Secondary Breast Cancer Awareness Day 2014

Focus Group Report

Background

Secondary Breast Cancer Awareness Day is internationally recognised on October 13 each year. In previous years, it has been acknowledged in the UK, US and Europe, but not Australia. This year (2014), Breast Cancer Network Australia (BCNA) plans to recognise Secondary Breast Cancer Awareness Day for the first time.

We know from research and feedback from our membership that women living with secondary breast cancer have unique needs and challenges. Sometimes women with secondary breast cancer tell us they feel ‘overlooked’ or ‘invisible’, particularly during October (Breast Cancer Awareness Month).

BCNA wants to ensure that women with secondary breast cancer are acknowledged and supported. In August 2014, we hosted a Focus Group in Melbourne with some of our members living with secondary breast cancer. Eleven women attended, and two more participated in individual telephone interviews. The Focus Group was asked to tell us how they felt BCNA should recognise Secondary Breast Cancer Awareness Day, and support women with secondary breast cancer more broadly. These women kindly shared with us their personal experiences, challenges and ideas. Their contribution is deeply valued by BCNA, and has been used to inform our planning – not only for Secondary Breast Cancer Awareness Day, but for how we can acknowledge, support and represent women with secondary breast cancer into the future.

This report summarises the Focus Group findings, including conversations with the two women who were unable to make the date but spoke to us later on the telephone.

How do women feel about Secondary Breast Cancer Awareness Day?

Most of the participants were aware that Secondary Breast Cancer Awareness Day is recognised overseas, but had little knowledge of what international groups do to mark its significance.

One participant told us that each year she holds her own, private day of acknowledgement on October 13.

All women felt that the general public, including women with early breast cancer, are not aware of Secondary Breast Cancer Awareness Day. Indeed, they feel that secondary breast cancer itself is poorly understood. This was a recurring conversational theme throughout the day, and a source of frustration for some participants.

The group was supportive of BCNA’s plans to recognise Secondary Breast Cancer Awareness day, with positive feedback given on our proposed ‘look and feel’. We have used the imagery and feel of BCNA’s *Hope & Hurdles* information resource to inform the images and colours that
recognise secondary breast cancer and Secondary Breast Cancer Awareness Day. Women felt the colour and pictures used to mark the day were ‘strong and soft at the same time’.

**How do women with secondary breast cancer prefer to be recognised?**

BCNA is often told that secondary breast cancer is now considered a ‘chronic disease’ by many health practitioners. Developments in treatments, diagnosis and care mean that women with secondary disease are living for longer, some for many years after their diagnosis. We wanted to know whether terming secondary breast cancer as a ‘chronic disease’ is acceptable to the women living with the condition.

Although the feedback we received on this matter varied between women, many felt that using the term ‘chronic’ undermined the seriousness of secondary breast cancer.

*I find it dismissive.*

Many women believed that the term ‘chronic disease’ has a number of connotations not relevant to their own experience. For example, one woman believed that the term implies women with the condition are always in pain, and that women will not die from the condition.

‘Chronic illness’ doesn’t cut it. It is too soft. We need to state it as it really is. It is a disease from which people are going to die.

In contrast, other women liked the term, with many noting that the terminology chosen to describe secondary breast cancer must depend on the audience.

*If you want to be active in the workforce, you would never use the term incurable or terminal to describe your situation. However, if you’re applying for early access to superannuation, you have to use the word ‘terminal’.*

Some women said that using the term ‘chronic’ to describe their condition helped to make their diagnosis less scary when they were first diagnosed. A few women said it felt ‘hopeful’.

Women were unanimous in their dislike of the term ‘terminal’ to describe secondary breast cancer, unless it was for a specific administrative purpose such as obtaining access to superannuation. Generally, the term ‘incurable’ was preferred.

There was also some discussion around the preferred name for secondary breast cancer. While BCNA has historically preferred to use ‘secondary breast cancer’ based on previous work and feedback from women, this was an area in which a wide range of views was expressed. Some women preferred ‘metastatic breast cancer’ whereas others liked ‘advanced breast cancer’ or ‘stage four breast cancer’.

*There’s too much confusion with ‘secondary’ or ‘advanced’. Metastatic is very clear.*

**Recommendation:** BCNA believes that terminology to describe secondary breast cancer must be realistic so as not to confuse women, their families, or the public. BCNA notes that many women felt that ‘chronic illness’ was not suitable language to describe secondary breast cancer.
as it does little to convey the seriousness of the condition. However, using the term may be suitable in some circumstances – BCNA notes that some women felt it gave them hope, particularly early on after their diagnosis.

