Individual and household hours worked by time since diagnosis by residential location



Taken from a graph provided by Deloitte Access Economics, *Financial impacts of breast cancer in Australia*, Nov 2016.

Metastatic breast cancer



Metastatic breast cancer, also known as advanced, secondary or stage 4 breast cancer, is breast cancer that has spread beyond the breast to other organs in the body, most often the bones, liver, lungs or, less commonly, brain. Metastatic breast cancer is incurable, but there is a range of treatments available to control the growth and spread of cancer, relieve symptoms and promote quality of life. Women can live for a number of years with metastatic disease.

Introduction

A diagnosis of metastatic breast cancer is devastating news. It brings with it uncertainty about what life will be like, including the financial impact it will have on a woman and her family.

A woman may have had a previous experience of early breast cancer. She may get the news that she has metastatic disease months after she has finished her treatment or she might be many years post her first diagnosis. She may have experienced financial difficulty as a result of an earlier diagnosis and might still be recovering financially.

For some women, metastatic breast cancer will be their first cancer diagnosis.

As discussed in the limitations section of this report, BCNA's survey collected data only about a woman's most recent diagnosis of breast cancer. For many women with metastatic breast cancer this means that the data they were reporting in our survey excluded costs relating to a prior incidence of early breast cancer. Lifetime costs for women with metastatic disease may be much higher than those presented in this report, which is based on a five-year snapshot.

Being a long-term patient, my family has incurred significant expense due to my health – \$50,000 out of pocket, including an outlay of \$15,000 to access Kadcyra through the patient access program. It goes without saying that this is a tremendous financial burden for my family.
– Karen

The \$5,600 out-of-pocket cost for Profile 5 – the cost profile representing women with metastatic breast cancer in the bones – is similar to the out-of-pocket costs for the whole survey sample of around \$5,000 up to five years from diagnosis. Despite the similarity in the dollar amount, the way these costs are experienced by women with metastatic breast cancer can be very different to the way they are experienced by women with early breast cancer. There are additional financial worries that women with metastatic breast cancer face related to the unpredictable and ongoing nature of their treatment.

Ongoing costs of treatment

While women with early breast cancer will most likely know at the start of their treatment how long they will be receiving treatment (surgery, chemotherapy, radiotherapy and/or hormone therapy), women with metastatic disease do not have an 'end point' to their treatment. Generally they will receive treatment for the rest of their lives. Treatment often involves regular monitoring tests and scans, which can be expensive. An MRI scan, for example, costs several hundred dollars (\$450–\$1,500). A PET scan, which costs around \$370, may also be ordered. Breast MRI and PET scans are not covered by Medicare or private health insurance. When these tests are repeated multiple times in a year, costs accumulate quickly.

Depending on how their cancer responds to treatment, women with metastatic disease may have several 'lines' of treatment. When one line of treatment stops working, another treatment is tried. It is difficult to predict how long each line of treatment will work and how many lines of treatment may be given. What each line of treatment will be, how much it will cost, whether it will be subsidised by the PBS, or whether the household budget will have to stretch to cover the costs of non-PBS medicine, are all questions that are part of the ongoing uncertainty for people with metastatic breast cancer.



Difficulty planning

While uncertainty is always a part of life, it can become particularly difficult to manage for people who are living with an incurable illness where disease progression is unpredictable and the treatment path is not always clear.

Difficulty with planning and budgeting can be especially hard for people who do not live in major cities, who have children, or who are trying to run a small business. Not knowing when new treatment expenses will come up makes planning a monthly budget challenging and adds to the emotional distress of living with metastatic cancer. It can be almost impossible to manage a budget when unplanned expenses keep coming.

The combination of the uncertainty of metastatic cancer and living in a regional area adds to the financial stress and worry for Christie and her family. While they are in a stable financial position and are good at saving and budgeting, having to absorb unanticipated costs when Christie needs to be in Melbourne for treatment that is not available in her hometown of Sale, Victoria is hard. This has an emotional impact on Christie.

