The support and information needs of women with secondary breast cancer

Survey Report
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<td>30</td>
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</tbody>
</table>

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**Suggested citation**

About Breast Cancer Network Australia

Breast Cancer Network Australia (BCNA) is the peak national consumer organisation for Australians personally affected by breast cancer and consists of a network of more than 100,000 individual members and 300 Member Groups across Australia. 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.

Since 2007, BCNA has offered women with secondary breast cancer a free, comprehensive information resource, *Hope & Hurdles*. *Hope & Hurdles* was developed in consultation with leading breast cancer clinicians and women living with secondary breast cancer. It includes a practical, evidence-based information guide, a brochure with personal messages of hope and inspiration from women affected, booklets on the treatment and care of secondary breast cancer in four particular sites (bone, liver, lungs, brain), a booklet of practical information for women preparing for end of life, and other useful booklets and brochures. To date, we have provided more than 7,100 *Hope & Hurdles* packs to Australian women living with secondary breast cancer.
Introduction

In August 2014, Breast Cancer Network Australia (BCNA) undertook research with Australians living with secondary breast cancer. The purpose of the study was to better understand the needs and challenges faced by women with secondary breast cancer and to establish key information and support gaps that could inform BCNA’s future resource development and advocacy efforts.

The aims of this report are to provide a summary of the research findings and to raise awareness of the key issues affecting women living with secondary breast cancer and their families. The paper is for use by health professionals, policy decision makers, and all those with an interest in the issues and challenges facing women with secondary breast cancer.

What is secondary breast cancer?

Early breast cancer, where breast cancer is confined to the breast and/or axillary lymph nodes, is the most common form of breast cancer. Early breast cancer can be successfully treated and most women survive and live long lives. In Australia, the five-year relative survival rate for breast cancer is 89.6 per cent.1

Secondary breast cancer, also known as advanced, metastatic or stage 4 breast cancer, is breast cancer that has spread from the breast to more distant parts of the body, such as the bones, liver, lungs, and, less commonly, the brain and other areas.

Secondary breast cancer is essentially an incurable disease. There are no reliable figures for the number of women (and men) living with secondary breast cancer. State based cancer registries collect data on cancer diagnoses in Australia. However, not all states collect data on the incidence of secondary breast cancer, including stage at diagnosis and time to progression. We therefore do not know how many Australians are diagnosed or living with this disease.

In 2015, approximately 15,600 Australian women are expected to be diagnosed with breast cancer.2 It is unknown how many of these women will have metastatic disease at presentation, although estimates based on NSW Cancer Registry data between 1980–2004 suggest it may be around 5%.3

Each year around 2,800 Australian women will die from secondary breast cancer.4 A number of factors influence the survival times for women with secondary breast cancer, including the type of breast cancer (hormone receptor positive breast cancer, HER2-positive breast cancer, triple negative breast cancer), the site(s) of metastases, women’s response to treatment and the presence of co-morbidities.5 It is, therefore, not possible to summarise women’s survival time in a single number, as it varies. Survival data for women with secondary breast cancer...
matched for cancer type, stage, treatment and co-morbidities would be very useful, but this data is rare.6 Clinical trials provide a useful source of survival data, however, women who participate in clinical trials are not always representative of women being treated in routine practice, and the data is usually summarised as the median survival time for women, thereby having little meaning for individuals. Research has shown that survival times are better presented as a range of possible scenarios, including best case, most likely and worst case scenarios. Estimating and explaining these scenarios to women conveys the inherent uncertainty of survival predictions and can give more hope than a single number estimate, which can be interpreted by women as a limit.7 Secondary breast cancer is a complex disease and there is no single standard of care. Every woman’s experience is different, meaning treatment is individualised, based on multiple factors. This results in complicated treatment decision-making for a woman and her family, at a time when they are grappling with the implications of an incurable illness.

Despite the complexity of decision-making, there are disproportionately fewer resources available for people diagnosed with secondary breast cancer than for those with early breast cancer.

Many women and their families struggle daily with the emotional impact of their secondary breast cancer diagnosis. Women with secondary breast cancer report high rates of unmet needs and can feel that their situation is poorly understood or acknowledged, particularly during Breast Cancer Awareness Month each October when the emphasis is on survival and cure.

Secondary breast cancer is a strategic priority area for BCNA, and we will continue to develop and promote ways to better support and acknowledge women, men and their families affected by this disease.
Method

The survey objectives were to identify the unmet supportive care, financial, practical and information needs of Australian women with secondary breast cancer. The survey was a mixed methods survey that was developed by BCNA, with input from research and clinical experts working with women with secondary breast cancer. A number of BCNA Consumer Representatives living with secondary breast cancer also provided feedback.

We identified 1,802 BCNA members on our database as having been diagnosed with secondary breast cancer and having an email address and invited them to complete the survey. This included some men living with secondary breast cancer. An email invitation that contained a link to the online survey was sent to these members. The survey was conducted over three-and-a-half weeks in August and September 2014.

Participants were excluded if they indicated they did not have secondary breast cancer. Not all respondents answered every question.

Demographics

In total, 582 eligible women and men living with secondary breast cancer participated in the survey, a response rate of 32%.

Age

The majority of respondents were aged 50 to 69 years. Twenty-four per cent (139) were aged 49 or younger (see Table 1).

Table 1: Age of survey respondents

<table>
<thead>
<tr>
<th>Age Category</th>
<th>n.</th>
<th>% of total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 30</td>
<td>2</td>
<td>0.3%</td>
</tr>
<tr>
<td>30–39</td>
<td>21</td>
<td>3.6%</td>
</tr>
<tr>
<td>40–49</td>
<td>116</td>
<td>20.0%</td>
</tr>
<tr>
<td>50–59</td>
<td>239</td>
<td>41.0%</td>
</tr>
<tr>
<td>60–69</td>
<td>146</td>
<td>25.0%</td>
</tr>
<tr>
<td>70–79</td>
<td>37</td>
<td>6.4%</td>
</tr>
<tr>
<td>80+</td>
<td>7</td>
<td>1.2%</td>
</tr>
<tr>
<td>Unknown</td>
<td>14</td>
<td>2.4%</td>
</tr>
</tbody>
</table>

Gender

Three men living with secondary breast cancer participated in the survey.

While both men and women can be diagnosed with secondary breast cancer, this report will refer to ‘women’ given that less than 1% of survey respondents were men.
Language

Twenty-four respondents (4%) spoke a language other than English at home.

Location

Respondents lived in all states and territories in Australia (Table 2). One quarter of women (143) lived in New South Wales and almost one third in Victoria (31%; 178). Seventeen per cent lived in Queensland (100).

Table 2: Location of respondents by state and territory

<table>
<thead>
<tr>
<th>State / territory</th>
<th>n.</th>
<th>% of total</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACT</td>
<td>18</td>
<td>3%</td>
</tr>
<tr>
<td>NSW</td>
<td>143</td>
<td>24.6%</td>
</tr>
<tr>
<td>NT</td>
<td>3</td>
<td>0.5%</td>
</tr>
<tr>
<td>QLD</td>
<td>100</td>
<td>17%</td>
</tr>
<tr>
<td>SA</td>
<td>50</td>
<td>8.6%</td>
</tr>
<tr>
<td>TAS</td>
<td>18</td>
<td>3%</td>
</tr>
<tr>
<td>VIC</td>
<td>178</td>
<td>31%</td>
</tr>
<tr>
<td>WA</td>
<td>57</td>
<td>9.8%</td>
</tr>
<tr>
<td>Unknown</td>
<td>15</td>
<td>2.6%</td>
</tr>
</tbody>
</table>

The majority of survey respondents lived in a metropolitan area (59%; 328), and 41% (228) lived in a regional, rural or remote location (Figure 1).

Living arrangements

The majority of survey respondents lived with a partner (44%; 256) or a partner and children (29%; 169). Fifteen per cent of the women (85) lived alone (Table 3).