BCNA will continue to use the term ‘currently incurable’ to describe secondary breast cancer. While the term conveys the impact of the diagnosis in a realistic manner, we believe it is important to maintain and cultivate hope for women living with secondary breast cancer. We have seen significant gains in treatments and outcomes for women with secondary breast cancer over recent years, and believe women should feel that we are ‘realistically optimistic’ about the future.

**Do women have access to adequate assistance from GPs, allied health and mental health professionals?**

We found significant variability in the levels of support women reported receiving from their GPs.

*I get the most support from my GP.*

GP Management Plans (which include Chronic Disease Management Plans and Team Care Arrangements) were designed to help Australians living with chronic disease, including women with secondary breast cancer.

GP Management Plans are written plans that identify the individual health care needs of women. For women who require assistance from other health professionals (such as physiotherapists, dieticians, or exercise physiologist), the GP can coordinate this through a Team Care Arrangement. This entitles the woman to Medicare rebates for up to five visits per year to the health practitioners she needs.

A minority of women had been offered a GP Management plan. One woman had heard about the plan through a friend, and asked her GP specifically for one to be written for her. A few women spoke extremely highly of their GP and their relationship with him or her, whereas others felt that their GP was only interested in treating them if he/she was able to write a prescription.

Most women had not heard of GP Management Plans, and were interested in hearing more about them. Those women who had been referred for a plan spoke highly of their experience.

*I had a GP Management Plan for about six months when I needed physiotherapy and was doing Pilates. I used up my private health entitlements, and then had the GP Management Plan to see me through to the end of the year. I haven’t had one since as I haven’t needed one.*

*My GP doesn’t understand secondary breast cancer. I think information needs to be developed for GPs, discussing the different sites {where breast cancer can spread}, the symptoms of each and side effects of treatments.*

**Recommendation:** BCNA believes that GP Management Plans are a useful tool for enabling women to access affordable allied and mental health services when needed. We feel that there should be increased awareness of these plans and their suitability for women living with
secondary breast cancer among women, specialists and GPs. BCNA will continue to advocate for increased uptake of GP Management Plans, and will focus on this in particular during Breast Cancer Awareness Month (October) and Secondary Breast Cancer Awareness Day (October 13).

**What are the greatest unmet needs of women with secondary breast cancer?**

Unmet information and services needs were a major focus throughout our discussion. Although the unmet needs identified by women at the focus group are consistent with our earlier research findings and anecdotal experience, they are by no means exhaustive. BCNA understands that secondary breast cancer impacts on women and their families in different ways.

**Information for families and children**

Women felt there was not enough information and dedicated resources available for their families. In particular, the need for information pitched at children of various ages was identified as an area in which suitable resources is currently lacking.

*When I was diagnosed with early breast cancer, my surgeon gave me a simple book for young children that talked about cancer. But there’s nothing for secondary cancer. The books are always “mummy gets better”. We need something the children can actually read on their own, pitched at a level they can understand.*

**Help in the home and community support**

Many women felt that there was a significant gap in suitable home help support services, such as cleaning and other household-based assistance. Many expressed dissatisfaction with the help they had received from council-based and other community services. Women reported encountering helpers who did not understand the nature of their illness.

*My last help would say, “You look okay – why can’t you do it yourself?”*

Understandably, women felt that although home-help services may be available through community organisations and local councils, these services were often lacking in suitability for their own needs. Women felt that even when helpers were provided, the helpers and/or service provider demonstrated a critical lack of understanding of and empathy for their circumstances. Councils often refer to community household support as ‘age and disability assistance’. Many of the women felt that the councils did not understand why a younger woman who looked well – often with a partner and children - would need this sort of assistance.

**Access to and information about financial planning**

Women talked about the importance of adequate financial planning advice. Many women felt that financial planning should be addressed and services offered at an early stage of a diagnosis of secondary breast cancer, before it became too difficult.

Women asked about how to go about protecting investments for their children, how to plan a will. Many women noted that although planning a will is straightforward, there are additional
concerns they felt are not adequately addressed, such as how to financially protect their children in the case of their husband re-marrying after their deaths. All women noted that discussing these hard realities with their families and partners can be very confronting and sometimes depressing. Resources and services that are freely available are needed to help women make these difficult decisions with their families.

Organising funeral arrangements were also touched on. Some of the women had already planned their funeral and encouraged others to do the same at an early stage if they felt they wanted a hand in organising their own.

Funeral arrangements are important – I’ve organised that while I’m well – I want information about how to do that. I want someone to discuss this with. Information about the logistics of planning this type of thing from someone knowledgeable would be helpful.

