



BreaCan
BREAST CANCER SUPPORT

BreaCan

Annual Report 2005-2006

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BreaCan is a service of
Womens Health Victoria

BreaCan



"For the first time, I felt I was no longer alone. It was the first time I have sat in a room with other women with the same problems, emotions and experiences as myself"

BreaCan Service User

A Message from the Service Manager



(L-R: Nicole Wilton, Helen Shepherd, Di Missen, Josie Scott)

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The past year has been one of transition for BreaCan. Moving from a pilot project to an ongoing service has required much energy to establish the solid foundations needed for the future growth of our service.

Relocating BreaCan to the Queen Victoria Women's Centre (QVWC) symbolised a significant step in BreaCan's development. Having outgrown our original space, our new home feels like exactly the right place to be.

The recruitment and training of new volunteers has also been a major priority in 2005/06. It has enabled us to double our volunteer workforce and increase the capacity of the service we offer. We can now respond to an increasing number of requests for information and support from people affected by breast cancer, as well as their carers, families and friends.

The way in which BreaCan provides information and support for people experiencing breast cancer is unique. Our trained volunteers bring remarkable skill and dedication to their roles.

Approximately 3,000 women are diagnosed with breast cancer in Victoria each year. One of the challenges for a service like ours is to be creative about developing ways to reach these women – as well as the small number of men who are diagnosed. From what women tell us, they are often overwhelmed by a sense of being alone so the importance of creating a space where people can not just access reputable good quality information, but also share their experiences and ways of coping is invaluable.

As a community based service model, BreaCan has lots to offer the cancer services system and we look forward to sharing what we have learnt so far. The value of providing support and care – of caring for the person, and not just treating the cancer is obvious but there are still many system changes that need to occur for this approach to be universal.

Just as we have made some advances in supporting people affected by breast cancer, we have begun planning an expansion of our service to provide information and support to women with gynaecological cancers, which is an exciting new phase to BreaCan's development.

With another year of change, I am reminded of what a privilege it is to be part of this service – many people, staff, volunteers and friends of BreaCan give their time, skills and support. In our new home at QVWC we are surrounded by a rich history of women's lives and I hope BreaCan will continue contributing to this well into the future.

Di Missen

Di Missen BreaCan Service Manager

About Us

BreaCan is a quality women-centred, holistic service providing information and support to people living with breast cancer in Victoria.

Through our caring and flexible approach we provide a safe environment for people to share their personal experiences of breast cancer and to seek information relevant to their needs as they define them. BreaCan provides a range of supportive care programs and continually seeks to create new avenues of access through developing specific initiatives.

The personal breast cancer experience and skills of our volunteers are central to the service we provide.

In 2005/06 BreaCan had just over 1,500 contacts from people affected by breast cancer. Over 90% of people who contact BreaCan are women who have personally experienced breast cancer. Carers, family members, friends and men with breast cancer use the service too. Health professionals also access and value our information resources.

BreaCan is a service of Women's Health Victoria (WHV), which is a Victorian state-wide health promotion organisation run by women, for women.

"I feel welcomed and at ease whenever I visit the service".

BreaCan Service User



BreaCan Resource Centre



The BreaCan resource centre is open three days a week and provides a safe and welcoming place for women, their partners, family and friends outside a medical setting. They can browse and borrow information, seek support, attend information sessions, share personal experiences or simply have a cuppa and chat.

In 2006, we introduced a 1300 number so that people, including rural Victorians could call the service for the cost of a local call.

The resource centre is staffed by trained volunteers who have either personally experienced breast cancer or cared for someone who has. BreaCan staff work alongside volunteers, providing assistance, support and debriefing.

Volunteers



BACK
L-R: Sandra, Janine, Julie,
Florence, Joy, Christine, Rosemary
MIDDLE
L-R: Ang, Pauline, Lea, Jenni, Angela
FRONT
L-R: Betty, Mary, Rita, Meril,
Rhonda, Michele

ABSENT: Heather, Ellen, Toni,
Marianne, Ojdana, Teresa, Chris,
Frederika, Pam, Judy, Khim, Pat.