Table 3: Living arrangements

<table>
<thead>
<tr>
<th>Living arrangement</th>
<th>n.</th>
<th>% of total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Live with partner and children</td>
<td>169</td>
<td>29%</td>
</tr>
<tr>
<td>Live with partner</td>
<td>256</td>
<td>44%</td>
</tr>
<tr>
<td>Single parent with children</td>
<td>32</td>
<td>5%</td>
</tr>
<tr>
<td>Live alone</td>
<td>85</td>
<td>15%</td>
</tr>
<tr>
<td>Live with extended family members</td>
<td>19</td>
<td>3%</td>
</tr>
<tr>
<td>Other</td>
<td>19</td>
<td>3%</td>
</tr>
<tr>
<td>Did not answer</td>
<td>2</td>
<td>0.3%</td>
</tr>
</tbody>
</table>
Results

Breast cancer history

Sixty-four per cent (370) of respondents had experienced a diagnosis of early breast cancer before being diagnosed with secondary breast cancer.

For 27% (155) of women, secondary breast cancer was their first diagnosis of breast cancer.

Fifty-seven women (9%) did not answer this question.

Time since diagnosis

The majority of respondents (77%; 447) were diagnosed with secondary breast cancer within the previous five years (Figure 2).

Eleven per cent (71) had been living with secondary breast cancer between six and 10 years and 7% (39) had been living with secondary breast cancer for 10 years or more. Four per cent of respondents (25) did not provide a response.

Sites of metastases

Respondents reported breast cancer metastases in a number of areas of their body (Figure 3). The three main sites were bone (71%; 411), liver (32%; 187) and lungs (31%; 178). Other sites included the ovaries, stomach and regional lymph nodes, such as the neck.

Current treatments

Women reported a range of current treatments including hormone therapy (41%; 236), chemotherapy (36%; 209), bone targeted treatments (23%; 131) and HER2 therapy (22%; 127) (Figure 4). Twenty-two women (4%) indicated they were on a break from treatment, 13 women (2%) were not receiving further treatment and two women had not yet started treatment.

Thirty-eight women (7%) reported participating in a clinical trial. This is in line with Australian statistics that report 6% of people with cancer participating in a clinical trial.8
Almost half of participants (49%; 286) reported being treated in the private health system; with 44% treated in the public health system (255). The remaining 41 respondents (7%) did not answer this question. Of the women treated in the private system, 41% (116) said they were aware that their treatment recommendations had been discussed by a multidisciplinary team. In comparison, 56% (142) of women in the public health system said they were aware their treatment recommendations had been discussed by a multidisciplinary team.

When asked how often they were seeing a health service for breast cancer treatment or review, 27% of respondents (156) indicated it was monthly, while just under a quarter of women (24%, 139) reported attending a health service every three weeks. Fourteen per cent of respondents (83) attended a health service weekly (Table 4).

**Public and private health systems and multidisciplinary teams**

*Women could select more than one treatment*
Financial difficulties

A significant proportion of women reported financial difficulties associated with their diagnosis and treatment.

Sixty per cent of women (351) reported that their secondary breast cancer had resulted in some financial difficulty in the previous week. Of these, 38% (133) characterised this financial difficulty as ‘quite a bit’ or ‘very much’ (Figure 6).

“This is a very difficult and uncertain time financially. There is a definite drop in my standard of living and coping with ongoing bills.

Figure 6: Financial difficulties in the past week (n=541)

![Financial difficulties chart]

* 41 women did not answer the question

When asked about the sources of financial difficulty, respondents could choose more than one source or nominate their own. For women in the public system, loss of income was most often reported as a source of financial difficulty (37%; 93), followed by out-of-pocket expenses (28%; 70).

I am working part time and have income protection insurance but I am earning less than I was before diagnosis, when I was working full-time.

We are not on the poverty line, but I have lost half my wage and we relied on that to live.

For women in the private health system, the out-of-pocket costs associated with their treatment were most often cited as a cause of financial difficulty (44%; 126), followed by loss of income (36%; 101).

When women were asked to estimate out-of-pocket costs related to their secondary breast cancer that they had incurred over the previous month, costs ranged from $0 to $25,000 for women treated in the private health system and $0 to $10,500 for women treated in the public health system.

While these women are unlikely to be incurring these costs every month, it is reasonable to assume that there are women at any point in time incurring these sorts of costs as part of their treatment and care.

Figure 7: Out-of-pocket costs for the previous month reported by women (n=343)

![Out-of-pocket costs chart]
The average monthly out-of-pocket cost for all women was $687.17. For women in the private health system, the average monthly out-of-pocket cost was $816.69. Women treated in the public system reported an average monthly out-of-pocket cost of $530.80.

Women were asked to nominate the aspect of their treatment that has incurred the most significant out-of-pocket cost for them, and the cost of this (Figure 8).

Drug treatments not available on the Pharmaceutical Benefits Scheme (PBS) accounted for the greatest out-of-pocket costs, with an average out-of-pocket cost per person of $5,277.

Surgery also attracted high out-of-pocket costs, with an average reported cost per person of $2,890. Respondents did not specify what type of surgery had incurred theses costs, e.g. whether it was related to orthopaedic surgery for bone metastases, neurosurgery for brain metastases or other surgery.

Radiotherapy costs were also significant. Radiotherapy is usually conducted as an outpatient service, so women in the private health system are unable to claim a rebate from their private health fund unless they are in hospital during this treatment.

The costs associated with PBS drugs may include script fees for breast cancer drugs and associated treatments such as anti-nausea and neutropenia medications.

The initial diagnosis of secondary breast cancer combined with treatment was so overwhelming; I couldn’t really take in, let alone make decisions about financial and some practical matters. Since my diagnosis, I have told everyone I know to make sure they have appropriate insurance and that they understand exactly how it works.

Women in the private health system reported higher out-of-pocket costs for surgery than women in the public health system. On average women in the private system reported total out-of-pocket costs for surgery of more than $3,700, with women in the public system reporting just over $900 for surgery.

Women in the private system also reported higher total out-of-pocket costs associated with radiotherapy treatment (just over $2,700 compared to around $1,500 for women in the public system), and scans (approximately $1,800 compared to $922 for women in the public system).

Physiotherapy, dentist, nutritionist/naturopath and lymphoedema laser treatment are financially draining as well as time consuming. These are all due to the side effects of cancer and its treatment.
Other out-of-pocket costs identified by respondents included:

- travelling for treatment, including petrol, flights, accommodation and parking
- associated treatment and care, including dental work, hospital admissions for infections, second opinion appointments, lymphoedema treatments and psychological support
- complementary and alternative treatments, including vitamins, massage, naturopathy and Chinese medicine
- practical assistance such as employing home help.

Travelling to hospital every day for treatment is incurring high petrol and parking expenses. Buying painkillers and other medication puts a big strain on our pension.

I need to employ a cleaner and gardener, and pay for cost of scans, MRIs, parking fees and specialist fees that bear no relationship to Medicare schedule fees.

**Employment**

Two hundred and forty-six women (42%) indicated they had been working full-time before being diagnosed with secondary breast cancer. Following their diagnosis, just 60 (10%) of women were working full-time (Table 5). Forty-eight of these were aged 40 to 59 years.

Thirty-two per cent (185) of respondents indicated they were retired and 16% (95) reported working part-time. Eight per cent of women (46) reported being on sick leave.

Thirty-one per cent (182) reported a change in their working role for the worse.

When asked about discrimination in the workplace, 6% (33) reported instances of workplace discrimination related to their secondary breast cancer diagnosis.

