

## The strength of a network—creating opportunities for consumer engagement

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With a Bachelor of Social Work, Amanda Winiata is passionate and energetic about her career in health, and particularly in promoting better health outcomes for individuals and communities.

Amanda's career in social work has included supporting children and families as a child protection practitioner, and providing positive opportunities for young people through the Big Brothers Big Sisters mentoring program.

In 2007, Amanda was thrilled with the opportunity to re-focus her career and join Breast Cancer Network Australia (BCNA). She has a longstanding interest in the impact of breast cancer on individuals, families and the community.

As the manager of BCNA's Community Programs team, Amanda is responsible for programs, which aim to act as a catalyst for community participation and development. These include:

- BCNA's program of national forum events, which provide women with an opportunity to meet others affected by breast cancer, to learn about local supportive services, and to hear the latest information about treatment and care from key clinical health professionals
- BCNA's Community Liaison program, which develops the capacity of women to engage with their communities to foster greater awareness of breast cancer and its impact; and
- BCNA's Member Groups program, which helps to support the work of BCNA registered breast cancer support groups in communities across the country.

The work of these programs is reflected in BCNA's mission to empower, inform, represent and link together breast cancer survivors across Australia.

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### Background

In 2011 it is estimated more than 14,000 women in Australia will be diagnosed with breast cancer, making it the most common cancer for women<sup>1</sup>. Of those diagnosed this year, 30% which is over **4,200** will live outside a major city. It is estimated that about **43,000 women** in rural areas have been diagnosed with breast cancer in the last 25 years<sup>2</sup>.

A diagnosis of breast cancer is a challenging and emotionally distressing time for women and their families. The diagnosis is only the first step—the journey is on-going. Women continue to seek up-to-date information long after their initial diagnosis and for many, the impact of their experience is the driving force to instigate local community initiatives.

Breast Cancer Network Australia (BCNA) works to ensure that women diagnosed with breast cancer, and their families, receive the very best information, treatment, care and support possible, no matter who they are or where they live. As the peak national breast cancer consumer organisation we support these women and families on a national and local level by:

- **informing** women and families by providing quality, up-to-date information about breast cancer, its treatment and services
- **empowering** women to have a voice in their own health care and to play an active role in improving breast cancer treatment, care and services
- **representing** women's voices and ensuring they are heard by policy makers, health providers and planners through our programs, policy and advocacy work
- **linking together** those affected by breast cancer, through our events, Member Groups, and online network.

In addition to a cancer diagnosis, geographic isolation and limited contact with specialist health care workers may impede access to the full range of treatment options and supportive care services for women in rural areas. Travel to major cities for treatment and visits to specialists, often result in extended periods of time

away from family and existing support networks. The resulting emotional and financial impact may therefore influence decisions individual women make about their treatment and care.

If you live 300 or 3,000 miles or more from treatment centres the issues are basically the same. Leaving your home, family and friends, that important network which supports you is shattering. Being alone in a place you are not familiar with and people who are strangers is so hard. It makes the breast cancer journey all the more difficult. I felt so alone.—Judy

### A need to engage and support rural communities

Research has shown breast cancer survivors living outside major Australian cities have limited access to medical follow-up care, and psychosocial and lifestyle support programs<sup>3</sup>. BCNA's commitment to supporting rural women is further guided by the fact that relative to the number of women diagnosed, BCNA membership is strongest in remote and very remote areas.

In a joint project funded by the Australian Federal Government, BCNA and the National Breast and Ovarian Cancer Centre (NBOCC) have implemented a program to address some of the challenges faced by rural women. The aims of the *Supporting Women in Rural Areas Diagnosed with Breast Cancer (SWRDBC)* Program are to:

- target gaps in the provision of information and supportive care for rural and Aboriginal Torres Strait Islander women, families and health professionals
- improve access to information about the latest advances in breast cancer treatment and care
- explore, develop and implement innovative ways, through technology, to provide support networks for rural and Indigenous women, including providing locally tailored information.

The Program draws on the respective expertise of NBOCC and BCNA in the delivery of evidence-based information and the provision of support for women with breast cancer and their families. The program elements discussed in this paper focus on:

- improving access to information for women with breast cancer living in rural areas
- strengthening capacity to provide support for women diagnosed with breast cancer within rural communities.