Volunteers are vital to the work of Breacan, and we are fortunate to have a group of motivated and committed women who continually inspire and inform us. Peer support is the cornerstone of our service – it demonstrates the enormous value of people’s shared experience. The exchange of knowledge between women comes from the experience of living with breast cancer, which helps to legitimise and normalise what they are experiencing in a way others cannot. It is also reassuring for women who have been recently diagnosed to talk with our volunteers who are living well years after their diagnosis. Our volunteers come from diverse backgrounds and bring with them many skills and qualities.

“I’m enjoying myself and gaining a lot more confidence each day. I’m feeling more prepared to meet the challenge of being a volunteer”.

Breacan Volunteer

Volunteers



“I am still a volunteer but I also receive amazing personal support from all members. The staff and other volunteers have been an amazing addition to my support network. THANK YOU”.

Breacan Volunteer



Breacan doubled its volunteer workforce to 30 volunteers in 2005/06. The process of recruitment began in November 2005 with over 70 enquiries from women interested in becoming a volunteer. Eight months later, after a rigorous selection process 15 volunteers were offered places on the 40 hour training program, conducted over a six week period. In June 2006, 14 women

successfully completed the training. The recruitment and training of new volunteers is a time consuming process but is crucial to providing a quality service.

The training program was professionally facilitated and a range of health professionals gave their time on a pro bono basis to cover topics such as breast cancer treatments, the role of the Breast Care Nurse, sexuality and relationships. The volunteers also participate in at least 1.5 days communication skills training – we emphasise that a good volunteer is one with the ability to listen.

The 14 new volunteers bring a range of diverse life (and breast cancer) experiences to our service. They vary in age from 29 to 71 years, and come from various cultural backgrounds including Croatian, Cambodian, Dutch and Filipino.

The Breacan volunteer training program has been carefully developed and extensively documented. In future, it will be important to publish and promote our program as a ‘best practice’ model.

Our new volunteers work alongside experienced volunteers in the resource centre to provide information and support to service users. On any given day there are two volunteers working in the centre with the Breacan staff. Together, they provide support by responding to calls and talking to women face-to-face either individually or through group information sessions. Volunteers occasionally attend speaking engagements to promote Breacan to health professionals and other interested organisations. They also speak to women participating in end-of-treatment programs at various hospitals.

An increase in our volunteer workforce means there is now scope to diversify the roles of volunteers in the future.

Information

“BreaCan provides a real feeling of support and connection for me with all of you and the women who attend the sessions ...it really hits the mark between providing information for women and some good old relaxation and pampering, so thank you for providing such a great service”.

BreaCan Service User



A major goal of BreaCan is to help people affected by breast cancer navigate a path through the complexities of their treatment and enhance their capacity to make informed choices. Helping carers, family and friends have a greater understanding of the impact breast cancer has on themselves and their loved one is also important.

From the outset, BreaCan has taken the approach that providing information must be a genuine exchange, based on the individual's needs. Some women may contact the service on a one-off basis while others will use the service over a period of time. BreaCan does not provide medical advice, and we source consumer friendly, technical or medical information specific to an individual's needs. Women are encouraged to recommend and comment on BreaCan's resources to inform the ongoing development of our resource collection.

Library and Resources: The BreaCan library provides a diverse range of credible and up-to-date information and materials, including pamphlets, journal articles, books, tapes, CDs and videos. The library includes a display of breast forms (prostheses), bras and accessories for women to examine. BreaCan also has access to the larger Women's Health Victoria Clearinghouse. The WHV Clearinghouse collects and analyses a broad spectrum of literature, information and resources relating to women's health. Resources can also be posted to women and returned at no cost to them.

Referrals: BreaCan helps women access specialist services such as counselling and links them into local community-based services, including community health centres and support groups.

Information Sessions: BreaCan holds *What's On* information sessions each fortnight. During 2005/06, we conducted 27 information sessions covering a spectrum of issues from the clinical to general well-being, and on the challenges of living with breast cancer. Examples of topics covered include breast reconstruction, fatigue, lymphoedema, nutrition and adjusting to life after treatment.

Information sessions allow women to socialise, exchange ideas and discuss personal experiences in a safe and welcoming group setting. They provide the opportunity to hear reputable speakers on topics relevant to their needs. Women can also ask questions and mingle with other women with similar experiences. In May/June 2006, we ran a four week meditation program which proved popular.

Our information sessions are also available on CD from our library for people unable to attend.