**Table 5: Working arrangements by age category**

<table>
<thead>
<tr>
<th>Age</th>
<th>Working full time</th>
<th>Working part-time</th>
<th>Not employed/taking time off</th>
<th>Home duties</th>
<th>Retired</th>
<th>Studying</th>
<th>Sick leave</th>
<th>Other</th>
<th>Not specified</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 30</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>30–39</td>
<td>2</td>
<td>3</td>
<td>5</td>
<td>3</td>
<td>4</td>
<td>3</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>40–49</td>
<td>17</td>
<td>22</td>
<td>19</td>
<td>22</td>
<td>6</td>
<td>3</td>
<td>19</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>50–59</td>
<td>31</td>
<td>55</td>
<td>36</td>
<td>30</td>
<td>38</td>
<td>1</td>
<td>18</td>
<td>26</td>
<td>4</td>
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<tr>
<td>60–69</td>
<td>6</td>
<td>12</td>
<td>8</td>
<td>6</td>
<td>97</td>
<td>1</td>
<td>4</td>
<td>10</td>
<td>2</td>
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<tr>
<td>70–79</td>
<td>1</td>
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<td></td>
<td>33</td>
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<td></td>
<td>1</td>
</tr>
<tr>
<td>80+</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>6</td>
</tr>
<tr>
<td>Unknown age</td>
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<td>1</td>
<td>5</td>
<td>1</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Values in table indicate the number of women in each column
Women described examples of discrimination.

I was not given my usual duties on return, and am not given or considered for more ‘responsible/important’ tasks anymore. I am used to ‘fill up the gaps’ instead of my usual work.

I feel that attitudes toward my ability to do my job have changed and I miss out on certain opportunities.

My last employer told me early on in my job of five years that if he had known about my health issues earlier, he would not have given me the job.

I was bullied and harassed about my health situation, despite my oncologist clearing me as ‘fit to work’. I was treated differently to my colleagues, and having privileges withdrawn and working under different conditions that disadvantaged me. My employer called me a ‘liability’ and a ‘risk’ and did everything in their power so that I would resign.

Superannuation

Superannuation refers to the arrangements that people in Australia make to have funds available for them in retirement. Superannuation is supported by the federal government, and employers are required to pay a proportion of an employee’s salaries and wages (9.5% in 2015) into a superannuation fund. Employees are encouraged to supplement their superannuation.

Some women with secondary breast cancer need access to their superannuation before they reach retirement age.

Women with secondary breast cancer are eligible to claim their lump sum superannuation early, these all incur tax. The terminal illness provision is the only tax-free option. Until 1 July 2015, two doctors, including one specialist, needed to certify that a woman is likely to die within 12 months in order to meet the terminal illness provision requirement. From 1 July 2015, after lobbying from consumer organisations including BCNA, the 12-month requirement in the superannuation legislation was extended to two years.

Women were asked about accessing superannuation since being diagnosed with secondary breast cancer. In total, 170 women (29%) indicated that they had not been able to access their superannuation. When asked why not, 159 women (27%) responded with free text information.

The most common reasons women gave for being unable to access their superannuation were related to the terminology around the number of months they were expected to live and the complexity of paperwork required.

Even though I now have a limited life span, I am not expected to die within 12 months and am therefore not eligible. Shame they don’t take into account how all the medical bills set us back. I am not going to reach retirement age anyway. Releasing my super early would take an enormous amount of financial pressure and stress off our family.

I’m not considered terminal i.e. 12 months to live. My oncologist thinks I have between 33 to 55 months. I feel I could live another 20 years.

I am in the process of gaining super … a lot of time and paperwork … and uncertainty.
Some women who were able to meet the 12-month prognosis criteria were distressed at having to wait three months before receiving any funds once their paperwork had been accepted.

I am still filling in the paperwork required by the insurer. I thought I had filled in all the required information but they wanted more. There is a ninety-day waiting period also.

A number of women also discussed encountering difficulties when dealing with their superannuation fund. These included being sent incorrect forms or not receiving clear information about entitlements. Others discussed being unsure about entitlements associated with their superannuation policies, including Total and Permanent Disability (TPD) benefit and Income Protection (IP) benefits.

Not sure how to go about this ... I have called the Super people and, as I am not wanting to cease work immediately and have more than 12 months to live, no one seems to know what I can access.

I have been trying to work out how [to access my superannuation]. I have called the Super fund people, and they keep sending the wrong forms.

Still waiting after two months for a decision to be made.

Some women also discussed confusion around the financial implications of accessing their superannuation.

Even though I could access my super, I had to pay half in tax because I was four months shy of 55 when I cashed it in.

I was not allowed [to access my super] under my super company’s rules. I had to sell a property, then paid capital gains tax of $35,000. There was no flexibility, no compassion. It’s heart breaking.

A number of women appeared to be unaware of their rights around access to their superannuation under the terminal illness provision.

Nobody told me that I could access this.

While some women were advised about accessing funds through other provisions, including compassionate ground provisions, they did not receive adequate explanations around the various eligibility criteria by their funders.

I rang my company and they told me I couldn’t access it unless I was retired or with financial difficulty. I thought you could access your super once you turned 55. I want to have access to it though so we don’t struggle with our bills.

I have asked to access some of my superannuation under terms of hardship. The company now wants Total and Permanent Disability ... it’s an ongoing process.
Specialist healthcare professionals

Almost two-thirds of women (60%, 350) nominated their medical oncologist as the main point of contact to help manage their care since their diagnosis of secondary breast cancer.

Women who did not nominate their oncologist as the main point of contact predominantly identified general practitioners (GPs) (8%; 38) and chemotherapy nurses (6.5%; 38).

*My GP and I head up the team called ‘keep me alive’ and we have achieved that so far.*

Three per cent of women (15) reported coordinating their own care.

*I have coordinated some of my own care, that is, I have found out on my own and followed through.*

Extremely difficult to select ‘only one’ when all my treatments have been a superb team effort. Basically, I am coordinating my own care by way of regular reviews (and scans when required) by consulting with my neurosurgeon for my secondary breast cancer mets, along with having a mammogram and ultrasound organised in conjunction with my breast surgeon review, annually.

When discussing the healthcare professionals they would like to see more often:

- 79 women (13.6%) wanted to see a breast care nurse more frequently
- 55 women (9.4%) wanted to see their medical oncologist more frequently
- 42 women (7.2%) wanted to see a physiotherapist more frequently
- 28 women (4.8%) wanted to see a psychologist more frequently

When asked about the healthcare professionals they had not seen, but would like to see:

- 123 women (21%) indicated they wanted to see a cancer care coordinator
- 119 women (20.4%) indicated they wanted to see a complementary therapy practitioner
- 117 women (20%) indicated they wanted to see an exercise physiologist
- 105 women (18%) indicated they wanted to see a dietitian.
Table 6: Contact with healthcare practitioners

<table>
<thead>
<tr>
<th>Healthcare Practitioner</th>
<th>Happy with amount of contact</th>
<th>Want to see more</th>
<th>Have not seen but want to</th>
<th>Not interested or did not need to</th>
<th>Did not answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical oncologist</td>
<td>433</td>
<td>55</td>
<td>2</td>
<td>107</td>
<td>92</td>
</tr>
<tr>
<td>Surgeon</td>
<td>273</td>
<td>24</td>
<td>16</td>
<td>107</td>
<td>162</td>
</tr>
<tr>
<td>Radiation oncologist</td>
<td>295</td>
<td>24</td>
<td>11</td>
<td>89</td>
<td>163</td>
</tr>
<tr>
<td>Breast care nurse</td>
<td>215</td>
<td>79</td>
<td>68</td>
<td>67</td>
<td>153</td>
</tr>
<tr>
<td>Cancer care coordinator</td>
<td>92</td>
<td>21</td>
<td>123</td>
<td>128</td>
<td>218</td>
</tr>
<tr>
<td>Chemotherapy/Oncology nurse</td>
<td>348</td>
<td>17</td>
<td>12</td>
<td>61</td>
<td>144</td>
</tr>
<tr>
<td>General practitioner (GP)</td>
<td>406</td>
<td>31</td>
<td>6</td>
<td>26</td>
<td>113</td>
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<td>Physiotherapist</td>
<td>104</td>
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<tr>
<td>Exercise physiologist</td>
<td>30</td>
<td>13</td>
<td>117</td>
<td>189</td>
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<tr>
<td>Psychologist</td>
<td>111</td>
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<td>173</td>
<td>206</td>
</tr>
<tr>
<td>Dietitian</td>
<td>65</td>
<td>20</td>
<td>105</td>
<td>177</td>
<td>215</td>
</tr>
<tr>
<td>Palliative care physician or specialist nurse</td>
<td>73</td>
<td>14</td>
<td>60</td>
<td>212</td>
<td>223</td>
</tr>
</tbody>
</table>

* Values in table indicate the number of women in each column
Breast care nurses

Two hundred and sixty women (44.6%) reported having seen a breast care nurse since being diagnosed with secondary breast cancer (Table 7). Two hundred women (34%) indicated that they had not, 29 (5%) were unsure and 93 women (16%) did not answer the question.

