



Year in
Review
06/07

BreaCan

Service Manager's Message

Di Missen

BreaCan Service Manager



The past year has been another one of change and growth for BreaCan.

The expansion to provide information to women with gynaecological cancers has been a significant – and complex transition for the service. It's only just over four years ago that we began to trial a model of information and support for people affected by breast cancer. Since then BreaCan has become an important and well recognised support service. However, we know that as much as we have achieved, there are still more opportunities to grab hold of.

Each year approximately 3,000 women are diagnosed with breast cancer and about 1,000 women are diagnosed with gynaecological cancer. Many women, having completed their treatment are living well, but from time to time they may also want to access support.

Being part of Women's Health Victoria, means that the work of BreaCan is firmly underpinned by a social model of health. One of the strengths of the service is that we recognise that a diagnosis of cancer impacts on every aspect of a person's life – and that is reinforced each time we speak to women. They reflect on the multitude of changes that happen in their lives as a result of having breast cancer or a gynaecological cancer. Supportive care which embraces a holistic approach is so essential to the provision of good quality care and treatment.

We talk about BreaCan as a 'women focussed' service and the reality is that over 90% of the people who use BreaCan are women. Undoubtedly women's experiences as consumers, service users, volunteers and staff have shaped the way in which the service model has developed. However, there is still more work to be done to inform and support their carers, family and friends. Similarly there is scope to engage with people from diverse backgrounds whose limited access to support may be compounded because of their cultural background, income or where they live.

A lot of time and energy this year was devoted to the planning and establishment of our new gynaecological information service. It is important to acknowledge the commitment and hard work of the staff and volunteers in dealing with what was a significant time of change. When most of our volunteers began with BreaCan they came with an understanding that the service was for women like them – having experienced breast cancer. The transition has meant that we have all needed to learn about different cancer experiences. We have had to think about how to promote the service as a whole as well as engage with women with gynaecological cancers and the health professionals who support them. Despite the changes they have had to deal with, the volunteers continue to be enormously committed and dedicated to the service – and to making a difference to other women's lives.

So it seems to have been another year of transition – but perhaps that is how it will always be. I would like to thank the many people that have given their time, skills and support to us in the past year – staff, volunteers, health professionals, support groups, and the many 'friends of BreaCan'.

A handwritten signature in black ink that reads "Di Missen". The signature is written in a cursive, flowing style.

BreaCan staff

Di Missen

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NOTE ON THE COVER:

The crane is a symbol of longevity in the Japanese culture. The crane featured on the front cover was made by a Japanese woman who used BreaCan and gave a crane to each of the BreaCan staff.

DESIGN Lin Tobias/La Bella Design
PRINT by Red Rover on
150gsm REVIVE SILK
(Australian Made Recycled)

About Us

Resource Centre

BreaCan is a statewide information and support service for people affected by breast cancer and gynaecological cancers.

It is a women-centred, holistic service which recognises that every person's experience of cancer will be different. The ways in which information and support are provided has evolved from the expressed needs and lived experiences of women with breast cancer – and more recently women with gynaecological cancers.

BreaCan is a service of Women's Health Victoria (WHV), which is a Victorian state-wide health promotion organisation run by women, for women. Over a three-year pilot period a unique, peer-based model for the provision of information and support to women – and men – living with breast cancer was developed.

In March 2005 Women's Health Victoria was granted recurrent funding from the Department of Human Services (DHS) for BreaCan to continue as an ongoing service. In May 2007 BreaCan took another significant step forward when it 'opened its doors' to women with gynaecological cancers.



BreaCan is located at the Queen Victoria Women's Centre in Lonsdale Street, Melbourne.

The Resource Centre is open three days per week and provides a safe, welcoming place for women, their partners, family and friends. Women often say that it is important to them that the service is not located in a hospital setting. People call in to browse and borrow information, seek support, attend information sessions or share their own cancer experiences. Many people also make contact by phone and email.