Juggling things that are a priority when you have that extended bill or hospital stay when I'm away from home – it's the anxiety this creates that changes our regular monthly routine. So for me it rolls onto other emotional impacts as well as just the financial impact.

New drugs not listed on the PBS

The Australian Government subsidises the cost of many prescription medicines through the PBS. This means that people who need medicine do not pay the full cost of the drug. The approval process to get a new drug listed on the PBS can be lengthy and means that drugs are often registered for sale in Australia well before they are listed on the PBS. This is often the case with new and innovative cancer drugs, which can cost thousands of dollars each month if they are not listed on the PBS. For women with metastatic breast cancer, new drugs can represent hope for prolonged life, but also fear around whether these drugs will be affordable to them.

BCNA has a proud history of advocating for a range of drugs for metastatic breast cancer to be listed on the PBS, including drugs such as Herceptin, Tykerb and, more recently, Perjeta and Kadcyła. However, we know there is more work to do as new drugs continue to be developed. For example, palbociclib (Ibrance) was recently approved by Australia's Therapeutic Goods Administration (TGA), but is not currently listed on the PBS. The cost to women to buy this drug is around \$5,000 per month. For many women and families who are already facing the financial challenges of metastatic breast cancer, paying thousands of dollars a month for a new treatment is not an option. If they do choose to pay, it can place the household budget under unbearable strain. Not knowing if, or for how long, the new drug may be effective means that there is considerable emotional strain in making decisions about whether to pay for new drugs.

Living with advanced cancer puts an enormous stress on families. Decisions about whether to pay for an expensive treatment can create conflict when that money also needs to be spent elsewhere. It also leaves women feeling guilty that they are spending money on treatments when the family really needs it for other things. – Lynne

Navigating insurance and superannuation claims

Many people have life insurance or total and permanent disability (TPD) insurance as part of their superannuation. Australians living with a terminal illness and with a life expectancy of less than two years can also access their lump sum superannuation payout tax free, although this is dependent on having two doctors, one of whom is a specialist, complete forms specifying life expectancy.

Accessing insurance and superannuation can be a complex process. A number of women in our survey provided additional comments about the challenges in completing this paperwork while unwell.

Women with metastatic breast cancer often need expert help and advice – and cooperation from their doctors – to successfully make claims. This sort of expert help and advice can be difficult to come by and can be an additional expense. However, the right help at the right time, can make a huge difference to household finances.

Marie knew she could access her superannuation through the TPD provision. However, she knew that she would need to do some paperwork to make the claim and was worried she would not have the energy to do it. Through her professional networks, Marie had a contact who was able to give her specialist advice and help. Having an expert to help her meant that the process of claiming TPD across her different superannuation accounts was straightforward. Marie's doctors were also helpful in this process. She felt she had a great team behind her. When her claims came through, Marie and her family felt a great sense of relief and empowerment.

We're living with our hearts not heavy anymore.

Discussion

Cancer is a life-altering, stressful experience and worries about money make it even more so. While Australia's health care system provides good quality health care, many people find themselves out-of-pocket for the services they need – regardless of whether they have their treatment in the public or private health system. However, this is especially the case for those who have their treatment in the private health system.

Some have the financial resilience to recover, but many do not. Costs can be ongoing and impact weekly budgets ('Can I pay my electricity bill?') and long-term life goals ('Will I be able to afford a house deposit?'). Financial independence – something that many women fiercely prize – is lost. Single women who do not have a partner's income to fall back on are also affected. They may find themselves in a situation where they have to live with their parents, friends or flatmates, to make ends meet.

I had to move in with my parents. I lost my independence. – Kylie

BCNA has received anecdotal reports of the financial impact of breast cancer for many years. This report provides the evidence that these stories are not isolated experiences but an all-too-common part of the breast cancer journey.