Support

Giving people time is fundamental to providing quality supportive care. Each woman's experience of breast cancer is different and influenced by factors such as age, personal values, available support and resources. BreaCan provides a service that is tailored to the needs of each individual for as long as their need exists.

Women who have used our service say that talking to a volunteer who is living with breast cancer has helped 'normalise' what they are experiencing. It is also enormously powerful to talk to another woman who having been through diagnosis and treatment, is living well.

The types of issues which women seek support for are varied. Some common issues are:

- The fear and anxiety of being recently diagnosed and coming to terms with 'why me?'
- Breast reconstruction: What the options are, what having reconstructed breasts feels like, the healing time and the timeframe for making a decision.
- Understanding the treatment options and the challenge of making decisions about the options.
- How to manage the side effects of treatment, especially chemotherapy and Tamoxifen.

- The physical and emotional impact of experiencing early menopause.
- The challenge of dealing with loss of fertility, and losing confidence in your own body.
- The impact on relationships with loved ones and ways to communicate with them.

Examples of support include:

One-on-One: Women can talk one-on-one with a volunteer, as they need and when they need. This can happen face-to-face, on the phone or via email.

Group Programs: Some women feel more comfortable participating in group activities. Women can attend an information session or a group activity such as meditation or creative writing.

Feel Good Gentle Exercise Program: A free fortnightly gentle exercise session for women living with breast cancer, conducted by a qualified instructor, who is a BreaCan volunteer.



Making Connections for people living with advanced breast cancer



The *Making Connections* program began as a pilot project and is now an ongoing component of BreaCan's service. During the last 12 months it has continued building on the original concepts including monthly information sessions, the *Here and Now* eight week support program, as well as the advanced breast cancer mailing list and the ongoing support component.

Information sessions have provided an opportunity for women living with advanced breast cancer, their carers, friends and family members to meet and listen to speakers on a wide range of topics. *Making Connections* offers a varied information program including sessions on stress and anxiety, art therapy, music therapy, meditation, caring for the carer, treatment options and choices. Information sessions are recorded onto CDs and are available with speaker's hand-outs to borrow.

“Being part of *Here and Now* has firstly lifted my spirits...I am a part of something very important...shared by others with whom I now feel a closeness ...There is a fluid and collaborative nature to this service that makes you feel that while you have access to the very best care and support...you may even contribute to the process and improve on it for others in the future. How privileged are we to be a part of this very beneficial ministry”.

Here and Now Participant

To improve access for rural women, the *Making Connections* program continues to offer an eight week *Here and Now* teleconference program as well as the availability of resources from the library.

As part of BreaCan's ongoing commitment to providing a high quality service each *Here and Now* program is evaluated. Feedback shows very positive outcomes for participants. These include feeling less isolated, good practical information, which in some cases has led to improvements in quality of life – for example, being able to access financial support they were previously unaware was available. Women have also found a sense of connection with group members, leading to ongoing support and friendship.

The fourth component of *Making Connections*, ongoing support is one that has been left much more open. Women from each of the four *Here and Now* programs maintain contact with each other in an informal version of a peer support group and so far this has worked successfully. As a result of participating in the *Making Connections* program many women have made a strong support network.

“I think BreaCan just existing shows how important it is for women to have such a resource”.

Here and Now Participant

Partnerships



During the past year BreaCan has continued forging relationships with hospitals, cancer services and consumer groups.

BreaCan has a key role to play in working alongside clinical services. Not only does the service support women at their time of treatment, but it also helps them live well and adjust to the many challenges of living with breast cancer. The number of referrals from hospitals, clinicians and Breast Cancer Nurses continues increasing.

Our partnerships take many forms. Some examples include:

“What I have gained – several things. One of these has been a special kind of listening ear – a patient, caring, considered, understanding and honest ear – thank you to all”.

BreaCan Service User

- With Women's Health Victoria acting as the sponsor, BreaCan supported Young Action on Breast Cancer (YABC) to stage their play 'Changes in the Making' in October 2005. YABC is an advocacy group committed to improving outcomes for young women who have experienced breast cancer. The play was funded through a Polo Ralph Lauren grant from the National Breast Cancer Centre.
- BreaCan received a grant from The Cancer Council Victoria to produce a DVD exploring the impact of breast cancer on young women's lives. The production of the DVD is currently underway and will be available as a resource later in 2006.
- BreaCan has also begun to work collaboratively with four metropolitan hospitals to improve the access of women from culturally and linguistically diverse backgrounds to the service. This work will continue into 2006/07.
- A range of health professionals have given their time, free of charge to BreaCan, to help train our new volunteers and to offer their speaking services to the BreaCan information sessions.