Of the 260 women who had seen a breast care nurse since being diagnosed, 145 (55.7%) were treated in the public system, 114 women (44%) were treated in the private system and one woman did not specify.

Table 7: Women who had contact with a breast care nurse

<table>
<thead>
<tr>
<th>Healthcare system</th>
<th>n.</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public</td>
<td>145</td>
<td>55.7%</td>
</tr>
<tr>
<td>Private</td>
<td>114</td>
<td>44%</td>
</tr>
<tr>
<td>Unknown</td>
<td>1</td>
<td>0.3%</td>
</tr>
</tbody>
</table>

Of the 260 women who had seen a breast care nurse since being diagnosed with secondary breast cancer, 30% (77) had seen a breast care nurse ‘very rarely - about once every six months or less’ (Table 8).

Table 8: Frequency of contact with a breast care nurse (n=260)

<table>
<thead>
<tr>
<th></th>
<th>n.</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Once only</td>
<td>77</td>
<td>30%</td>
</tr>
<tr>
<td>Very rarely - about once every six months or less</td>
<td>59</td>
<td>22.6%</td>
</tr>
<tr>
<td>Once every 2-4 months</td>
<td>47</td>
<td>18%</td>
</tr>
<tr>
<td>About once a month</td>
<td>39</td>
<td>15%</td>
</tr>
<tr>
<td>2-3 times per month</td>
<td>22</td>
<td>8.4%</td>
</tr>
<tr>
<td>More than 3 times per month</td>
<td>16</td>
<td>6%</td>
</tr>
</tbody>
</table>

Of the women who were seeing a breast care nurse two or more times per month, 100% were ‘very satisfied’ or ‘fairly satisfied’ with the amount of contact. Reports of dissatisfaction lessened according to the amount of contact women had with their breast care nurse (Figure 9).

Figure 9: Satisfaction with amount of breast care nurse contact

![Satisfaction with amount of breast care nurse contact](image)

Of the 254 women who responded to the question regarding how satisfied they were with the quality of care they received from their breast care nurse, the majority of women were either ‘very satisfied’ (61%; 155) or fairly satisfied (20%; 75) (Table 9).

Table 9: Satisfaction with quality of care received from breast care nurse (n=254)

<table>
<thead>
<tr>
<th></th>
<th>n.</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very satisfied</td>
<td>155</td>
<td>61.0%</td>
</tr>
<tr>
<td>Fairly satisfied</td>
<td>75</td>
<td>29.5%</td>
</tr>
<tr>
<td>Fairly dissatisfied</td>
<td>15</td>
<td>5.9%</td>
</tr>
<tr>
<td>Very dissatisfied</td>
<td>9</td>
<td>3.5%</td>
</tr>
</tbody>
</table>

Less than 50% of women reported seeing a breast care nurse since their diagnosis of secondary breast cancer.
A total of 485 women responded to a question about whether they had contact with a breast care nurse during their early breast cancer experience. Of these women, 252 (52%) indicated that they had, 26% (128) said they had not, and 22% (105) reported that they had not as secondary breast cancer was their first breast cancer diagnosis (Table 10).

Table 10: Proportion of women who saw a breast care nurse during their early breast cancer experience (n=485)

<table>
<thead>
<tr>
<th></th>
<th>n.</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>252</td>
<td>52%</td>
</tr>
<tr>
<td>No</td>
<td>128</td>
<td>26%</td>
</tr>
<tr>
<td>No, secondary breast cancer is my first diagnosis</td>
<td>105</td>
<td>22%</td>
</tr>
</tbody>
</table>

When asked whether their experience of contact with a breast care nurse for their early breast cancer was different from their secondary breast cancer, 37 women said they were happy with the support they had received in both instances.

Same level of extraordinary support.

It was an easy continuation of the relationship. By this stage, I knew them all at my hospital quite well and they provide an excellent support resource.

Several women discussed receiving more specific assistance and support following their secondary breast cancer diagnosis.

More relevant information and care is provided instead of just general information.

The breast care nurse provided more information regarding support groups for women with secondary cancer. Other than that, the treatment is the same – friendly, helpful and comforting.

However, a number of women noted that they did not see their breast care nurse as frequently and discussed a desire for greater support.

I felt abandoned after my diagnosis of secondary breast cancer. All supportive care from the hospital ceased and no helpful advice was available.

Visits became less frequent, she suggested I see a psychologist and I think they became her replacement in a way.

I didn’t see her as it was a different process and I was diagnosed in a different setting. I have seen her in passing when going to oncology but we actually haven’t talked yet. This is after 18 months of various treatments.

Women appeared to be more likely to receive enough information about their treatment if they had seen a breast care nurse. Eighty per cent of women (208) who had seen a breast care nurse reported that they had received enough information generally about treatment, while 71% of women (142) who had not seen a breast care nurse reported that they had received enough information generally about treatment.
General practitioners (GPs)

Seventy-seven per cent of respondents (446) reported having one particular doctor they considered their GP. Fifty-seven per cent of those women (256) had seen this GP for over five years.

Women reported a high level of trust in the clinical judgement and knowledge of their GP. Of the 444 women who responded to the question, 72% (318) with a regular GP ‘agreed’ or ‘strongly agreed’ with the statement ‘I trust my GP’s judgement in helping me to manage my cancer care’. Women also rated highly their GP’s level of knowledge about their worries and concerns. Seventy per cent (310) of the 441 women who responded to the question rated their GP’s knowledge about what worries them most about their secondary breast cancer as ‘excellent’, ‘very good’ or ‘good’.

When asked about the accessibility of their GP when they need help with their secondary breast cancer, 78% of women (343) who responded to the question said that their GP was accessible ‘always’, ‘almost always’ or ‘a lot of the time’ (see Figure 10).

Figure 10: Is your GP easily accessible when you need help with your secondary breast cancer? (n=441)

Eighty-six per cent (409) of women reported having a medical visit with their GP in the previous three months, 57% (274) less than one month ago. This suggests that women with secondary breast cancer have regular and ongoing contact with their GP.

Twenty-three per cent (131) of the total number of survey respondents reported having a GP Management Plan. A GP Management Plan that incorporates a Team Care Arrangement provides up to five Medicare-subsidised visits to relevant allied health professionals per year.

Fifteen per cent (90) of the total number of respondents reported having a GP Mental Health Care Plan, which provides up to 10 Medicare-subsidised visits to a mental health professional such as a psychologist or counsellor.

Information needs

Eighteen per cent of women (102) reported that they had not received enough information about their treatment.

Women were specifically asked whether they required information about a range of practical issues, including Centrelink, employment, financial assistance, home help and transport to appointments. Table 11 outlines women’s practical information needs according to their age.
Table 11: Practical information needs by age category

<table>
<thead>
<tr>
<th>Age</th>
<th>Centrelink</th>
<th>Employment</th>
<th>Financial assistance</th>
<th>Transport to appointments</th>
<th>Home help</th>
<th>Shopping/preparing meals</th>
<th>Child Care</th>
<th>Early Access to Super</th>
<th>Help for family/friends</th>
</tr>
</thead>
<tbody>
<tr>
<td>30–39 (21)</td>
<td>14</td>
<td>7</td>
<td>14</td>
<td>7</td>
<td>11</td>
<td>10</td>
<td>9</td>
<td>13</td>
<td>11</td>
</tr>
<tr>
<td>40–49 (116)</td>
<td>47</td>
<td>38</td>
<td>41</td>
<td>36</td>
<td>45</td>
<td>46</td>
<td>26</td>
<td>42</td>
<td>55</td>
</tr>
<tr>
<td>50–59 (239)</td>
<td>80</td>
<td>46</td>
<td>63</td>
<td>69</td>
<td>65</td>
<td>58</td>
<td>6</td>
<td>74</td>
<td>65</td>
</tr>
<tr>
<td>60–69 (146)</td>
<td>56</td>
<td>11</td>
<td>21</td>
<td>36</td>
<td>36</td>
<td>20</td>
<td>0</td>
<td>23</td>
<td>31</td>
</tr>
<tr>
<td>70–79 (37)</td>
<td>12</td>
<td>1</td>
<td>5</td>
<td>7</td>
<td>7</td>
<td>5</td>
<td>0</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>80+ (2)</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

* Values in table indicate the number of women in each column
** Values in parentheses indicate total number of women in each age category

As outlined in Table 12, the top three information needs for women differed somewhat according to age.