The most significant financial stressors

Taking time out of the paid workforce to complete treatment is a major contributor to financial stress. Data from 2016 indicates that only 62 per cent of Australia's workforce has paid leave entitlements.¹¹ With 38 per cent of the workforce having no paid leave, a significant proportion of women who need to stop work for treatment find themselves forced to rely on other sorts of income. This can include income protection insurance, a partner's income, Centrelink benefits, superannuation or help from family. A small proportion of women – around 7 per cent of survey respondents – were forced to return to work earlier than they expected to make ends meet. While this survey did not seek to quantify total costs incurred by a woman over her lifetime, including lost wages and lost superannuation, other studies have indicated that the lifetime cost for people with breast cancer is significant. A study conducted by Access Economics in 2007 found that the lifetime costs for a woman diagnosed with breast cancer were \$28,500.¹²

A majority – 74 per cent – of women who responded to our survey held private health insurance at the time of their diagnosis. The results show that women with private health insurance typically pay more than twice as much in out-of-pocket costs for their breast cancer treatment and care when compared to women without private health insurance – approximately \$7,000 for insured women compared with approximately \$3,600 for uninsured women. Sometimes the out-of-pocket costs are much higher than \$7,000 for privately insured women, with the costs for some women amounting to more than \$21,000. Women with private health insurance paid approximately 10 times as much as women without private health insurance for their direct medical costs at \$3,723 compared to \$355 respectively. The greater financial burden for women with private health insurance does not come from accessing extra supportive care

items or choosing more expensive products – for instance, a \$2,000 wig as opposed to a \$400 wig. Rather, it comes from higher out-of-pocket costs for direct medical expenses including surgeries, chemotherapy, radiotherapy, breast MRI and other diagnostic tests, and specialists' consultations.

A recent report prepared for the Prostate Cancer Foundation of Australia (PCFA) by the Actuaries Institute found, similarly to our report, that holding private health insurance results in higher out-of-pocket costs¹³. PCFA recommended that a trauma benefit of \$5,000 be paid by private health insurers if a policy holder is diagnosed with cancer. BCNA supports this recommendation as a way of reducing the financial toxicity of breast cancer for those who hold private health insurance. This one-off payment should be in addition to the normal private health fund rebates paid for treatment and care.

A recent report from the Grattan Institute has found that excessive costs for specialists are an issue for many and may discourage people from seeking the care they need.¹⁴ It has called for greater transparency in disclosing medical specialists' out-of-pocket costs as a way of helping health consumers reduce their financial burden.¹⁵ Based on the evidence in this report, BCNA supports the call for greater transparency around out-of-pocket costs.

Women living in a rural or regional area face issues such as travelling long distances, staying away from home and disruption to work and family life.

All of these can tighten the household budget. Some women find that paying for cancer treatment and its associated costs pushes them to the brink. They are forced to rely on government benefits, charity handouts and emergency help from family, friends and community to get by. Even an expense as simple as car parking at the hospital can add a significant burden to the household budget. Cancer Council Victoria found that costs of

parking contributed significantly to the financial burden of breast cancer, with an estimated \$1,128 spent on parking in the first year of treatment alone.¹⁶ While the Queensland and New South Wales governments have recently introduced measures to reduce the cost of car parking in public hospitals in response to public pressure, more needs to be done across Australia to reduce this burden.

This financial burden is unequally shared. Our research has found that while 12 per cent of women reported no out-of-pocket costs for their breast cancer treatment and care, 88 per cent reported some cost in the first five years after diagnosis. This cost was usually around \$5,000 across all our respondents (both privately insured and uninsured women), with some people paying significantly more, into the tens of thousands of dollars. Many women will have costs that continue for longer than the first five years after diagnosis, which were not captured in this survey, but contribute to the cost of breast cancer over a woman's lifetime. These may include paying for ongoing lymphoedema treatment, hormone therapy drugs such as tamoxifen, letrozole and anastrozole, and counselling.