Some women told us that finances have been significantly affected since being diagnosed with secondary breast cancer.

The most difficult issue for me now is financial. My husband has to work six days a week when he should be retired and I have had to go on a disability pension, which really irks me. I would love to work part-time but feel discriminated against in the workforce because of my disease.

Better access to drugs

Women noted that the time for the Pharmaceutical Benefits Scheme to approve new drugs for secondary breast cancer can be extremely lengthy. One focus group participant reported having to pay thousands of dollars for access to a drug that is pending PBS consideration/approval.

Sexuality issues and body image

Women discussed the importance of sexuality issues and felt that generally sexuality was not discussed as freely as it should be with their health professionals. Women felt that their sexual relationships with their partners had been adversely affected by their diagnosis, and believe that this issue should be discussed more openly.

Body image is an issue too. I don’t look the same and I don’t look like me, this can make sex hard straight off the bat. Your partner often thinks they can’t touch you because they might break you.

Emotional support

Many of the women discussed the vital importance of having adequate emotional support. Only two women had seen a breast care nurse since being diagnosed with secondary breast cancer. Many others reported that they would have liked to access support from a BCN, but that the service had not been offered to them.

The need for emotional support from professionals, families and partners was a consistent theme throughout our discussion.
**Recommendation:** The issues raised by our focus group participants are consistent with earlier research findings and BCNA’s experience. BCNA has a range of resources and services available for women with secondary breast cancer, and recognises where there are gaps. Secondary breast cancer is an identified strategic priority for BCNA – the outcomes from this focus group will inform our work.

**What do women think people need to know about secondary breast cancer?**

The focus group discussed at length how secondary breast cancer seems to be misunderstood by the general public. Many women said that the amount of ‘pink’ and ‘positivity’ in October (Breast Cancer Awareness Month) propagates a myth that all women survive the disease and led to public misunderstanding of what secondary breast cancer means.

*A lot of women (with secondary breast cancer) get upset with all the October pink – the smiling, happy faces. There are no smiling, happy faces with secondary breast cancer.*

Women also reported feeling marginalised or invisible during October. They told us that our messaging should encompass all women with breast cancer, not just those with early breast cancer. The women recognised that pitching this messaging in a sensitive manner that does not unnecessarily frighten those with early disease can be difficult.

Some women told us that people will ask them, “how long do you have?” suggesting a very simplistic and misguided understanding of what incurable means. Women felt that people need to understand incurable illnesses better: that it is possible to live for many years with secondary breast cancer. Women also reported that people are often confused by how ‘well’ they look, almost as if they don’t believe their condition is incurable. They also feel as though people do not adequately understand the individual nature of a secondary breast cancer diagnosis or indeed that secondary breast cancer is breast cancer cells spread to distant parts of the body.

*They don’t understand secondary breast cancer and that it is incurable. The message needs to be that there is no cure and that the best outcome is to be able to live with it as a chronic illness, with constant treatment, for as long as possible. However, it is not easy to live.*

**Recommendation:** Throughout the month of October, leading up to Secondary Breast Cancer Awareness Day, BCNA will release 13 facts about secondary breast cancer through social media channels to dispel myths and educate people about the meaning of secondary breast cancer. We are also incorporating information and awareness messaging around all of our communications planned for October, and will continue to provide accessible information about secondary breast cancer on our website and other resources for women and their families.

**What would you like to tell a woman newly diagnosed with secondary breast cancer?**

*There’s always hope.*

*Don’t give up hope.*
You CAN live with this – women think that they’re going to die in a matter of months. This is not the case.

Point women straight to the essential information.

Sometimes the only thing that helps is talking to others who understand.

Although you are terrified at first, you snap out of ‘I’m going to die mode’ and into survival mode.

We are still people, we are not a disease. I am often defined by my disease and treated differently. I don’t want pity – caring, but not pity.

For More Information

Breast Cancer Network Australia has a range of resources available for women with secondary breast cancer and their families.

If you have been diagnosed with secondary breast cancer and would like more information, you may like to visit some of the following pages:

- You can order BCNA’s free resource, *Hope & Hurdles*, which is a comprehensive information resource especially for women diagnosed with secondary breast cancer.
- **Subscribe to The Inside Story** - BCNA’s free, quarterly magazine for women living with secondary breast cancer, which accompanies *The Beacon* magazine.
- **News and resources for women with secondary breast cancer.**
- The personal stories section has stories by women living with secondary breast cancer.
- You can also join **BCNA’s online network** if you think that talking to others in a similar situation will help.

Acknowledgements

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