Table 12: Practical information needs by age category

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>Top three unmet needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>30–39</td>
<td>Centrelink, financial assistance, early access to superannuation</td>
</tr>
<tr>
<td>40–49</td>
<td>Help for family/friends, Centrelink, shopping or preparing meals</td>
</tr>
<tr>
<td>50–59</td>
<td>Centrelink, early access to superannuation, transport to appointments</td>
</tr>
<tr>
<td>60–69</td>
<td>Centrelink, transport to appointments, home help</td>
</tr>
<tr>
<td>70–79</td>
<td>Centrelink, transport to appointments, home help</td>
</tr>
</tbody>
</table>

Women were asked whether they had received enough information about these practical issues. In total, just over one fifth (21%; 123) of the total number of respondents ranked ‘financial assistance’ as a topic about which they had either not received any or enough information. Twenty per cent (114) of respondents said they have not received any or enough information about Centrelink (the Australian Government agency responsible for delivering support services to Australians on a low or no income). Eighteen per cent (107) indicated they had not received any or enough information about available help in their home, and 17% of women (99) wanted more information about how to access superannuation early (Table 14).

As outlined in Table 15, when asked about the most helpful sources of information, respondents nominated the following five sources:

1. Internet – breast cancer / cancer organisations (BCNA, BreaCan, Cancer Australia), including online newsletters (68%; 397)
2. Printed information (68%; 396)
3. BCNA’s Hope & Hurdles (66%; 383)
4. Internet – general information about secondary breast cancer (65%; 381)
5. Family members or friends (57%; 333)
### Table 14: Practical information needs of respondents

<table>
<thead>
<tr>
<th>Information need</th>
<th>Did not receive information, but needed it</th>
<th>Received information, but not enough</th>
<th>TOTAL (Not enough information)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Centrelink</td>
<td>68 (12%)</td>
<td>46 (8%)</td>
<td>114 (20%)</td>
</tr>
<tr>
<td>Employment</td>
<td>53 (9%)</td>
<td>39 (7%)</td>
<td>92 (16%)</td>
</tr>
<tr>
<td>Financial assistance</td>
<td>66 (11%)</td>
<td>57 (10%)</td>
<td>123 (21%)</td>
</tr>
<tr>
<td>Home help</td>
<td>75 (13%)</td>
<td>32 (5%)</td>
<td>107 (18%)</td>
</tr>
<tr>
<td>Early access to super</td>
<td>64 (11%)</td>
<td>35 (6%)</td>
<td>99 (17%)</td>
</tr>
<tr>
<td>Help for family/friends</td>
<td>50 (9%)</td>
<td>41 (7%)</td>
<td>91 (16%)</td>
</tr>
<tr>
<td>Transport</td>
<td>59 (10%)</td>
<td>30 (5%)</td>
<td>89 (15%)</td>
</tr>
<tr>
<td>Shopping/preparing meals</td>
<td>55 (9%)</td>
<td>27 (5%)</td>
<td>82 (14%)</td>
</tr>
<tr>
<td>Child Care</td>
<td>51 (9%)</td>
<td>12 (2%)</td>
<td>63 (11%)</td>
</tr>
</tbody>
</table>

### Table 15: Sources of information and support for women with secondary breast cancer

<table>
<thead>
<tr>
<th>Source</th>
<th>Helpful</th>
<th>Unhelpful</th>
<th>Didn't need it</th>
<th>Didn't know about it</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer Council Helpline</td>
<td>157</td>
<td>38</td>
<td>198</td>
<td>29</td>
</tr>
<tr>
<td>Printed information</td>
<td>396</td>
<td>25</td>
<td>27</td>
<td>7</td>
</tr>
<tr>
<td>BCNA's <em>Hope &amp; Hurdles</em></td>
<td>383</td>
<td>29</td>
<td>32</td>
<td>35</td>
</tr>
<tr>
<td>Internet – general information about secondary breast cancer</td>
<td>381</td>
<td>42</td>
<td>44</td>
<td>9</td>
</tr>
<tr>
<td>Internet – breast cancer / cancer organisations (BCNA, BreaCan, Cancer Australia), including online newsletters</td>
<td>397</td>
<td>17</td>
<td>34</td>
<td>16</td>
</tr>
<tr>
<td>BCNA’s online network</td>
<td>242</td>
<td>34</td>
<td>116</td>
<td>33</td>
</tr>
<tr>
<td>Support groups</td>
<td>193</td>
<td>34</td>
<td>154</td>
<td>39</td>
</tr>
<tr>
<td>Information forum / session</td>
<td>176</td>
<td>16</td>
<td>120</td>
<td>75</td>
</tr>
<tr>
<td>Family members or friends</td>
<td>333</td>
<td>20</td>
<td>56</td>
<td>13</td>
</tr>
<tr>
<td>TV / radio talk shows</td>
<td>98</td>
<td>19</td>
<td>178</td>
<td>57</td>
</tr>
<tr>
<td>Magazine columns</td>
<td>91</td>
<td>26</td>
<td>183</td>
<td>54</td>
</tr>
</tbody>
</table>

* Values in table indicate the number of women in each column.
When asked specifically about whether they had received *Hope & Hurdles*, BCNA’s free information pack for women diagnosed with secondary breast cancer, 435 women (74.7%) indicated that they had (Table 16).

**Table 16: BCNA’s information resource *Hope & Hurdles***

<table>
<thead>
<tr>
<th></th>
<th>n.</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Women who received</td>
<td>435</td>
<td>74.7%</td>
</tr>
<tr>
<td><em>Hope &amp; Hurdles</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Women who did not receive</td>
<td>69</td>
<td>11.9%</td>
</tr>
<tr>
<td><em>Hope &amp; Hurdles</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td>78</td>
<td>13.4%</td>
</tr>
</tbody>
</table>

Of the 428 women who responded to the question regarding when they had received *Hope & Hurdles*, half of the women (50%; 214) indicated that they had received it within one month of their diagnosis (Table 17).

**Table 17: Length of time between diagnosis of secondary breast cancer and receipt of *Hope & Hurdles* (n=428)**

<table>
<thead>
<tr>
<th>Length of time</th>
<th>n.</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Within a month of diagnosis</td>
<td>214</td>
<td>50%</td>
</tr>
<tr>
<td>Within six months of diagnosis</td>
<td>98</td>
<td>23%</td>
</tr>
<tr>
<td>6–12 months after diagnosis</td>
<td>31</td>
<td>7.2%</td>
</tr>
<tr>
<td>More than a year after diagnosis</td>
<td>36</td>
<td>8.4%</td>
</tr>
<tr>
<td>I don’t remember</td>
<td>49</td>
<td>11.4%</td>
</tr>
</tbody>
</table>

When asked when would have been most useful time to have received *Hope & Hurdles*, more than two thirds of the respondents (68.6%; 293) said within one month of diagnosis (Figure 11).

**Figure 11: When would have been the most useful time to receive *Hope & Hurdles*? (n=427)**

Survey respondents described a range of strategies they used to help keep themselves well. Many of the women discussed exercise, socialising with family and friends, and participating in pleasurable hobbies and activities as key strategies.

**Exercise, laughter, good friends and my family. Gardening and my beautiful dog.**

**Exercise, food, hobbies, friends – maintaining normal. More shared experiences with my partner and our daughter e.g. theatre, long weekends, breakfast dates, etc.**

A number of women mentioned meditation, massage, activities such as yoga or Pilates, and reducing overall stress in their lives. Women commonly described trying to maintain a positive outlook.