People living with metastatic breast cancer carry additional financial burdens because of the unpredictable and ongoing nature of their disease. The incurable nature of metastatic breast cancer means that additional financial burdens include the ongoing costs of treatment, difficulty planning for the future, not knowing whether a life-extending new drug will be listed on the PBS, and navigating complex insurance and superannuation claims. Women living with metastatic breast cancer will share many financial pressures in common with those living with early breast cancer. However, these pressures are amplified by the nature of metastatic breast cancer and add to the burden.

Accessing government assistance through Centrelink is a challenge for women with both early and metastatic breast cancer. Women have reported inconsistencies, lengthy wait times,

being unaware of programs and services for which they may be eligible, or, conversely, being overwhelmed by the different services offered and unsure where to start. Many report that they learn about help services in ad hoc ways, often through talking to others with cancer.

Farrah found the information about financial support in the hospital brochures confusing. Mainly, she found out about financial help through talking to other people with cancer.

I think sometimes the only reason I could access the things that I've used is because I've happened by accident to meet someone who knew about it.

Government bureaucracy can be a significant barrier to accessing entitlements, for instance Centrelink benefits or superannuation. These experiences are common across people with all types of cancer. Cancer Council NSW¹⁷ has found that people who access its pro-bono support services report difficulties understanding Centrelink entitlements for which they may be eligible. They have difficulties speaking to Centrelink staff, either because of long hold times on the telephone or difficulty visiting a Centrelink office when unwell. Long waiting times for payments to start is also a reported issue.

Having a designated team of chronic illness liaison officers available at Centrelink (on the phone and in physical locations) would assist people with cancer – and other chronic illnesses – by being able to provide them with tailored information for their individual situation. This would streamline the process for people living with chronic illnesses such as cancer and allow them to get the help to which they are entitled.

RECOMMENDATIONS

For private health insurance companies

1. Private health insurance companies increase the number of practitioners with whom they have a 'no gap' arrangement to allow for greater choice in treating doctor and fewer 'gap' payments.
2. Private health insurance companies better promote their lists of 'no gap' providers.
3. A \$5,000 trauma insurance benefit is paid by private health insurance companies to policyholders diagnosed with cancer to help cover out-of-pocket costs. This one-off payment should be in addition to the normal private health fund rebates paid for treatment and care.

For government

4. Centrelink provides specialist chronic illness liaison officers to help people with cancer (and other chronic illnesses) navigate the various entitlements and benefits that are available to assist them.
5. Medicare rebates are increased to better reflect the cost of providing services to reduce the out-of-pocket costs faced by patients. In particular, breast MRI and DXA bone mineral density scans are rebated by Medicare as these are tests commonly used in treatment and care of breast cancer.
6. Changes are implemented to enable radiotherapy services to be covered by private health insurance.
7. State and territory patient assisted travel schemes are updated to reflect the real cost of travelling away from home for cancer treatment and follow-up.
8. Free parking is introduced at hospitals for people with cancer.

9. A metastatic cancer card is introduced to acknowledge the additional financial burden people with metastatic disease face. This card could be similar to the pension or Department of Veterans' Affairs (DVA) card to allow services to be provided at a discounted rate.
10. PBS approval processes for new cancer drugs are reviewed to ensure that Australians can access medications in a timely and affordable way.

For health service providers

11. Health practitioners provide patients having treatment in the private health system with comprehensive written information about all out-of-pocket costs of any proposed procedures prior to those procedures taking place to improve transparency and avoid 'bill shock'.
12. Health practitioners advise patients they are entitled to a second opinion on the costs of treatment quoted to them.

For BCNA

13. People with breast cancer are empowered with information about their rights in the workplace. Employers are made aware of their responsibilities to staff while they are undergoing treatment and afterwards.
14. High-quality and appropriate financial advice is provided to people with breast cancer at the time of diagnosis. This advice should be sensitive to a person's age, acknowledging that young people may not have accumulated resources, and whether a person's breast cancer is early or metastatic. This advice should also explore insurance and superannuation options and involve referral as necessary to services that can help people make their claims.