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

The opening of BreaCan's new premises at the Queen Victoria Women's Centre (QVWC) was officially celebrated at a launch in July 2006. The Hon Mary Delahunty MP, (the then) Minister for Women's Affairs welcomed BreaCan to the Centre and presented long-term volunteers with a certificate of appreciation to acknowledge their contribution to the service.

The launch was an important milestone in the evolution of the service from a pilot project to an ongoing service



Information & Support



Alongside the common or shared elements of the experience of cancer the service recognises that the experience will be different for each person. The extent to which people will seek support partly depends on being able to create different opportunities for them to access the service.



The provision of good quality information underpins the unique support role of the service. BreaCan views information provision as a shared process – an exchange between the individual seeking the information and the person providing it. This may occur on a one-off basis or women may utilise the service in a range of ways over a longer period and at different stages of their breast cancer experience.

Women often talk about feeling overloaded with information, yet sometimes women also 'fall through the net' and do not receive basic information which may assist them to better understand and make well informed decisions about their care and treatment.

BreaCan does not provide medical advice or counselling. The service focuses on people's supportive care needs – such as the practical, emotional, social and financial issues that emerge when diagnosed with a life threatening illness.

One-On-One Services

- BreaCan provides centre-based, face-to-face information and support on a 'drop-in basis'; no appointments are necessary. Women can simply talk about their experience confidentially.
- Women come with a broad range of questions and may need information about treatment options, the availability of other services, adjustment issues, the impact of cancer on relationships and general well-being including nutrition and exercise.
- BreaCan provides telephone support and information via a 1300 number. Women are also able to make contact with BreaCan via email.
- A select library of over 300 catalogue items, including books, pamphlets, journal articles, videos, tapes and CDs are available for loan and an information service is linked to the Women's Health Victoria (WHV) Clearing House. The linkage to WHV allows us to provide specific and up-to-date quality information.





What Women Say...

Group Programs

BreaCan provides centre-based group programs that offer women living with early or advanced breast or gynaecological cancer the opportunity to share experiences and to build their own support networks. Group programs are varied and may involve medical and allied health professionals or other specialists, such as creative therapists.

BreaCan groups include:

Information sessions are held regularly and aim to respond to women's information needs. Sessions include a mix of clinical, general health and wellbeing. In 2006-2007 BreaCan conducted 37 information sessions. Examples of topics covered include chemotherapy, anxiety, lymphoedema, breast reconstruction, coping with fatigue and naturopathy. CD recordings of most information sessions are available for loan.

The fortnightly **Feel Good Exercise Program** is designed for women recovering from surgery and provides safe and practical instruction on appropriate exercise. In 2006/2007 19 sessions were conducted by a trained volunteer instructor who herself has had breast cancer.

A **Meditation Workshop Series** was conducted in 2006/2007. Over four sessions, women living with breast cancer, their friends and family learnt meditation techniques to incorporate into their daily lives.

Creative Group Projects are an opportunity for women living with breast or a gynaecological cancer to learn about the importance of creative expression as a way of understanding, sharing and coping with their experience. In 2006/2007 BreaCan conducted several creative workshops including art therapy, writing, belly dancing and a drumming workshop.

BreaCan has over 2,000 consumers and health professionals on its mailing list. The quarterly **What's On** program keeps service users informed about BreaCan programs and provides a simple means of staying connected.

'I'm empowered, I'm taking control of my own body. I am accepted!'

BreaCan Service User

Feedback from service users indicate that some of the benefits of using BreaCan include:

- > The reassurance and sense of hope that comes from talking to the volunteers who, having been previously diagnosed with breast cancer, are now living rich and full lives.
- > The value of being able to access a 'one stop shop' that houses good quality accurate information from reputable sources.
- > Being given the time and 'space' to demystify some of the complex terminology relating to treatments and to 'unpack' some of their misconceptions and anxieties, which helps them to more confidently participate in decisions about their care and treatment.
- > The opportunity to validate their thoughts and feelings as 'normal' through talking to other women, both individually or at a group session.
- > Learning practical coping skills and being able to better manage the day-to day challenges of living with the disease – and the uncertainty it brings.