**Look good, feel good, smile as much as you can. Try Pilates, Tai Chi/Meditation and remove people from your life who are negative.**
Yoga, Pilates, meditation (though a little lapsed for now), try to eat well, be positive.

Sleep and eating well were also commonly mentioned.

I ensure that I don’t become overtired by a power nap of 10-15 mins each day. Otherwise, I continue to eat and exercise sensibly.

When asked specifically about exercise, 341 women (59%) indicated that exercise was an important part of their self-care. One hundred and thirty one women (22.5%) said that exercise was not an important part of their self-care and 110 women (19%) did not answer the question.

When asked how often they exercised at a moderate intensity, 175 women (30%) reported that they exercised between two and three times per week. Sixteen per cent of women (96) exercised daily, 8.7% (51) exercised once per week, and 14% (82) less than once a week. One hundred and seventy eight women (30.5%) did not answer the question.

When describing the role exercise played in their self-care, 43.6% (254) said it made them feel better and 43% (252) said it helped with their emotional wellbeing (Figure 12). Just over one-fifth (21.6%; 126) said exercise helped them to manage side effects of treatment.

Figure 12: Why exercise is/is not an important part of self-care

<table>
<thead>
<tr>
<th>Emotional support</th>
</tr>
</thead>
<tbody>
<tr>
<td>In total, 29% of women (169) indicated they were not receiving enough emotional support from their treating team.</td>
</tr>
<tr>
<td>When asked if there was any other type of emotional support that would have been helpful, including from family and friends, 230 women provided additional information. Out of the 230 responses, ‘family’ was mentioned 87 times (38%), ‘friends’ 59 times (26%), ‘husband’ 21 times (9%), and ‘support group’ eight times (3%).</td>
</tr>
</tbody>
</table>

More understanding from my partner, family and friends.

Friends tend to stay away now that I am quite unwell. They say that they don’t want to bother us. It’s such a lonely path to tread.

Emotional support from friends and work colleagues diminishes after chemotherapy. One is then reliant mainly on family. My husband has been my rock through all. I am also finding the BCNA online network – Living with Advanced Breast Cancer Group – a good source of camaraderie and support.

A number of women discussed difficulties experienced by family and friends in understanding or coming to terms with a diagnosis of secondary breast cancer and indicated that more emotional support for their family would have been useful.

Family and friends find it extremely hard to understand the concept of Stage 4 cancer, being incurable and meaning that you have to be on treatment for the rest of your life. If you are on a treatment with no visible side effects, e.g. hormonal treatment or Xeloda, even the most intelligent and loving friends and family members don’t really remember that you have cancer.

More emotional support for my children.
Some women also mentioned types of health professionals who had provided emotional support, or health professionals they would have liked to have seen.

The psychologist who spoke at the BCNA community forum was excellent. The opportunity to hear more from someone like her would be beneficial.

It has been my experience that family and friends are less able to provide emotional support when they simply want you to be well and able to cope. They often lack the skill to be objective enough with their own feelings.

More access to phone support e.g. 24 hrs cancer helpline or longer hours and weekends.

Unmet supportive care needs

A total of 474 women answered questions about their supportive care needs.

The highest unmet needs were:

1. Fears about the cancer spreading further (68%; 317)
2. Lack of energy / tiredness (67%; 315)
3. Uncertainty about the future (57%; 261)

Of the 317 women who reported needing help with fear about the cancer spreading further, 43% (136) wanted help from their medical oncologist. Whilst fear of cancer spreading further is classified as a ‘psychosocial’ need, our results reflect the fact that this unmet need may also be an ‘information’ need.

Other strategies women identified to help them meet needs around fear of cancer spreading further included self-care strategies and contact with other women with secondary breast cancer, highlighting the importance of peer support (Figure 13).

Although I stay as positive as possible, there is always the horrible doubt of ‘what if’ and ‘when’.

Of the 315 women who reported a need for help with lack of energy / tiredness, 47% (144) wanted strategies for self-care (Figure 14). Women also indicated that help from an exercise physiologist would be useful.

Have help from family to run household when necessary. Some strategies to get more energy, but I am on chemo tablets which doesn’t help.

Figure 13: Strategies for help with fears about the cancer spreading further

<table>
<thead>
<tr>
<th>No. of women</th>
</tr>
</thead>
<tbody>
<tr>
<td>Help from a medical oncologist</td>
</tr>
<tr>
<td>Strategies for self-care</td>
</tr>
<tr>
<td>Contact with other women with SBC</td>
</tr>
<tr>
<td>Help from a counsellor/psychologist</td>
</tr>
<tr>
<td>Help from a BCN or oncology nurse</td>
</tr>
<tr>
<td>Help from a GP</td>
</tr>
<tr>
<td>I don’t need additional help</td>
</tr>
<tr>
<td>Other</td>
</tr>
</tbody>
</table>

Figure 14: Strategies for help with lack of energy / tiredness
Strategies for self-care

Of the 261 women who reported needing help with uncertainty about the future, 42% (107) wanted strategies for self-care and 41% (105) wanted help from a counsellor or psychologist. (Figure 15).

You know, this is just an ongoing issue. I try to focus on the moment as much as possible. I was a great planner but now I don’t do too much of it. Thinking about a future for my children without me is just too distressing. I give a prayer of thanks each birthday that they are a little older and more independent.

Unmet needs by age group

The greatest unmet needs were also analysed according to age. Findings from the analysis of unmet needs by age should be interpreted with caution due to small numbers in some of the age bands.

Four women who provided information about their unmet supportive care needs did not specify their year of birth. Not every woman responded to every question.

30–39 (n=12)
- Lack of energy / tiredness (92%; 11)
- Fears about the cancer spreading further (83%; 10)
- Uncertainty about the future (83%; 10)

40–49 (n=85)
- Uncertainty about the future (80%; 68)
- Lack of energy / tiredness (76%; 65)
- Fears about the cancer spreading further (76%; 65)

50–59 (n=191)
- Lack of energy / tiredness (64%; 122)
- Fears about the cancer spreading further (63%; 120)
• Concerns about the worries of those close to you (53%; 100)
• Having access to professional counselling (e.g. psychologist, social worker, counsellor, nurse specialist) if you, family or friends need it (53%; 100)

60–69 (n=136)
• Fears about the cancer spreading further (66%; 90)
• Lack of energy / tiredness (63%; 85)
• Not being able to do the things you used to do (49%; 66)

70+ (n=46)
• Lack of energy / tiredness (65%; 30)
• Work around the home (54%; 25)
• Fears about the cancer spreading further (63%; 29)

The unmet needs were similar in all age groups, including those relating to lack of energy/tiredness, and fear about the cancer spreading. However, women with financially dependent children reported significantly more unmet needs in all domains assessed. Women aged 60 to 69 and women aged 70 and above, reported higher unmet practical needs including not being able to do things they used to do and coping with work around the home.

Unmet needs related to sexual wellbeing

Over one quarter of women (30%; 138) indicated they had experienced changes in their sexual feelings and almost one quarter of women (24%; 113) reported changes in their sexual relationships since being diagnosed with secondary breast cancer.

Of the 138 women who indicated what type of help they would like to address changes in sexual feelings, 38% (51) wanted self-care strategies and 38% (50) wanted help from a relationship counsellor (Figure 16). Of the 113 women who indicated what type of help they would like to address changes in their sexual relationships, 46% (52) wanted help from a relationship counsellor and 43% (48) wanted strategies for self-care (Figure 17).

The highest unmet needs related to sexual wellbeing were reported in women aged 30 to 50 years.

Figure 16: Strategies to help with changes in sexual feelings

* Women could select more than one strategy

Figure 17: Strategies to help with changes in sexual relationships

* Women could select more than one strategy
**Greatest challenge following a diagnosis of secondary breast cancer**

When asked about the greatest challenge women had faced since their diagnosis of secondary breast cancer, 75% (437) of women discussed one or more serious challenges.