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- ¹⁰ This figure varies depending on the performance of the Australian dollar compared to the US dollar as Oncotype DX testing is performed in the US. The figure of approximately \$5,000 reflects the cost in Australian dollars reported by women in their survey responses.
- ¹¹ Australian Bureau of Statistics, 2016. *Characteristics of Employment, Australia, August 2016*. <http://www.abs.gov.au/ausstats/abs@.nsf/mf/6333.0>. Accessed 17 July 2017.
- ¹² Access Economics and The Cancer Council NSW, 2007. *Costs of Cancer in NSW: A report by Access Economics Pty Limited for The Cancer Council NSW*. Accessed 10 August 2017 at https://www.cancercouncil.com.au/wp-content/uploads/2010/11/costofcancer_summary.pdf. (This will be reference 12)
- ¹³ Lowe, A and Reid, J. 2017. *Private health insurance bill shock: what can insurers do to help?*. Accessed at <https://actuaries.asn.au/Library/Miscellaneous/2017/TheDialogueIssue1Embargo2.pdf>, 14 August 2017.
- ¹⁴ Duckett, S. 2017. *Why it costs so much to see a specialist – and what the government should do about it*. Accessed at <https://grattan.edu.au/news/why-it-costs-you-so-much-to-see-a-specialist-and-what-the-government-should-do-about-it/> 15 August 2017.
- ¹⁵ Duckett, S. 2017. *Why it costs so much to see a specialist – and what the government should do about it*. Accessed at <https://grattan.edu.au/news/why-it-costs-you-so-much-to-see-a-specialist-and-what-the-government-should-do-about-it/> 15 August 2017.
- ¹⁶ Cancer Council Victoria, 2016. *Investigation of parking at Victorian cancer treatment centres*. Accessed at http://www.cancervic.org.au/downloads/CISS/Parking_report/Parking-Report.pdf, 14 August 2017.
- ¹⁷ Email correspondence with BCNA

Acknowledgements

Thank you to the almost 2,000 BCNA members who responded to our survey and took considerable time and effort to go over past receipts and records and report each cost diligently. You made this report possible.

Special thanks are owed to the 15 women who agreed to share their personal stories as case studies for the report: Christie, Dannette, Farrah, Georgie, Helen, Jill, Karen, Kylie, Lisa, Louise, Lynne, Marie, Penny, Ruth and Susan.