'We're from different races, different religions, different beliefs and backgrounds, but we feel supported, feel free and connected.'

BreaCan Service User

Volunteers



Some of the Breacan volunteers

‘To be in such a position of trust, sharing with others the physical and emotional roller coaster ride of breast cancer, is for us all, a job beyond remuneration’.

BreaCan Volunteer

BreaCan is built on a partnership between paid staff and trained volunteers. Peer volunteers are integral to the BreaCan service model. The contribution, knowledge and experience of the volunteers – women who are living with breast cancer, or have cared for a family member – ensure that BreaCan provides the most responsive, supportive care.

Peer support is the cornerstone of our service; it validates the immeasurable value and power of shared experience in making a difference to people’s lives and capacity to deal with the impact of cancer. The volunteers are able to help normalise people’s experiences, listen to their fears and uncertainties, discuss ways to cope and adjust to living with cancer – in a way which is very different from a health professional. Just by being themselves they become role models for many of the women using our services.

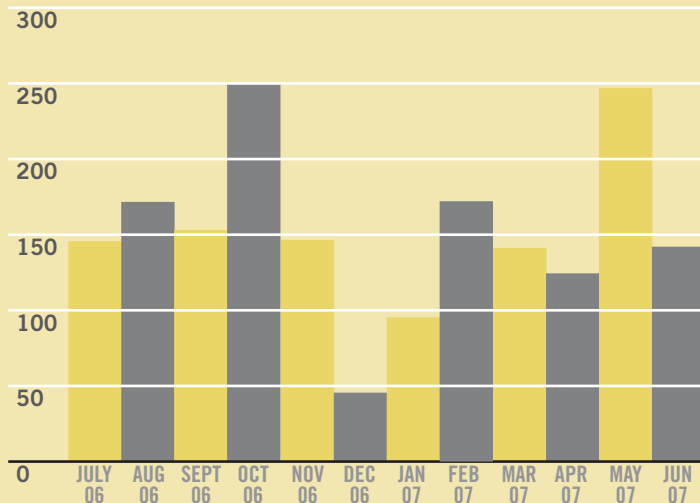
BreaCan currently has 27 volunteers working in the program. They are women from a diverse range of backgrounds and experiences – different cultural backgrounds, ages, family situations, types of treatment and different stages of cancer, including advanced breast cancer. 24 volunteers work in peer support roles, one woman facilitates the exercise program, another provides administration support in the resource centre, and one makes shortbreads for users to enjoy when they come into the Centre.

‘If you said you had cancer, you’d see people’s eyes glaze over. It was sort of like it was a death sentence. It is good to say ‘no, I am here and got through it all’. I want to give encouragement and hope (to other women) they will get through it as well.’ BreaCan Volunteer

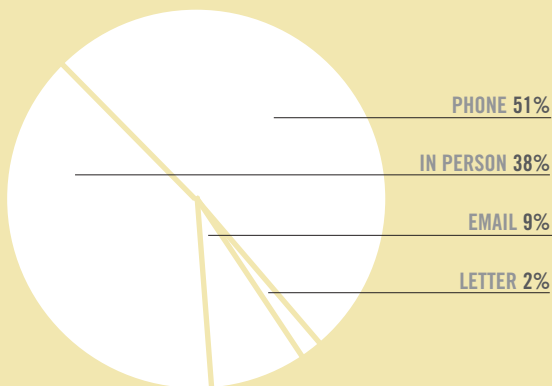
BreaCan – At A Glance

For the period July 2006 to June 2007 there was a total of 1,839 individual and group contacts with the service. This represents a growth of 14.7% from 2005/06.

TOTAL SERVICE USER CONTACTS – JULY 06 TO JUNE 07



TYPE OF CONTACT – SAMPLE (JULY 06 – APRIL 07)



Opening the Doors for Women with Gynaecological Cancers

In May 2007 BreaCan opened its doors to women with gynaecological cancers.

While extending the service was part of the ongoing funding conditions with the Department of Human Services (DHS) it has provided a welcome opportunity for women affected by such cancers to access information, participate in BreaCan programs, talk to other women and use the resource centre.