Some women discussed practical challenges, such as difficulties around employment and finances.

*Not being able to go back to work after treatment. Out-of-pocket expenses and no government assistance for private working patients.*

*Remaining in paid employment. I am the main income earner and have been unable to fulfil my roster obligations due to surgery, treatment, etc.*

*Financial – the cost of treatment meant I used all my life savings ... this is tough and has resulted in uncertainty ... Am I going to have enough money to see me out? How does all of this affect my standard of living and therefore my relationships with family and friends?*

Many others spoke about their fears for the future, having to come to terms with having an incurable disease, and anxiety around not knowing what may happen to themselves and their families.

*Coping emotionally with the diagnosis and the treatment ... and the constant thoughts of dying from this disease ... and not knowing how much longer I have to live ... unable to feel I can plan for the future.*

Dealing with the shock, uncertainty, initial fear, and bringing my life back into some sort of normality. Deciding that for as long as I can I will live life to the fullest and continue to do the things I had planned to do prior to diagnosis.

Other women talked about some of the physical challenges of ongoing treatment, including issues with mobility, and having to rely on others for help.

*Acceptance of diagnosis. Uncertain future. Changes in mobility and energy levels. Not being able to do what I used to be able to do. Less independence and more reliance on others.*

Some women also discussed the difficulty of watching other women’s disease progress.

*The biggest challenge I have faced since my diagnosis of secondary breast cancer has been watching other women whose cancer has kept advancing, or come back even up to 20 years later, and ultimately have lost their battle. There have been very many over this time.*

The word cloud on page 26 depicts the words most commonly used by women when discussing the challenges they faced following their diagnosis of secondary breast cancer.
Discussion

This research examined the unmet needs and challenges faced by women living with secondary breast cancer in Australia. The majority of respondents were aged between 50 and 69 years. Women lived in all states and territories in Australia. Forty-one per cent lived in rural, regional or remote Australia.

Only 4% (24) spoke a language other than English at home. This is a limitation of our study. Australia is an increasingly multicultural society. One in four of Australia’s 22 million people are born overseas and more than four million Australians speak a language other than English. Our methodology of only using email format to reach survey participants may have inhibited participation by women from culturally diverse backgrounds.

Twenty-seven per cent of women (155) advised that secondary breast cancer was their presenting diagnosis, which is significantly higher than available Australian data suggests. The demographic findings of our survey indicate the importance of providing information in rural/regional areas as well as metropolitan areas, and ensuring that women who are diagnosed with secondary breast cancer at first diagnosis receive appropriate information for their particular needs. This is particularly important because women whose first diagnosis is secondary breast cancer may not have had the opportunity to learn about breast cancer previously. Depending on their earlier life experiences, these women may have little experience in developing coping skills around a life threatening diagnosis, and fewer skills in navigating the complex health system. The high number of women with a first diagnosis in our study compared to Australian statistics suggests that these women are more likely to seek and require assistance from community support organisations such as BCNA.

Although the majority of respondents (77%; 447) had been diagnosed with secondary breast cancer in the past five years, 11% (71) had been living with secondary breast cancer for more than five years and 7% (39) had been living with secondary breast cancer for 10 years or more. This highlights that long-term survivorship needs must be addressed, in addition to supportive care and palliative care needs for some women.

Women received treatment in both the private (49%; 286) and public health systems (44%; 255). While it is internationally recognised that treatment of secondary breast cancer
should be conducted by a multidisciplinary team, less than half (41%; 116) of women in the private system and just over half of women (56%; 142) in the public system reported being aware that their case had been discussed by a multidisciplinary team. Women who are treated outside a multidisciplinary program may not have the same access to specialised health professionals who could be involved in their care.13 It is unknown from our data whether there is higher incidence of multidisciplinary case discussion than the women reported. It is possible that women are unaware of their case being discussed and of the outcomes of that discussion. There appears to be a need for further investigation into why some Australian women with secondary breast cancer are not aware that their case has been discussed by a multidisciplinary team and why recommendations from team discussions are not always communicated to individual women.

Only 7% of women (38) reported participating in a clinical trial. While in line with Australian statistics which report 6% of people with cancer participating in a clinical trial,14 this statistic is disappointing. Clinical trials can be an important avenue for women with secondary breast cancer to access new treatments or therapies that may benefit them. Future research could explore in greater detail whether women are being offered options around clinical trials, particularly women who are treated outside major cancer centres.

A key finding was the financial difficulties experienced by many women living with secondary breast cancer. Women treated in the public and private health systems reported financial difficulties. Sixty per cent of women (351) reported that their secondary breast cancer had resulted in some financial difficulty in the previous week.

Many women also discussed employment difficulties related to their secondary breast cancer. Almost one third of women (31%; 182) indicated that there had been a change for the worse in their working role since their diagnosis and 6% (33) reported experiencing workplace discrimination. Women discussed experiencing forced changes to their work duties, and loss of promotions and other opportunities due to their diagnosis.

When asked about accessing superannuation since being diagnosed with secondary breast cancer, 170 women (29%) indicated that they had not been able to access their superannuation. The most common barriers women discussed related to terminology around the number of months they were expected to live and the complexity of paperwork required. In July 2015, the Australian Government altered the terminal illness provisions to extend the life expectancy provision from 12 months to two years. While this will deal with some of the issues raised, it is unlikely to address all of the problems raised by women, especially those relating to complex and lengthy paperwork, confusion by staff of superannuation funds about women’s entitlements and the length of time it takes for women to receive their superannuation payout. There is also a need for more detailed information around implications for accessing superannuation, including the impact on life insurance, Total and Permanent Disablement (TDP) benefits and Income Protection (IP) benefits attached to superannuation policies.

The survey highlighted the important role GPs play in providing treatment and care for women living with secondary breast cancer. Seventy per cent (446) of respondents indicated they had one particular doctor who they consider their GP and 57% of those women (256) have been seeing this GP for over five years, indicating that around half of the respondents have lasting relationships with individual GPs. The majority of survey respondents values the role of their GP and trusts his or her judgment and clinical advice when it comes to their secondary breast cancer.

Women also indicated wanting to see a range of other healthcare practitioners, including cancer care coordinators, occupational therapists, complementary therapy practitioners, exercise physiologists and dietitians. It is disappointing
to note that more than three quarters of women do not have a current GP Management Plan that may assist in providing them with access to these health professionals. GP Management Plans and Team Care Arrangements provide up to five subsidised visits to allied health professionals each year and can play an important part in assisting women to manage not only the ongoing side effects of their treatment and care but their financial challenges as well.

In addition, only 15% of survey participants (90) have a GP Mental Health Care Plan in place. These plans offer up to ten subsidised visits with a mental health professional such as a counsellor, psychologist or specially trained social worker. Whilst not all women may need or want a GP Mental Health Care Plan, some women may not be aware of this option.

An important finding of the survey is the limited contact women are having with specialist breast care nurses. The majority of women who had seen a breast care nurse reported being satisfied with the quality of care they received. The greater the level of contact women had with a breast care nurse, the greater their level of satisfaction. However, it should be noted that more than one third of survey respondents had no access to a breast care nurse and, of the women who had contact with a breast care nurse, more than half had infrequent access.

Thirty per cent of women (77) had seen a breast care nurse only once and 22.6 per cent (59) saw a breast care nurse ‘very rarely’.

Further research into why there are such low levels of contact with breast care nurses for women with secondary breast cancer is required. This may include a work force analysis to establish how breast care nurses are distributing their time amongst patients within their individual practice. Research into whether breast care nurses feel confident dealing with the unmet needs of women with secondary breast cancer is also required so that training programs can address educational requirements.

The provision of relevant and up-to-date information to women following a diagnosis of breast cancer is a high priority for women. It is concerning that 18% of women (102) indicated that they had not received sufficient information regarding their treatment. The survey also found that 21% of women (123) had unmet information needs regarding financial assistance, including information about Centrelink entitlements.

The survey indicated that women find a range of sources of information useful, with more than two-thirds of women (68%; 397) reporting online information from organisations such as BCNA, BreaCan (Victoria) and Cancer Australia to be the most useful source.