There is still much scope to increase awareness within the cancer services sector of the resources available at BreaCan for women.

Increasingly, the importance of supportive care is being recognised and we are well placed to promote the learnings of our service model to other cancer services. We aim to work in partnership with cancer services towards increasing peoples access to supportive care that is responsive and good quality.

BreaCan At A Glance

During 2005/06 BreaCan has:

- Had over 1,500 contacts with people affected by breast cancer.
- Conducted 27 information sessions with over 600 attendees.
- Run 19 *Feel Good* exercise sessions.
- Conducted two *Here and Now* programs for women living with advanced disease.

Mariah is in her early 40s, of Asian background and has a young daughter. She was referred to BreaCan by a Breast Care Nurse (BCN). Not long before being diagnosed with breast cancer Mariah's husband died of cancer. She has no family in Australia and is extremely isolated and on a pension.

When Mariah was initially referred to BreaCan she was very sad and distressed. She would make contact regularly by telephone. Mariah was extremely concerned about her daughter and what might happen should she no longer be able to care for her. BreaCan contacted the BCN and suggested Mariah be referred for some professional counselling and also suggested some community support services for her daughter.

Mariah recently contacted BreaCan again wanting information on radiotherapy and financial assistance as her radiotherapy costs far exceeded the original quote which caused her distress. BreaCan has worked as an advocate for Mariah to try and get some further financial assistance.

Lyn who is in her early 50s has recently had a lumpectomy. As she was about to begin chemotherapy she rang wanting to talk to someone about how to cope with the possible side effects and for information about wigs. She was also starting a new job. She had a long phone conversation with one of the volunteers to talk through strategies to cope with work while on chemotherapy. BreaCan sent her a DVD about chemotherapy as well as information on wigs.

Sandra in her mid 60s had a lumpectomy and recently completed radiotherapy. She phoned BreaCan because she was struggling with her family feeling that 'she should be normal now'. She was distressed by their lack of understanding and had low energy levels and felt she was not ready to return to work. She also had a follow up appointment with her surgeon in the next week and while she had questions to ask she wasn't sure how to ask them. She spoke to the BreaCan volunteer who suggested she write a list of questions and take them to the appointment.

A week later she visited BreaCan to talk at length about her family's reaction to her cancer diagnosis. She borrowed a CD on *'What Happens When the Treatment Is Over'* and some other books. She felt that having spoken to other volunteers about how they coped after finishing treatment had been very worthwhile.

"BreaCan, thank you very much for your help and advice during this confusing time. You spent many hours with me and it is greatly appreciated". **BreaCan Service User**

BreaCan's Relocation



In April 2006, BreaCan moved from its original premises, co-located with Women's Health Victoria, to a more spacious premises at the Queen Victoria Women's Centre (QVWC). The move was preceded by months of planning and involved a major repair, refurbishment and re-design of the space we are now in. BreaCan was very fortunate to enlist the design expertise, time and enthusiasm of PTID Environments, on a pro bono basis, to help with the building works. It was a very challenging project – but it was worth it. Women who have visited the service talk about how welcoming and comfortable it is. The staff finds it wonderful to work in such a light filled environment surrounded by the rich history of the QVWC, together with other services orientated towards women.

"To all the lovely caring women at BreaCan, many thanks for your patience and guidance during my first year with breast cancer".

BreaCan Service User

The Future

Now that BreaCan has established itself in its new home...

Planned actions and initiatives for 2006/07 include:

- Expanding the service in early 2007 to provide information and support to women with gynaecological cancers, their partners, family and friends.
- Continuing our work in rural and regional Victoria by increasing access to our resource centre.
- Enhancing BreaCan's ability to meet the changing needs of diverse groups of women, including women from culturally and linguistically diverse backgrounds and younger women.
- Continuing to increase service use by enhancing communication and promoting BreaCan to health professionals and women experiencing breast cancer.
- Continuing to work in partnership with individuals and organisations to further strengthen the role of BreaCan in the provision of supportive care.

We would like to say thank you to all the people who have donated their time or resources to BreaCan, over the past year.