The expansion has been a significant area of work for staff and volunteers in the past year. As part of the planning for the expansion of the service BreaCan consulted with 32 women ranging in age from their 30s to 70s who had experienced either endometrial, ovarian, vulval or cervical cancer. Service providers, consumer advocacy and support groups and other key stakeholders were also consulted. It was essential that the service: gain an understanding of the different gynaecological cancers and the impact on women and their families and; explore how the current service model could be modified.

The findings of BreaCan's consultation report *'Hidden Faces Hidden Voices-Meeting the Needs of Women with Gynaecological Cancer'* provided a rich insight into the women's needs and identified both similarities and differences with women with breast cancer. The report was written by consultant Sheila Hirst who worked with BreaCan throughout each stage of the expansion.



It identified that ‘while gynaecological cancers and their treatment may have significant impact on women and their families, they are relatively invisible and there are limited resources available to meet women’s needs.’

‘Now I have the reassurance that there are others with whom I can share my concerns on this very particular journey.’

BreaCan Service User

This invisibility is compounded by the relatively small numbers of women diagnosed with the range of gynaecological cancers, the hidden and private nature of women’s genital organs and the continuing ‘stigma’ that remains with sexuality, sexual health and illness. The aloneness experienced by many cancer patients in some ways appeared to be exacerbated for some women with gynaecological cancer by the nature of their cancer.’

BreaCan established a short term advisory committee which provided valuable input on the planning and implementation of the expansion. Committee members included consumers, consumer advocates, gynaecologists, a gynaecology service nurse, a social worker and other relevant health professionals as well as BreaCan staff. As part of planning for the expansion a comprehensive volunteer training program was implemented (refer p.7).

Promotion of the expanded service required BreaCan to communicate the change to already established networks. It also had to develop new networks and relationships with service providers in the gynaecological-oncology sector, relevant support services, consumer organisations and of course women who potentially may use the service. Underpinning the development of a communication strategy was the issue of the ‘branding’ of BreaCan. BreaCan consulted with a range of stakeholders with divergent views. As an interim approach the BreaCan logo has been modified. New brochures and posters signifying the change in the scope of the service have been developed and distributed.

On the 1st May 2007 BreaCan hosted an Open Day to celebrate the expansion. While it was a low-key event, there was a sense of achievement and optimism about this important step forward.

The initial emphasis of the expanded service has been on *providing information*. However, in the next stage of development the service will strengthen its support role for women with gynaecological cancers.

Since opening in May, feedback received from women with gynaecological cancers has been positive. Women have attended fortnightly information sessions, some being specific to women with gynaecological cancers and others have been more general. Also, BreaCan’s **‘Here and Now’** program for women with advanced disease has been broadened to include women with advanced gynaecological cancers.



Making Connections

BreaCan offers Making Connections a specific program for women living with advanced disease. The program seeks to strengthen connections between women with advanced cancer, providing a safe space that facilitates women sharing experiences and learning from each other.

With the expansion of the service, BreaCan has adapted the program to include women with an advanced gynaecological cancer and each year Making Connections continues to develop.



'My group has been my 'light at the end of the tunnel' each week. We laughed and cried, we had fun, we shared stories, we whinged about our treatments, our nausea, our pain, we let our defences down, we shared feelings and fears of dying, and we shared lots of practical tips in how to deal with the day-to-day reality of living with advanced disease. A brilliant program, beautifully facilitated. The other participants were fantastic – it was a privilege to spend 8 sessions with them'. BreaCan Service User



'Being able to discuss difficult issues openly and light-heartedly was a huge relief for me and helped me to feel 'normal' again.'

Here and Now Participant

The program incorporates four elements:

The **advanced breast cancer mailing list** aims to facilitate ongoing communication and promotion of BreaCan programs and resources specifically for women with advanced breast or gynaecological cancer.