Sixty-six per cent of women (383) also found Hope & Hurdles to be useful. However, although 69% (293) of the 427 women who responded to the question said it would be most helpful to receive Hope & Hurdles within one month of being diagnosed with secondary breast cancer, only half of the women who reported receiving Hope & Hurdles (214) had received it within one month.

The survey also explored the emotional and supportive care needs of women with secondary breast cancer. The results of our survey reflect similar findings from other studies, suggesting that women with secondary breast cancer consistently describe unmet needs in psychological and information domains. More than a quarter of women in our study (29%; 169) indicated that they were not receiving sufficient emotional support from their treatment team, and many women discussed wanting to receive more emotional support from family members, friends and health professionals. Women also expressed a desire for more emotional support to be available for their family members to help them cope.

The top unmet supportive care needs for women with secondary breast cancer were: fears about the cancer spreading; lack of energy / tiredness; and uncertainty about the future. Women expressed a consistent desire for more practical
self-care strategies to help manage these needs. Findings suggest there is a particular need to address whether women’s concerns around fear of cancer spreading are best conceptualised as a psychological need or as an information need. Interventions could then be developed that look to address fear of cancer progression in women with secondary breast cancer. This could include psychological interventions that aim to build resilience and enhance coping strategies amongst women and family members. In addition, psychological interventions could be directed towards empowering women and their family members to feel comfortable asking their medical specialists questions related to fear of cancer progression.

The importance of exercise as a strategy for self-care was evidenced by the high number of women who described exercise as something which made them feel better (43.6%; 254) and assisted with their emotional wellbeing (43%; 252). Thirty per cent of women (175) reported that they participated in moderate exercise between two and three times per week. Many women noted that assistance from other healthcare professionals, such as a counsellor or psychologist, would be helpful in helping them to manage unmet emotional needs.

Whilst unmet needs were similar across all age groups, young women aged 30 to 39 reported significantly higher unmet needs across all domains with the largest differences observed in the sexual and psychosocial domains. Women with financially dependent children reported higher unmet needs in all domains assessed. This data is consistent with other studies into the unmet needs of young women with secondary breast cancer and should guide clinical conversations. Similarly, older women reported higher unmet practical needs such as help around the house and should be asked about their practical needs.
Recommendations

BCNA has identified the following recommendations and research priorities to help support women diagnosed with secondary breast cancer and their families.

**Define the number of women living with secondary breast cancer**

Ensure that cancer registries across Australia routinely collect information about stage of disease and time to progression so that more accurate information is available about the numbers of Australians living with secondary breast cancer, in order to inform service planning.

**Address information needs**

Ensure high quality, evidence-based and culturally appropriate information is provided to all women as close as possible to the time of their diagnosis.

Promote current resources available through organisations such as BCNA, Cancer Council and Cancer Australia.

Develop new tailored educational materials for women who present with secondary breast cancer as a first diagnosis, in order to address the additional information and supportive care needs that may arise.

Develop new educational materials to increase women’s knowledge on strategies for self-care, including the importance of exercise, benefit of peer support networks and use of complementary therapies.

Develop educational materials to promote the benefit of GP Management Plans and GP Mental Health Care Plans for women with secondary breast cancer, including how they can assist women to better access allied health and counselling services within their local community.

Ensure that the information needs of women of culturally diverse backgrounds are addressed in future research projects.

**Address supportive care needs**

Develop evidence-based strategies on fear of cancer progression to empower women to develop coping and resilience skills, including adjustment to illness.

Ensure that all members of the multidisciplinary team have a role in the provision of supportive care.

Ensure that supportive care is offered across the continuum of treatment. This should include community-based care, particularly for women who may not be receiving hospital-based treatment.

Increase access to consistent and ongoing support from specialist breast care nurses, who have specific knowledge and skills in managing metastatic disease.

Increase access to a broad range of health care practitioners who can provide emotional and practical support, such as psychologists, counsellors, psychiatrists, and social workers.

Increase referral to counselling services that are accessible and free, such as telephone counselling services.

Ensure health professionals and health services providers of supportive care increase their emphasis on the impact of a secondary breast cancer diagnosis on family, especially for women with financially dependent children.

Foster a greater recognition of survivorship needs, especially for long-term survivors who may be denied access to traditional support programs that focus on absence of disease.
Financial and employment needs

Develop quality of life instruments that specifically address the unmet needs of women with secondary breast cancer, including the impact of financial distress on quality of life outcomes.

Ensure health care professionals and health care services providers offer women informed financial consent around all out of pocket treatment expenses.

Explore in greater detail the out-of-pocket treatment related expenses incurred by women, particularly for treatments that are Medicare funded.

Improve awareness by employers of the rights of women diagnosed with secondary breast cancer and develop strategies to support women in the workplace who require ongoing cancer related treatments.

Multidisciplinary care

Ensure that a multidisciplinary team is involved in treatment recommendations across both the public and private health systems and that women are informed when their case has been discussed, allowing women to participate in all aspects of the decision making process.

Clinical trials

Explore in greater detail the reasons behind low participation rates in clinical trials and whether women with secondary breast cancer are being provided with information about current trials that may be relevant to them. This includes information about clinical trials that are available to women outside their treating centre.

Develop strategies to better promote the Australian Cancer Trials Online database, a lay friendly, searchable database of clinical trials for cancer patients, hosted by Cancer Australia, developed in collaboration with consumers: www.australiancancertrials.gov.au

Superannuation

Develop a government-led taskforce around superannuation to ensure that there is effective and coordinated implementation of the revised regulations, effective from 1/07/2015, that relate to the terminal illness provisions.

Consult with relevant stakeholders, including the superannuation industry, health professionals, financial service providers and the general community, to ensure:

• information provision to those with an incurable illness is consistent and not confused with early release of superannuation under other provisions
• there is significant reduction in complexity of paperwork required
• women are informed about any entitlements around Total and Permanent Disability (TPD) benefit, Income Protection (IP) benefits or life insurance benefits associated with their superannuation policies.

Impact

The recommendations resulting from this survey have the potential to reach a broad audience, including consumers, supporters of women with breast cancer, health professionals, health care service providers, supportive care researchers, government bodies and the general community.

We hope that dissemination of the survey findings will contribute to an ongoing discourse around unmet needs that will translate into future improvements in service design and delivery for all Australians affected by secondary breast cancer.
BCNA thanks the 582 women and men who participated in our survey and shared with us their lived experience of secondary breast cancer.

We acknowledge the health professionals and researchers who assisted in the review of this report:

- Professor Phyllis Butow
- Associate Professor Prue Francis
- Dr Belinda Kiely
- Professor Christobel Saunders
- Associate Professor Andrew Spillane
- Associate Professor Jane Turner

We also thank Professor Sanchia Aranda (Cancer Council Australia) and Dr Karla Gough (Department of Cancer Experiences Research, Peter MacCallum Cancer Centre) for assistance in developing the Supportive Care Needs Survey, and Dr Gough for assistance with analysing responses and interpreting results.

Finally, we acknowledge former BCNA staff members Michelle Marven and Nicca Grant for their contributions to our research.

References

Donate
Make a one-off donation or set up a regular monthly donation.

Give back while you work
Workplace Giving is an easy and convenient way to donate to a BCNA via pre-tax payroll deductions.

Participate in research
Help with breast cancer research by joining BCNA’s Review & Survey Group.

Hold a Pink Lady event
These fundraising events can be anything from a simple afternoon tea to a fancy cocktail party. Contact BCNA with your idea and we’ll help you bring it to life!

Pink up!
Add a touch of pink to your life by shopping online and showing your support for BCNA.

www.bcnashop.org.au

Share your experience
Connect with others on BCNA’s online network or apply to become a Community Liaison in your community.

Sponsor us
We nurture relationships with selected organisations and individuals to help strengthen our network. Contact BCNA to find out how we can work together.

Challenge yourself!
Thinking about a fun run, or taking a trip of a lifetime? We have some great ways you can achieve a personal goal while supporting BCNA.

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