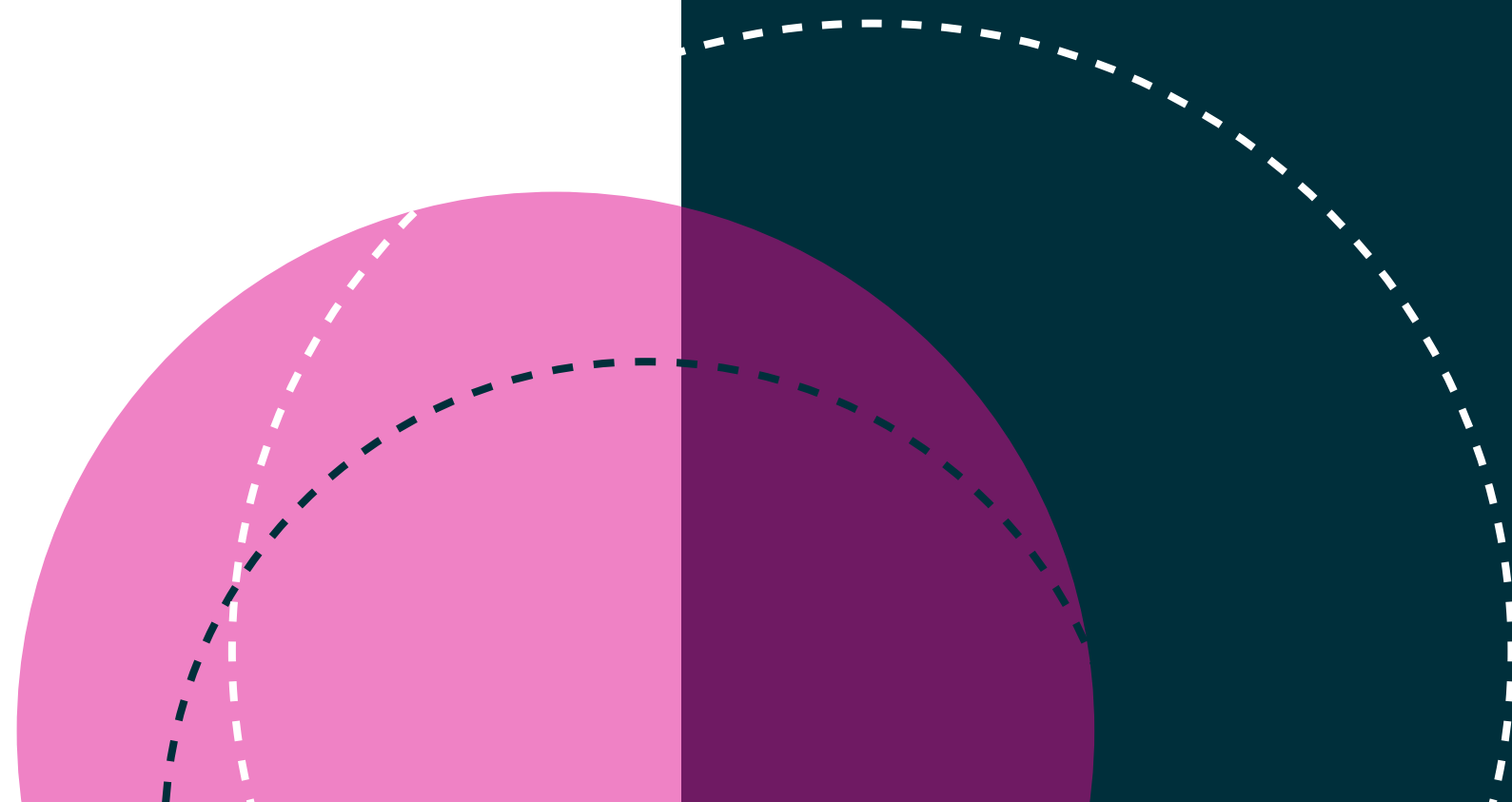
Thank you to the photographers who generously provided their time and skills to photograph the women featured in the case studies.

BCNA also acknowledges and thanks the following clinicians who assisted in the development of the five profiles and online survey:

- Professor Fran Boyle AM
- Mr Hamish Farrow
- Associate Professor Mustafa Khasraw
- Professor Bruce Mann
- Associate Professor Wendy Raymond
- Dr Andrew Saunders
- Associate Professor Kate Stern
- Mr Dean Trotter.

Finally, BCNA would like to thank the team at Deloitte Access Economics who were genuinely committed to conducting a quality piece of research within a small budget and improving the lives of Australians with breast cancer.

Photography by Andrew Burn, Diane Kitanoski (Love Kit Photography), Melissa Drummond, Paul Dunlop, Sylvia Liber, Victoria Fitzmaurice (Essence Images) and Breast Cancer Network Australia.



Call to action

BCNA calls on decision makers to make a difference to the lives of Australians with breast cancer. We encourage you to review the recommendations outlined in this report and consider how you can help reduce the financial impact of breast cancer.

We would welcome your commitment and contribution and look forward to working with you to help ensure a better journey for all Australians affected by breast cancer.

Who to contact

For media enquiries:

Penelope Davies
Media Manager

Phone: (03) 9805 2576

Email: pdavies@bcna.org.au

For policy and research enquiries:

Kathy Wells
General Manager, Policy

Phone: (03) 9805 2562

Email: kwells@bcna.org.au

Visit BCNA's website for further information on the financial impact of breast cancer, including the 15 case studies and videos of participants in our study, and the Deloitte Access Economics report.

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