Information sessions for women with advanced breast cancer or an advanced gynaecological cancer offer women the opportunity to connect with other women in a similar situation, in a group setting. In 2006/2007 BreaCan held eight sessions specifically for women with advanced disease including art therapy, adapting to changed energy levels, breast cancer and bones, palliative care, pain management and money matters. The sessions are recorded on CD so that women who have difficulty coming to the centre can listen to them in the comfort of their own home.

BreaCan also offers **Here and Now**, a professionally facilitated eight week supportive discussion group. The program enables women to share experiences and knowledge and to address more difficult issues in depth such as grief and loss, intimacy, relationships, death and dying, in a safe and trusting environment. In 2006/2007 BreaCan ran three face-to-face groups and one teleconference group.

The final component, **ongoing support** is much more informal. Women through their involvement in the Here and Now program determine the nature of the ongoing contact they have with each other. At the end of 2006 BreaCan hosted a morning tea to bring together women from past Here and Now groups. Significantly, participants in each of the Here and Now groups have maintained informal contact with each other, independently of BreaCan which has strengthened their individual support networks.

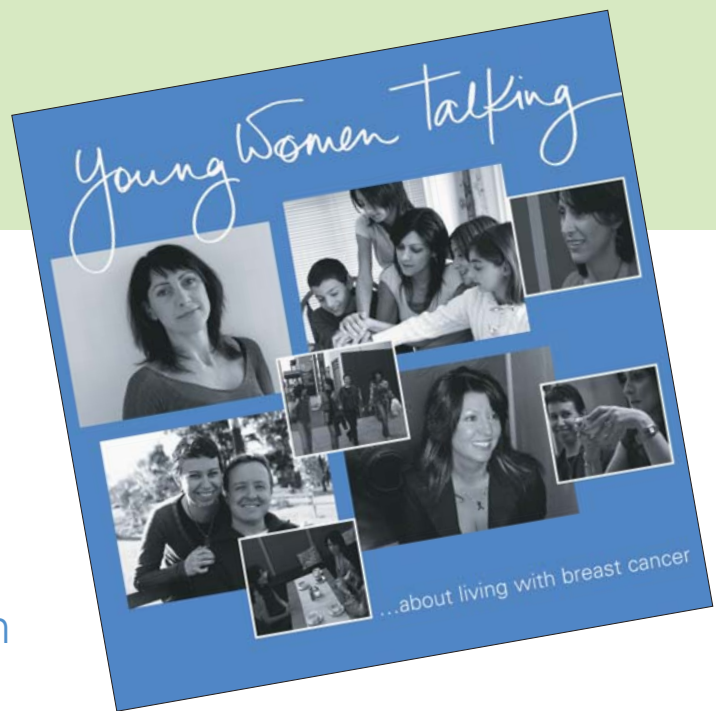
Partnerships and Projects

During the past 12 months BreaCan has been involved in several opportunities to raise the profile of the service, establish new relationships and consolidate existing ones.

Co-operative relationships are forged at a range of levels – whether it's through being a representative on the Victorian Oncology Co-operative Group – Breast Cancer Committee or presenting at the 9th National Breast Care Nurses Conference in February 2007. BreaCan's involvement in various forums provides an opportunity to advocate for the needs of women, from a holistic perspective as well as promote the service and work collectively for changes in the service system. Interestingly, other cancer resource centres are being established by various communities in regional Victoria and BreaCan has been well placed to share its learnings with other services.

BreaCan staff and volunteers also speak at various forums, end of treatment groups and to groups of health professionals.

In the past year BreaCan has been fortunate to draw on the expertise of many health professionals as presenters at information sessions and in the provision of volunteer training. Health professionals continue to be the main source of referral to BreaCan.



Young Women Talking

Late in 2006, BreaCan launched **Young Women Talking** a new and unique resource for young women affected by breast cancer. The resource includes a DVD and supplementary booklet, exploring the issues affecting young women with breast cancer, as told by a group of young women, in their own words.

The women discuss particular themes which reflect the unique issues that young women face. Underpinning the resource was a strong commitment to using women's voices to express, reflect and provide insight into how they understand their experiences. The resource addresses an important information need for young women under 45 years of age, as well as being a valuable resource for health professionals.