### BCNA information forums

BCNA has long recognised the value of connecting women with breast cancer through local information forums. These events have consistently proven to be well attended, and in many instances, demand has exceeded the capacity of venues at various locations.

Recognising that women in rural communities often have fewer opportunities to attend such events, BCNA has recently placed a particular emphasis on delivering forums in regional centres. As a result of the Government funding, since November 2009 twelve forums have been run in centres across Australia.

The program content focuses on 'survivorship' and provides a balance of medical information on the latest in breast cancer treatment and care, and psychosocial wellbeing. While different speakers appear at the forums, the basic structure of the day is consistent:

- session delivered by a medical oncologist on the latest developments in treatment and care
- short presentation by a local health professional involved in coordinating services for women diagnosed with breast cancer and their families
- session focusing on emotional, psychological and social issues for breast cancer survivors, with a focus on coping strategies

- lunch and networking time is provided, with participants able to view displays and meet with representatives of local support groups and health service providers.

As a consumer organisation, BCNA not only seeks to directly support women and families affected by breast cancer, but also sees value in establishing links amongst members of our Network. Our forum events provide the opportunity for women from rural areas to establish relationships with others affected by breast cancer, and engage with local peer-support groups and services.

Women at various stages of their breast cancer journey attend our forum events (i.e. women recently diagnosed to women five or more years down the track), and for some, our forums act as a catalyst to considering various opportunities which harness consumer involvement.

## Relevance and results

The forums act as a catalyst for connections to form within communities. Attendee evaluation data of twelve forums conducted between November 2009 to December 2010 demonstrate:

- **Breast cancer survivors continue to seek opportunities to remain informed about breast cancer treatment and care.** Rural women's lack of access to health care professionals results in fewer opportunities to receive information. On average, 82% of forum participants indicated their need to gain information on breast cancer as their main reason for attending. There is an ongoing need to ensure information is not only accessible, but appropriate for a consumer audience, as opposed to medical professionals. With such knowledge women are better placed to manage the side effects of their treatment. Informed consumers are also more likely to feel empowered to play an active role in decision making about their own health care. Additionally, an understanding of treatment and common experiences helps to relieve anxieties.
- **Benefit in rural women gathering and engaging with local peer-support groups.** Opportunities to meet others who have been affected by breast cancer help to establish supportive relationships within and amongst communities. Women often describe breast cancer as an emotional roller-coaster and find support from talking to others who have 'been there'. On average, 28% of participants attended forums for this purpose. BCNA's online network provides a further opportunity for relationships established at forum events to be maintained, regardless of location.
- **Value in the program providing both clinical and psychosocial content.** Research has demonstrated women perceived a lack of available psychosocial support and resources for rural breast cancer survivors<sup>4</sup>. On average, 97% of forum participants rated they feel either 'more' or 'much more' informed as an outcome of the forum. An understanding of the complexity of breast cancer as a disease, and its associated treatments, helps women to better understand their treatment pathway and ongoing care and support needs. Depending where women are on their breast cancer journey, they may have different information and support needs. During the acute phase of treatment, needs associated with psychosocial wellbeing can be overlooked or not be identified by women. If not addressed or managed, the impact of the emotional, psychological and social issues can not only affect the woman diagnosed, but those relationships around her.
- **Strong attendance by survivors and their supporters and health professionals.** Approximately 80% of attendees are survivors, with the remaining 20% comprising supporters and health professionals. Invitations are sent to BCNA members within the surrounding region of each forum location, and welcome supporters to attend. The events also aim to include key local health professionals, in an effort to provide further opportunity for community engagement and understanding of available health services. Local media and promotion via support groups aims to attract those who are not currently engaged with BCNA. Of those who provided registration information (n=1438), 80% were from inner and outer regional locations, and 13% remote and very remote areas. Consistent attendance supports the value in providing ongoing forum opportunities. Future planning needs to consider whether we approach the same locations, providing a new program, or take the existing program to new locations.

- **An increase in registration of rural/regional peer support groups with our organisation and opportunity to identify rural women for Community Liaison training.** Our forum registration process allows us to identify existing support groups which are not registered as BCNA Member Groups with our 'umbrella' organisation. BCNA's Member Group program, aims to support local peer-support groups across the country with their efforts. The forums provide promotional opportunities for groups within the region and further build our engagement with them. The forum program concludes with opportunities for women to 'get involved', offering different levels of opportunity for varying interests. Forums have proven to be a successful strategy to recruit women to be BCNA Community Liaisons.