The project was a joint initiative between BreaCan and The Cancer Council Victoria with funding generously provided by the Think Pink Committee. Nearly 1,000 copies have been jointly distributed by BreaCan and Cancer Councils throughout Australia.

Young Women Talking was officially launched by Sarah Watt, Director of the film 'Look Both Ways' in October 2006. Over 80 people attended the launch which celebrated not only the production of the resource but acknowledged the enormous goodwill, trust and skill contributed to the project by the various people involved.

'...Thank you for putting this DVD together – it is brilliant, as is the booklet with it'. Health professional

BreaCan Supporting Women in Rural Victoria

BreaCan supports people living in rural areas in a range of ways. Examples of BreaCan's on-going strategies include the free 1300 number, the resource library which women can borrow from and return items free of charge and the CD recordings of sessions available for loan. Women can also participate in the advanced cancer 'Here and Now' program via teleconference.

In the past 12 months BreaCan has also hosted and facilitated several initiatives including:

In partnership with local and regional services in the Hume region, BreaCan conducted two regional forums at Wangaratta, in October 2006. The forums – one for consumers and one for health professionals, focussed on the issues that people face after treatment. Over 60 people attended the forums.

In conjunction with the Breast Care Nurse from Shepparton, the service organised a bus trip for a group of 20 women to visit the centre for an organised day program. Women attended the breast reconstruction information session and participated in the **Feel Good** gentle exercise program. The visit provided the women with an opportunity to gain high quality, up-to-date information from a specialist that they may not otherwise have access to. The women also connected with other women and learnt more about BreaCan's services.

A group of Loddon Mallee Breast Care Nurses visited BreaCan for a professional training day which included an overview of the service as well as participating in a training session on sexuality.

A group of 12 women from the 'Breasties' Avoca Support Group organised a bus trip. Feedback from the women indicated they enjoyed the visit and found the breadth of information received useful.



Kokoda Trek

Donations are one way that BreaCan raises money to fund programs. Since BreaCan began people have generously donated to the service. The last 12 months have been no different with more than 40 donations, totalling over \$6,000. In late June 2007 two women – Maxine and Scharlaine walked Papua New Guinea's Kokoda Track and in doing so, raised money for BreaCan. For both women it was a challenge they had always dreamed of undertaking. The women raised over \$5,500 some of which is being used to fund a creative workshop series. BreaCan is extremely grateful to Scharlaine and Maxine for their generosity – and to all our donors.



The Future

Each year BreaCan continues to grow and develop. In the next twelve months the service will:

- > Establish an advisory structure comprising consumers and service providers from the breast and gynaecological cancer services systems to: facilitate input into BreaCan's future service development and; link with WHV's governance structure.
- > Develop a three year Strategic Plan which will establish a framework for the future development and strategic directions of the service.
- > Begin the recruitment process for a fourth intake of volunteers in mid 2008. As part of the intake BreaCan will actively recruit women with a gynaecological cancer as volunteers.
- > Maintain and further enhance relationships with the cancer services system in order to: increase the understanding of BreaCan's role in the provision of supportive care; increase service use; and enhance the responsiveness of BreaCan to user needs.
- > Explore scope to diversify the volunteer role in response to the changing demands on the service, and the views and experiences of the volunteers, with the aim of identifying ways in which the volunteers can provide outreach support.
- > Trial and develop the new gynaecological cancer information and support service while continuing to: learn about the needs of women with gynaecological cancers and; to improve the accessibility and responsiveness of the service.
- > Continue to develop ways for BreaCan to respond to the needs of diverse groups of consumers particularly in rural Victoria, and women from culturally and linguistically diverse backgrounds.



Some of the BreaCan staff:
L-R: Sacha L'Huilier, Justine Dalla Riva,
Di Missen, Gabrielle O'Brien and Helen Shepherd
ABSENT: Josie Scott, Nicole Wilton



Thank you

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



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Women's
Health
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Breacan is a service of Women's Health Victoria a state-wide women's health promotion, information and advocacy service