### BCNA Community liaison training

Crucial to our Network is recognition that many advances in breast cancer treatment and care have been driven by the collective voice and efforts of survivors. Breast cancer survivors continue to seek opportunities to contribute in an effort to improve outcomes for other women. BCNA's Community Liaison program has been an effective model to support women who wish to lead local community initiatives to foster greater awareness of breast cancer and its impact.

Women identified from rural and regional communities across the county travelled to Melbourne to participate in a two-day training program. The training model requires women to draw from their personal experiences of breast cancer. The program also aims to build knowledge of breast cancer and assist with developing strategies to engage their local community.

The program content has been developed to ensure women representing BCNA have:

- a thorough understanding of BCNA, how the organisation came to exist and its current priorities
- clear expectations of the Community Liaison role, including the range of activities they can participate in and support provided
- a basic understanding of breast cancer, including incidence and mortality and risk factors to respond to community queries and misconceptions
- confidence in explaining BCNA's range of services available to support women and families
- experience and develop skills in planning how to share their personal breast cancer story to various audiences
- an understanding of key BCNA sponsor relationships to inspire community involvement
- greater awareness of BCNA's online network as a platform for establishing supportive networks across the country regardless of geographic location
- developed community engagement action plans, consisting of various strategies to initiate in their community to raise awareness of breast cancer and its impact.

A key component to the success is Community Liaisons remain supported with their activities post-training.

Comparison and analysis of pre and post questionnaires from the **Community Liaison training** indicates:

- **The training is successful in increasing women's capacity to engage their rural communities.** Positive shifts in participants' ratings across all measures including knowledge, confidence and motivation, and capacity to undertake initiatives, is evident.
  - Prior to training, 44% rated their level of knowledge of breast cancer (i.e. incidence, treatment and care) 'high' or 'very high' compared to 88% post training.
  - 56% rated their level of knowledge of BCNA services, resources and support for women with breast cancer as 'high' or 'very high' before training. After training 100% rated their knowledge 'high or very high'.

- Participants’ confidence in describing BCNA and our services was understandably lower prior to training, with only 24% rating this as ‘high’ or ‘very high’. After training, 100% of participants rated their confidence as ‘high’ or ‘very high’.
  - Motivation to undertake local initiatives was sustained two months post training, with 96% rating their level of motivation as ‘high’ or ‘very high’.
  - With an increase in knowledge and confidence, participants’ ratings of their efforts to assist their community members/groups to access BCNA services, resources and support increased. 29% rated their efforts as ‘high’ or ‘very high’ prior to training, and 80% post training.
  - Prior to training, 53% rated their capacity to raise awareness of breast cancer and BCNA in their community as ‘high’ or ‘very high’. After training, 76% rated their capacity as ‘high’ or ‘very high’.
- **New Community Liaisons have initiated a range of local awareness activities.** Activities range from generating media outcomes, participating in community events, speaking to local community groups and starting peer-support groups. A number of Community Liaisons have taken their supportive role to our online environment as BCNA ‘Online Network Champions’. Their role helps to set the tone of the online network as safe and welcoming and actively engage with new members posting for the first time. Local BCNA representatives further help BCNA to maintain personal relationships with members in communities across the country and keep us informed of local issues.

Before the training I wanted to do something in the community, but didn’t know how to go about it.  
 After training I have the knowledge and information to make a difference.—Community Liaison  
 Training Participant

## References

1. Breast Cancer in Australia, an overview 2009. Australian Institute of Health and Welfare and National Breast and Ovarian Cancer Centre. AIHW Cancer Series No. 50; pp 112
2. Breast Cancer in Australia, an overview 2009. Australian Institute of Health and Welfare and National Breast and Ovarian Cancer Centre. AIHW Cancer Series No. 50; pp 61
3. Sheleigh L, Spathonis K, Masters J, Adams J and Eakin E. Follow-up care after breast cancer treatment: experiences and perceptions of service provision and provider interactions in rural Australian women. Supportive Care in Cancer 2010
4. Sheleigh L, Spathonis K, Masters J, Adams J and Eakin E. Follow-up care after breast cancer treatment: experiences and perceptions of service provision and provider interactions in rural Australian women. Supportive Care in Cancer 2010

